Information Needs of Children of a Parent with Cancer

by

Suzanie Adina Mat Saat

A Doctoral Thesis

Submitted in partial fulfillment of
the requirements for the degree of
Doctor of Philosophy of Loughborough University

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KEY WORDS
Information Science, Health Informatics, Impact of parental cancer to children, Information provision for children of cancer patients, Caregiving, Information Needs, Information Behaviour, Children's Reactive Information Seeking Behaviour – An Integrated Model

ABSTRACT

This PhD thesis explored the experiences of dependent children and children care-givers facing challenges with their parent's cancer. The aim was to understand children's information experience including their perception of cancer and information culture; information needs, information seeking behaviour, barriers and enablers.

The research used a six-stage process. This was informed by an extensive literature review and discussions with cancer specialists, psychologists and researchers from United Kingdom, United States, Australia and Malaysia. This study used a three-cycle, eight-step process of Participative Action Research (PAR) with participation from ten Malay breast cancer patients and their dependent children.

Three bilingual (English and Bahasa Malaysia) instruments were developed; 1) An Inquiry to Participate Form to select participants who had dependent children, 2) Three opened-ended questions to obtain children's cancer experience and information needs where drawing was used to encourage children's responses and, 3) A 15-question questionnaire to understand children's experience and information preference.

Cancer affected parenting abilities and challenging experiences identified the lack of culturally relevant information and the shift in caregiving responsibilities to dependent children. Children's understanding of cancer was influenced by their experiences and observations, many of which resulted in misconceptions about cancer, its causes, treatment and preventative measures. Children participant's reaction to a health situation triggered their information behaviour. The burden of caregiving and the consequences of a lack of information were greater than anticipated; children had many dimensions of concern and experienced many challenges. This advocated for a more assessable, attractive and sensitive information system.

Data synthesis contributed to the development of a "Children's Reactive Information Seeking Behaviour – An Integrated Model" that seeks to explain the relationship between children participants' reaction to a health situation and the subsequent processes they undergo to resolve their state of information need.

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'NISI DOMINUS FRUSTRA"

Truly, "without God, all is in vain". Praises to the Creator for His Blessing, Mercy, Guidance and Compassion.

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The National Cancer Society of Malaysia is acknowledged for devoting time and resources to this research, believing in the necessity of the project, cooperating and providing feedback.

This thesis is dedicated to families whose members have experienced cancer for their *iktibar* and strength in coping with the challenges of the diagnosis. It is also dedicated to those present and in the future with a prayer for a cure and that this research may contribute a better experience.

LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
AR	Action Research
CIP	Consumer Information Processing Model
CIS	Cancer Information Service
DABDA	Denial, Anger, Bargaining, Depression, Acceptance Cycle
GHKL	General Hospital Kuala Lumpur
GLOBOCAN	Global Burden of Cancer Study
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HPLS	Hopelessness Scale
HSA	Hopeful Scale of Adolescents
INHCC	International Health Care Consultants
IPA	Interpretative Phenomenological Analysis
MAKNA	National Cancer Council Malaysia
MRI	Magnetic resonance imaging
NCI	National Cancer Institute
NCSM	National Cancer Society of Malaysia
NHS	National Health Service
NSLC	Nowick-Strickland Locus of Control Scale
PAR	Participatory Action Research
RSE	Rosenberg Self-Esteem Scale
SCT	Social Cognitive Theory
SES	Self-Efficacy Scale
SLT	Social Learning Theory
UICC	Union of International Cancer Control
VSD	Value sensitive design
WBCA	Women’s Breast Cancer Association Malaysia
WHO	World Health Organisation

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CHAPTER ONE
INTRODUCTION

This study is an Interpretative Phenomenological Analysis (IPA) (Smith and Osborn, 2007) of the experience and the information needs of Malay children whose parent has cancer. This study was developed as a response to observations while employed at National Cancer Society Malaysia (NCSM) that, cancer's consequences to children of cancer patients exacerbated an already difficult situation.

This chapter provides an introduction to the research. This introduction provides background information about the importance of information to cancer patients and their families. It also provides an explanation about the rationale and aim of this study. This chapter then provides the research process and, the structure of the thesis.

1.1 INTRODUCTION

In order to facilitate understanding of why research about the information needs of cancer patients' children is of concern, an introduction providing background information is necessary. This is done by a discussion about i) the prevalence of cancer, ii) cancer's consequences for the family, iii) the need for information and, iv) the need for research.

1.1.i THE PREVALENCE OF CANCER

"Cancer is a serious global health problem" (Anandakumar, 2012, p.8). GLOBOCAN (2013a, para. 1) reported that in 2012, there were "14.1 million new cancer cases, 8.2 million cancer deaths" and a 5-year prevalence[1] of "32.6 million people living with cancer". 2020 projections estimated, "17.1 million" new cancer incidences[2] (GLOBOCAN, 2013b) and "10 million" cancer-related deaths are predicted worldwide (GLOBOCAN, 2013c).

In the United Kingdom, the Office for National Statistics reported that in 2010, there were "268,758 newly diagnosed cases of malignant cancer registered" (Office for National

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[1] 5-year prevalence: According to GLOBOCAN 2012 ("*Glossary of Terms, Prevalence")* this refers to "the number of persons in a defined population who have been diagnosed with a particular type of cancer, and who are still alive at the end of a given year". Earlier cancer statistical report terms this as the "5-year relative survival rates" (Parker et al., 1996, p.7).

[2] Incidence: According to GLOBOCAN 2012 ("*Glossary of Terms,* Incidence*")* this refers to "the number of new cases arising in a given period in a specified population". Cancer registries collect this information routinely. This provides an approximate average risk (per 100,000 persons yearly) of developing a type of cancer.

Statistics, 2012, para. 1) and cancer was attributed as the “most common cause of death” (Office for National Statistics, 2013a, para. 5). There was a 2010 lifelong risk assessment for four in ten people (Cancer Research UK, 2013, para. 2).

In Malaysia, at the time of this thesis, the most updated cancer report on incidence and mortality was the 2007 Malaysian National Cancer Registry (Omar and Ibrahim, 2011). In 2007, “cancer was the third common cause of death” (Omar and Ibrahim, 2011, p. 19). In the same year, “18,219 new cancer cases” (Omar and Ibrahim, 2011, p. 24) were reported. According to Looi et al. (2004, p.13), Malaysians had a “cumulative lifetime risk of about 1:4” This suggests in 2010, out of the 28.3 million Malaysians (Department of Statistics Malaysia, 2010) approximately 7 million Malaysians were at risk of developing cancer throughout their lifetime.

While cancer is a preventable disease, in most cases late diagnosis and lack of cancer education and/or information about symptoms, preventive measures and risks were cited as reasons for the high mortality rate (Chiu and Winstow, 2002, pp.5-6; NHS Scotland, 2002, p.5; Cooley, 2010, p. 24; Miller et al., 2012, pp. 47-49). Anandakumar (2012, p.8) stated that the severity of the cancer issue is compounded by the fact that “more than half of all cancers occur in developing countries”, which have “only 5% of the resources to deal with cancer” and that most people report as “advanced stage cancer patients”.

Malaysia’s National Cancer Registry Report 2007, similarly published that at diagnosis, 57.6% were already at advance stages of cancer (Omar and Ibrahim, 2011, p. 23). Braun et al. (2002, p.192), believed that the high cancer mortality rates were due to “fatalistic attitudes toward the disease, poor access to care, and lack of consideration of cultural values in Western approaches to healthcare” which can have detrimental implications for minority or ethnic groups. In addition to that, differing cancer experiences, racial divisions and religious attitudes may influence adherence to medical treatment (Schultz et al., 2003, p.156).

Ngoh (2002, para. 3-4) reviewed that the methodology of previous cancer incidence reports in Malaysia as early as 1958 were based only on “statistical data of hospital discharges”, “mortality reports” and on “pathology-based series in favour of sites more accessible to biopsy”. However, according to cancer-centric organisations Union for International Cancer

Control (UICC) (2013) and National Cancer Alliance (2002, pp. 18-19), cancer management should be more than just archiving statistical data about incidence, locality, illness progression, 5-year prevalence and mortality. Statistical data provides little explicit data or evident knowledge that relates to the wider context of people's cancer experience and cancer's consequences for the family. This is discussed in the next subsection.

1.1.ii CANCER'S CONSEQUENCES FOR THE FAMILY

Granet (2002, pp. 169-175) wrote that cancer is a prolonged illness that presents challenges. Cancer also affects other family members (National Cancer Institute (NCI), 2012a; breastcancer.org, 2012; Davey et al., 2005, p. 247; Scott et al., 2003a, 2003b, 2003c; McCue and Bonn, 2003, pp. 47-51). According to Kilicarslan-Totuner and Akgun-Citak (2012, p. 176), Kornreich et al. (2008, p.64), Granet (2003, p. 171) and Scott et al. (2003b, p. 1), illness in the family effects children and their life. Visser et al. (2003, pp. 683-694) reported that parental cancer impacts children's emotional and behavioural functions as well as school performance. Kornreich et al. (2008, p. 65) reported that children's behavioural and psychological changes during the cancer crisis are often unnoticed. Furthermore, according to Kilicarslan-Totuner and Akgun-Citak (2012, pp. 176-183), children do not have effective coping strategies and are usually not prepared to deal with illness-related issues.

It was observed while employed at National Cancer Society Malaysia (NCSM) in 2004 that cancer's consequences to the family exacerbated an already difficult situation. Dependent children of cancer patients were observed to have several reactions to parental diagnosis and the cancer treatment process. Children frequently accompanied their ill parent for medical check ups and NCSM activities. Some children actively sought out cancer information by using the NCSM library and talked to staff. Patients oversaw their children's homework while waiting to see their doctor and some read magazines together. Some children seemed to distance themselves from their parent; some appeared to have separation anxiety; some appeared lost, listless and uncaring; and some seemed to be very caring and concerned with parental well being. These children's reactions infer that cancer affected them in many ways.

These experiences prompt further questions about the information needs of children when faced with parental cancer. Courtright (2005, para. 1) believed that it was "particularly important to examine the dynamic interactions among study populations and their information environments". However, despite the consequences, awareness for health information and attention to adolescents' and children's needs were limited (Visser et al., 2004, p. 684). According to Finch and Gibson (2009, p. 214) "Little attention has been paid to what or how young people should be told about their parent's cancer diagnosis" and, "parents are seeking help with this aspect of communication". Kennedy and Lloyd-Williams (2009, p.149) reported similarly. The need for information is discussed in the next section.

1.1.iii THE NEED FOR INFORMATION

The need for information for the patient as well as for family members was increasingly evident (Adams, 2013; breastcancer.org, 2012; Chiu and Wistow, 2002; McCue and Bonn, 2003; NCI, 2012; Scott et al, 2003a, 2003b, 2003c). Furthermore, the available cancer information and reports of patients' and their families' experience suggests that information needs were not being met (Cline et al., 2007, p. 168; NHS, 2002; Smith and Preston, 2000, para. 29; The National Cancer Alliance, 2000, p. 5; Rolinson, 1998, para. 7; Wilson and Walsh, 1996, para. 11, Chapter 4.1.1). Even though "information reassures cancer patients by providing them with realistic expectations, empowers them to enquire further and helps to prevent unnecessary distress", not many studies looked into the effects of communication of information to "patient health outcomes" (Kerr et al., 2003, p. 421).

According to Chiu and Wistow (2002, p.2), "the fact that carers felt that they were not listened to highlights the need for improvement". According to Lockwood and Manaszewicz (2004, p. 632), "silence does not equate satisfaction with provided information or a lack of questions". Cline et al. (2007, p. 170) suggests that communication strategies may be of help to reduce barriers to information seeking. A 2004 sentiment of Lord Warner, the UK Health Minister, was that disease prevention through behavioural change was key to reducing deaths from cancer (National Cancer Research Institute, 2004, para. 6).

However, Tu and Hargraves (2003, p. 1) reported that while "people living with chronic conditions were more likely to seek information, yet more than half did not". Baker and Pettigrew (1999, p. 445) posed the question that if "people who were better informed were also better able to reduce their personal uncertainties about their health care, why do people seem not to want it and why do they prefer to obtain it from non-institutional or non-professional sources?"

Baker and Pettigrew (1999, p. 445) believed that there were shortcomings in communicating health information. “False assumptions about users” (Eschenfelder et al., 2004, p.586), “disproportionality of access” (Wilson and Walsh, 1996, Chapter 4.1.5, para. 1), “emotional barriers” (Baker and Pettigrew, 1999, p. 447; Kassulke et al., 1993, pp. 51-56), failure to meet information needs and their attendant motive (Wilson and Walsh, 1996; van Zuuren and Wolfs 1991, pp.141-149; Dervin, 1983) and “low literacy skills” (Doak et al., 1998, pp.151-162) seem to exacerbate problems with effectiveness in communicating cancer information.

Specifically, one of the reasons for the low response rate can be attributed to low literacy where it was observed that, “people guessed their way through an instruction, read so slowly as to miss the context and reach an incorrect conclusion, “tune out” oral advice, ask less questions as they are less fluent and fear being found out as a low literacy individual” (Doak et al., 1998, pp.151-162). While employed at NCSM, preliminary discussions with cancer patients suggest that information in ethnic-specific language and cultural context may be of greater relevance to them.

In addition to these concerns, Morrison and Meier (2004, pp. 2583) suggest, “in typical clinical encounters, clinicians elicit fewer than half of patients’ concerns” and with regards to treatment, doctors fail to discuss patients’ values, goals of care, and preferences. Insensitive remarks by doctors contribute to patients’ distress (Adams, 2013). This seemed to be typical in Malaysia as well. According to Somasundaram[3] (personal communication, 29 November 2011), some doctors were taught that patients did not need to be informed about everything related to their situation. She attributed this to the power relationship between doctors and patients; the perception of doctors as health specialists and that a patient could not possibly know or understand anything medical. She also felt that the constraints of time and the perception of patients being a medical condition rather than a person with multiple roles and responsibilities, contributed to doctors’ attitude in sharing information.

It was also identified that patients increasingly require more diverse types of information and that there were expanding priorities in healthcare (Anderson and Chu, 2007, pp. 209-211).

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[3] Somasundaram, S. (personal communication, 29 November 2011): Interview on 29 November 2011. Further discussion about her experience as the Executive Director of National Cancer Society of Malaysia and surviving parental cancer, cancer support services, information needs, cultural response to a cancer diagnosis and how cancer impacts family members.

One of these concerns is that advances in medicine necessitates more economical cancer management that results in an increased patient preference for home-based care (National Cancer Institute, (NCI) 2009b, p.1). Kilicarslan-Totuner and Akgun-Citak (2012, p. 176), Kornreich et al., (2008, p. 64) and Granet (2003, p. 169) reported that home-based care has implications for the patients' family and children. In many cases, parent's chronic illnesses have positioned children in care giving roles that surpass their skill sets, cognitive ability and physical abilities (Skovdal and Ogutu, 2009; Rowlands, 2005, pp.16-21; Sweeny, 2003, p. 21-23; Granet, 2002, pp. 169-186; Farnham et al., 2002, pp. 375-382) which can present many difficulties (Atherton, 2004, para. 1-5) for children. Rolinson's 1998 study reported there was "little evidence of adolescents needs addressed in the provision of health information" (Rolinson ,1998, para.7).

Preliminary discussions with Malaysian health practitioners, cancer patients and their children suggest that children's difficulties are made more challenging with information that was not digestible and used language that was either not native or too complex, culturally insensitive or contextually irrelevant. It was observed while employed at NCSM that the lack of information for children seemed to be further compounded by parental attitudes to information sharing. This could be attributed to the "continued censorship of adult information to maintain and protect the innocence of children and adolescence at the price of continued ignorance and relative information poverty" (Kerslake and Rolinson, 1996, p.58).

The National Cancer Institute (NCI) provides another possible explanation. In situations of critical illness, some parents may not be ready to talk about their situation; either they first needed more time in sorting things out mentally or they did not know how to talk about upsetting things with their children (NCI, 2012b, para. 5-9). However, "most children can sense when things are worse" (American Cancer Society, 2012b, para. 19) and that "children will often imagine the worse if they are not told the truth" (American Cancer Society, 2012c, para. 5). Granet (2002) writes that withholding information, even for their supposed good, compounds the difficulty and makes it harder for children to cope.

Children's experiences and situational difficulties suggest that there are many issues related to provision of health information to be investigated. Rolinson (1998, para. 4) emphasized the need for good personal and written information for children. Kalbach's (2000, para. 47) article called for the development of “more intelligent, intuitive systems that were user-centred and supported fundamental human information needs and goals”. Studies by Mooney and Blackwell (2004, pp. 76- 78), Kerr et al. (2003, pp. 424-427) and Schattner (2002, pp. 135-136) identified that patients and their carers wanted information about wellness, quality of life, how to cope with the effects of the diagnosis and how to prepare for role changes.

The advocacy to improve access to services for prevention and treatment, palliation and rehabilitation has been promoted as a Key Action by the World Cancer Declaration and UN Political Declaration (UICC, 2012, pp.2-3). Doak et al. (1998, pp.151-162) suggests that there should be “a reasonable match between the logic, language, and experience in the information to the patient” such that patients “evaluate advice as making sense to them”, be “logical from their perspective”, “fits into their current lifestyle”, “is achievable”, and “is worth their time to implement”.

Prior to developing a cancer control policy, it may be prudent to consider cultural, societal and religious factors that may influence community participation or act as barriers (National Cancer Alliance, 2002, pp. 36-41). In Malaysia, Mahathevan (1999, p. 23) advocated similarly. Hodge et al. (1998, p. 1593) wrote that people “responded favourably to a culturally framed health information”. Wilson and Walsh (1996, Chapter 2.5, para. 1) suggested that focusing on the proximate causes of information seeking behaviour would be a good place to start. In addition, an awareness and respect for how information flows was an important contributor to improving public awareness of consumer health issues and practices, and to information among service providers (Friedman and Kahn, 2003, para. 1).

1.1.iv THE NEED FOR RESEARCH

As indicated above, there were reports of unmet information needs of cancer patients and their families, advocacies for information provision to children and, reports of behavioural consequences of parental illness. These reports combined with observations while at NCSM suggested a need for a better understanding of cancer patients’ and their dependent children’s experience, specific information needs and information seeking behaviour. This might mitigate some of the issues and problems that many families faced.

Aim and objective of research:

It was with the above observations and problems that the overall aim of the study was to explore the experiences of Malay children whose parent has cancer to identify priority information needs and to seek possible solutions to their information-needs problems. More specifically, the objectives of this research were to better understand Malay children's information experience when they have a parent with cancer. This included:

- Children's perception of cancer (for example, cancer is a dangerous disease),
- Children's' information culture (for example, doctor's attitude to informing children),
- Children's information needs (for example, how to care for a parent at home) and,
- Children's information seeking behaviour (information sources, preferences and sharing attitudes) that included barriers (for example, low literacy) and enablers (for example, discussions with parents).

In order to meet these objectives, the following research questions were developed:

1. What are Malay children's understanding of their parents' cancer; its causes, effects, implications and consequences?

2. What consequences does children's understanding or lack of understanding about cancer have for them?

3. What interventions may benefit children and enable them to cope with their parents having cancer?

These research questions are further detailed in Chapter 3, Methodology on page 54.

1.2 PROPOSED RESEARCH PROCESS

The research aim and objective necessitated an exploration of Malay children's information experience when they have a parent with cancer. This included their perception of cancer and information culture. This also included the exploration of information needs, information seeking behaviour, barriers and enablers. In order to do this, first explore the factors influencing information seeking, secondly to better understand information needs, and then thirdly to identify how information was synthesized and used by Malay children.

This exploration was a six step process:

The **first step** was to conduct a desk-based literature review to investigate the importance of health information to patients and their children, children's experience with parental cancer and current information interventions for children with parental cancer.

The **second step** was to develop the methodology to undertake the research. This involved evaluating research methodologies to identify appropriate approaches, methodologies and techniques that have been applied to investigate children's experience with health related, traumatic life events and care giving.

The **third step** was to recruit participants. Volunteer participants were sought through a series of activities through the National Cancer Society of Malaysia and participation requests through General Hospital Kuala Lumpur and Ministry of Health Malaysia. Among the requirement criteria was for participants to either be 1) a cancer patient with informed children or, 2) a child already informed about parental diagnosis.

The **fourth step** was to explore the experience and information needs of participants. Two focus groups were created to explore patients' and children's experience, information seeking behaviour, barriers and enablers. The first group consisted of cancer patients. The second group consisted of their dependent children. This exploration was guided by a Participative Action Research (PAR) approach and utilised focus group techniques. Activities included participant's narratives and drawings as an alternative platform for participant's voice. All of these activities were audio recorded while drawings and written essays were photographed.

The **fifth step** was to synthesize and analyse findings. This is supported by data collected from the fourth step. Utilising an Interpretative Phenomenological Analysis (IPA), themes were developed to better understand relationships and information flow as well as to categorise findings. This step also identified priority information needs, information seeking behaviour, barriers and enablers.

The **sixth step** was to seek participants' suggested solutions and/or interventions for key information needs identified in the fifth step. Findings led to recommendations for a user-centred and culturally sensitive information system.

Details of these steps are discussed in the Methodology chapter on page 67.

1.3 THESIS STRUCTURE

CHAPTER ONE provides a structural rationale and the description of the research. The aim and objectives of the research are discussed and its description was provided by reference to six stages of data collection and collaboration with participants.

CHAPTER TWO reviews the literature related to the research. As the research used resources from various subject areas, the chapter is divided into various sections. One section reviews issues related to information-seeking behaviour in addressing the needs and development of user-centric information systems with a particular emphasis on issues related to critical illnesses. Another section reports on defining and understanding the concept of health informatics and the importance of health information to patients and their children. Another section reviews theoretical and methodological approaches applied to research with children.

CHAPTER THREE describes the theoretical and methodological approaches adopted in this study. Data collection process and research tools were discussed.

CHAPTER FOUR reported on findings and provided an analysis of the data. It highlights key information needs of children participants and their suggested solutions.

CHAPTER FIVE provides a discussion of the findings, addresses the research's primary aim and, the implications of the study.

CHAPTER SIX concludes the study and highlighted key findings. It also discusses how these findings contribute to the knowledge and understanding of ethnic-based information problems, needs and provision. This chapter also acknowledges the limitations of the research and discusses possible further research.

1.4 CONCLUSION

Research as early as 1979 and up to 2013 suggested that a parent's cancer diagnosis had psychological and behavioural consequences for dependent children. These consequences were documented in western countries and among children of predominantly Caucasian ethnicity (Chiu and Winstow, 2002; NHS Scotland, 2002; Cooley, 2010; Miller et al., 2012, Granet, 2002; National Cancer Institute, 2012; breastcancer.org, 2012; Davey et. al, 2005; Scott et. al, 2003a, 2003b, 2003c; McCue and Bonn, 2003). A few documented studies from among African American and Asians living in either United States of America or United Kingdom (Rowlands, 2005; The National Cancer Alliance, 2002; Archibald, 2000; Schultz et al., 2003). Some of cancer's consequences were attributed to a lack of accessible, relevant, digestible and age appropriate information about cancer, its treatment, in what way cancer may impact the patient and their families, and what can be done to mitigate problems that may occur. However, very little research has been conducted with Malay patients and their dependent children's information needs. This thesis therefore aims to explore the experience of Malay children whose parents have cancer and their information needs.

In order to explore this, a review of the literature is undertaken followed by an intensive process of data gathering, involving children and parents. Utilising an Interpretative Phenomenological Analysis (IPA), the data was analysed for themes and findings about children's perception of cancer, key information needs, information seeking behaviour, barriers and enablers. The search strategy, methodology, analysis and findings are presented in subsequent chapters. Discussion and Recommendation chapters are included towards the end of this thesis.

The review of literature is presented in the next chapter.

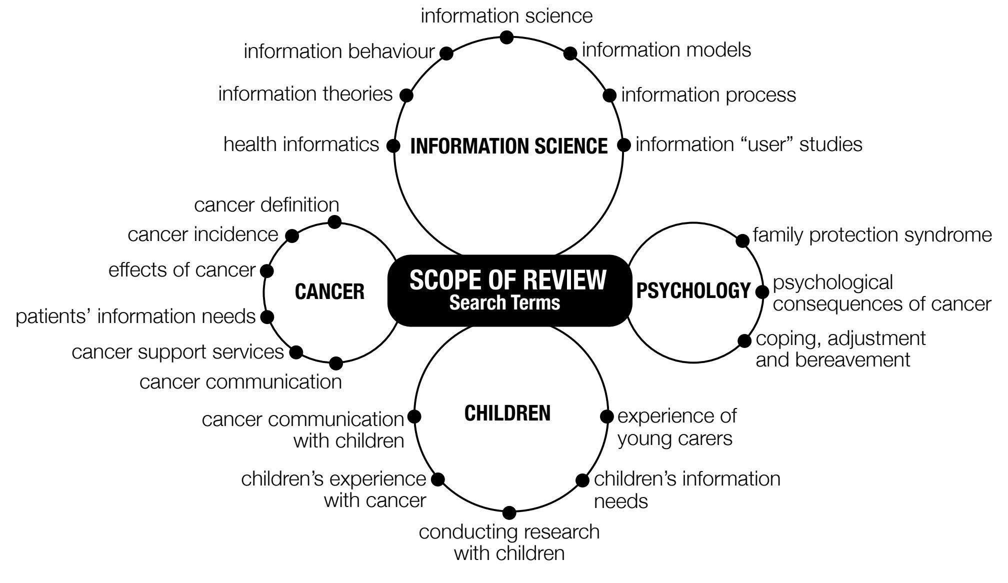
CHAPTER TWO
LITERATURE REVIEW

This chapter is a literature review that reports the desk-based research and discussions with health practitioners. The review explores the importance of health information to patients and their children, children's experience with parental cancer and current information interventions for children with parental cancer. The chapter is divided into several sections: 1) Methods for literature search, 2) The role of information, 3) Review of interventions with children and, 4) Factors influencing information use. It concludes with a summary of key findings.

2.1 METHODS FOR LITERATURE SEARCH

This research was interdisciplinary in nature because it focused on various topics related to information science (health informatics), cancer (patient's information needs), children (experience of young carers) and psychology (psychological consequences to cancer). The scope of review strategy and search terms is illustrated in Diagram 2.1 below.

Diagram 2.1: Scope of Review and search terms used in this study



The search was limited to publications written in English and Bahasa Malaysia. This review focused on publications from 1979 and up to 2013. This was because, according to Wilson (1994), the movement away from system-centred studies to person-centred studies did not begin until the late 1980's. This was found to be true as preliminary research and articles in support of person-centric studies were only available beginning 1979. Another reason for this scope of review was that research about consequences of cancer to children and their role in caregiving was sourced from multiple disciplines. Publications were also traced from 1979. Review sources were from academic databases; Internet databases; electronic journals; cancer centric organisations and; research, reports and personal communication with several research-relevant organisations and individuals. This is listed in Table 2.1 below:

Table 2.1 Sources for the literature review

A. Academic Databases

Cochrane Library, DARE, Digital Dissertations, ElSIVE, Loughborough University's MetaLib, MEDLINE, PubMed, Sage Publications, ScienceDirect, and Wiley Interscience.

B. Internet Databases

Yahoo!, and Google Scholar: "information science", "information behaviour", "information models", "information theories", "information process", "cancer", "cancer communication", "communicating with children", "coping" and "young carers".

C. Electronic Journals

- A Cancer Journal for Clinicians
- American Association for Cancer Research online journals (AACR)
- American Journal of Pathology
- American Journal of Public Health
- American Society of Clinical Oncology access to abstracts (ASCO)
- Applied Nursing Research
- BioMedCentral
- Bulletin of the Medical Library Association
- British Journal of Cancer
- British Medical Journal (BMJ)
- CA - A cancer journal for clinicians
- Cancer
- Cancer Control
- Cancer Forum - Journal of the Cancer Council of Australia
- Cancer Nursing
- Cancer Practice
- Clinical Cancer Research
- Clinical Oncology
- Communication Monographs
- European Society for Medical Oncology
- Health Education Research Online
- Health Education Quarterly
- Human Communication Research
- Information Processing and Management
- Information Research
- informationR.net
- International Health Care Consultants
- Journal of the American Medical Association
- Journal of Cancer Education
- Journal of Child Psychology Psychiatry
- Journal of Clinical Ethics
- JCO - Journal of Clinical Oncology
- Journal of Communication
- Journal of Consumer Research
- Journal of Medical Internet Research
- Journal of Medical Research
- Journal of Palliative Care
- Journal of Personality and Social Psychology
- Journal of Primary Prevention
- Journal of Urban Health,
- Journalism Quarterly
- Lancet Oncology
- Medical & Paediatric Oncology
- NLM Gateway
- Palliative Care
- Patient Education and Counselling
- Paediatric Nursing
- Psychology Today
- Qualitative Health Research
- Quality in Health Care
- The New England Journal of Medicine
- Western Journal of Medicine
- World Cancer Research Fund
- World Health Organization
- World Journal of Surgical Oncology

D. Cancer Centric Organizations

- American Cancer Society*
- breastcancer.com*$^{+}$
- cancercareconnection.org
- CancerSource.com
- Cancer Bakup, United Kingdom*$^{+}$
- Cancer Care Connection
- Cancer Control - Journal of the H. Lee Moffitt Cancer Center
- Cancer Council Victoria, Australia*$^{+}$
- Cancerlink, Malaysia*
- Cancer Journal for Clinicians
- Cancer Research, United Kingdom*
- Doncaster, Nuffield Institute for Health
- GLOBOCAN*
- International Union Cancer Control Council*
- Macmillan Cancer Relief*$^{+}$
- National Cancer Alliance, America
- National Cancer Council, Malaysia (MAKNA) *$^{+}$
- National Cancer Institute, America*
- NCI Cancer Institute, Malaysia*$^{+}$
- National Cancer Society Malaysia (NCSM)*$^{+}$
- Malaysia Radiology*
- NHS Doncaster
- NHS Scotland
- NHS UK*$^{+}$
- Scottish Cancer Index
- The Oncologist
- WEST Cancer Hospital Project
- Women's Breast Cancer Association, Malaysia (WBCA)*$^{+}$

(* including education and/or marketing materials, $^{+}$including interviews/discussions)

E. Reports By:

- 18th Asia Pacific Cancer Conference Seoul 2005: Toward the Tailored Therapy for Cancer
- Annieappleseed project
- Cancer Information Strategy, Department of Health, UK (2000b)
- Calman-Hine Report: A Policy Framework for Commissioning Cancer Services: A report by the Expert Advisory Group On Cancer To The Chief Medical Officers of England and Wales (1995)
- Improving Outcomes: A Strategy for Cancer (Policy) (2011), Department of Health, UK
- Improving Access to Cancer Information for Doncaster Residents. Doncaster NHS 2002
- Making Health Communication Programs Work, National Cancer Institute, 2001
- National Cancer Registry, Malaysia (2002, 2003, 2007)
- Scottish Health Statistics
- The NHS Cancer Plan: next steps, Department of Health, UK (2000a)
- The Teamwork Project – A Personal Information File for Cancer Patients working with their Healthcare Professionals. National Cancer Alliance
- The Pew Internet & American Life Project 2002
- US Department of Health and Human Services
- WEST Cancer Hospital Project
- World Health Organisation

F. Personal communication with:

- Adeline Joseph, Administrator and cancer survivor, National Cancer Society Malaysia
- Dr. P.A. Anandakumar, Director, WEST Cancer Hospital Project
- Breastcancer.org, about children's reactions and concern about mother's cancer. Obtained cancer information materials.
- Cancer Research UK about cancer statistics
- Elizabeth Kubler-Ross Foundation, About DABDA and implications in children's reactions to parental cancer
- Dr. Anne Greig, about conducting research with children
- Dr. Mark Hepworth, Reader in People's Information Behaviour, Loughborough University
- Dr. Mat Saat Mohd. Baki, Clinical Psychologist, Pantai Medical Hospital, about "child protection syndrome"
- Dr. Saunthari Somasundaraom, Executive Director, National Cancer Society Malaysia about experiences in a cancer support center
- Dr. Tim Scott, author of 'Interventions for improving communication with children and adolescents about a family member's cancer'

G. Participation in:

National Summit on Breast Cancer Education 2006. 30 June-2 July at Sunway Lagoon Resort Hotel Malaysia

The above sources provided background information and guided the research. The review is presented as three global themes; 1) The role of information, 2) Overview of interventions with children and, 3) Factors influencing information use.

2.2 THE ROLE OF INFORMATION

This global theme is presented from several organising themes: i) The concept of information behaviour, ii) The concept of information need, iii) Inclusion of information into health provisions, iv) Importance of information to patients, and v) Importance of information to patients' children.

2.2.i THE CONCEPT OF INFORMATION BEHAVIOUR

According to Gray's (2003, p.259) review of Case's 2002 *Looking for Information: A Survey of Research on Information Seeking, Needs, and Behavior*, information-seeking behaviour is a study that included components from psychology, management, communications, and information science. Gray (2003, p.259) concluded this from Case's estimation of more than 10,000 publications from various disciplines associated with people's quest for knowledge.

Case (2012, p.275) reiterated this as more than 10,000 publications concerned with the different aspects of information behaviour. Rieh (2013, para. 1) believed that information behaviour was a "complex information and communication activity requiring access to diverse information systems and resources in order to deal with work-related, personal, and social information problems". According to Wilson (2000, p.49), information behaviour "... is the totality of human behaviour in relation to sources and channels of information ..." His definition also included all forms of active and passive information seeking and information use. Johnstone et al. (2004, para. 48) compared that while "human information processing defines what must be done, information behaviour describes how they do it". In a similar line of thought, Taylor (1991, p. 221) believed that information science was the collection of "activities through which information becomes useful". These activities were believed to be dependent on the "type of person, the problem, the setting (of both people and problem)" and what an individual considered to have resolved the said problem (Taylor, 1991, p. 221).

Davenport believed that information behaviour was "how individuals approach and handle information", which would include "searching, modifying, sharing, hoarding, and, even ignoring it" (Davenport, 1997, p.83-84). He clarified that sharing information was a "voluntary act of making information available to others", that managing information overload was a process of filtering for usefulness, and that there were varied and multiple meanings to information (Davenport, 1997, p. 87-88). According to Urquhart (2001, para. 1), information behaviour research was conducted in order to obtain better understanding about information needs and use, through "sense-making as advocated by Dervin and Nilan (1986)" or "features as proposed by Ellis (1989)" or from an "uncertainty phenomenological viewpoint by Kuhlthau (1991)" or a "problem-solving activity/process which considers uncertainty as promoted by Wilson (1999)." Specifically, Bonner et al. (1998. pp. 68-74), further elaborated that information behaviour included determining the information need and finding the said information; recognising the said information's new potential uses; recombining different and seemingly unrelated information; assessing the said information's value; communicating the said information as needed; recontextualising the said new information into already known information; and effectively archiving it.

Related to information behaviour is information seeking, searching and information use behaviour. Wilson (2000, p. 49) defines the three nuances as follows:

> **"Information Seeking Behaviour:** The purposive seeking for information as a consequence of a need to satisfy some goal.
>
> **Information Searching Behaviour:** The 'micro-level' of behaviour employed in interacting (of all types and levels) with information systems.
>
> **Information Use Behaviour:** The physical and mental acts involved in incorporating the found information into the person's existing knowledge base."

According to Bacon (1994, p. 448), this focus on information behaviour may help to identify specific kinds of information that leads to "purposeful and relevant action". Furthermore, according to Urquhart (2001, para. 9), the aspects of exhibited information behaviour may indicate different "dimensions of information seeking strategy: method of interaction (scanning/searching), goal of interaction (learning/selecting), mode of retrieval (recognition/specification) and resource considered (information/meta-information)", all of which revolves on the human element as a 'user'. This was vital to an understanding of an effective information system (Urquhart, 2001, para. 2) and that information systems designers should not ignore these important dimensions (Urquhart, 2001, para. 3).

As informed by the literature review, an understanding of what constitutes a 'user' would then be necessary. According to Wilson and Walsh (1996, para. 3-7, chapter 2), this suggests that at the root of information seeking behaviour is the concept of information need and its attendant motive. A review about the concept of information needs is presented below.

2.2.ii THE CONCEPT OF INFORMATION NEEDS

In tracing the concept of information needs, Saracevic (1997a, p. 6) advocated for seeking the most "effective and efficient interaction between people and literature" through people's information need. Burnkrant (1976, p. 22) argued that 'need' was a psychological concept referring to a mental state of a "desired future goal". According to Wilson and Walsh (1996, Chapter 2, para. 10), 'needs' was a cognitive recognition to provide order and meaning depicted through a person's "need to know, curiosity, and the desire to be informed". Wilson and Walsh (1996, Chapter 2, para. 6) further attributed this as a result of one of three motives: psychological motive, unlearned motive and, social motive. Wilson and Walsh (1996, Chapter 2, para. 7) believed that when a motive was triggered, a "belief-value matrix" containing relevant images of objects or elements of past experience, was called on.

Burnkrant (1976, p. 23) explained that this matrix becomes a benchmark for meeting or satisfying an individual's need.

In tracing the concept of 'motive', Wilson and Walsh (1996, Chapter 2, para. 9) suggested that people actively sought information in order to gratify their needs as a form of diversion, for personal relationships, or for personal identity. An important distinction is the understanding that information need was "a subjective experience occurring only in the mind of the person in need" Wilson (1981, p.4) and hence, its occurrence can only be documented through deduction from observed behaviour or through self-reports. Wilson (1994, para. 61) further refined this concept by including Belkin's (1980, p. 135) belief that a user's information need was because of an "anomalous state of knowledge" and Ford's (1980, p.100) belief that an awareness of a state of "not knowing – or some conceptual incongruity or cognitive inadequacy" led to information seeking.

However, a different nuance to this was Dervin's (1983, p.3) belief that information need was a "coherent set of concepts and methods" use of information and, of how people cognitively and procedurally constructed their world in order to make sense of their experience. Dervin's sense-making approach included concepts of "**situations"** referring to the time-space patterns where sense is made (Dervin, 1983, p.6), "**gaps"** referring to the place where questions led to sense making (Dervin, 1983, p.9) and "**uses"** referring to how newly created sense are put to use (Dervin, 1983, p.3).

Wilson (1994, para. 67) suggested that the essence of information need should merge concepts from Dervin, Belkin and Ford; it was a result of comparative shortcomings (a state of "not knowing") between constructed meanings embedded in information systems and an individual's meaning attributed to their problem(s). This provides a reasonable definition for information needs and will be used as a framework to better understand the information needs of children of cancer patients. Closely related to information needs is information requirement(s). It was understood from Taylor (1991, p. 221), that the type of information required depended on a specific problem and the decision making process in order to resolve the said problem. Thus, information requirement can be considered as the values, types and variables of information necessary to address the issue (or solve a problem) of an information need aroused by a person's state of "not knowing".

However, most research concerns about information requirements dealt with the manner in which information was provided and portrayed as a means to meet the requirements or need of users. According to Urquhart (2001, para. 1-12) conventional systems approach information requirements with the aim of providing three views of data; i) a formal role for the ‘user’, ii) analysing the data, and iii) the ‘display’ of data. This contradicted Bacon’s (1994, p. 448) advocacy for information to be “kinetic” by first considering the purpose, relevance and value of information to trigger action. In order to assimilate the above concepts, the researcher developed Diagram 2.2 below.

Diagram 2.2: Overview of the relationship between ‘user(s)’, information needs and motives, information requirements, information behaviour and information seeking strategies

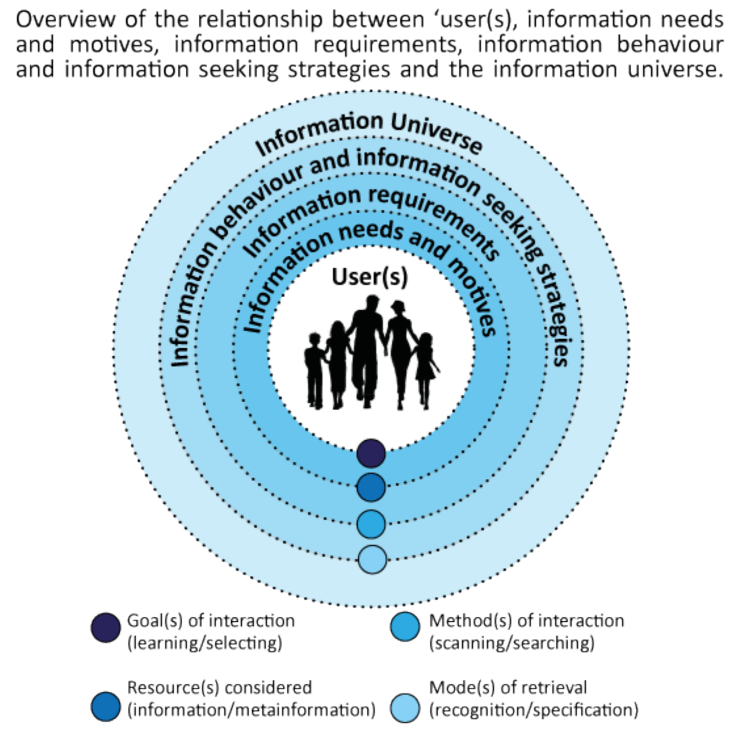


Diagram 2.2 presented an overview of what the researcher understood about the relationship between ‘user(s)’, information needs and motives, information requirements, information behaviour and information seeking strategies. The central concept of the Information Universe was “User(s)” as placed in the centre. User(s) are identified either as individuals or people (being the genesis of an information need, motive and seeking behaviour) having a goal or goals of interaction (learning or selecting) for their information needs and motives (second circle from centre of Diagram 2.2) to be triggered. The information needs and motives circle represents the concept of “motive” by Burnkrant (1976), Wilson and Walsh (1996) and how it relates to user(s). This is also representative of Ford’s (1980) awareness of

a state of “not knowing” and Belkins (1980) "anomalous state of knowledge" that motivated information need.

Once an information need has been identified, the information flows from user(s) towards refining their information requirements (third circle from centre). User(s) move from their information needs and motives by refining their method(s) of interaction (scanning or searching) in order to meet, satisfy or answer or resolve their information need. This was representative of Taylor’s (1991, p. 221) belief about the relationship between information required and the decision making process in order to resolve a specific problem. After refining methods of interaction, user(s) move to a information behaviour and information seeking strategies (fourth circle from centre) that they are familiar with or have identified as ways in which they can best obtain their required information. User(s) undergo a cognitive process of resource(s) considered (information or metainformation). After this behaviour, user(s) then have mode(s) of retrieval (recognition or specification) of the information they needed from what is available or accessible to them from the information universe (fifth circle from centre). In doing so, user(s) utilise their preferred methods (as identified by Dervin, 1983) to make sense of the found or retrieved information. The new information is then assimilated (compared, validated and recontextualised) into new and useable knowledge that is archived for future use. This was representative of Bonner et al. (1998)’s belief of what information behaviour constitutes.

Diagram 2.2 depicted what the researcher understood about the relationships of the different information science nuances; how humans (as the genesis of any information need and behaviour) relate to how sources and channels of information are considered. It was an overview of the researcher’s understanding of how user specific inquiries and strategies related to the type of information sought, how information relevancy was developed and what were the possible information use from what is known or can be found/retrieved from what information is made available. Diagram 2.2 also provided a framework in which this research was guided. Research participants were user(s) of information and the research explored their information needs, information seeking behaviours, enablers and barriers.

2.2.iii INCLUSION OF INFORMATION INTO HEALTH PROVISIONS

This organising theme reviews the inclusions of information into health provisions. As mentioned earlier (on page 16**),** the concept of information need and its attendant motive is at the root of information seeking behaviour (Wilson and Walsh, 1996, Chapter 2, para. 3-7). However, most communication materials providing health information do not address nor make more use of these two important elements. This was evidenced by the few research efforts to understand the information needs of individuals for health information.

Understanding human behaviours in accessing health information was crucial because according to Brashers et al. (2002, p.259) "the communicative and cognitive activities such as seeking, avoiding, appraising and interpreting environmental stimuli component of coping with illness and illness-related uncertainty" are pivotal to information management. Reviews found that interest in the information-seeking behaviour of specialised health groups, consumers and patients, and occupations were strong. In North America this was expressed as a progression for personal responsibility to actively seek health information (Alpay et al., 2004, pp. 1-2; Brashers, et. al., 2002).

According to Chen (2011, slide 26), "Information is required not just to exist, but to survive and prosper". According to International Health Care Consultants (1999, para. 3), health care providers have realised that information was required for policy formulation, implementation and monitoring. The World Health Organisation (WHO) recognised that there was a need to evaluate services and patients outcomes (WHO, 2012; WHO, 2005). This was because they identified that "there has been little or no development of systems to evaluate the quality of health care" (WHO, 2013, Objective 6, p. 32) in many countries.

Baker and Pettigrew (1999, pp. 445) posed the question that if "information service practitioners and researchers believed that people who are better informed are also better able to reduce their personal uncertainties" about their health care, "why do people seem not to want it and why do they prefer to obtain it from non-institutional or nonprofessional sources?" They advocated for a more informed framework for the provision of health information services (Baker and Pettigrew, 1999, p. 445). The Internet Health Care Consultants (1999, para. 6) believed that a systematic collection of information increases efficiency and usability for all types of information seekers.

Wilson and Walsh (1996, Chapter 2.5, para. 1) suggested that focusing upon the "proximate causes of information seeking behaviour", would be a good place to start when investigating the information needs and motive of individuals seeking information. In the case of cancer, the individual's information need can either consist of cognitive needs (to obtain factual information about cancer prevention, detection, and/or treatment) or affective needs (to obtain information that aids in dealing with cancer emotionally). According to Baker and Pettigrew (1999, p. 446) this could be a result of monitoring or blunting as developed by Miller (Miller Behavioural Style Scale, Miller, 1987, pp. 345-346) and used by Baker (1995), van Zuuren and Wolfs (1991) and, Steptoe and O'Sullivan (1986). Miller (1987) developed her scale based on how individuals looked for information when coping with uncontrollable stressful events. "Monitors" described people who sought information to help them cope with stress and "blunters" described people who avoided information instead (Miller, 1987, p. 345). However, according to van Zuuren and Wolfs (1991, p. 141) and Dervin (1983, p. 22), other factors such as perceived degree of ease or threat and unpredictably played a role too. Baker and Pettigrew (1999, p. 446) wrote that the kind of information sought also varied with intent; facts versus "I am not alone" feeling.

Additionally, other variables have an impact on the depth of information sought and could become barriers to information seeking. Wilson and Walsh (1996, Chapter 4.1, para. 4) identified eight variables: "Personal characteristics", "Physiological, cognitive and emotional characteristics", "Educational level", "Demographic variables: age, sex and other factors", "Economic barriers", "Social/interpersonal barriers", "Environmental/situational barriers" and, "Information source characteristics". These barriers suggest that information systems and information providers may need to be more cognizant of motives, information needs and problems that people face. Kalbach (2000, para. 47) advocated for the development of "more intelligent, intuitive systems that were user-centred and supported fundamental human information needs and goals". Baker and Pettigrew (1999, p.447) believed that knowing a layperson's preference for information "helps in tailoring information and meeting the extent of their required needs".

These findings influenced the research to further review information provisions for health. This is because according to Shankle et. al. (1999, para. 1), "Health Care Services is an information intensive industry". In addition to that, according to Campbell (2001, p.2)

"Information is a necessary tool in health education". As such it was felt important to have an understanding of the differences between "Health Education" and "Health Informatics".

2.2.iii.a. Health Education

In tracing the concept and definition of health education, Catford and Nutbeam (1984, p. 38) proposed that health education "seeks to improve or protect health through voluntary changes in behaviour as a consequence of learning opportunities". Nutbeam (1998, p. 353) later reiterated this as "consciously constructed opportunities for learning involving some form of communication designed to improve health literacy, including improving knowledge, and developing life skills which are conducive to individual and community health". Slaughter (2001, p.89) suggested that health education was developed as a way to promote "active consumer participation in personal health decisions and concerns".

According to the World Health Organisation (2004b, para.1), Health Education was "any combination of learning experiences designed to help individuals and communities improve their health, by increasing their knowledge or influencing their attitudes". It has also been defined as "Education that increases the awareness and favourably influences the attitudes and knowledge relating to the improvement of health on a personal or community basis" (reference.md, 2012, para. 1). Health education was the "bigger picture that involves the individual, the community, health care providers, policy makers and every person throughout the health value chain" (Glanz, et al. (eds.), 2008a, pp. 9-11). The importance of health education has progressed towards the establishment of the 'Health Education England" (HEE) in 2012 (Health Education England, 2012, para. 1) as a 'Special Health Authority'. HEE was responsible "to improve care and outcomes for patients" and "to help ensure delivery of the highest quality healthcare to England's population" through recruitment, education, training and development (Health Education England, 2012, para. 3).

2.2.iii.b. Health Informatics

Health informatics was traced to the 1970s and was borrowed from the French expression *informatique médicale* which was interchangeably referred to as medical informatics, medical computer science, medical information science and, computers in medicine (Van

Bemmel and Musen, 1999, pp. 3-16). According to Shankle et al. (1999, p.11), this involved the study of "how computers and related technology can support health information systems, health care management, health research and health care education". According to the UK Department of Health, Health Informatics was "the knowledge, skills and tools that enable information to be collected, managed, used and shared to support the delivery of healthcare and to promote health and wellbeing" (Department of Health, 2013, para. 2). Health Education and Health Informatics were inter-related and shared some objectives. However, taking into consideration Shankle et al. (1999) definition, the key difference is that Health Informatics seems more computer-based and is not only concerned with data and information, but also in the management, organisation and delivery of health-based information to patients, health-care providers and other relevant health-oriented users.

In conclusion, the establishment of more health informatics organisations in both government and private practice suggested that information has become a pivotal concern and importance to many. Information seemed even more essential to improved attitudes towards health provision, healthcare and health outcomes. This is discussed in the next subsection.

2.2.iv IMPORTANCE OF INFORMATION TO PATIENTS

This organising theme will review precedent studies about the importance of information to cancer patients and their families.

> "Information is the greatest gift"-- Cancer Patient (Gibson, 2004, para. 1)
>
> "Having all of the information enabled me to replace uncertainty with hope "
> – Cancer Patient (Macmillan Cancer Relief, 2003, The Cancer Guide, p.6)
>
> "Information is often an essential foundation for health decisions" (National Cancer Institute, 2008, p.222)

UK's NHS Department of Health 2011 National Cancer Plan continued to stress the role of information as a major component (Department of Health, 2011, p. 3). This built upon the 2000 National Cancer Plan (Department of Health, 2000, pp.10-14) that contributed to Chiu and Wistow's (2002) needs assessment project for improving access to cancer information for Doncaster residents. Chiu and Wistow (2002, p.ii) reported five key findings that are summarised as: 1) Many patients and their carers were unable to access information and provision should consider patients' vulnerability and diverse social backgrounds, 2) The psycho-social needs of carers were not addressed, 3) There were gaps between primary, secondary and continuity of care, 4) Cancer was still taboo in the public's consciousness, and 5) Community Health Educators could facilitate information to patients and carers.

The National Cancer Alliance (2000, p.5) advocated that patients, families and carers should be given clear and understandable information about treatment options and outcomes from diagnosis and throughout the cancer journey. Leydon et al. (2000, p. 909) wrote that in recent years, communication and information have increasingly been considered important in helping people to cope with cancer. Jenkins et al. (2001) employment of Cassileth's Information Needs questionnaire from a heterogeneous sample of 2,331 patients showed that "87% (2,027 patients) wanted all possible information, both good and bad news" and "98% (2,203 patients) preferred to know whether or not their illness was cancer" (Jenkins et al., 2001, p.49). Furthermore, the study concluded that information alleviated uncertainty, fear and loss about the diagnosis. Results of Jenkins et al. (2001) study was similar to findings by Meredith's 1996 study where a majority of cancer patients wanted more information about their situation than they actually received (Meredith, 1996, p. 725).

According to Scott et al., (2003a, p.2), these information needs differed between individuals and over time. Chiu and Wistow (2002, p. 39) reported similar findings. Scott et al (2003a, p. 2) found that many cancer patients, especially at times of distress, had difficulty in remembering information during medical consultations. Scott et al., (2003a, p. 2) also found that information needs "differ between individuals and over time". Chiu and Wistow (2002) reported similar findings. Scott et al (2003a, p. 2) observed that potential barriers included "limited access to cancer practitioners, learning difficulties, cultural or language differences, or a failure by some practitioners to listen and respond to individual patients' concerns". These experiences raised questions as to how information provision may be developed to create greater relevancy and support in problem solving for variable situations in ethnic patients and their families.

Friedman and Khan (2003, para. 1) reported a lack of information about cancer among disadvantaged people. This was attributed to the flow of information (Friedman and Khan, 2003, para. 1). CancerCareConnection of North America (2004, p.1), was cognizant of cancer patients' frustrations in their search for information. They believed that "information is good medicine" and this was reflected in their 1999 inaugural discussion focusing on the lack of information for cancer patients who often felt that they were alone and that their lives were out of control (Cancer Care Connection, 2003, AboutHistory, para. 1). Gibson (2002, para. 1) similarly wrote "accessible information can lead to a greater sense of being in control at a time when everything can seem out of control." Information seemed to help cancer patients fight and survive their conditions however, according to Chiu and Wistow (2002, p.10) current information was seen as "inappropriate (i.e., information style and language did not commensurate with target audience)" and its dissemination was "inadequate, uncoordinated and inefficient".

An Internet based service, The Cancer Information Service (CIS), a programme of the National Cancer Institute America (NCI), is a resource for information and education about cancer. They believed in providing the latest and most accurate cancer information to patients and families, the public and to health professionals. This was similarly advocated by National Cancer Alliance (2000, para. 2) and the Calman-Hine report (Department of Health, 1995, pp.1-2) whereby cancer patients should be provided with information that facilitated their understanding about options throughout all stages of their illness. Besides being fully informed of their condition, communication of information should be given with "sensitivity, respect and with emotional support" (Chiu and Wistow, 2002, p. 16), a practice that is very seldom experienced by patients and their families (Blum and Sherman, 2010, p. 245; Christ and Christ, 2006, p. 199; Jenkins et al., 2001, p. 50; Meredith et al, 1996, p.724).

As an alternative, "millions of people are turning to the Internet for health-related information" (Shuyler and Knight, 2003, para. 1), and the found information often directly effected the decisions they made. According to Cohen and Adams (2011, p. 1), "74% of all U.S adults use the Internet and 61% have looked for health or medical information on the Internet." This was estimated from the first National Health Interview Survey (NHIS) in 2009 participated by 27,731 people. These participants indicated their Internet use was to seek health information, communicate with health care providers or pharmacies, and to access an electronic health record (Cohen and Adams, 2011, p. 5). Cline et al. (2007, p. 167) reported that of the U.S adults who use the Internet, many seek information online about cancer treatment and clinical trials. Helft et al. (2005, p. 4957) reported that of their 200 survey respondents, the Internet was used to “understand the disease better (81%), research treatment options (71%) and to get help in dealing with cancer (43%).”

However, while the Internet changed the way people learnt about health and illness, according to Ziebland et al. (2004, p. 1), it was “often hedged with concerns” and there was “little empirical research on how people diagnosed with a serious illness used information from the Internet” (Ziebland et al., 2004, p. 1). Some of the concerns were security and confidentiality issues (Cohen and Adams, 2011, p. 5). Neuhauser and Krepps (2008, p. 377) reported, “online cancer communication has not met the literacy, cultural, and linguistic needs of diverse populations”. Helft et al. (2005, p. 4957) reported that 53% of their participants indicated the most common barrier to seeking online cancer information “was not having access to a computer”. According to Cline et al. (2007, p. 168), “Regardless of Internet use, patients with cancer report receiving insufficient information about their disease, want more information, and want to participate actively in medical care”. Cline et al. (2007, p. 170) suggest that communication strategies may help to reduce these issues.

These findings suggest that patients’ information needs and health seeking behaviour certainly merit further attention (Leydon et al., 2000). Ian Gibson, chairman of Patient Information Sub-group of the Scottish Cancer Group wrote, “We know that in Scotland people affected by cancer do not always get the information that they need and are often confused about what is happening to them” (Gibson, 2002, para. 2). Satterlund et al. (2003, para. 1) believed that many want to become more informed with the most current information about their illness. Jenkins et al. (2001, p.49) reported 87% of their cancer patients “wanted all possible information”, whether good or bad.

The 2000 National Cancer Plan of Doncaster NHS recognised the importance of information in cancer prevention, detection and treatment (Department of Health, 2000, pp.10-14; Chiu and Wistow, 2002, p. 1). The need for access to fast, reliable and appropriate information that was sensitive to patients’ experience could help in making informed decisions for patients’ care (Department of Health, 2000, p.6) was outlined. This report and Chiu and Wistow (2002) expanded on the 1995 ‘Calman-Hine Report’ advocacy for cancer care (Department of Health, 1995).

The ‘Calman-Hine Report’ (Department of Health, 1995) provided seven principles, three of which are extracted here as of particular relevance to this research;

1) Patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment.
2) Cancer services should be patient centred and should take account patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions may differ and good communication between professionals and patients is especially important.
3) In recognition of the impact that screening, diagnosis and treatment of cancer have on patients, families and their carers, psychosocial aspects of cancer care should be considered at all stages” (Department of Health, 1995, p.6).

The other four principles advocated cancer screening programmes, cancer services, role of the primary care team and, cancer registration and monitoring.

The above literature review suggested that information plays a very important role and function in the well-being and recovery process for cancer patients. However, tailoring information to those needs is still being investigated as many nuances of information gaps and concerns are still being identified.

2.2.v IMPORTANCE OF INFORMATION TO PATIENTS’ CHILDREN

This organising theme seeks to be better informed about the importance of information to cancer patients’ children. Health professionals have begun to recognize cancer as a phenomenon experienced by the entire family (Kristjanson and Ashcroft, 1994, p.1). According to the National Cancer Institute (2012c, para. 3) most discussions about cancer focused on new treatments and their impact on cancer patients resulting in the needs of family members “often gotten lost in the shuffle”. According to the National Cancer Institute (2012c, para. 4) while family members provide majority of care, “most are often unprepared and undervalued”. The 2011 National Cancer Policy acknowledged the role of families in providing care and thus advocated for clinicians to communicate cancer concerns better (Department of Health, 2011, p. 48).

When cancer is diagnosed in a parent, this may also have consequences for their children (Greig et al., 2007, p.6; Huizinga et. al., 2003, p. 195; Northouse et. al., 2012, p. 237). However, there has been limited documentation of children’s adjustment to a cancer diagnosis in the family (Christ and Christ, 2006, p. 1999; Davey et. al., 2005, p. 247; Finch and Gibson, 2009, p. 214; Kornreich et al, 2008, p. 65; Lewis and Hammond, 1996, p. 456). Children of cancer patients may go through a distressing time (Visser et al, 2004, p. 67**)** and the burden of palliative care is substantial (Northouse et. al., 2012, p. 237; Becker, 2007, p. 24: Department of Health, 1995, p.3). Somasonduram (personal communication, 29 November 2011) observed similarly for Malaysian families.

According to Brashers et al. (2002, p. 263) challenges in caregiving include coordinating information. NCI (2006, para.1) reported that researchers have recently documented the extent of caregiving duties and its consequences. It was found that caregivers have now taken on roles and services of health professionals, providing and administrating skill based care at home instead of in a hospital setting, without proper training (NCI (2006, para. 3). The quality of tasks cannot be ensured and young caregivers are unprepared for such responsibilities (NCI, 2006, para. 4).

The National Alliance for Caregiving (2009, p. 17) identified that out of 1,480 survey respondents, only one in five obtained formal caregiving training and 78% of respondents felt they need more information to help them in providing care. Furthermore, with an estimated 65.7 million people in North America having served as unpaid family caregivers (National Alliance for Caregiving, 2009, p. 4), information becomes an acute need for many. According to Becker (2007, p. 24) while adult carers in United Kingdom contributed an estimated GBP57billion in health cost savings, no estimate is available for how much an estimated 174,996 children (Becker, 2007, p. 27) contributed through their caregiving.

In their study of person with AIDS, Miller and Zook (1997, p. 64) found that direct contact between care providers and physicians provided invaluable information for providing home care, monitoring the patient's symptoms and advocating for the patient. However, the literature review revealed that the normative practices in patient's family relationships with doctors seem to inhibit such contact and information exchange (Back et al., 2005, p. 164; Blum and Sherman, 2010, p. 245; Christ and Christ, 2006, p. 199; Finch and Gibson, 2009, p. 214; Meredith et al, 1996, p.724).

In addition to this barrier, Chiu and Wistow (2002, p.2) reported that carers felt that news about cancer diagnosis was delivered insensitively. Carers also often felt that they were not listened to and that they lacked information that could have helped them to prepare for and respond to difficult situations; "information could enable carers to give the best care to their loved ones" (Chiu and Wistow, 2002, p. 4). DuBenske et al. (2009, p, 721) reported: "little is known about the factors that influence caregiver's individual differences in receptiveness to cancer-related information".

Given et al. (2001, p. 214) reported the growing prevalence of home-based care of cancer patients increased the role of families. This was similarly reported by Donovan et al. (2011, p.339) and Cooley (2010, p.24). People with cancer spent more time recuperating at home (NHS Executive, 2011, p.62). According to National Cancer Institute (2009b, para. 1), "cancer patients often felt more comfortable and secure being cared for at home; they did not want to be separated from family, friends, and familiar surroundings". This suggests that while the survival rates for cancer patients improve, the duration of caring and the number of patients and their families requiring information, advice and support grows (Chiu and Wistow, 2002, p.52 and p. 56; Cooley (2010, pp. 24-25); Donovan et al., 2011, p. 339).

Literature review suggested an evident need to address the myriad issues surrounding the communication and information about the cancer journey to family members. This was compounded when cancer is increasingly diagnosed from among people who are more likely to have young children and adolescents living with them and, technology advancements lead to increased and prolonged home-based care. For example, according to Schiffman and Castle (2005, p. 2158), "cervical cancer remains a leading form of cancer among women living in low-resource regions of the world and often kills women at young ages, when they are still raising families".

According to The Cancer Research Campaign (1996, Fact Sheet 6) and as cited in Barnes et al. (2000, p.480; 2002, p. 209), breast cancer, for example, affected "1 in 12 women in the UK" and "about 30% of whom are likely to be diagnosed while they have children of school age living at home". Lewis and Hammond (1996, p. 456) reported similarly. Specifically, having children at a later age increased the likelihood of "developing cancer while there is still a young child or adolescent" (Kornreich et. al., 2008, p.64) was still at home. According to NCI (2006, para. 5), "1.4 million youths between ages 8 and 18 were providing care to a relative; 400,000 of these were children between ages 8 and 11". According to Becker (2007, p. 26), there were 175,000 children and young people under the age of 18 in the UK who provided care in families with illnesses and disabilities.

For Malaysia, the 2007 National Cancer Registry[4] reported 18,219 new cancer cases, 5,944 people (1,812 male patients and 3,682 female patients) who were of child-bearing age (within the 20 to 59 year old bracket) (Omar and Ibrahim, 2011, p.31). This suggests, that with an average of 2.5 children per household (*Banci Penduduk dan Perumahan Malaysia, Jabatan Perangkaan, 2011*), these cancer patients were potentially parents to approximately 14,860 dependent children. This number did not factor in and compound the adult 5-year prevalence for surviving a cancer diagnosis.

Cancer diagnosis creates multiple problems for affected families, including major changes in living patterns, roles and relationships (Christ and Christ, 2010; Donovan et al., 2011; Kornreich et. al., 2008; Scott et. al. 2003b; Sweeney, 2004, p.21). One of these changes according to Brashers et. al. (2002, p. 265) was that for the cancer patient "cognitive capacity might be diminished". Parents facing life-threatening illnesses and chronic health conditions were found to experience anxiety, depression, and other emotional difficulties (Barnes et. al., 1998, pg.441; Fallowfield et al., 1994, p. 448; Maguire, 1994, p. 1649; McCue and Bonn, 2003, p. 47). According to Barnes et al. (2002, p. 209), "maternal psychological distress is likely to be greater when there are more children under the age of 21 in the family".

According to the National Cancer Institute, cancer patients who have children "worry about the future of those who will outlive them" (National Cancer Institute, 2009b, p.1). The diminished cognitive capacity and psychological reactions to cancer can "impair parenting and place children at risk for problems" (Rait and Lederberg, 1990 p. 589). Buchwald et al. (2011, p. 229) reported that parent's were unable to focus on their children when they had to cope with their reactions to cancer. This may influence patients' information sharing attitudes to their children and how the family may be affected. This is substantiated by Barnes et al. (2000, p. 479) report that patients find informing their children difficult, more so when

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[4] At the time of this thesis, the National Cancer Registry Report 2007 was the latest available report on cancer incidence and mortality in Malaysia.

having to manage their own reactions and implications of the cancer diagnosis. When in situations of critical illness, some parents may not be ready to talk about their situation; either they need more time in sorting things out in their own minds first or they do not know how to inform their children (National Cancer Institute, 2003a, pg. 17).

Parents worried about exhibiting unpleasant emotions and alarming their children about a cancer diagnosis, however, cancer cannot be kept a secret (American Cancer Society, 2012c, para. 2). Children were always affected by a parent's illness; efforts in protecting them from emotional responses and shielding children from information are difficult and can be counterproductive (Finch and Gibson, 2009, pp. 213-214; Sweeney, 2003, p.21; McCue and Bonn, 2003, p. 47). Granet (2002, p. 185) wrote that keeping children ignorant, "even for their supposed good", exacerbates children's difficulty in coping.

This issue of not sharing of information has the potential to create complex problems for the family unit and the inherent shortcomings needs to be addressed. Mohd. Baki[5] (personal communication, 8 March 2013), provided feedback, that in his over 40-years' experience as a psychologist, the pattern of information seeking and avoiding in a family or social network has implications for how the family and its individual members function and develop.

In addition to that, in the past neither health practitioner nor adult family member would share information to children or adolescents about a parent's cancer situation (Scott et al, 2003b, p.1). Children or adolescents were not allowed to express their feelings or to be involved (Scott et al, 2003b, p.1; Rittenberg, 1996, p. 196). Hermann (2000) attributed that in part to how members of a family tried to protect each other from bad things. Moreover, Barnes et al. (2000, p. 479) reported that the responsibility of informing a patient's children was largely unaided; many parents did not know how to obtain information and how much to inform. Finch and Gibson (2009, p. 214) found that parents sought help with this.

Even though parents sought to protect their children from the cancer diagnosis and parental cancer experience, very young children reported sensing something was wrong with their parent and they were almost always aware of a change in their lives (National Cancer

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[5] Interview with Mohd. Baki, Psychologist, Pantai Medical Hospital. Discussion about observations of psychological impact of cancer to adult patients and their dependent children, the role of information to patients and their families and feedback about research findings on 8 March 2013.

Institute, 2013, 2012a, 2012b, 2003e). Barnes (2000, p. 482), Finch and Gibson (2009) and Sweeney (2004, p.21) reported a similar finding. The National Cancer Institute (2003a, pp. 17-26; 2003f, pp. 17-19), that children may be frightened from the consequences of a parental cancer and may worry that they might have caused the illness. According to the American Cancer Society (2012b, para. 8-22), parental cancer changed how patients' children felt about themselves, may raise questions and fears concerning children's own life and, may influence their priorities.

According to McCue and Bonn (2003, p. 47), in situations of an adult's potentially fatal illnesses, it is "all too easy to overlook the effects on the children" within their family. Finch and Gibson (2009, p. 214) reported that children's experience of parental cancer was underexplored in literature because most of these children's experiences were articulated from parent's perspective. In times of illness, many parents were often not aware of the extent of the "psychological symptomatology and distress of their children" (Barnes et. al., 2000, p.479). Some parents "did not perceive" these distress (Welch et al., 1996, p. 1417) and information needs of children continue to be unrecognised.

In research of children whose mother had early stage breast cancer, Zahlis (2001) found that children voiced nine categories of worry. These were: "worrying that the mother was going to die; feeling confused; worrying that something bad would happen; worrying about the family and others; worrying when the mother did not look good; worrying that their mothers would change; wondering if the family would have to cut back financially; worrying about talking to others; and wondering if they, the children, would get cancer" (Zahlis, 2001, p. 1023).

Earlier research by Rosenheim and Reicher, (1985, pp. 995-998) already indicated that the increasing number of serious illness among adults who have dependent children makes the issue of information and communication about illness an important and growing public health concern. According to Given et al. (2001, p. 214) and Northouse et al. (2012, p. 237), in the case of cancer, exposure and responsibilities for caregiving at home has shifted from providing short-term care into a complex, multifaceted role that can last months and years.

A review by Barnes et. al. (2000, p. 479) reported that “no study to date has examined the timing, nature, and extent of communication between parents with cancer and their children or studied why parents do or do not talk to their children about such difficult and important issues or inquired about what help parents have received or might have liked”. This suggests that as of 2000, awareness for health information and such recourse to adolescents’ and children’s needs were limited.

The diagnosis and treatment of cancer in a family member can be very stressful to children and adolescents (Scott et al., 2003b, p. 2; Kornreich et al., 2008, p.64). Being uninformed increases children’s anxiety (Barnes et al., 2002, p. 209; Huizinga et al., 2003, p. 195; Nelson et al., 1994, p. 30; Rosenfeld et al., 1983, pp. 244-245). This can result in children experiencing “psychological consequences” of “trauma, insecurity, and future psychological and behavioural problems” (McCue and Bonn, 2003, pp. 47-50). Davey et al. (2005, p. 248) evidenced children faced “significant psychosocial stressors” from the possibility of parental death, parental absence due to treatments and, changes to roles and routines.

In an attempt to address these issues, Barnes et al. (2000, p. 479) reported that when children were told about parental illness, anxiety was reduced. Health professionals generally agree that telling children the truth about an illness reduces stress and guilt (National Cancer Institute, 2003a, p. 18; American Cancer Society (2012a, 2012b, 2012c). According to Scott (2003b, p. 2) information contributed to children’s ability to construct understanding about illness and death. Information also contributed to children’s “better sense of wellbeing” (Scott, 2003b, p. 7).

This is because children can “construct their own explanations”, which may be “a worse situation than is actually the case, and lead to a mistrust of adults and health practitioners in the future” (Scott et al., 2003b, p. 2). According to the National Cancer Institute (2012, pp.2-3), when children were not told the truth about an illness in the family, they often depended on their imagination and fears to explain the changes around them. According to the American Cancer Society (2012a, para. 6; 2012b, para. 5), when children were not informed about their parent’s illness and/or progress, they “often imagine the worst”.

Similar to Barnes et al. (2000) review, an earlier research by Rolinson (1998, para. 7) reported that a literature search revealed “little or no evidence of the expressed needs of adolescents addressed in the provision of health information within the community setting”. Rolinson’s research, the “Children’s Act 1993” and “Children First, A study of Hospital Services 1993” based in United Kingdom, emphasized the need for “good personal and written information for children” (Rolinson, 1998, para. 4). This is because, according to Rolinson (1998, para. 4), the censorship of information in order to ensure children’s innocence resulted in continued ignorance and information poverty. However, a number of interventions have taken place in subsequent years.

Since Rolinson’s (1998) and Barnes et. al. (2000) findings, a few studies, interventions and advocacies have been developed. By 2003, some progress was made and access to more research suggested there was a growing recognition by researchers and practitioners that children could “benefit by being better informed about … and having more opportunity to communicate their responses to cancer in the family” (Scott et al., 2003c, p.2). Kornreich et al. (2008, p. 65) study suggested that information and discussions between parents and children managed to improve children’s knowledge and understanding about cancer and its effect to their parent. A review of interventions is reported in the following section.

2.3 REVIEW OF INTERVENTIONS WITH CHILDREN

This section informs about advocacies and interventions for children of cancer patients, their cancer experience and the challenges children faced. This review included reports and findings by Scott et al. (2003a; 2003b; 2003c), National Cancer Institute, Breastcancer.org., McCue and Bonn (2003) and, Davey et al. (2005). Literature published between 2006 and 2013 were reviewed to obtain more current and timely studies. Findings by Brewer and Sparkes (2011, p. 283), Dubenske et al. (2009, p. 721), Donavan et al. (2011, pp. 338-339), Finch and Gibson (2009, p. 214) and Kornreich et al. (2008, p. 65) maintained that little was still known about information provisions to children of cancer patients, their cancer experience and the caregiving they provided. The review of interventions with children is divided thematically as i) 3rd-Party moderator and ii) Parents as moderator.

2.3.i 3rd-PARTY MODERATOR

Several literature reported intervention modalities that consisted of a 3rd-Party moderator. A moderator is defined as a non-family adult who provides information and either facilitates or controls intervention objectives, information flow and anticipated outcomes for intervention activities participated by children with a family member who has cancer. Studies by Scott et al. (2003b) and Davey et al. (2005) are compared below.

Scott et al. (2003b, p. 5) reviewed five studies against two outcome measures of children's knowledge and understanding of cancer and its treatment and, children's coping and adjustment to the effects of a family member's treatment. These studies were Sahler (1989), Dolgin (1997), Williams (1997), Heiney (1990) and Houtzager (2001). According to Scott et al. (2003b, pp. 14-26), Sahler (1989) organised a 5-day residential camp program that provided medical information, opportunities to handle medical equipment and peer support for siblings of cancer patients. Sahler's (1989) intervention resulted in 1) children increased their knowledge about cancer procedures, 2) children reduced their fear of "catching" sibling's cancer and 3) children had significant improvements in behaviour, positive behaviour items and positive mood states (Sahler, 1989 in Scott et al., 2003b, pp. 6, 14-26).

According to Scott et al. (2003b, p. 5), Dolgin (1997) had a "structured group intervention" that included "facilitated group discussion, art therapy, role-play and informal social interaction". After intervention, children were significantly more knowledgeable about cancer and had reduced interpersonal problems (Scott et al., 2003b, p. 6). According to Scott et al. (2003b, p. 5), Williams (1997) had a "structured educational and support group intervention" which resulted in children being more knowledgeable about cancer (Scott et al., 2003b, p. 6). According to Scott et al. (2003b, p. 6), Heiney (1990) "compared a group that participated in a support group and a group that received no intervention". This resulted in "no significant difference in social adjustment before and after intervention" (Scott et al., 2003b, p. 6). According to Scott et al. (2003b, p. 5) Houtzager (2001) studied a "psychosocial sibling support program" and found lower mean scores for anxiety after intervention (Scott et al., 2003b, p. 6).

The relevance of Scott et al. (2003c) review was the report of a range of different methods to provide information to children with the aims of reducing their anxiety and increasing their knowledge about cancer. These moderated activities with components of medical education and, engagements with peers resulted in a positive impact to children participants' coping, anxiety, adjustment and wellbeing. However, these studies assumed what interventions children required and may benefit from. Children participant's preference for type of activities and information were not solicited. Children's spectrum of concerns was limited to how the moderator perceived children might react psychologically and children's possible reactions of anxiety and coping to parental or sibling illness. These studies neither explored the meaning, experience and range of concerns of children of cancer patients from their perspective nor explored the needs of children who provided care to their parents.

A different approach to developing interventions was conducted by Davey et al. (2005) whom solicited user-centric solutions. Unlike Scott et al. (2003c) review, the role of a third-party moderator would be to encourage discussion and help participants to develop positive coping skills targeting anxiety and depression. Children participants were actively engaged in determining the direction of discussions, anticipated outcomes and what they wanted from such activities. These children also helped to identify ways in which discussions could be better moderated.

According to Davey et al. (2005, p. 254), several of their teenage participants suggested developing interventions that were either "a mixed gender teen group close to diagnosis (within 4 months of diagnosis) so as to have a different point of view on things" or a "multiple-family therapy group where adolescents can share their feelings openly … may help to assuage some of the loneliness they felt during the course of the illness … facilitates empathy and understanding". In further exploring this role of adults, it was found that research by Chowns (2010, slide 28) specifically suggested for adults to employ listening skills and to be more accepting of children's contextual experience rather than providing only answers when questioned.

In comparing these studies, the role of a moderator whom facilitated discussions resulted in children participant's greater satisfaction and perceived well being. Children had a more participatory role. Rather than control and assuming needs, the moderator guided a free-flow of discussions and listened with empathy. This kind of user-centric group therapy seemed to be more satisfactory to children participants as it appeared they felt more in control with discussions. This led to greater understanding of participant's concerns and issues which then led to better support mechanisms and more relevant advise.

2.3.ii PARENTS AS MODERATOR

Several literature reported intervention modalities that advocated for either the healthy or ill parent to become information providers or moderators. It was believed that a parent moderator would create a more conducive, closer exchange of information and a more supportive environment for their own children. Reports by McCue and Bonn (2003), National Cancer Institute (NCI) (2003), breastcancer.org (2004), Kornreich (2008), Chowns (2011) and, Finch and Gibson (2009) are presented below.

McCue and Bonn (2003) found similar reactions to parental cancer as reported by Scott et al. (2003c) and Davey et al. (2005). However, McCue and Bonn (2003, p. 48-49) highlighted three common concerns of children of all ages; 1) Did the child cause the illness? 2) Was the illness contagious? and, 3) How would their lives be affected? With these concerns, McCue and Bonn (2003, p.50) suggested that parents should provide the onus of interventions. Parents were advised to inform their children openly, honestly and, with age- and child-appropriate information. Specifically, parents should inform a child at the very beginning about the seriousness of the illness, the name of the disease and the parent's understanding of what may happen (McCue and Bonn, 2003, p. 50). More recent findings by Kornreich et al. (2008, pp. 64-65), Chowns (2010, slide 17) and NCI (2012a) advocate similar strategies.

NCI advocated that parents play an important role in providing information and support (National Cancer Institute, 2012a, 2012b, 2012d, 2012e). Interventions focused on NCI's belief that parents should inform their children that they were still loved and important and that they will continue to be cared for (National Cancer Institute, 2012e, p. 37). Parents were advised to not pretend that "everything is okay" (National Cancer Institute, 2012d, para. 1) as children can "sense when something is wrong". Children can sense that a parent feels unwell or parents were not spending as much time with them as they used to (National Cancer Institute, 2003f, p. 17).

NCI provided parents with a list of things that children should know about cancer. This included information about if the cancer can be cured, information about how cancer developed, cancer treatment options and possible side effects and, the people who would be involved with the treatment (National Cancer Institute, 2003a, p.3). In addition to that, parents were advised about the boundaries of what children of all ages should know about cancer and some pertinent facts and messages that parents should communicate to their children (National Cancer Institute, 2003f, p. 17-19).

Breastcancer.org (2004, para. 2) also advocated for parents to moderate interventions, as they believed telling children the “truth was better than letting them imagine the worst”. Hermann (2000), who responded to scenario questions to help both mothers and their children to come to terms with a diagnosis of cancer, advised on how much information and the type of information should be shared. Discussions were about topics like death, going bald, importance of screenings, and concerns of ‘catching’ the disease from mother to daughter. Key interventions were for children to be informed about the name and location of parent’s cancer, what will happen as a result of cancer treatments and how children’s lives may be affected (Hermann, 2000).

Even though the literature listed the benefits of parents as moderators, several problems have developed. Findings by Barnes et al., (2000, p.481) suggested that parents required assistance in introducing their situation to children and that they required supportive information to address children’s concerns. Finch and Gibson (2009, p. 214) reported that cancer patients have sought help to communicate to their children about their diagnosis. However as of this thesis, information on nuances of parental concern in communicating about their diagnosis to their children have yet to be explored for specific treatment and illness trajectories, racial and cultural experiences and, children’s role as caregivers.

In addition to parental information needs, a better understanding of what children needed as information recipients was important. This review found that interventions for children who undertook caregiving roles during their parent’s illness were very limited (Buchwald et al., 2011, p. 229; Blum and Sherman, 2010, pp. 244-245; Brewer and Sparkes, 2011, p. 283; Donavan et al., 2011, pp. 338-339; Dubenske et al., 2009, p. 721; Finch and Gibson, 2009, p. 214). Excerpts from Hermann (2000) indicated that there were many more nuances of concerns and issues than has been researched. This included questions about the amount of information children should be informed, children’s possible reactions to side effects, involvement with support groups and, management of bereavement and emotional upheavals. This further suggested the complexity surrounding young people's information needs.

Similar to Scott et al. (2003c), Finch and Gibson (2009, p. 214), reported that few studies "explored the experience from a young person's perspective within a qualitative frame of enquiry". According to Chowns (2010, slide 10), prior research about children's bereavement from a parent's death were based on North American demographics, were adult-focused and designed and, had conflicting findings. It was possible "uncertainty of pre-bereavement (was) more challenging than post-death support" (Chowns, 2010, slide 11). This suggested that children's concerns were underestimated.

These studies suggested that more research is needed to explore how children were challenged and how they tried to overcome difficulties when faced with parental cancer. This was important, as not only are "access to supportive services to mitigate burden is often inadequate" (Donavan et al., 2011, p. 338), but additionally because such research with children was rare Brewer and Sparkes (2011, p. 283).

In order to emphasize this importance, Brewer and Sparkes (2011, p. 283) explained that there were three reasons for the gaps in understanding what children undergo in the face of bereavement. This was: 1) a lack of models based primarily of what children experienced and self-reported, 2) little was known about the meaning and its construction that children developed and attached to their experiences and resources they accessed and, 3) a lack of understanding of how children processed their experiences in order to make sense and/or overcome the challenges they faced (Brewer and Sparkes, 2011, p. 284).

Another perspective to consider was that these three gaps and issues might also be a result of cultural factors that may shape caregiving experiences and concerns in other, previously undocumented ways. According to Donovan et al. (2011, p. 338), cultural influences tend to be neglected. Chowns (2010, slide 10) highlighted similarly. Davey et al. (2005, p. 254) advised that interventions "should be sensitive to gender and racial differences" and this extended to intervention modality, advise and, support requirements. This suggested that cultural influences provided different nuances of experiences and issues and, further justified exploring a Malay demography.

In conclusion, the review suggested that children were impacted by parental cancer and that efforts were made to redress or mitigate some of the issues and concerns children faced. However, sharing and/or providing such information to children was still uncommon (Scott et al., 2003b, p.2; Kornreich et al., 2008, p. 70). Both parents and 3rd party moderators still needed help in providing information and engaging with children. Precedent research had not identified children's preference for information topics, how children obtained information and their information pathways. Identifying this was important because such inquiries may better inform information provisions that may create greater relevance and use to children.

With the above context, it was evident that more research was needed to identify children's concerns and ways in which parents may be better prepared to help children understand and face challenges. One of the approaches in conducting such a research suggests for a qualitative methodology. This is discussed in the Methodology chapter on page 55. Having discussed some of the precedent interventions with children, the next section reviews factors that may influence information use.

2.4 FACTORS INFLUENCING INFORMATION USE

This global theme seeks to study precedent research about the problems and issues related to information provision. Specifically, there were three organising themes: i) health literacy of intended recipients, ii) culture of information sharing and iii) other challenges. Culture of information sharing has three themes of a) Culture of information sharing between patient and doctor, b) Culture of information sharing between parent and children and, c) information avoidance. Other challenges has three themes: a) The image of cancer, b) cancer as taboo, and c) The Internet.

2.4.i HEALTH LITERACY OF INTENDED RECIPIENTS

This organising theme seeks to understand the importance of health literacy and its implication for the development of interventions. According to Glassman (2012, para. 1), the US Department of Health and Human Services defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions". However in cancer communication, health literacy is an often-overlooked problem (Doak et al, 1998, p. 151). Different word choices can “direct thoughts about a single situation in many different ways” (Langer, 2000, p. 28). According to Wilson (1994, para. 97), “how effective would information be if the information materials were barriers to understanding?” Literacy was identified as a barrier in using cancer information (NCI, 2001, para. 7).

According to Baker et. al. (1997, pp.157-159) and Doak et. al. (1996, p. 152), “language has the interesting property of being able to increase and decrease our perceptions of control” and a number of researches have been conducted to support the need for specifically designed information. Davis et al. (2002, p. 140) found that a reasonable match between the logic, language and experience of information and patients should be present to “turn on” the process of understanding and remembering information. However, the mismatch in language; “readability level, choice of words, use of conceptual words, category words and value judgement words and language fluency” (Davis et al, 2002, p.140) has become a large barrier to understanding and processing information.

Tu and Hargraves (2003, p.1) believed that education was key to explaining differences among people living with chronic conditions who were more likely to seek information. People with a college degree were more likely to seek health information compared to people without (Tu and Hargraves, 2003, p.1); “information seeking rose sharply as the level of education increased” (Tu and Hargraves, 2003, p.2). For example, Chiu and Wistow (2002, p.45) reported the illiteracy of a patient hampered his ability to respond and act on information sent to him.

Kirsch et al.’s, (2002, pp. xvi-xvii) study reported the American National Adult Literacy Survey (NALS) estimated that approximately four in five Americans (79%) performed poorly in prose, document, and quantitative literacy assessments. This suggests that many who lack literacy skills and who also been diagnosed with cancer are at a disadvantage. They would be limited in their ability to obtain, process, and understand cancer information and services needed to make appropriate health care decisions. Reports by Baker et al. (1997, p.135-136) showed that individuals with poor reading skills often have “poorer health, higher medical expenses, and an increased number of hospital and outpatient visits”. The problem was compounded when “44 million Americans read at the fifth-grade level and lower” (Kirsch et al., 2002, pp. xvi) whereas in comparison most cancer information was on average "between the tenth-grade and eleventh-grade level" (Davis et al., 2002, p.142). This suggested that cancer information may be ineffective, more so to non-native English language speakers. This may lead to "later diagnosis… misunderstood treatment options…and suboptimal intervention decisions" (Merriman et al., 2002, p.132).

According to Parikh et al. (1996, p.37) "communication differences" and the "fear that illiteracy may be found out" also become significant barriers to comprehension. Davis et al. (2002, pp. 136-146) argued illiteracy has consequences for cancer prevention efforts, identifying symptoms, understanding treatment options and procedural requirements. Doak et al. (1998, p. 151) similarly reported that literacy affected comprehension and action in health care. These reports suggested that a lack of familiarity with health-related language, made it difficult for many patients to ask questions and seek information. To address this, Weiss and Cyone (1997, p.273) argued that literacy limitations were rarely obvious but this awareness can guide doctors to facilitate patients' understanding about medical needs. It was important to make a distinction here that low literacy does not mean low intelligence (Doak et al., 1998, p. 154). According to Doak et al. (1998, p.154), "for most people, new information can be learned and acted upon by linking the new information to already known information and making it relevant". Low literacy individuals acquired information through non-print materials (television and radio) and from demonstrations and explanations (Doak et. al., 1998, p. 152).

According to Davis et al.'s (2002, p. 145) study, it was "easier to change the communication skills of the health care provider". With this context, information provision should have a behavioural goal and respect the anxiety and stress people developed when confronted with a cancer diagnosis (Davis et al, 2002, pp. 135-138). The studies by Davis et al. (2002), Doak et. al. (1998) and Weiss and Cyone (1997) concurred that medical advice should facilitate patients' understanding and recall. In addition to this, the increasing number of people making trade-offs by comparing the cost, quality and accessibility of care, necessitates information that addresses all levels of literacy. Merriman et al. (2002, p.132) points out "that individuals with better literacy skills also face difficulties with unfamiliar terms", more so when they are under physical and emotional stress where comprehension often diminishes. Merriman et al. (2002, p. 132) suggested using a variety of formats to present complex medical information in a simpler manner. When it comes to cancer information, people prefer information that is easy to understand, simple and in a clear, conversational language designed to communicate effectively to help patients and their family members throughout the cancer journey (breastcancer.org, 2012; National Cancer Institute, 2012a, p. 27).

From the review, it was evident that health literacy was important. According to Davis et al. (2002, p.134) health literacy was "increasingly recognized as a critical factor affecting communication throughout cancer care" and research of methods for educating and communicating information successfully is needed. Closely related to the issue of Health Literacy is its attended causes and demography. According to Sudano and Baker (2005, p.910), most health illiterate individuals and people were of ethnic or racial backgrounds that contributed to disparate "socioeconomic status" and "health behaviours" than those of the health literate. Chiu and Wistow (2002, p. 53) found that "social deprivation can affect health behaviours and access to services" Moreover, people with low incomes were "less likely than higher-income people to seek health information" (Tu and Hargraves, 2003, p.2).

People from minority ethnic groups and people with learning disabilities have particular requirements including culturally sensitive information (NHS Improving Outcomes: Strategy for Cancer, 2011, p. 42). According to Brashers et al. (2002, p.264), "social support, doctor-patient communication and uncertainty management occur within a sociocultural context that may shape how specific behaviours are understood and interpreted". Cross-cultural considerations may further complicate the relational demands of information seeking and avoiding (Baldwin and Hunt, 2002, pp. 276-277). Studies have shown that in some family centered cultures (such as Chinese, Vietnamese, Cree, and Ethiopian cultures) information sharing and decision-making were responsibilities of family members instead of the patient (Blackhall et. al., 1995, pp. 821-824). Information seeking and avoidance becomes a complex coordination between health care providers, patients, patients' families and sometime interpreters (Hsieh, 2009, pp. 135-156).

In some ethnic families, both the patient and the family members see information and treatment seeking as a designated family member's responsibility (Kaufert, 1999, p. 410; Blackhall et. al., 1995, pp. 821-824). In some cases, family members have informed care providers about their "unwillingness to discuss the diagnosis with the patient…explicitly declined the use of interpreters…emphasized that direct communication with the patient being diagnosed was unacceptable…or simply distorted the doctor's diagnosis when acting as interpreters to the patient" (Kaufert, 1999, p. 405-412).

According to Sorenson (2004, p. 727), American minority populations have poorer cancer survival and experienced disparities in access to and use of health care services. Her study reported that Hispanic women were more likely to have a more advanced stage at diagnosis. While according to Orom et al. (2012, p.467) and Shavers et al. (2003, p.146), people at advanced stage cancer had more diverse information needs about survival and better quality of life, most of the Hispanic women from Sorenson's (2004, p.727) study faced many barriers in accessing them. This is a similar situation with patients in Malaysia. According to NCI Cancer Institute's 2003 'NCI Cancer Registry', "61% of patients were in advanced stages of the disease (stage III and stage IV)" (NCI Cancer Institute, 2003, slide 10). The Malaysian community, represented by three major races; Malay, Chinese and Indian, represents a diverse group of languages, cultures and national origins. This can affect health perceptions and experiences that contribute to the information problem.

Kalbach's (2000, para.47) article concluded with a call to develop more "intelligent, intuitive systems that are user-centred and support fundamental human information needs and goals". Pursuant to that, the Information Management Strategic Framework for the NHS in Wales, Better Information – Better Health recommended the development of "service-focused information frameworks" (Griffiths, 2000, p. 7). This review highlights the importance of developing relevancy of cancer issues and delivering information that were culturally sensitive and that would make cancer-related information more acceptable.

In an attempt to understand a layperson's preference, the work by Ewald et al. (2011), Ewald (1985), Deaver (2009) and Osborne (2006a; 2006b), in using pictures, drawings and photographs, was identified as a means of communicating thoughts, ideas, expressions and narratives. According to Bradding and Hortsman (1999, p. 170), drawing and writing techniques can be used to good effect as a research strategy. This was considered as a viable alternative in collecting data from children because creating and speaking grammatically correct complex sentence structures or complex ideas can be difficult. This belief was thought to be especially true for people of "lower education and for children" (Blackstone, 2010, p. 247). This was done to respect children's different ways of communicating their understanding, concept and knowledge about cancer and, the nuances of their individual experiences (Blackstone and Pressman, 2012, p.32). Moreover, documenting these experiences may not be possible through traditional methods (Blackstone, 2010, p. 247).

This technique was conducted successfully in Skovdal and Ogutu's (2009) research of children providing chronic care for adults affected by HIV/AIDS in Western Kenya. Photography was thought as a viable method to provide children an alternative method to present their experiences (Skovdal and Ogutu, 2009, p.11). It was thought that children would not be bounded with writing legibly, developing complex sentence structures and spelling correctly in order for their experiences to be shared. It was also an attempt to encourage the feeling of familiarity and comfort to children when placed in a setting to solicit their thoughts and feelings about a possibly emotionally charged subject matter (Skovdal and Ogutu, 2009, p.11).

Drawing responses was considered a strategy in which children may be prompted to expound on their self-reports. It was a way to solicit data with depth and richness that traditional data collection methods may not uncover. In order to analyse children's drawings, the research adapted Skovdal and Ogutu (2009, p.3) methods in soliciting clarity and meaning. Similar to Osborne's (2006a, p.1) rationale, it was assumed that children's drawings would help to develop better understanding of the nuances of children participants' preferences, problems and needs. The methods of eliciting responses and data are explained in Chapter Three.

2.4.ii CULTURE OF INFORMATION SHARING

This organising theme seeks to understand 1) the culture of information sharing between patient and doctor, 2) culture of information between sharing parent and children and, 3) the concept of Information Avoidance and its implication for the development of the methodology and recommendations of interventions.

2.4.ii.a. Culture of information sharing between patient and doctor

According to Brashers et al. (2002, p. 266), in attempting to manage uncertainty, a person may engage with others who were also managing their own uncertainty while at the same time addressing the said person's information seeking and avoiding. Abraham Maslow (1963,

p. 116) wrote, “What you don’t know has power over you; knowing it brings it under your control, and makes it subject to your choice. Ignorance makes real choice impossible”. Review of the study by Jenkins et al. (2001), Meredith (1996), CancerCareConnection of North America (2003, p.1) and Gibson (2002, para. 1) suggested that patients’ and their families’ information needs were not met during consultation sessions with doctors.

Goals of individuals and their health care providers, friends and families may be matched or mismatched, which may be problematic or beneficial for the individual concerned, depending on the circumstance (Doak et al., 1998, p.152). Different perceptions for an individual’s needs and desires about information may differ from that of the information provider and this “may result in behaviours that are unresponsive or intrusive” (National Cancer Alliance, 2001, pp. 9-10). Davis et al. (2002, p. 142-145) suggested that cultural or cross-cultural context and the information environment (channels or situational levels of stress or anxiety) shape information management activities and influenced how information systems were developed. Doak et al. (1998, p.152) further suggested that characteristics of the information provider may also influence the likelihood of seeking support and reactions to information (adherence to advice, treatment, medication). For example, earlier works by Dakof and Taylor (1990, p.89) suggests that information was more valued when it came “from fellow cancer patients and cancer survivors rather than from family and friends who might be well meaning but less expert”.

Another point to consider was that as noted by Anandakumar (2012, p. 15) in India, “several of the health practitioners may also have misconceptions of cancer and even may perpetuate myths about cancer care and survival”. Brashers et al. (2002), wrote that there exists an ‘*Asymmetrical Information Exchange’*, whereby,

1. “Collaboration between doctor and patient leaves margins for information errors, i.e. misinformation or misjudge extent and type of information required.
2. There is misperception of information needs and desires.
3. Language, cognitive and health understanding level and health education/knowledge is disparate” (Brashers et. al., 2002, p. 261).

As reviewed above, the culture of information sharing between patients and doctors and the dissonance between their goals can have implications to the extent, quality and type of information shared.

2.4.ii.b. Culture of information sharing parent and children

As mentioned earlier (page 42), parents play an important role in meeting the information needs of children when a family member has cancer. According to Scott et al (2003b, p.2), “Parents are usually, though not always, gatekeepers or conduits for communication for their child” where communication should be made from the perspective of the family. This can make communicating with children about parental cancer and its treatment a more sensitive and complex task. As mentioned earlier, in the past neither health practitioner nor adult family member would share information to children or adolescents about a parent’s cancer situation (Scott et al., 2003b, p.2; Kornreich et al., 2008, p. 70). “It has not been common practice for families and health practitioners to share information with children or adolescents about a family member's cancer, or to allow them to express their feelings about this” (Scott et. al., 2003c, p. 2). According to Hermann (2000) protecting children from certain information and the pattern of information seeking and avoiding has implications for the family dynamics. For example, Brashers et. al. (2002, p. 264) related that parents, as patients, “may resist family member’s attempts to solicit information directly from them”. Breastcancer.org (2004a, para. 1) found that mothers with breast cancer withheld information to protect their daughters.

While the researcher was employed at NCSM, information sharing between children and their parents about a family member’s cancer and treatment seemed to be limited. In discussing this observation, it seemed that children or adolescents would not even be allowed to express their feelings or to be involved in decision making about health concerns. Mohd. Baki (per. Comm., 8 March 2013) attributes the exclusion of children in health decision-making and information sharing as the 'family protection syndrome' where parents seek to protect family members from ‘bad things’. Somasundaram (personal communication, 29 November 2011) observed that there is also a role shift form the understanding that parents were always healthy and in a position of power to an understanding of a parent was very ill or critically ill and may not be able to assert their dominant power over the family any longer. This may prove very difficult to communicate between family members about cancer-related concerns and to control the family environment.

Scott et al. (2003b, p.7) believed that in communicating to children about cancer, parents should consider “the child’s or adolescent's levels of cognitive, emotional and physical development, readiness and ability to communicate, and with whom they prefer to communicate concerns about their family member's cancer and treatment". Scott et al. (2003b) further advocated for research into this area and proposed researchers to investigate, utilize and evaluate a range of approaches, from formal education to the expressive arts.

In Greig et al. (2013) book "Doing Research with Children", it was understood that in child developmental research, listening to children and their views was an aspect often neglected (Greig et al., 2013, pp.4-7). Greig et al. (2013) suggested several principles and methods to address this aspect. Firstly, children were different from adults and "do not exist in vacuums and their lives are naturally complex" (Greig et al., 2013 pp. 4-5), which influenced their development into adulthood. Secondly, children perceived and understood the world in a different way from adults (Greig et al., 2013 pp. 22-45). Thirdly, children were a product of, and were influenced by their ethnicity, level of education, social class, upbringing and other influencing elements that made up the child's universe (Greig et al., 2013 pp. 45-55).

These principles further suggested that children have different sets of thought processes, beliefs, motives and behaviours that could differ from adults. This makes research instruments to encourage listening to children and gaining a better understanding of their experiences an important concern. Greig et. al. (2013, pp.215-226) suggested to utilise activities that were age-specific, demographic specific and children sensitive to facilitate learning, observation, recording and measurement. Among the activities were: simulation, role-play, self-expression through drawings and recording actual behaviour and facial expressions (Greig et. al., 2013, pp.215-226), Kornreich, (2008, p. 65) similarly listed play and talk therapies as methods to enhance research through children's more participatory involvement.

2.4.ii.c. Information Avoidance

Research indicated that majority of cancer patients want to be informed about their illness (Bowling and Ebrahim, 2001, p. i3; Lockwood and Manaszewicz, 2000, p. 632; Meredith et. al, 1996, para. 7). It was also recognized that patients vary in how much information they wanted and that this may change during their illness (Fourie, 2012, para. 38; Lockwood and Manaszewicz, 2000, p. 632). Tu and Hargraves (2003, p.1) reported, "people living with chronic conditions were more likely to seek information, yet more than half did not".

According to Johnson (1997a, p. 70) “Beyond obsessions, curiosity, and creativity, lies a host of motivations not to seek information.” These attitudes were reflected in the efforts that patients made to not obtain further information or to resist information that was offered to them (Fourie, 2012, para. 16; McKenzie, 2000, p. 632). According to Chiu and Wistow (2002, p.39), some people thought, “more information with little knowledge might cause anxiety”. This hints at the complexity of providing information in oncology; information may be ignored or avoided by patients, regardless of their prior knowledge or occupation.

According to Brashers et al. (2002), research indicated that avoiding information was also an important element in information management. “People who were ill or believed themselves to be at risk for disease may avoid information when it is distressing” (Leydon et al., 2000, p. 911) or “when central values or beliefs are at stake” (Babrow, 2001, p. 565). Seeking and avoiding information were weighed against multiple goals (Brashers et al., 2002, p. 261). Brashers et al. (2002, p. 259) believed that “information can be used to decrease uncertainty that is distressing, to increase uncertainty that allows for hope or optimism, and to invite reappraisal of uncertainty”. According to Brashers et al. (2002, p.259), information can “increase stress-producing certainty or uncertainty” and avoiding information allowed people to retain their “current state of knowledge or beliefs” (Brashers et al., 2000, p. 259).

It was understood from Dervin’s (2001) paper that people’s awareness about the type of information available, how accessible the information was, as well as what information they currently have or believed in, may influence how they solicit, search, process and retain information. Bonner (1995, p. 218) however, defined information awareness as “… an individual’s level of awareness for the existence, purpose and value of information and of its probable impact at the individual and organizational level”. According to Leydon et. al. (2000, p. 909), patients’ attitudes to cancer and their strategies for coping constrained their wish for information and their efforts to obtain it. Leydon et. al. (2000, p. 909) attributed three overarching attitudes of faith, hope, and charity as influencing patients' desire for, and subsequent efforts to, obtain information. Patients had faith in their “doctor's medical expertise” which formed a barrier for information seeking, patients had hope of continuing to live “as normal” by avoiding information and, patients expression of charity to fellow patients recognised that limited resources had to be shared, which meant that “limited information was accepted as inevitable” (Leydon et. al., 2000, p. 909-913).

The review suggested that the motives for information avoidance have implications for patients' and their families' information seeking behaviour.

2.4.iii OTHER CHALLENGES

This organising theme seeks to understand other challenges for the research. There themes are reviewed: 1) The image of cancer, 2) Cancer as taboo and, 3) The Internet.

2.4.iii.a. The image of cancer

Chiu and Wistow (2002, p.35) conducted a study to gauge the perception of cancer. Their participants were asked to draw the images that they had about cancer or use words or phrases to describe it on a blank paper. Many of the resulting images had a negative connotation; alarm bells, a gravestone and hospital beds were a frequent theme. Words used to represent cancer were 'death', 'pain', 'fear' and 'anger' (Chiu and Wistow, 2002, p.35). Eventhough patients were aware of the possibility of surviving cancer, several influencing factors (i.e., uncertainty about prognosis, treatment, personal and social consequences) made them have a pessimistic view on cancer (National Cancer Alliance, 2000, p. 11). Similarly, the topics discussed during the 'Ask-the-Expert' Conference; Kids and Mom's Breast Cancer (breastcancer.org, 2006), were about children's concerns of parental death, baldness, importance of screenings, and concerns of 'catching' the disease. These responses suggest that the image of cancer continue to elicit emotional responses and negative perceptions.

2.4.iii.b. Cancer as Taboo

The National Cancer Alliance (2000, p. 12), Calman-Hine (1995, p.3) and Chiu and Wistow (2002, p. 37) reported that cancer was still regarded by the American and United Kingdom public as a threatening disease and a taboo subject.

In Malaysia, the regard from among the Malaysian public was similarly taboo (Mount Miriam Cancer Hospital, 2013, para. 2; NCSM, 2012, para. 7; Parhizkar, 2012, p. 50; Zatar, 2009, para. 2). The word 'cancer' on its own was taboo and terrifying (Joseph, personal communication, 29 November 2011). According to Somasundaram (personal communication, 29 November 2011), for the longest time in Malaysia, households and hospitals alike used the 'C-word' or 'the big C' rather than 'cancer'. Many believed that by saying the actual word, one might catch the disease. It seemed that according to these observations and reports, stigma and derision between family members and society about cancer and a person with cancer was still prevalent, in both rural and urban areas in Malaysia.

Joseph (personal communication, 29 November 2011), a cancer survivor and social care worker at the National Cancer Society of Malaysia, said that in Indian families and in the Indian community, talks of cancer were avoided. Death due to cancer was whispered with pity and a degree of derision behind closed doors. Peoples' fatalistic attitudes to prevention, awareness of risk factors and self-examination was more often ignored as many believed the information was irrelevant and many felt that cancer only happened to 'bad' people. There was an apathetic attitude to cancer; some felt that they would only require cancer information at the point of diagnosis, if ever they were unfortunate enough to be in that situation (Joseph, pers.comm., 29 November 2011; Somasundaram, personal communication, 29 November 2011). Chiu and Wistow (2002, p. 38) reported similar attitudes. There were also Malay, Chinese and Indian community sentiments in Malaysia that having cancer in the family would influence family status and the desirability for marriage (Somasundaram, personal communication, 29 November 2011; Joseph, personal communication, 29 November 2011). However there is little empirical data.

2.4.iii.c. The Internet

According to the Office for National Statistics (2013c), "in Great Britain, 21 million (83%) households had Internet access" and that out of the "36 million adults (73%) in Great Britain" who accessed the Internet daily, 43% sought health information (Office for National Statistics, 2013c, p.1). This is marked increase from 2007, where comparatively only 17% of Internet users looked for such information (Office for National Statistics, 2013c, p.5). Shuyler and Knight (2003, para. 3) reported that the Internet changed the way patients accessed health care information, learnt more about their conditions, and made health care decisions. According to Brozekowski and Rickert (2001, p. 813) the Internet was an important source for health information because of it's accessibility, confidentiality and perceivably less threatening manner and, could provide personalised information to specific concerns. According to Brashers et al., (2002, p. 260) the Internet allowed people to search for health information comfortably from home.

Critics questioned the quality and accuracy of online health information. According to Wang et al. (2012, para. 3), fundamental questions remained about the "nature of their needs, information access, and health outcomes”. Internet-based information was cautioned as “not the be-all and end-all” of information provisioning (Fox, 2005, p.1). Instead of surfing the Internet, the 38% of Americans who did obtain health information relied more often on traditional sources such as books or magazines (Tu and Hargraves, 2003, p.2).

According to Berland et al. (2001, p. 1), many credible sources provide website information that may be written in technical language and present minimal information, which may contribute to increased uncertainty and confusion about contradictory advise about illness and treatment options. In health care decision making, people “need help interpreting what they find on websites and resolving inconsistencies between discrepant “facts” about illness and treatment options” (Brashers et. al., 2002, p. 265). With “70% of U.S. adults” who sought information, care or support from a health professional, clinicians are still pivotal as a “resource for information or support during serious health episodes” (Fox and Duggan, 2013, pp.2-3). Kotenko (2013) reported doctors validating information and that several doctors thought the “potential for misinformation on the Internet is high” (Kotenko, 2013, para.5). Patients were diagnosing themselves from Internet-based assessment of symptoms and then believing “they have the worst diagnosis out of the many possibilities and create unnecessary anxiety within themselves.” (Kotenko, 2013, para 25).

In addition to this, there was a mismatch in Internet literacy and skills of users. Brashers et al. (2002, p. 265) reported, “despite the potential for technology to improve systems of information delivery in healthcare, it can be underutilized or utilized in ineffective ways”. Individuals with the greatest need for health information may lack the technology or access to Internet resources (NHS England, 2013, para. 4; Cline and Haynes, 2001, p.677). The NHS Commissioning Board (NHS England, 2013, para. 4.) were concerned that “People over the age of 65 account for more than half of NHS spending, but 36% of those over the age of 65 have never been online before and half of the 8 million people who have never used the internet have a disability.” Access was inequitable and use was hindered because of navigational challenges and design features which included disorganization, technical language and lack of permanence (Brashers et al., 2002, p. 265). “When people have access to the technology, individuals may find the information confusing or contradictory … and the volume of information, overwhelming” (Cline and Haynes, 2001, pp.677-680). Limited information-evaluation skills added to people’s vulnerability, and reinforced the need for quality standards and criteria for evaluating health information (Brashers et. al., 2002; Cline and Haynes, 2001, p. 680).

This review suggested that even though the Internet has brought widespread access to health information and many more people refer to the Internet for their health issues, there were still concerns from both users and information providers about accuracy and usability.

2.5 CONCLUSION

This literature review reinforced that improving information and communication for children and adolescents about cancer in the family may help to reduce future problems (American Cancer Society, 2012a, 2012b, 2012c; breastcancer.org, 2006; National Cancer Institute, 2013, 2012a, 2012b, 2012c; Scott et. al., 2003a, 2003b, 2003c). It also highlighted the complex array of factors that may influence the information experience, the design of information solutions and, the need for further research to provide a deeper understanding. Communication and information was likely to be more effective if it was provided as user-centric, written for layman information in a native language, culturally sensitive and, was clear and relevant to the cancer experience of patients, their families and the public rather than only relying on what is believed to be important by the experts (Chiu and Wistow, 2002, p.51 and p.56; Davey et. al., 2005; Dervin, 2000; Department of Health, 1995; Fox and Rainie, 2002; McCue and Bonn, 2003; Ziebland et al., 2004).

Cancer was increasingly regarded as a chronic and long-term illness that necessitated more economical cancer management at home. This phenomenon increased the scope and duration of responsibilities for families who provided care. Children were reported exhibiting negative behaviours of anger and jealousy, being overburdened with caregiving responsibilities that were not age appropriate and, guilt in not being able to cope or contribute to alleviate their parent's situation (breastcancer.org, 2012; CancerCareConnection, 2003; Davey et al., 2005; Doak et al., 1998; National Cancer Institute, 2012a, 2012b; Scott et. al., 2003b). However, there has been very little research and interventions available for children caregivers, especially in ethnic families (Barnes et. al., 2002; Scott et. al., 2003a, 2003b and 2003c).

Since health care was one of the highest priority sectors for socio-economic development, this suggested that introducing appropriate healthcare information systems should enhance the effectiveness and efficiency of Malaysian healthcare institutions. A comparative review from reports from North America, United Kingdom, and Scotland suggested that the information provision as generally practiced by Malaysia has not meet the needs of cancer patients, their children and, the public. This deserved further exploration.

Given the varying quality of information available from health practitioners, cancer organisations and the Internet, doubts, anxiety, and uncertainty about cancer among the public seems to have persisted. This could be detrimental to the overall quality of life and survival rate of new cancer patients and their families. The mismatch between access, literacy, misconceptions about cancer and, fatalistic attitudes towards cancer prevention, symptoms and treatment will also deter the development of a cancer control programme. The "failure to improve cancer-related information, education and training could perpetuate grievous problems some of which are misdiagnosis and or delayed diagnosis" (Chiu and Wistow, 2002, p. 55) and may exacerbate problems associated with parental diagnosis (breastcancer.org, 2004; Scott et. al., 2003a, 2003b and 2003c; Thastum et al., 2009; Visser et al., 2007; Watson, 2009). It was with these findings and observations while employed at the National Cancer Society Malaysia and the NCI Cancer Hospital, as well as the impact of cancer to individuals and families that necessitates this research.

Findings from this literature review advocated for a research methodology that employed a user-centric approach to solicit the nuances of a cancer experience of participants. It informed about the strategy in using drawings as a method of participant self-reports and narrative experience to facilitate discussions and overcome children's cognitive limitations (breastcancer.org, 2012; Decan, 2000, para.15-18; Ewald, 1985; Ewald, 2011; Skovdal and Ogutu, 2009; Sweeney, 2003). Findings of precedent research about cancer experiences helped the researcher to development some anticipated themes (breastcancer.org, 2012; McCue and Bonn, 2003; Scot et. al., 2004a, 2004b, 2004c; Skovdal and Ogutu, 2009). The precedent use of participative action research provided considerations for the research process. This review also helped to identify participants' possible concerns, the spectrum of information needs of dependent children and, possible recommendations in strategizing solutions to the problems in cancer patients' information needs. How the research was conducted and, how data was obtained and analysed is reported in the next chapter.

CHAPTER 3
METHODOLOGY

Findings from the literature review suggested that information about children who provided caregiving and support to their parents diagnosed with cancer were very limited. The concern for the consequences of parental cancer diagnosis to dependent children was established in Chapter One and Chapter Two. Guided by the literature review and observations while employed at NCSM, the aim of this research was to explore the experiences of Malaysian children whose parent has cancer in order to identify priority information needs and information seeking behaviour. Specifically, to explore children's perception of cancer and information culture and; information needs, information seeking behaviour, barriers and enablers. As mentioned in Chapter One (pg. 9), in order to meet these objective, three research questions were developed, with further details as follows:

1. **What are Malay children's understanding of their parents' cancer; its causes, effects, implications and consequences?**
    - What studies have been conducted about children and the impact of a parent's cancer?
    - What do children experience when a parent was diagnosed with cancer?
    - What role do children play in their parent's cancer treatment?

2. **What consequences does children's understanding or lack of understanding about cancer have for them?**
    - How are children informed and to what extent is the information shared?
    - What is the process for children's information seeking behaviour and what format do they prefer?
    - What are children's key information needs?
    - What are the consequences to children having or not having information?

3. **What interventions may benefit children and enable them to cope with their parents having cancer?**
    - What are current resources to support children in this situation?
    - What do children want to know and, do existing information systems meet those needs?
    - What strategies should be considered when providing information to children with a parent who has been diagnosed with cancer?

In order to inform the methodology and to explore these research questions, this chapter was divided into four sections: 1) Choice of data 2) Review of precedent research methods and its implications, 3) Conclusions of precedent methodologies and, 4) Research study design which is a procedural framework that included the development of a participant selection method, data collection approaches and choice of instruments and, data analysis methods.

3.1 CHOICE OF RESEARCH

This section provides a discussion and justification for choosing to collect qualitative data for this research. In order to be better informed about the choice of data, a comparative review of quantitative research and qualitative research is discussed below.

3.1.i Quantitative Research versus Qualitative Research

According to Greig et al. (2013b, p.62), conducting research with children can be described as a systematic and scientific activity. Scientific activity has two principal methods; deduction and induction. Deduction was where theories are developed from which researchers "can 'deduce' likely outcomes" (Greig et al., 2013b, p. 67). Induction was where theories may not have been particularly developed but researches can and may "observe, measure and examine potential patterns" from produced data that will help to develop a theory (Greig et al., 2013, p. 68).

Greig et al. (2013b, p. 68) explained deduction as likely to lead to quantitative research that was based on assumptions or pre-existence of a "law-like" formula about the objective nature of children and that the child's "behaviour, understanding, knowledge or meanings are structured, determined and universal". This resulted in data empirically proving or disproving a theory or hypotheses. Induction assumed a more qualitative research framework in which new theories emerged from collected data (Greig et al., 2013b, p. 71). Greig et al. (2013b, p. 71) explained that this was based on assumptions about the subjective nature of children and that the child's behaviour, where "understanding, knowledge and meanings" were complex, dynamic and developed or nurtured as a result of "interaction with others in a given context". Data was collected through "observations, interviews, conversations, written reports and texts" and then interpreted to develop a theory to explain the phenomena under study (Greig et al., 2013b, p. 71). In selecting the choice of data, Greig et al. (2013b, p. 75) proposed that a research approach should be "guided by the nature of research questions, the participants, the sort of findings you require and what you intend to do with them". The justification for choosing quantitative data is provided below.

3.1.ii Justifications for choosing quantitative research

As mentioned at the beginning of this chapter (p. 63), this research explored the experiences of children. The purpose was to understand how children made sense of their situation, how they found out information and what information they required to overcome the challenges they faced. This context suggested that the underlying philosophical system for this research was subjective and multiple. In order to obtain data, children would be solicited for their unique self-reports of experiences. This line of enquiry assumes a natural and socially constructed phenomenon. Anecdotal narratives of experiences were more readily obtained by open-ended questions and explorations of enquiries and themes, hence a qualitative approach.

Another justification was the approach of conducting children's focus group. As reported by Scheidlinger (2004, p. 69), structured group activities were regarded as a better method to elicit self-reports as it was believed this would be less limiting to children's free expression of feelings, thoughts, narrative and experiences. Being among family and peers was believed to promote a "benign regression"; encouraging discourse that has fewer opportunities for children's disruptive reactions and, would also encourage conceptual clarity for data collection and observation (Scheidlinger, 2004, p. 69). This method and the research scope cannot be elicited nor managed through quantitative data collection means.

In entering the world of children (observing how they operate, interact, learn and conceptualise things), the description and analysis of the contextualised social phenomena (of actions, thoughts, intentions and meanings) cannot be transcribed numerically (Greig et al., 2013b, pp. 65-66). In addition to that, the nature of the research is an inquisitive, interactive and engaging narrative of dependent children's experience and nuances of issues, problems and challenges in coping with their parental cancer. The research itself necessitated a data collection approach that made this exploration possible.

In collecting data, the encouragement for drawing as a communication and narrative tool was identified as a means of communicating thoughts, ideas, expressions and narratives (Ewald, 2011; Skovdal and Ogutu, 2009; Ewald et al., 1985; Osborne, 2006a; Osborne, 2006b) because traditional verbal accounts or written words may not be as successful in soliciting data of the nuances of children's experience and understanding about cancer. When combined with the nature of the research and precedent methodologies, the collection of qualitative data seems more suitable.

However, this research was not entirely qualitative as quantitative data for participant demography and ranking data was required. Quantitative data was to obtain median number of children per cancer patient, language preference (English versus Bahasa Malaysia), list of care-giving tasks and a priority scale of information (what kind of information participants perceived as the more important). Having decided on a more qualitative data collection, options for a procedural framework were assessed. In order to do this, a review of research methods is presented in the next section.

3.2 REVIEW OF RESEARCH METHODS

This section provides a review of methodologies involving children and investigating health concerns and, people-centred design. While there have been several methods, the range of research techniques and approaches presented below was compared against the scope and focus to be explored. This section presents i) Methods to conduct research involving children, ii) People-centred design and, iii) Other methodological concerns.

3.2.i METHODS TO CONDUCT RESEARCH INVOLVING CHILDREN

According to Greenberg and Harris (2011, p.1), there were considerable concern that the experience of poor physical and mental health affected children's scholastic achievements, the use of harmful substances, tendency for violence and being unhealthy. In addition to these concerns, according to Camras (1977, p. 1431), "children as young as 5 and 6 years old can recognise facial expression of such emotions as happiness, sadness, anger and, fear at above-chance levels" and keeping a health situation a secret does not protect a child. Several research methods have been employed to identify the needs, concerns and problems that affect children. A review of Positivism, Social Constructionism, Learning Theory and, Cognitive Theory and their implications to the research is reported below.

3.2.i.a Positivism

Greig et al. (2013b, pp. 65) reported that several child study researchers used a positivist approach. Positivism was attributed to Auguste Comte in the 1800's (Landow and Everett, 2012, para. 1). It is an approach that assumes "law-like relationships can be drawn amongst constructs that child study researchers can identify, operationalise and measure" (Greig et al., 2013b, pp. 64). Children were studied in controlled settings with variables isolated, measured and correlated with other variables so as to develop generalised predictions (Greig et al., 2013b, pp. 64).

However, the very nature of children as study subjects and the ability of a researcher to individually and collectively construct varied conceptualisations of the research situation and its expected outcomes may undermine the supposedly unbiased judgement of data collection of the research. According Greig et al. (2013b, pp. 64) "the human capacity for language, thought and action" has the potential to 'sabatoge' a positivist based research because interpreting and defining human behaviour in its entirety (context, time, intent and meaning to the people involved) is complex and is unlikely to be limited to measurable law-like relationships. Greig and Taylor (1999, p. 47) supported their assertion by way of Vygotsky's criticism that the positivist approach "does not address a child's individual motives, talent, potential for development or the important effects of the historical, cultural and social context upon the research situation". In reviewing this research method, a positivist approach was less suitable to reach the aims of the research to be explored.

3.2.i.b Social Constructionism

Greig et al. (2013b, pp. 51-54) reported that social constructionism was another approach to studying children. Introduced by Berger and Luckmann (Andrews, 2012, para 4-10), social constructivists believed that people constructed and provided meaning to knowledge through social interactions. Specifically, it was concerned with how knowledge and reality was constructed and understood through everyday interactions between people (Andrews, 2012, pp. 39-46; Kim, 2001). Children are "subjective, contextual, self-determining and dynamic beings" and the interactions among children and between their caretakers are built around and in social relationships and environments that develop or result in "joint meanings" and "joint actions" (Greig et al., 2013, p. 65). This principle tracks how knowledge was commonly understood by a group of people and, their consensual notion as to "what constitutes knowledge across individuals, gender, age, context, time, culture, historical practices and social norms" (Andrews, 2012, pp. 39-46).

In reviewing this research method, a social constructionism approach enables the analysis of thought processes, underpinning cultural mores and information seeking behaviour processes that guide children's information seeking, motivation and development of solutions to the research aims and objectives. This approach may support the exploration of the inherent human and socio-cultural constructs that motivate and justify information seeking and communication preferences of children with a parent with a critical illness.

3.2.i.c Learning Theory

According to Chavis (2011, p. 472), learning behaviour adapted and evolved from Ivan Pavlov's Classical Conditioning Theory and Skinner's Operant Conditioning. The learning theory explains the process of learning as a response to a stimuli or conditioned stimuli (Sherlin et. al., 2011, p. 293). Further developed by Skinner in 1974, this theory believed that behaviour can be learned, changed or modified through reinforcement and punishment and, children learned through observing, modelling and cognitively processing the behaviour of others (Greig et al., 2013, pp. 31-32; Bandura, 1993, pp. 119-145).

Mineka and Zinbarg (2006, p. 11) reported that "Vicarious conditioning" – simply observing another's experience and reactions to a situation- may be sufficient to make the observer develop a similar reaction towards a similar situation. According to Wilson (2012, para. 1), "people learn not only from their own experiences, but by observing the actions of others and the benefits of those actions". This suggested that in situations of critical illness, when a child is exposed to the reactions and experience of their ill parent, they too could develop a similar reaction were the illness happen to them, or experience somatisation in reaction.

In reviewing this research method, learning theory's principles may help to guide the research's observation of children's ability to learn certain information behaviour through their own observations and modelling of other's behaviour.

3.2.i.d Cognitive Theory

Adapted and evolved from Jean Piaget's Cognitive Development in 1974 and Lev Vygotsky's Social Development in 1978, this theory advocated that children have the capacity and capability of learning and processing thoughts, behaviours and relationships that is different from adults and is influenced and nurtured by environmental conditions, social relationships and cultural conventions (Greig et al., 2013, pp. 35-38).

According to Papert (1999, para. 1), children had their own thought processes: "children had their own kind of order and their own special logic". According to McLeod (2007, para. 6-7), social interaction and the community influenced children's cognition, psychological function, cultural development and "making meaning". According to Papert (1999, para. 3), "children are not empty vessels to be filled with knowledge but active builders of knowledge — who are constantly creating and testing their own theories of the world" and "children can develop and practice their own explanatory principle" that makes sense to them when they lack sufficient information or the skills to process information intended for adult recipients.

Carring (2013, para. 1) wrote that this theory might accurately convey how a person's environment influenced acquiring and maintaining "particular behavioural patterns that can affect their personality and the way they communicate with others". She believed that "the behavioural patterns and environment children are introduced to … shape the way they will interact and communication with others…" could help shape children and adolescents life (Carring, 2013, para. 2).

Cognitive theory principles may help to guide the research by way of exploring how knowledge developed in children. Furthermore, according to McLeod (2007, para. 15), the belief in children's development as being influenced by Vygotsky's "zone of proximal development" (a level of development attained when children engage in social behaviour and social interaction that help them learn), might help identify cancer-related skills development with adult guidance or peer collaboration. In the context of the Malay culture this area has had very little research and it would be interesting to observe what Malay children think, how they construct their world and what are the important themes and values they have about their world that is impacted by cancer.

3.2.ii PEOPLE-CENTRED DESIGN

The importance of information to people who are critically ill and to their family members make a compelling argument to use a user-centred approach to this research. The user as the central element to an information system was mentioned in Chapter One (page 17). Allen (1996), in his book *Information tasks*, collected much of the academic literature advocating user-centred approaches to information system development. A *user-centred approach* is one where "the needs of the users play a more influential role than data or technology." (Allen, 1996, p.1). He provided insight into how a user's "knowledge structures" and "abilities, styles and preferences" influenced their information behaviour. Allen (1996) and Wilson (1994, para. 100-107) argued that these factors must be incorporated into the system design process. This approach contradicted the *traditional paradigm*, "... information is seen as the objective ...", where according to Dervin and Nilan (1986, pp. 3-33), Information Science (IS) academics tended to see information, information processing, and consequently information systems from an engineering perspective rather than the needs of users. In contrast, the user-centred design "... begins with the user rather than the data ... emphasizes the process by which users become informed, rather than the information things that are used in the process" (Allen, 1996, p. 16).

Prior to developing strategies and/or designing an information system, it was essential to investigate the information needs and information seeking behaviour of users. In order to accomplish this, Participatory Action Research (PAR) is reviewed below.

3.2.ii.a Participatory Action Research (PAR)

Participatory Action Research (PAR) evolved from social and educational research, Kurt Lewin's Action Research (AR) developed in 1944, the influences of Eduard Lindeman, John Dewey and Jean Piaget and, William Foote Whyte (Glassman et al., 2013, pp. 273-274; Chevalier and Buckles, 2013a; Smith, 2001, para. 26; Hughes and Seymour-Rolls, 2000, Introduction, para. 1; McTaggart, 1997, p. 81). According to Baum et al. (2006, p. 854), PAR differed from other health research approaches because "it is based on reflection, data collection, and action" aimed at improving health outcomes and reducing health inequities with input by people the interventions were for. PAR was one of the few research methods that included and embraced principles of participation and reflection, empowerment and emancipation of groups seeking to improve their social situation (Smith, 2001, para. 26-32). Hence, for the purpose of this research, the definition as follows: "collective, self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social...practices" (Kemmis and McTaggart, 1988, p. 5) will be used.

According to Baum et al. (2006, p.854) PAR used "lived experiences" of participants as a source of knowledge that were more closely involved with the research process. Furthermore, PAR allows observations and data explication of how participants derive a meaning, develop knowledge and understand their experiences. This results in more rich and depth of data from participants' who are not as rigidly bounded as by other research methods.

Kemmis and McTaggart (1988, p.5), described PAR as having four interdependent moments; reflection, planning, action and observation, that follow each other in a cyclic spiral. These moments as explained by Hughes and Seymour-Rolls (2000, para. 3-11), Grundy (1988, p. 28) and Kemmis and McTaggart (1988, p. 5, 13 and 54-90) are;

> “**Reflection:** that moment when research participants examine and construct, then evaluate and reconstruct their concerns. This includes pre-emptive discussions where participants identify a shared concern or problem.
>
> **Planning:** that moment that is constructive and arises during discussions among the participants of what to do about a shared concern or problem. The Plan critically examines action of each participant and includes evaluation of the change.
>
> **Action**: that moment when the deliberate and strategic Plan is put into place and the hoped for improvement occurs. The action or change is happening in reality.
>
> **Observation:** that moment of 'research' when the changes as outlined in the Plan are observed for its effects. Research tools, such as questionnaires, are utilised to ensure scientific methods are followed and results have meaning.”

PAR has four basic themes: empowerment of participants; collaboration through participation; acquisition of knowledge; and social change (Masters, 1995, para. 10). In this way, PAR is a more ‘grounded’ way to gather people's experiences and knowledge than traditional top-down research approaches, in which planning, decision making and implementation are predetermined (Williams, 1999, pp. 4-39). Participants have opportunities to share and reflect on their experiences that may lead to nuances of knowledge and data other research approaches may be unable to obtain.

Waterman et al. (2001, p. 21) reported that PAR encourages stakeholders to participate in making decisions about all stages of research, or empowering and supporting participants which help to either solve practical, concrete or material problems or to evaluate change; and that it “acknowledges complex contexts or can be used with complex problems in complex adaptive systems”. This methodology was instrumental in the development of the Community Health Educator (CHE) Model (Chiu and Wistow, 2002, pp. 6-7). According to Hughes (2008, pp. 381-393) and Hughes and Seymour-Rolls (2000, para. 11), the possibilities of using PAR in healthcare are enormous and entirely appropriate; there were a few researches that focused on community participation in understanding and developing interventions for health concerns. Systematic reviews showed the increased use of PAR in health-related issues (Baum et al., 2006, pp. 854-855; Chevalier and Buckles, 2013a; Chiu and Wistow, 2002, pp. 6-7; Cochran et al., 2008, pp.23-26; Erick et al., 2008, p. 5-6; Green et al., 2001, pp. 26-28; Read, 2012; Waterman et al., 2001, p. iv).

PAR was useful for cultural issues because data gathering and observations reflect localised conditions that result in information that was more complete, rich and as accurate as possible (Read, 2012; Mok and Hughes, 2004, para. 19). The PAR process has implications for this research as Hughes (2008, pp. 381) believed; “We cannot frame the health professional, the intervention and the client as independent and separate entities. They are mutually interdependent and participating actors in a larger system.” PAR was useful in conceptualising and designing a systematic step-by-step process of organising and conducting the observation and ‘research’ part of the project. It was particularly useful to identify what were participants’ information/communication problems and how they collaboratively proposed a viable solution. PAR provided a mechanism to capture information of culturally held attitudes and beliefs toward informing children about a critical illness. PAR also provided a mechanism to capture little known information about the dynamics of children’s approach to soliciting information and their preferences.

3.2.iii OTHER METHODOLOGICAL CONCERNS

Cautionary advice was reported by Dervin (2001) and Kubler-Ross (1969) in working with people who experienced stressful situations. Findings by Dervin (2001) indicated that participants may be less willing to share their experiences with the researcher. Dervin (2001, Section 3, para. 1-7) highlighted that there were six problems with information. Firstly, “The Undiscussable”; there were limits or boundaries of perspective and ‘whole story’ to information. Secondly, “Information Seeking Complexities”; information and its related activities were extraordinarily complex and very changeable across time. Thirdly, “Context as Foundational Construct”; an information seeker’s culture, cognition, or emotional state influences information needs and seeking behaviour. Fourthly, “Sense-Making Metaphor”; data collection and interpretation should place emphasis on a person in a situation, facing a gap, building a bridge over the gap using different sense-making strategies, and then assessing the outcome and moving on to the next information-seeking moment. Fifthly, “The Caesar Effect”; what conditions influence people’s contextual information motives and needs. Lastly, “Responsive design”; a solution that can be responsive to users and their information seeking behaviour.

According to Kubler-Ross (1969, pp.35-49), people's resistance to death and a diagnosis of an incurable disease undergoes a cyclic process. This had five states (acronym DABDA):

> **"D:** **Denial** – a state of refusing to admit a problem or situation. This may have implications in providing the type, depth and angle of information a person in denial may be able to accept.
>
> **A:** **Anger** – a state of negative emotion; a strong feeling of displeasure or hostility as a result of an unagreeable situation. This may have implications in providing the type and channel of information a person experiencing anger may be able to accept.
>
> **B:** **Bargaining** – a state where an individual bargains for alternatives to provide a solution to a problem. This may have implications in providing the type (causation and risk factors of cancer) and channel (doctor, nurse, close relative) of information a person bargaining may be able to accept.
>
> **D:** **Depression** – a state of feeling sadness, guilty, helplessness, hopelessness, and despondent and is often characterized by inability to concentrate, insomnia and loss of appetite. This may have implications in providing the type of information (survival and treatment side effects) and conformity to information (as provided by doctor, nurse, and close relative) a person in depression may be able to accept.
>
> **A:** **Acceptance** – a state of feeling of having coming to terms with a situation and a willingness (of sort) to do something (anything or everything) to do something about the situation. This may have implications in providing the type of information (treatment options) and the conformity to health messages (or health myths) a person in the acceptance stage will be able to act on." (Kubler-Ross, 1969, pp.35-49)"

Kubler-Ross' (1969) work may have an effect of developing a solution to help communicate to children about a parent's critical illness. In communication with the Elizabeth Kubler-Ross foundation (personal communication, 28 July, 2006[6]) and in Kubler-Ross (1997, p. iv), it was thought that children might be in any one of the DABDA cycle. This may limit children's abilities or willingness to share experiences. Another consideration was that participants were not native English speakers. According to (Morales et. al., 1999, p. 409), a language sensitivity may be required to address the issue of "increased risk of lower quality of care and poor health outcomes" where English is not the main language spoken by intended information health recipients. This suggested the need to conduct participatory research in Malay instead of English.

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[6] E-mail discussion with representatives from the Elizabeth Kubler-Ross foundation on 28 July, 2006 about children's experiences when facing parental death or cancer.

3.3 CONCLUSIONS FROM REVIEWED METHODOLOGIES

This research has conditions favouring a methodology that was user-centric and one that would provide insights into the world in which information seekers inhabit. Similar to Wilson's (1994) belief, it was likely that information seeking and problem solving would be organized around preferred information sources and where meanings and sense-making share common grounds to that of information seekers. Furthermore, similar to conditions identified by Dick (1997, para. 23), children's comprehension about cancer, identifying information needs and seeking strategies seemed to form a research paradigm that was based in action research. Moreover, the issues and research questions were interrelated and built upon the reflection of findings from precedent activities suggested a cyclical methodological process.

According to Granet (2003), Dervin (2001) and Kubler-Ross (1969), caregivers and people impacted by a health situation require special information needs and attention. Very few researchers have investigated the impact of dependent children's information needs and the challenges they faced. Also, very little research has been conducted with children that acknowledged and identified their roles, the influence of socio-cultural norms and attitudes to information sharing within the family and community about cancer. These gaps in knowledge were likely to have significant consequences for children's development in most non-English-speaking cultures like the Malay.

These problems argue for a user-centric, participatory action research that respected social contracts and needs as well as the information pathway, motives and norms of research participants. This was especially crucial in the exploration of information needs and experiences of dependent children of cancer patients. In conclusion, this review suggested a social constructivist approach with an emphasis on qualitative data collection obtained through the use of a participatory action research process and the influence of Learning Theory and Cognitive Theory. The research study design is explained below.

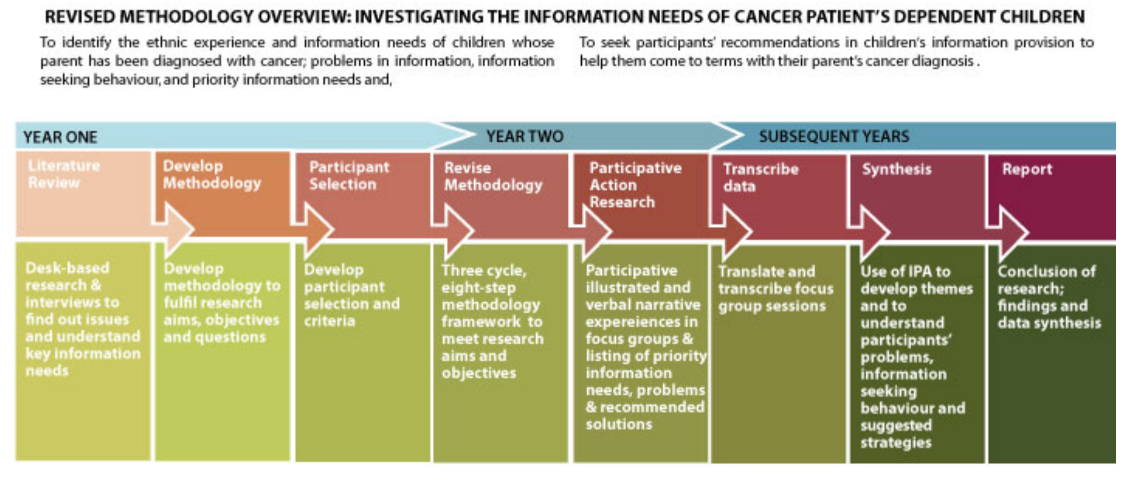
3.4 RESEARCH STUDY DESIGN

The following section outlines how the research was carried out by 1) Research process, 2) PAR Methodology and, 3) Data Transcription and Analysis.

3.4.i RESEARCH PROCESS

In order to present this process, Diagram 3.1 summarised activities involved throughout the research. Specific activities are reported below.

Diagram 3.1: An overview of the revised research process



According to Diagram 3.1, **Year One** was an exploratory desk-based review, work-based observation and personal communication with key individuals about the situation dependent children of cancer patients experienced. As informed by the literature and methodological review and, the requirements of the research questions (on page 55), a preliminary selection and criteria for participation was developed.

In **Year Two**, the research methodology was developed as a qualitative approach using a Participatory Action Research (PAR) framework. Upon ethical and procedural approvals, the fieldwork took place. Activities included data collection from families that fulfilled the participation criteria. The activities upheld conducting qualitative research with children advocated by Ewald et al. (2011), Grieg et al. (2013), Rollinson (1998) and Scott et al. (2003b; 2003c).

Activities included specific questions and semi structured questions in phenomenological interviews. As advised by Groenewald (2004, p.12) the questions were focused on obtaining participants' experiences which included what they felt and believed in. Participants described their thoughts, feelings and experiences in a language and descriptive manner they were comfortable with. In this way, the narratives had scope and depth. This was replicated for each focus group session. Discussions were audio recorded with the permission of all participants before each session started. Drawn or written narratives were recorded with a camera and labelled accordingly. Descriptions of the methodology and data collection activities are discussed in 3.4.ii PAR Methodology (on page 67).

In **Subsequent Years**, data collected from 32 participants amounted to about 100 contact hours of audio recording, notes and participant's written, verbal and drawn self-reports. Since participants' first language was Bahasa Malaysia, most of the transcription activities underwent a two-step process. Responses were first clarified with each participant for their meanings and typed verbatim. These were then translated into English, with further clarification of contextualised meanings from participants' and research observations.

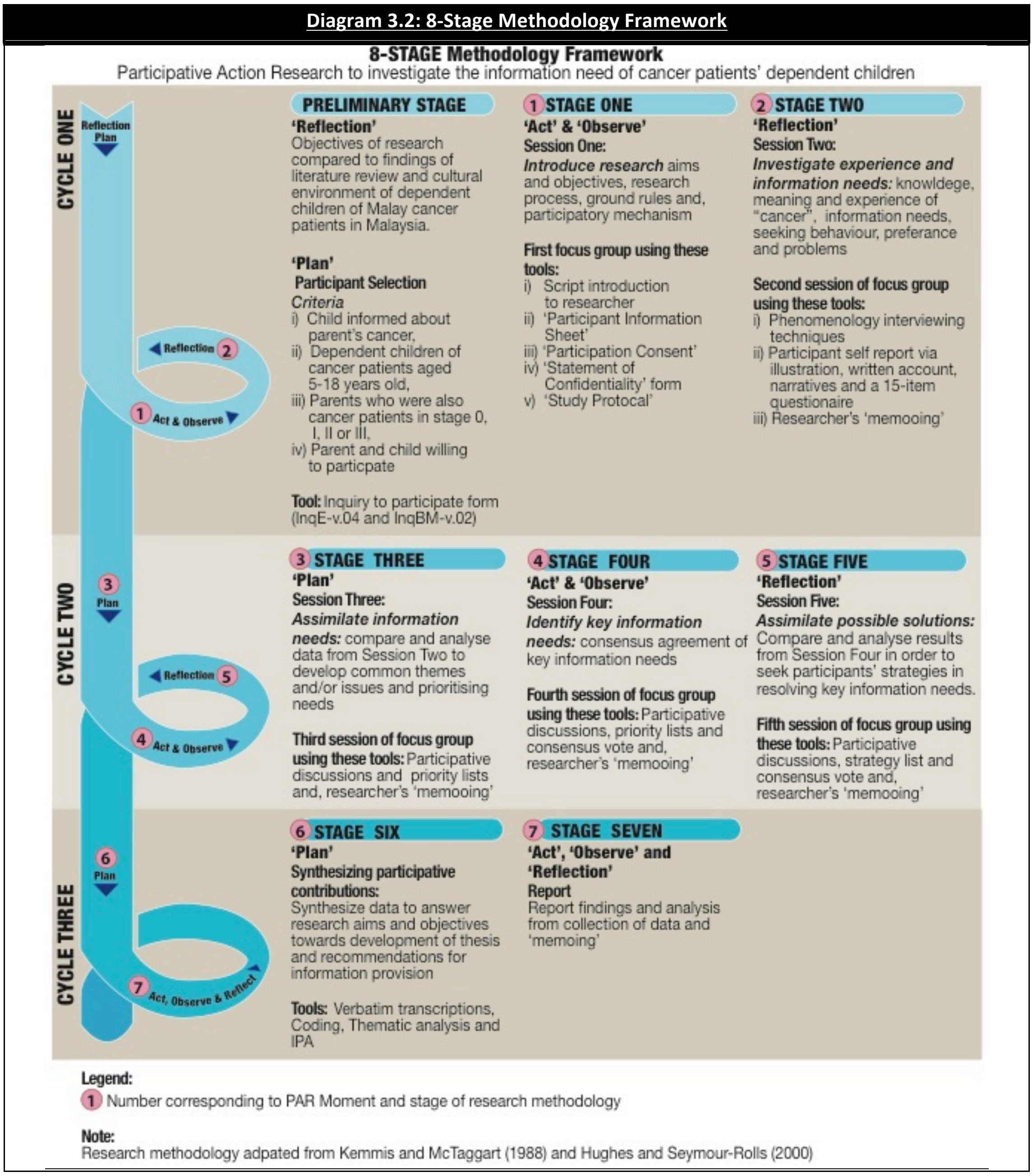
Data was then synthesized. Guided by Biggerstaff and Thompson (2008, pp. 179-182), Groenewald (2004, pp. 17-22), Hycner (1999, pp. 143-164), Rolls and Relf (2006, p. 287), Tuffard and Newman (2010, p. 84), this was done utilising an Interpretive Phenomenological Analysis (IPA) approach to develop themes and to understand participant's problems, information seeking behaviour and suggested strategies to mitigate identified priority information needs. Data was coded and digitally duplicated into separate files with specific identifying markers. Coding of participants was explained on page 72.

Transcribed narratives were given notations as explained on page 75. Coding for themes was explained on page 94. In addition to this, the researcher actively practiced "memoing" (Glaser, 2004, para. 1-5) described on page 80. The thesis report was developed and subsequently submitted.

3.4.ii PAR METHODOLOGY

This research adapted Kemmis and McTaggart (1988) and Hughes and Seymour-Rolls (2000) PAR methodology. It was adapted to explore the experiences of children whose parent has cancer. This was to identify priority information needs and seek possible solutions to participants' information-needs problems. The methodology consisted of three cycles. This included eight stages and five focus group sessions. The eight stages corresponded to different PAR moments of 'Plan', 'Act', 'Observe' and 'Reflection'. The five focus group sessions had activities and participatory engagement for data collection. Data was from responses to structured and semi structured questions in phenomenological interviews, narratives through drawings or written responses and, answers from a questionnaire. In this way, data was triangulated for validation. Data collection continued until the topic was exhausted or when participants did not contribute more information. The research methodology is illustrated in Diagram 3.2: 8-Stage Methodology Framework.

Diagram 3.2: 8-Stage Methodology Framework



8-STAGE Methodology Framework

Participative Action Research to investigate the information need of cancer patients' dependent children

CYCLE ONE

PRELIMINARY STAGE
'Reflection'
Objectives of research compared to findings of literature review and cultural environment of dependent children of Malay cancer patients in Malaysia.

'Plan'
Participant Selection
Criteria
i) Child informed about parent's cancer,
ii) Dependent children of cancer patients aged 5-18 years old,
iii) Parents who were also cancer patients in stage 0, I, II or III,
iv) Parent and child willing to particpate

Tool: Inquiry to participate form (InqE-v.04 and InqBM-v.02)

① STAGE ONE
'Act' & 'Observe'
Session One:
Introduce research aims and objectives, research process, ground rules and, participatory mechanism

First focus group using these tools:
i) Script introduction to researcher
ii) 'Participant Information Sheet'
iii) 'Participation Consent'
iv) 'Statement of Confidentiality' form
v) 'Study Protocal'

② STAGE TWO
'Reflection'
Session Two:
Investigate experience and information needs: knowldege, meaning and experience of "cancer", information needs, seeking behaviour, preferance and problems

Second session of focus group using these tools:
i) Phenomenology interviewing techniques
ii) Participant self report via illustration, written account, narratives and a 15-item questionaire
iii) Researcher's 'memooing'

CYCLE TWO

③ STAGE THREE
'Plan'
Session Three:
Assimilate information needs: compare and analyse data from Session Two to develop common themes and/or issues and prioritising needs

Third session of focus group using these tools: Participative discussions and priority lists and, researcher's 'memooing'

④ STAGE FOUR
'Act' & 'Observe'
Session Four:
Identify key information needs: consensus agreement of key information needs

Fourth session of focus group using these tools: Participative discussions, priority lists and consensus vote and, researcher's 'memooing'

⑤ STAGE FIVE
'Reflection'
Session Five:
Assimilate possible solutions: Compare and analyse results from Session Four in order to seek participants' strategies in resolving key information needs.

Fifth session of focus group using these tools: Participative discussions, strategy list and consensus vote and, researcher's 'memooing'

CYCLE THREE

⑥ STAGE SIX
'Plan'
Synthesizing participative contributions:
Synthesize data to answer research aims and objectives towards development of thesis and recommendations for information provision

Tools: Verbatim transcriptions, Coding, Thematic analysis and IPA

⑦ STAGE SEVEN
'Act', 'Observe' and 'Reflection'
Report
Report findings and analysis from collection of data and 'memoing'

Legend:
① Number corresponding to PAR Moment and stage of research methodology

Note:
Research methodology adpated from Kemmis and McTaggart (1988) and Hughes and Seymour-Rolls (2000)

3.4.ii.a CYCLE ONE

According to Diagram 3.2, Cycle One consisted of the Preliminary Stage (PAR moment of 'Reflection'), Stage One (PAR moment of 'Plan') and Stage Two (PAR moment of 'Act' and 'Observe'). This is explained below.

Preliminary Stage

According to Diagram 3.2, the Preliminary Stage was the beginning of the fieldwork activity. As explained by Kemmis and McTaggart (1988) and Hughes and Seymour-Rolls (2000), the researcher began PAR by reflecting on the objectives of the research. This was compared against the literature review and the cultural environment of dependent children of Malay cancer patients in Malaysia. Following this, a recruitment exercise was developed.

Recruitment exercise

As advocated by the literature review, there should be a preliminary selection and criterion-based selection of respondents to a participative-driven research. Discussions with the research supervisor resulted in a 9-question single page inquiry form to recruit participants.

The form had three objectives. Firstly, the objective was to investigate the sentiments of cancer patients about informing their children about their cancer diagnosis. This helped to identify foreshadowed issues (Scheidlinger, 2004, p. 69-75) that may have instigated problems children experienced as caregivers. Secondly, the objective was to find out first tier common variables of what are the issues/concerns/problems of parents in communicating cancer diagnosis and relevant information. Thirdly, the objective was to find out language preferences in communicating and sharing cancer related information to dependent children and, to obtain demographic information. This form also helped to filter respondents who did not meet the research objectives.

The finalised version of this form was called “Invitation to Participate” and was provided in Bahasa Malaysia (InqFBM-v.02) on one side of the form and English (InqFE-v.04) on the other side. A sample is attached in Appendix 1. Answers provided in the form ranged from ‘Yes-No-Not Sure’ options and open-ended questions. The forms were distributed to patients at the National Cancer Society Malaysia (NCSM) and Tung Shen Hospital’s Cancer Centre with approval from their administrators. These places were targeted for their high traffic and accessibility to patients and the researcher. The forms were placed at the point-of-payment and registration counters. Both locations were provided with a weekly supply of 50 forms for two months. This time frame reflected the average treatment cycle for chemotherapy and radiotherapy.

The Star (a Malaysian newspaper) helped to publish two articles about the research and call for participation[7]. Five people e-mailed in response to the articles. Unfortunately responses were not relevant to the research. The researcher also solicited participants from NCSM organized events and database. It was included as part of a welcome gift pack prior to participating in NCSM's 'Cancer Survivor's Tea' which was held at the KLCC Convention Centre. 200 forms were distributed. Guests were asked to fill in the forms as they took their seats. 177 forms were collected before the end of the event. These efforts resulted in a total of 405 forms distributed and 205 responses received. The resulting 50.61% response rate was deemed sufficient (Sekaran, 2003, p. 237). This is summarized below in Table 3.1 Summary of activities and responses to "Invitation to Participate" exercise.

Table 3.1 Summary of activities and responses to "Invitation to Participate" exercise

NUMBER OF FORMS	DISTRIBUTION ACTIVITY	NUMBER OF RESPONSES
200	i) Cancer Treatment Centre, Tung Shen Hospital ii) Women's Cancer Detection Centre & Breast Clinic and Nuclear Medicine Centre, NCSM iii) Breast Cancer Support Group, NCSM iv) Prostate Cancer Support Group, NCSM	28
5	i) Newspaper articles in The Star ii) E-mail response	0
200	'Cancer Survivor's Tea', KLCC Convention Centre	177
405	**TOTAL**	**205**

Participant criteria

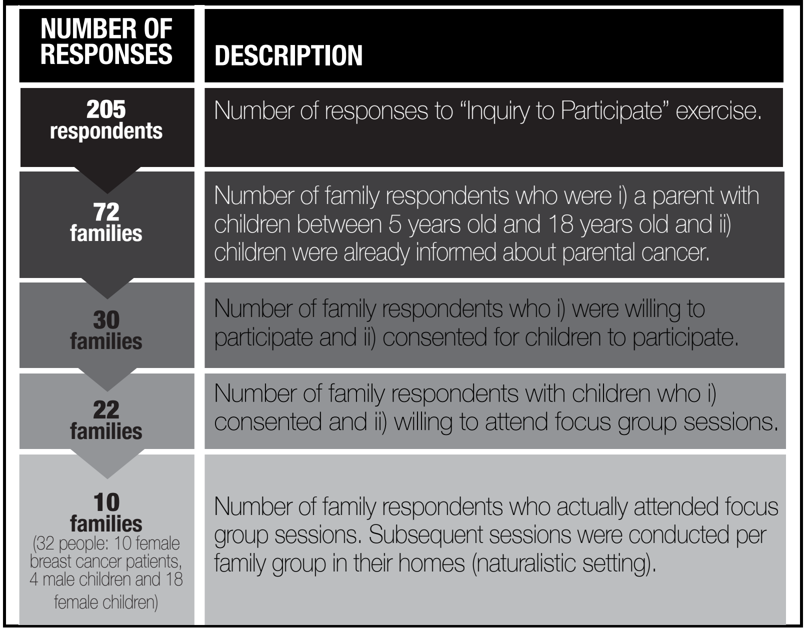
The 205 responses helped to select potential participants. The first criterion was that a child was informed about a parent's cancer (Question 6) to mitigate emotional upsets in children and patients if the diagnosis was not shared before focus group commenced. The second criterion was for cancer patients having dependent children aged between 5 years old and 18 years old (Question 5). Patients who were diagnosed in the stages of cancer with a better prognosis or 5-year survival (stages 0, I, II and III) (Question 3) were selected. This provided more time to engage with participants and their families when a diagnosis was not considered at a terminal stage. Willingness to participate was an important criterion. Only respondents who indicated their willingness (Question 8) and provided their consent for children (Question 9) to participate were selected.

---

[7] The researcher was interviewed by K.S. Usha Devi about the research, literature findings and request for participation on February 15, 2007 at NCSM. This resulted in the publication of the researcher's work through two articles written as: K. S. Usha Devi, "To help kids deal with cancer", *The Sunday Star*, February 18, 2007 and K. S. Usha Devi, "One in four Malaysians could get dreaded disease", *The Sunday Star*, February 18, 2007.

From 72 families who had children between 5 years old and 18 years old, only 30 families were willing to participate in the sessions. Out of these 30 families, only 22 families and their children indicated their consent and were able to attend. Participation was limited due to children's school examinations, school holidays, tuition classes and family emergencies (a child was diagnosed with dengue, an older daughter had a difficult pregnancy, a car accident and several respondents caught the flu virus). On the day of the scheduled first session, only 10 families attended (32 individuals). This record is summarized in Table 3.2 below.

Table 3.2: Summary of participant selection



NUMBER OF RESPONSES	DESCRIPTION
205 respondents	Number of responses to "Inquiry to Participate" exercise.
72 families	Number of family respondents who were i) a parent with children between 5 years old and 18 years old and ii) children were already informed about parental cancer.
30 families	Number of family respondents who i) were willing to participate and ii) consented for children to participate.
22 families	Number of family respondents with children who i) consented and ii) willing to attend focus group sessions.
10 families (32 people: 10 female breast cancer patients, 4 male children and 18 female children)	Number of family respondents who actually attended focus group sessions. Subsequent sessions were conducted per family group in their homes (naturalistic setting).

The qualitative research suggested for a small number of respondents. In accordance to Groenewald (2004, p. 11) and Creswell (1998, pp. 65 and 113), 32 individuals with "long interviews", was considered sufficient for a phenomenological study. Creswell (2007, p. 126) suggested between 20-30 respondents should help to develop saturity and that for phenomenological studies, 10 people would be sufficient when information was collected from in-depth interviews (Creswell, 2007, p, 131). Demographic detail from this form is presented in Chapter Four (4.1. Demographic Details, pg.93)

Ethical consideration

In order to ensure ethical research, the researcher made use of informed consent (Greig et al., 2007; Hill, 1997; Hill, 2005). As pointed out by Grieg et al (2007), conducting research with children and their families required deliberate consideration and specific consent forms for both parental and children consent. The Malaysian Medical Council's Code of Professional

Conduct (1986) and Dissemination Of Information By The Medical Profession (2006) were used as a guideline. Specific documentation was developed based on advice and sample forms from Lancanstar University, Stanford University and adapted from Bailey's (1996, p. 11) recommended items.

Ethical consideration about confidentiality, data collection process and the right to not answer questions were addressed by briefing participants during the first focus group session and discussed in detail through specific documentation. The documentation were 'Participant Consent Form' (Appendix 2) for adult and children participants, a 'Participant Information Sheet' with a 'Statement of Confidentiality' (Appendix 3) detailing procedures to protect participant's identity and confidentiality and, a 'Study Protocol' (Appendix 4) providing details about the research. In addition to that, in soliciting support from NCSM, ethical approval was obtained through the submission of all of the above-mentioned documents. Approval was also obtained from Loughborough University through the research supervisor.

The documents were provided to all participants at the introduction to the research. Explanations were provided about the forms and participants were given opportunities to question the form's content and context. Both cancer patients and their children signed the consent form after they responded with an understanding of the research, the documents content and their participatory role. They signed two copies of the consent form, one for their keeping and one for the record of the researcher. The parent from each participating family was provided a copy of the research's' 'Statement of Confidentiality' and 'Study Protocol'.

To protect the identity of participants, their names were coded. Parent participants were coded as (P). This was placed after the code for their family unit. For example, the symbol [F1(P)] identified the participant as "F1" being Family One and "P" being parent participant. Children participants were coded as (C), followed by their birth order from youngest in the family (1) to oldest in the family (3 or 4). For example, the symbol [F1(C1)] identified the participant as "F1" being Family One and "C1" being the youngest child participant from Family One. With the selection of participants completed, the research methodology continues to Stage One of Cycle One as described below.

Stage One

According to Diagram 3.2, Stage One formed the ‘Act’ and ‘Observe’ moments of PAR as explained by Kemmis and McTaggart (1988) and Hughes and Seymour-Rolls (2000). This stage introduced participants to the research aims and objectives, research process, ground rules and the participatory mechanism of a separate parent and child focus group. This informed the research justification and general expectation of results upon completion.

Stage One was conducted as the first focus group session at NCSM. During the introduction, three documents were distributed and explained. These documents were a ‘Participant Consent Form’ (Appendix 2), a ‘Statement of Confidentiality’ form (Appendix 3) and a ‘Study Protocol’ (Appendix 4). A session script (Appendix 5) aided this. This stage had the following assumptions: 1) Parents already told their children that they had cancer, 2) Parents wanted to tell their children more about the prognosis but did not know how and sought to use the research as a platform to be better informed and, 3) Children wanted to know more about their parent’s situation but needed help in obtaining the information.

After the introduction, a question and answer activity was conducted. Before concluding the session, participants were tasked to identify questions or issues they had about their experiences or problems in communicating or sharing cancer information for the following focus group session. This gave participants time to think about their situation and to begin to apply the fourth moment of PAR; ‘Reflection’.

Stage Two

According to Diagram 3.2, Stage Two formed the ‘Reflection’ moments of PAR. From the task requested in the first focus group session, participants shared what they recalled of their experiences. The objectives were to firstly, obtain data on participants’ perception of cancer. Secondly, to investigate and analyse what were parental issues and concerns. Thirdly, to investigate children’s preferred source of information. Fourthly, to investigate how parents informed their children and what they were willing to tell. Fifthly, to find out what children wanted to know and if their needs were met. Sixthly, to investigate how each group perceived the cancer experience for themselves and to each other.

In Stage Two, a specific parent focus group and a children focus group was established. The focus group format was used because it allowed participants to interact with one another; eliciting their comments and reactions (Davey et al., 2005, p. 250). It was also appropriate for activities planning and was useful in gathering opinions from the cultural experience of the Malays. This helped to identify foreshadowed problems (Scheidlinger, 2004, p. 69-75) in communicating critical illness to children. Parents' group and children's group were separated so that the other won't unduly influence the other's responses. The groups had separate activities to find out their information needs and behaviours.

The specific activities in Stage Two were divided into two parts: firstly to gain an understanding of participant's perspective on cancer and their cancer experience and, secondly to find out how they obtained information. This was in accordance to the research question of: "What is Malaysian children's understanding of their parents' cancer?" and, partly in accordance to the research question of: "What consequence does children participants' understanding or lack of understanding have?" Participants were asked to illustrate or write what a) they thought cancer is, b) what cancer meant to them and, c) what they perceived cancer meant to their parents/children. Drawing as a communication and narrative tool (Ewald et al., 2011; Osborne, 2006a; Osborne, 2006b) was identified earlier. Respondents were supplied with A3-sized paper, colour pencils, crayons, broad-tip felt markers in various colours, coloured pens and, HB and 2B pencils. An explanation of these questions are provided below:

> **'What is cancer?'** requested for all participants i) understood definition and/or ii) observed experience of the symptoms or treatment of cancer and/or iii) what cancer can do to either a person or self. This question was to capture a respondent's general understanding of cancer and what cancer information was already known. For example, a child wrote that cancer was someone becoming sick and drew a person lying in bed. This suggested an understanding that cancer equated to something that caused a person to be ill and feel too sick to be active, i.e. cancer made people feel sick.
>
> **'What does cancer mean to you?'** sought to capture the individual's experienced impact and/or effect of cancer. This question was divided into children's and parents' self-report. This question opened up a discourse in which cancer-related information related to experiences that occurred as a result of the cancer diagnosis. For example, a child answered that he had to do more housework. This led to the development of information provision about the parent's inability to carry out their normal housework.
>
> **'What do you think cancer means to your children or parent?'** was adapted to reflect the type of respondent. Specifically, for the parent group, the question was phrased as 'What do you think cancer means to your children?' to obtain information

on parental perception about cancer's impact to their children. The question was rephrased for the children's group as 'What do you think cancer means to your parent?' to obtain information on children's perception about cancer's impact to their parents. Both groups were exposed into how each perceived cancer. This led to a preliminary base for identifying areas in which information gaps may be bridged. For example, a parent answered that their child(ren) saw the parent resting because they were too tired from the devastating effects of chemotherapy. The child(ren) saw the parent resting as a way to get better. This suggested a need for information about what caused the fatigue and why resting was important in the recovery process. Additional information, such as the ways in which the child could help the parent rest easier (for example, to be quiet or to be less argumentative between siblings) was added.

Participants were given 15 minutes to answer each question. This was sufficient for participants to express their understanding of a conceptual term and their experience after a weeklong deliberation from the introductory session. This activity was conducted in Bahasa Malaysia. Participants drew or wrote their responses on an A3-sized paper. Participants were informed that the activity was to gain an understanding of what they thought about cancer and that there were no right or wrong answers. All responses were individual work. After completion, both groups had a show-and-tell discussion to share their thoughts and explain their illustrations or their written responses. Clarification was asked for each participant's experience and the issues and concerns were highlighted. This activity was audio recorded and excerpts were used to substantiate perceptions of children about cancer. Written and illustrated responses were photographed and recorded. Samples are attached in Appendix 6.

As informed by Lomaxa et al (2011, para. 1 and 18-19), recorded data was transcribed and analysed according to the system developed within conversation analysis (Heath et al., 2010, p. 110; Flewitt et al., 2009; Goodwin, 2000, pp. 157-182) and IPA. As advocated by Heath et al., (2010), Flewitt et al. (2009) and Goodwin (2001) the anonymity of participants were protected in the transcription by codes. Narratives were given notations as described below in Table 3.3 Description of transcription notations.

Table 3.3: Description of transcription notations

Symbol	Explanation
SUZIE	Researcher's questions or comments
[F1(P)]	Identifies speaker as "F1" being Family One and "P" being parent participant.
[F1(C1)]	Identifies speaker as "F1" being Family One and "C1" being youngest children participant.
…	Indicates that verbal recording was unclear or there was a short pause prior or after
cancer *is a* ***sickness*** *that* ***damages***	Bold and italic words were identified as a theme or used in key word assessment.
(laughs)	Bracketed Italic words add clarification to the preceding word or described a physical reaction that happened during that particular statement.

In addition to the three questions, a 15-item questionnaire (CQ1) was distributed. In order to understand children's experience in obtaining information, participants were asked:

- Who informed children about their parent's diagnosis
- How were children informed and what they felt about it
- Sufficiency of information about treatment process and cancer's impact to parent and self
- Sources of information
- Types of information required
- The information's format and in what way could it be improved

The questionnaire also sought strategies for resolving perceived information problem(s). A sample of this questionnaire is available as Appendix 7. Some of the written answers led to a narrative experience of the children, which was clarified, recorded and later analysed. The responses were collected for preliminary analysis and to identify common themes. A follow-up focus group was arranged for the following week. To prepare for this, participants were requested to recall their experiences in obtaining information and what information they lacked or felt they needed.

3.4.ii.b CYCLE TWO

According to Diagram 3.2, Cycle Two contained the four moments of a traditional PAR process. This was done through Stage Three (PAR moment of 'Plan'), Stage Four (PAR moments of 'Act' and 'Observe') and Stage Five (PAR moment of 'Reflection').

Stage Three

According to Diagram 3.2, in Stage Three, participants shared with the researcher their experiences in how they obtained information and what information they lacked or felt they needed. The objective was to assimilate participants' information needs and for participants to 'Plan' for priority information needs. Two activities were conducted. In the children's group, the first activity was to list what information children had. The second activity, utilizing the nominal group technique to generate responses, was to list what information children wanted or needed by creating a 'What information I want' list. This list was passed to the next person in the group until requests and ideas were exhausted.

The parent group was first asked to list what information they had given to their children. Secondly, what information they thought their children may have wanted by creating a 'What information I think my children need' list. When this activity was completed, the researcher gathered the lists to conduct a preliminary analysis. Participants' lists were photographed, recorded and analysed using IPA. This analysis was to develop priority information needs that were confirmed against participants' assessment in the following focus group session. At the conclusion of this stage, another follow-up focus group was arranged.

Stage Four

According to Diagram 3.2, in Stage Four, the objective was for both groups to compare other's information needs and experiences to their own. This helped the researcher to identify key information needs. This involved two activities. In the first activity, the session was introduced to both groups by sharing children's 'What information I want' list and the parent's 'What information I think my children need' collected from the previous session. This activity formed the PAR moment of "Act".

The children's group presented their opinions first. In this way, children was provided a voice (Greig et. al., 2013, pp.215-226;, Kornreich, 2008, p. 65; Rolinson, 1998). Children formed opinions independently and without the overriding influence of their parent. The parent group was exposed to children's thoughts and were prompted to assimilate the informational needs of their children. The children was provided an opportunity to observe how parents were willing to interact, provide information and contribute to the discussion.

After sharing thoughts and opinions, the second activity was initiated. This formed the PAR moment of 'Observe". Both groups of participants observed the researcher presenting a preliminary analysis of participants' responses into themes and issues. Participants' opinions and confirmation of the researcher "being on the right track" was made throughout this presentation. Subsequently, both groups were then requested to prioritise through consensus vote on key themes that the researcher could further explore. A summary is compiled as 'Topics: Children's concerns' and 'Topics: cancer specific information' in 'Table 4.26 List of Participants' Suggestions' on page 201.

After that, participants were asked to consider solutions for the information needs they prioritised. This prepared participants for the subsequent focus group session and provided participants a moment of 'Reflection'. Participants were given a week to reflect about those needs, the problem of communicating to children about a parent's diagnosis and, to compare strategies in obtaining/sharing information from among themselves and the sources at their disposal. Participants were told that there were no wrong nor right way of solving problems. They were encouraged to be creative and novel in developing strategies.

Stage Five

According to Diagram 3.2, Stage Five's main objective was to find out and assimilate the strategies considered by participants. Another objective was to observe the communication and information flow between parents and children. An additional objective was to validate both participant groups' strategies to the other. This also supported validation of findings.

In order to meet those objectives, the information problems identified in the previous session were reiterated and the request for participants to develop strategies. Participants worked collaboratively within their groups to discuss, illustrate or write out their strategies to fulfil their "Information wish list" (with the assumption that they had planned for this over the week) and their preferred channel and platform of delivery. Participants were again told that there was no wrong or right way of solving problems and that they were to be as creative and novel in developing strategies. After 30 minutes, participants were asked to present their ideas. This provided children with another opportunity for their voices to be heard and considered (Greig et. al., 2013, pp.215-226, Kornreich, 2008, p. 65; Rolinson, 1998). The strategies were then assimilated and discussed for validity and relevancy.

It should be noted, that responses were limited to the type and extent of participants' exposure to information mediums and channels. Participants' ability to articulate ideas and justify solutions was limited by their personal capabilities. In addition to that, the time frame for responses was limited to focus group sessions, even though participants were given one week to prepare.

3.4.ii.c CYCLE THREE

According to Diagram 3.2, Cycle Three consisted of Stage Six (PAR moment of 'Plan') and Stage Seven (PAR moment of 'Act', 'Observe' and 'Reflection'). This is explained below.

Stage Six

According to Diagram 3.2, Stage Six was conducted without the participants. However, this stage was still in accordance to PAR as the results of the two earlier cycles were utilised to 'Plan' data explication. The objectives of this stage was to firstly, collate data to answer the research questions. Secondly to understand what children participants would like to have known. Thirdly to develop a model to either guide or report information provision for children.

Recorded data throughout the five focus group sessions were transcribed, translated into English where required and then recontextualised into meanings. The data was then assimilated and explicated into themes using IPA. The results were compared against the literature review's suggested interventions. An explanation of how this was done is presented in 3.4.iii Data Transcription and Analysis Process (on page 79).

Stage Seven

According to Diagram 3.2, Stage Seven described the PAR moment of "Act", "Observe" and "Reflection" in reporting the findings of the research. These moments were inherent in the report of the experiences of participants, their information needs and information seeking behaviour and suggestions of possible solutions. The explication results are reported in Chapter Four and discussions of findings are reported in Chapter Five.

3.4.iii DATA TRANSCRIPTION AND ANALYSIS PROCESS

The data transcription activity was conducted for 32 individuals (10 adult cancer patients and 22 children whose parent had cancer) with about 100 contact hours of audio recording. This activity saw the verbatim transcription of participants in Bahasa Malaysia that was later translated into English and in some areas, recontextualised to clarify understanding and the context of participants' meaning.

The data was then synthesised and analysed. The term "analysis" and/or "analysed" at times referred to explication data activities. Explication of data followed the description by Smith and Osborne (2007, p. 66). This approach was used because according to Hycner (1999, p. 161) and Coffey and Atkinson (1996, p.9), explication of data was more suitable to the nature of a phenomenological research as it provided "systematic procedures to identify essential features and relationships" and guided the interpretation of data's meaning. This provided information about the beliefs and constructs participants experienced. This is consistent with phenomenological concepts (Smith and Osborne, 2007, p. 66).

The focus on describing events through an "understandable meaning" of experiences (Lindseth and Norberg (2004, p. 146), supported the research's advocacy of participants as "users" being central to the study of information behavior depicted in Diagram 2.2 (on page 18). This resulted in the identification of priority information needs that included children's perception of cancer and information-sharing culture.

In depth exploration and study (Smith and Osborne, 2007, p. 53), was aided by illustrated depictions of meanings and explanations by participants, the researcher's observation notes and, use of the Oxford Bahasa Malaysia-English dictionary. The comparison of contextual terms and its meanings were important because in a few instances a Bahasa Malaysia word could have different English meanings. For example, *"sakit"* could mean "in pain", "sickness", "illness" or "disease". In addition to verbal recordings, participants also wrote or drew their responses. There were 88 drawings, mixed drawings and texts and, mind mapping. A sample is provided in Appendix 6. Recontextualising data from these sources were new skill sets. This activity was the most time consuming and required a high degree of attention to detail. Further advise and instruction about interpretation and improving validity came from Greig et al. (2013, pp. 116-121), Skovdal and Ogutu (2009), Ewald et al. (2011), Ewald (1985), and Osborne (2006a; 2006b).

In order to explicate data, according to Tufford and Newman (2010, p. 82), contextual interpretation and meaning of exploring experiences required phenomenology and bracketing. There were two methods for explication used in this research. The researcher wrote notes (memoing) throughout the data collection process and analysis. This method formed a supportive data source to note observances about participants, reflect about responses, behaviours and meanings participants provided and, to aid in recall. The notes also helped to explicate the procedural aspects of research and made the researcher aware of participants' and the researcher's emotions; preconceptions and assumptions about the phenomenon studied. This method was recommended by Tuffard and Newman (2010), Rolls and Relf (2006) and Groenewald (2004).

Another method for explication as advocated by Rolls and Relf (2006, p. 287) was to engage in "interviews with an outside source to uncover and bring into awareness preconceptions and biases". This was done throughout the analysis and write up process. Opinions and insights from health professionals Dr. Somasundaram of NCSM, Dr. A. Mat Saat of Hospital Az-Zaharah and Dr. Anandakumar of the WEST Cancer Hospital Project was sought for topics about health, cancer patients and their families. Psychologists from two Malaysian universities, Dr. G. Mat Saat and Dr. Mohd. Baki, were involved with discussions about experiences related to psychological well-being, provided feedback and outside assessment of how the research was written and the approach to phenomenological reporting. Cancer survivor Ms. Joseph provided preliminary insight into the experiences and problems associated with a cancer diagnosis. This helped to inform the research. Personal Communication with the Elizabeth Kubler-Ross Foundation, Breastcancer.org, National Cancer Institute, Dr. Scott and Dr. Greig helped to clarify research concerns about cancer and issues from having children participants share their experiences on emotionally challenging topics. In addition to that, Dr. Hepworth was pivotal in providing guidance and feedback in his role as research supervisor.

Guided by Hycner (1999, pp. 143-164) and Groenewald (2004, pp. 17-22), the explication process had five steps of "i) Bracketing and phenomenological reduction, ii) Delineating units of meaning, iii) Clustering of units of meaning to form themes, iv) Summarising (and validating where needful) each interview and/or participant responses and, v) Extracting general and unique themes from all interviews and/or participant responses and then making a composite summary." This helped to systematically transform the data to develop themes and findings.

As advised by Groenewald (2004, p. 19), literal content and, the frequency of a term, meaning, emotion, reaction or event participants reported was considered when processing data. Data was rigorously examined and categorized into lists of related meanings and events that were continually scrutinized to obtain essences of meanings and experiences. Then, clusters of themes were developed from recorded discussions, drawings and written narratives against lists of related meanings developed in the first process of data explication (Hycner, 1999, p. 153; Biggerstaff and Thompson, 2008, pp. 179-182). Line-by-line coding and specific identification markers were developed to relate and categorise data. In order to uphold a satisfactory degree of data and analysis validity and truthfulness, the researcher practiced the concepts of phenomenology similarly practiced by Groenewald (2004, p. 21). Bracketing, validation and truthfulness was consciously conducted throughout the research process. In validating themes, meanings and experiences, the researcher sought confirmation from participants during each topic discussion to determine if the essence of experiences were accurately understood by way of context and language.

These methods resulted in rich data that provided better understanding of the nuances of the information needs problem, experiences and challenges participants faced. Results are presented in Chapter Four on page 92.

3.5 CONCLUSION

This study aimed to explore the experience and the information needs of Malaysian children whose parent has cancer. Qualitative approach to data was selected because the purpose of the study was to understand how children made sense of their situation, how they found out information and what information they required to overcome the challenges they faced. Data was obtained through anecdotal narratives of participants' experiences from open-ended questions and explorations of enquiries and themes.

In order to obtain qualitative data, several methodologies were reviewed. In considering methodologies, a Participatory Action Research (PAR) framework was selected. This is because the study necessitated participants' participatory involvement in identifying information needs, information seeking behaviour and strategies in resolving information-based problems. In order to do this, an 8-stage PAR methodology was adapted from Kemmis and McTaggart (1988) and Hughes and Seymour-Rolls (2000). This was necessary as the research aim and objective differed from Kemmis and McTaggart (1988) and Hughes and Seymour-Rolls (2000).

Data from PAR-led activities was collected in the form of audio recordings of participants' narratives and photographs of participants' drawings and written responses. In order to explicate data, an Interpretative Phenomenological Analysis (Smith and Osborn, 2007) was used. This method was selected because IPA helped in contextual interpretation of data and helped to develop meaning when exploring participants' experiences. This was guided by

Biggerstaff and Thompson (2008), Groenewald (2004), Hycner (1999), Rolls and Relf (2006) and Tuffard and Newman (2010).

This methodology and data explication resulted in rich data with depth and scope about children's experience and the challenges they faced from an information problem perspective. This resulted in findings that assisted in identifying nuances of information needs, information-seeking behaviour and problems in information provision to children. The methodology also led to suggestion of strategies that may influence the development and design of information systems for Malaysian cancer patients and their families.

Results and findings from the methodology are reported in the next Chapter. Demographic details and a description of the thematic analysis and coding of data were reported. Findings about what Malaysian children understood about their parent's cancer, what consequences children's understanding or lack of understanding about cancer have for them and, what interventions may benefit children and enable them to cope with their parents having cancer were also reported. Participants' suggested interventions are reported toward the end of the chapter. A discussion about findings and how they correspond to the research aims, objectives and research questions is reported in Chapter Five.

CHAPTER FOUR

DATA EXPLICATION AND RESULTS

This chapter reports on the results of data explication gathered throughout the focus group sessions held with children and parent participants as discussed in the preceding chapter. The three research questions of 1) "What are Malay children's understanding of their parents' cancer?", 2) "What consequence does children's understanding or lack of understanding about cancer have for them? and, 3) "What interventions may benefit children and enable them to cope with their parents having cancer" guided the data explication process. This process used an Interpretative Phenomenological Analysis (IPA) as described by Smith and Osborne (2007). It also used a Thematic Analysis and coding of data guided by Biggerstaff and Thompson (2008), Groenewald (2004), Hycner (1999), Rolls and Relf (2006) and Tuffard and Newman (2010). In organising this chapter, both the process of data explication and the results of that process are presented. This chapter is organised into six sections: 1) Demographic details, 2) Thematic analysis and coding of data, 3) What are Malaysian

Children's understanding of their parent's cancer?, 4) What consequences does children's understanding or lack of understanding about cancer have for them?, 5) What interventions may benefit children and enable them to cope with their parents having cancer? and, 6) Participants' suggested interventions.

4.1 DEMOGRAPHIC DETAILS

Participants' demographic detail provided background information and their general similar attributes. Adult participants were cancer patients who had informed their children about their diagnosis. Children participants still lived at home and were dependent on parents. The proximity and dependency exposed children participants to their parent's cancer journey. This exposure resulted in children participants' experience of parental diagnosis, surgery, treatment and its side effects. These children participants reported providing varying degrees of care to their ill parent. In order to report this information, this section is divided into two parts; Parent Participants and Children Participants.

4.1.i. Parent Participants

Data explication obtained parent participants demography about gender, ethnicity, religion, staging of cancer, age, number of children, average monthly income, academic level and, use and comprehension of the English language. In order to organise the data, parent participants were given an identity code, "P". Parent participants were identified as belonging to a particular family group, with an "F" symbol. Each family group was tagged with a number according to the sequence in focus group participation; with a numeric symbol of "1" to "10", representing the ten different family groups. Table 4.1 shows the coding and a summary of the Parent Participant Demography.

Table 4.1 PARENT PARTICIPANT DEMOGRAPHY

FAMILY GROUP	PARENT PARTICIPANT (P = Identification symbol for Parent)								
	Gender (F= Female, M= Male)	Ethnicity	Religion	Staging of cancer	Age	Number of children	Average monthly income bracket (MYR)	Academic level	Use and comprehension of the English Language
Family 1 **F1(P)**	F	Malay	Muslim	II	43	4	5,000	Secondary School	Some difficulty

Family 2 F2(P)	F	Malay	Muslim	III	43	4	5,000	Secondary School	Some difficulty
Family 3 F3(P)	F	Malay	Muslim	II	46	4	5,000	Secondary School	Some difficulty
Family 4 F4(P)	F	Malay	Muslim	II	34	2	5,000	Secondary School	Some difficulty
Family 5 F5(P)	F	Malay	Muslim	II	53	3	5,000	Diploma	No difficulty
Family 6 F6(P)	F	Malay	Muslim	III	55	3	5,000	Secondary School	Some difficulty
Family 7 F7(P)	F	Malay	Muslim	I	34	2	5,000	Diploma	Some difficulty
Family 8 F8(P)	F	Malay	Muslim	I	41	3	5,000	Diploma	No difficulty
Family 9 F9(P)	F	Malay	Muslim	I	56	2	5,000	Secondary School	Some difficulty
Family 10 F10(P)	F	Malay	Muslim	II	42	4	5,000	Secondary School	Some difficulty
TOTAL	**10 F**	**10 Malay**	**10 Muslim**	**Stage I = 3 participants Stage II = 5 participants Stage III = 2 participants**	**Median age: 44.7 years old**	**31 Avg 3.1**	**Avg. 5,000**	**7 Secondary School 3 Diploma**	**8 Some difficulty 2 No difficulty**

Table 4.1 is explained as follows:

1) Number of participants: There were ten adult female participants in this research.

2) Ethnicity and Religion: All ten parent participants were ethnic Malay and Muslim. This was obtained from participants' answer to Question 1 (from InqFE-v.04.and InqFBM-v.02) and derived from their names containing 'binti', a normal policy in Malaysia to identify ethnicity and a person's religion[8]. The literature review (Braun et al., 2002, p.192; Schultz et al., 2003, p.156) suggested that ethnicity and religion influenced information seeking behaviour and attitudes. This was explored and reported later in this chapter.

3) Stage of Cancer: Parent participants were cancer patients with three participants at Stage I, five participants at Stage II and two participants at Stage III of the disease. This information did not correlate to the literature finding that in Malaysia 57.6% were already at advance stages of cancer (Omar and Ibrahim, 2011, p. 23). While this suggested participants

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[8] Determining race and religious identity markers from a person's name in Malaysia:
Malay and Muslim: the use of "bin" (son of) or "binti" (daughter of) separating one's name from that of the father's name. The "bin" and "binti" is gender specific, of Arabic and Islamic origin and, is a custom when naming children and tracing lineage. (Kow, 2008, p. 49).

were more likely to have a better 5-year survival prognosis, parent participants' transcripts reported death was a reoccurring concern.

4) Age: Participants ranged from 34 years old to 56 years old and the median age of participants was 45 years old (rounded up from 44.7 years old). This was obtained through participant's birthdate indicated in their National Identification Number when they signed the 'Participant Consent Form' (Appendix 2).

5) Number of Children: Participants had an average of three children each (rounded up from 3.1 children). This is slightly above the 2.5 average number of children per household reported by *Banci Penduduk dan Perumahan Malaysia, Jabatan Perangkaan 2011* mentioned in Chapter Two (on page 30). This was to record the number of children possibly impacted by parental cancer while staying in the same household and to understand the nuances of cancer's consequences to children.

6) Average monthly income bracket: Parent participants reported an average monthly income bracket of RM5,000.00 (Approximately GBP888.02 with 1 GBP = 5.3 MYR, Exchange Rates.org.uk, 2013). The participant's were in the lower middle-income bracket with only one employed adult, in this case participants' husband providing income to the family. Parent participants informed they were unemployed housewives managing the home. The literature review (Chiu and Wistow, 2002, p. 53; Sudano and Baker, 2005, p.910; Tu and Hargraves, 2003, p.2) suggested that income contributed differentiating influences for information seeking behaviour and adherence to medical requirements. From participant's narratives and the researcher's observation, a lower middle-income bracket had consequences to patients and their family. One consequence was limited mobility. For example, one family group reported having only one family car for the husband's use to go to and fro work (from approximately 7am-7pm). This suggested most participants had logistic difficulties in seeking medical treatment and participating in the research at NCSM. This limited access to public libraries, hospital libraries and NCSM that were far from home.

Another consequence (at the time of this stage of the research in 2005-2007) was that participants did not have a home-based Internet connection. Cost was a deterrent. Another consequence was that all participants reported being in favour of home-based care;

recuperating was preferred to be at home rather than at the hospital. The cost of treatment and logistics were factors for home-based care. This substantiated literature review that cancer patients preferred convalescing at home (Kilicarslan-Totuner and Akgun-Citak, 2012; Kornreich et al., 2008; Skovdal and Ogutu, 2009).

7) Academic level: Seven participants graduated from secondary school at 18 years old, with three participants having obtained a diploma by 21 years old. The literature review (Baker et al., 1997, pp.157-159; Davis et al., 2002, p. 140-142; Doak et. al., 1996, p. 152; Doak et al., 1998, pp.151-162; Glassman, 2012, para. 1; Langer, 2000, p. 28; NCI, 2001, para. 7; Parikh et al., 1996, p.37; Tu and Hargraves, 2003, p.1; Wilson, 1994, para. 97; Weiss and Cyone, 1997, p.273) suggested that academic level might contribute to differentiating influences for information seeking behaviour and attitudes. This is closely related to "Use and Comprehension of the English Language" reported below.

8) Use and Comprehension of the English Language: English was not the first language of the ethnic Malay. Eight parent participants reported that they had some difficulty in the use and comprehension of English language while only two parent participants reported they had no difficulty. Since English was not a graduation requirement, it was not surprising that most participants reported some difficulty with its use and comprehension. This has implications for cancer information that was prevalently in English.

English literacy might contribute to differentiating influences in information seeking behaviour and attitudes and medical adherence (National Cancer Alliance, 2002, pp. 23-24). Participants' experience was that most cancer-related information was written in English and their made understanding information difficult. This consequence of limited literacy was reported by Baldwin and Hunt (2002, pp. 276-277), Blackhall et. al. (1995, pp. 821-824), Brashers et al. (2002, p.264), Davis et al. (2002, p.142), Hsieh (2009, pp. 135-156), Kaufert (1999, p. 405-412), Kirsch et al. (2002, pp. xvi), Merriman et al. (2002, p.132) and NHS Executive (2011, p. 42). This was further explored and reported later in this chapter.

4.1.ii. Children Participants

Data explication obtained children participants demography about gender, ethnicity, religion, number of siblings, number of participants within the same family, age, gender, informed about parental cancer, status of caregiver, academic level and use and comprehension of the English language. Children participants were tagged as belonging to a particular family group "F". This was followed by a number according to the sequence in focus group participation. Children participants were identified with a "(C)" symbol, followed by a number according to descending birth order, i.e youngest child = C1 and oldest child = C4. The demography of children participants were as follows:

1) Number of participants: There were 22 children participants in this research.

2) Ethnicity and Religion: All 22 children participants were ethnic Malay and Muslim. This was obtained from participants' answer to Question 1 and derived from their names containing 'bin' or binti', a normal custom in Malaysia to identify ethnicity and a person's religion[9]. Ethnicity and religion's differentiating influences for information seeking behaviour and attitudes was explored and reported later in this chapter.

3) Number of Siblings and Number of participants within the same family: Even though cumulatively participants had a total of 31 siblings, only 22 children met the selection criteria: were willing to participate and had parental consent to participate in the research. This helped to identify familial relationships and contribution of participants.

4) Age and gender: From among the children participants, there were two male children and five female children in 7-10 year old bracket. There were two male children and 11 female children in the 11-15 year old bracket and there was one female child in the 16-18 year old bracket. Literature review (breastcancer.org, 2012; CancerCareConnection, 2003; Davey et al., 2005; NCI, 2012a, 2012b; Scott et. al., 2003b) suggested age and gender had differentiating influences for information seeking behaviour and processing of information. This was explored and reported later in this chapter.

5) Informed about parental cancer: All children indicated that they were informed about their parent having cancer. However, children participants' and parent participants' self-

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[9] Determining race and religious identity markers from a person's name in Malaysia:
Malay and Muslim: the use of "bin" (son of) or "binti" (daughter of) separating one's name from that of the father's name. The "bin" and "binti" is gender specific, of Arabic and Islamic origin and, is a custom when naming children and tracing lineage (Kow, 2008, p. 49).

report indicated that the extent and scope of the information varied based on age and gender of the child participant. This was explored and reported later in this chapter.

6) Caregiving role: Seven children participants revealed in discussions that they were the main caregiver to their ill parent. These children participants were the eldest female children in each family. The remaining 15 children participants were not the main caregiver but reported providing some caregiving. The extent of caregiving roles and challenges were further explored and reported later in this chapter.

7) Academic level: Children participants were in various stages of scholastic education. There were ten children in primary school and 12 children in secondary school. As mentioned earlier, the literature review suggested that this might have some differentiating influences in information seeking behaviour and attitudes.

8) Use and Comprehension of the English language: All children, with the exception of one family, had some difficulty with the use and comprehension of the English Language. Similarly to that of parent participants, these children participants reported that in their experience most cancer-related information they found was written in English and their English literacy made understanding information more difficult. To explain this further, primary school children (depending on their education level) would have between one to six years of one 45-minute English Language subject exposure. Secondary school children would have between seven to eleven years of one 45-minute English Language subject exposure. English literacy's differentiating influence for information seeking behaviour and decontextualizing information was further explored and reported later in this chapter. Table 4.2 shows the coding and a summary of the children participant demography.

TABLE 4.2 CHILDREN PARTICIPANT DEMOGRAPHY	
FAMILY GROUP	CHILDREN PARTICIPANT "C" identification symbol for Child. Numbered according to descending birth order, i.e youngest child = C1 and oldest child = C4

	Ethnicity	Religion	Number of siblings	Number of participants within the same family	Participant Identity (C1, C2, C3 or C4)	Age bracket (7-10), (11-15), (16-18)	Gender (M= Male, F = Female)	Informed about parental cancer (Y= Yes, N= No)	Caregiver (Y= Yes, N= No)	Academic level (PS = Primary School, SS = Secondary School)	Use and comprehension of the English Language (SD = Some Difficulty, ND = No Difficulty)
Family 1 F1	Malay	Muslim	4	3	C1	(7-10)	M	Y	N	PS	SD
					C2	(11-15)	F	Y	N	PS	SD
					C3	(11-15)	F	Y	Y	SS	SD
Family 2 F2	Malay	Muslim	4	4	C1	(7-10)	F	Y	N	PS	SD
					C2	(7-10)	F	Y	N	PS	SD
					C3	(11-15)	F	Y	N	SS	SD
					C4	(11-15)	F	Y	Y	SS	ND
Family 3 F3	Malay	Muslim	4	4	C1	(7-10)	F	Y	N	PS	SD
					C2	(7-10)	F	Y	N	PS	SD
					C3	(11-15)	F	Y	N	SS	SD
					C4	(11-15)	F	Y	Y	SS	SD
Family 4 F4	Malay	Muslim	2	1	C1	(11-15)	F	Y	Y	SS	SD
Family 5 F5	Malay	Muslim	3	3	C1	(11-15)	M	Y	N	SS	SD
					C2	(11-15)	F	Y	N	SS	ND
					C3	(16-18)	F	Y	Y	SS	ND
Family 6 F6	Malay	Muslim	3	1	C1	(11-15)	F	Y	N	PS	SD
Family 7 F7	Malay	Muslim	2	2	C1	(7-10)	M	Y	N	PS	SD
					C2	(11-15)	F	Y	Y	SS	SD
Family 8 F8	Malay	Muslim	3	2	C1	(11-15)	M	Y	N	SS	SD
					C2	(11-15)	F	Y	Y	SS	SD
Family 9 F9	Malay	Muslim	2	1	C1	(7-10)	F	Y	N	PS	SD
Family 10 F10	Malay	Muslim	4	1	C1	(7-10)	F	Y	N	PS	SD
TOTAL	**22 Malay**	**22 Muslim**	**31**	**22**		**(7-10): 2M, 5F (11-15): 2M, 11 F (16-18): 1F**		**22**	**7**	**10 PS 12 SS**	**19 SD 3 ND**

These participants' demographics and their experiences helped the research to better understand the importance of health information to patients and their children. It also provided context to explore and inform about children's experience with parental cancer.

4.2 RESULTS OF THEMATIC ANALYSIS AND CODING OF DATA

As explained in Chapter Three (on page 80), participants' answers underwent a process of data explication using phenomenological concepts and an Interpretative Phenomenological Analysis (IPA). Studies and reports by Biggerstaff and Thompson (2008), Groenewald (2004), Hycner (1999), Rolls and Relf (2006), Smith et al. (2009), Smith and Osborn (2007) and, Tuffard and Newman (2010) guided this process.

The process of explication and analysis started with a combination of memmoed observations (Groenewald, 2004; Rolls and Relf, 2006; Tuffard and Newman, 2010), thematic analysis and coding for participants' responses to questions and activities. Preliminary analysis included the identification of participants, repeated words and clusters of responses to research questions. This helped to organise data and cohesiveness. Verbatim narrative transcripts were translated into English where needed. Data from the transcripts were coded to aid understanding and the development of themes.

After that, the transcripts and other forms of responses underwent five data explication steps as described by Hycner (1999, pp. 143-164) and Groenewald's (2004, pp. 17-22) reported in Chapter Three (on page 82). This was conducted through line-by-line coding and specific identification markers to relate and categorise data. This was supported by memmoed observations and discussions with others to clarify experiences and problems (Rolls and Relf, 2006, p. 287) associated with a cancer diagnosis and, as a feedback mechanism. The resulting data underwent an Interpretative Phenomenological Analysis (Smith and Osborn, 2007; Smith et al., 2009) where data was i) Analysed for frequency of a term, meaning, emotion, reaction or event, ii) Rigorously examined and categorized into lists of related meanings and events and, iii) Developed into clusters of themes.

The results were scrutinized against lists of related meanings developed in the preliminary analysis. This activity was in accordance to data explication processes as explained by Hycner (1999, p. 153) and Biggerstaff and Thompson, (2008, pp. 179-182). In order to validate themes and coding, the researcher sought confirmation from participants during each topic discussion to determine if the essence of experiences were accurately understood by way of context and language. Based on the context of the three research questions, the themes were then re-contextualised (Greig et al., 2013; Ewald et al., 2011; Ewald, 1985; Osborne, 2006a; 2006b; Skovdal and Ogutu, 2009). This process is tabulated in table 4.3.

Table 4.3 Steps in data explication, analysis and coding		
STEP	ACTIVITY	DESCRIPTION
1.	COLLECTION OF DATA	Collected participants' responses (drawings, written accounts and recorded narratives) from five focus group sessions. Data supported by memmoed observations of participants' behaviours and preliminary analysis for themes and codes (identification of participants, repeated words and clusters of responses).
2.	TRANSCRIPTION	Recorded narratives were i) transcribed verbatim, ii) translated into English where applicable and, iii) clarified and verified with participants for contextual meaning. Memmoed observations included in transcripts to describe participants' behaviours in-situ to aid in analysis and researcher's recall.
3.	DATA EXPLICATION PROCESS	This is the first process of data explication. This process followed Hycner (1999) and Groenewald's (2004, pp. 17-22) steps of bracketing and phenomenological reduction, delineating units of meaning, clustering meanings to form themes, summarising (and validating where needful) responses and, extracting general and unique themes to develop a composite summary. This was done by Line-by-line coding and specific identification markers to relate and categorise data. This was supported by memmoed observations and discussions with others to clarify experiences and problems (Rolls and Relf, 2006, p. 287) associated with a cancer diagnosis and as a feedback mechanism.
4.	DATA PROCESSING AND ANALYSIS	In accordance with Interpretative Phenomenological Analysis (IPA) (Smith and Osborn, 2007; Smith et al, 2009) principles, data was i) Analysed for frequency of a term, meaning, emotion, reaction or event, ii) Rigorously examined and categorized into lists of related meanings and events and, iii) Developed into clusters of themes. Resulting data was scrutinized against lists of related meanings developed in the first process of data explication (Hycner, 1999, p. 153; Biggerstaff and Thompson, 2008, pp. 179-182). Findings were validated with participants' confirmation to determine if the essence of experiences were accurately understood by way of context and language.

A sample of observations and memoing, the data explication process and, data processing and analysis is provided in Appendix 8. The process summarised in Table 4.3, resulted in 60 different topics and were organised into four loose groups of 1) Understanding of cancer, 2) What happens when one has cancer? 3) Reactions and concerns and, 4) Cancer information medium, content and source. This is tabled in Table 4.4 as a list of issues raised and/or discussed by participants.

TABLE 4.4 LIST OF ISSUES RAISED AND/OR DISCUSSED BY PARTICIPANTS			
ISSUES RAISED AND/OR DISCUSSED			
UNDERSTANDING OF CANCER	WHAT HAPPENS WHEN ONE HAS CANCER?	REACTIONS AND CONCERNS	CANCER INFORMATION MEDIUM, CONTENT, SOURCE

• Cancer is dangerous and can be deadly • Cancer develops from uncontrolled cell growth or mutation • Cancer damages cells • Cancer can spread and damage other parts of the body (metastases) • Surgery; mastectomy or lumpectomy and/or other invasive action to save life • Cancer treatment involves chemotherapy, radiotherapy and immunotherapy • Requires specialist doctors, complex equipment and special ward • Requires vigilant care and frequent medical check-up • Mastectomy causes pain • Chemotherapy causes nausea, vomiting and hair loss	• Parent’s bodily aches and pains • Rest as a precursor to getting better • Tamoxifin causes early menopause • Effects of frequent vomiting • Effects of bodily aches and pains • Effects of hair loss • Effects of early menopause • Spiritual state • Emotional state • History and genetic predisposition • Unhealthy habits • Polluted environment • Lifestyle • Attack • Test from God • Negative feelings • Negative behaviours	• Empathy • Increase in love • Positive behaviours • Negative feelings • Negative behaviours • Parent with cancer • Healthy parent • Self • Sibling • Housework • Distribution of chores • Family cohesiveness • Types of food • Preparation of food • Exercise • Cancer prevention • Health awareness • Prayer • God’s role	• Parent as information provider • Doctor as information provider • School as information provider • Other sources of information • Availability and willingness of information provider to share information • Access to the Internet, cancer resource centre and cancer information • Type of information • Wordiness as deterrent • Language barrier • Attractiveness of information • Handyness of information • Self-reported key information needs • Perception of cancer and self-report of experience • Co-developed solution to identified problems • Accessibility of solutions • Format of solutions

The process of explication, analysis (Coffey and Atkinson, 1996; Hycner, 1999) and bracketing (Tuffard and Newman, 2010) was later refined into 95 codes. These codes were developed from two perspectives: (a) participants’ understanding of cancer, and (b) recurrent issues in the discussion regarding participants’ own knowledge base and observations about the disease and how their parent experienced cancer.

It is to be noted that the 95 codes have some overlap. For example, some participants understood that cancer treatment caused hair loss and at the same time reported some emotional trauma of experiencing parental hair loss. The 95 codes are listed in Table 4.5.

Table 4.5 List of codes (in alphabetical order)

Access to information	Alien thing	Alone	Anger	Assimilation of information

Attitude to information	Automatic assistance	Bald	Being Active	Book
Cancer in the family	Cells	Chemotherapy	Chores	Cleaning
Comic	Cooking	Damage	Death	Depressed
Disgust	Disheartened	Divorce	Exercise	Experience
Faith	Fear	Food	Fruits	Frustrated
God’s test	Good deeds	Hair loss	Hate	Health knowledge
Hospital stay	Illustration	Immediacy	Information culture	Information problem
Ironing	Language	Less fat	Less preservatives	Less salt
Love	Massaging	Menopause	Menses	Monitoring health
Negative emotion	Non fast food	Non fried food	Other health practices	Pain
Palliative care	Pity	Pollution	Polygamy	Poor school performance
Prayer	Prior knowledge	Reactions	Reality drama	Resentment
Rest	Role of doctor	Role of father	Role of mother	Role of prayer
Role of sibling	Role of to self	Sadness	Second-hand smoke	Self-check
Separation anxiety	Sources of information	Spread	Still love parent	Stress
Suggested solution	Surgery	Thanks to God	Treatment process	Type of information
Uncaring	Uncommunicative	Uncooperative	Vegetables	Video
Vomiting	What faith can do	Willpower	Wordiness	Worry

As informed by Biggerstaff and Thompson (2008), Groenewald (2004) and Hycner (1999), the most salient constructs in the discussions were identified and shaped into a finite set of 20 anticipated and emerging themes that was not redundant but still managed to be meaningful. The themes were then analysed for patterns and relationships.

Organising themes were developed from common attributes or elements found in these themes. This resulted in ten organising themes that were further analysed for patterns and relationships. Subsequently six global themes emerged. This development is provided in Table 4.6 Development of Global Themes for children’s information needs and information behaviour about their parent’s cancer.

Table 4.6 Development of Global Themes for children’s information needs and information behaviour about their parent’s cancer

THEMES	ORGANISING THEMES	GLOBAL THEMES

1. A type of possibly deadly illness, sickness or disease	Medical Inference	1. Children made sense of cancer through their experience, observations and beliefs.
2. Requires hospitalisation, special medication and long treatment process		
3. Physical side effects of cancer and cancer treatment	State of Parent Being Sick	
4. Effects of side effects*		
5. Non physical side effects of cancer and cancer treatment*		
6. Medically proven cause	Causes	
7. Perceived cause*		
8. Negative psychological impact	Psychological impact to children	2. Lack of information resulted in children not knowing and/or being unprepared for cancer's impact on their lives.
9. Positive psychological impact*		
10. Changes to roles of family members	Changes to family dynamics	3. Cancer changed familial dynamics.
11. Familial responsibilities	Changes to family processes	
12. Problems in the family*		
13. Changes to diet	Lifestyle changes	4. Cancer changed lifestyle.
14. Changes to health behaviour*	Changes to health practices	
15. Religious fervour*	Increased religious attention	
16. Types of information provider	Information sources	5. Children had limited access to information.
17. Problems in accessing information	Information problems	6. Children reacted to a health-based situation or stimuli and required topic-based information to make sense of their situation and to guide their adult-expected behaviour.
18. Relevancy and readability of information		
19. Types of information needs	Prioritised information needs	
20. Viability of suggested solutions	Suggested solutions	

The resulting themes answered research question one, **"What are Malaysian children's understanding of their parents' cancer; its causes, effects, implications and consequences?"** in this manner: children made sense of cancer through their experience, observations and beliefs. Knowledge and understanding of cancer was assimilated from medical terms they were aware about or by identifying parent as being "sick" or, by what they perceived was the cause of the disease.

The resulting themes answered research question two, **"What consequences does children's understanding or lack of understanding about cancer have for them?"** in this manner: lack of information resulted in children not knowing and/or being unprepared for cancer's impact on their lives. This global theme emerged from the participants' reporst of various psychological impact, changes to familial dynamics and changes to their lifestyle.

The resulting themes answered research question three, "**What interventions may benefit children and enable them to cope with their parents having cancer?"** in this manner:

Children had limited access to information, children reacted to a health-based situation or stimuli and, children required topic-based information to make sense of their situation and to guide their adult-expected behaviour. Children reacted a stimulus in order to trigger their mechanism to solicit information. Children then assimilated what they knew and new information into action. However, most participants, acknowledged that children had limited access to information systems in which to meet their information needs. The children participants also highlighted several health-based events that they had problems with. These problems were identified and a list of priority information needs was developed. Participants co-developed interventions by providing suggestions to mitigate identified problems.

These global themes helped to identify information-seeking behaviours, information gaps and information content needs of children whose parent had cancer. The next sections were divided into headings that paralleled the research questions. In order to understand the tone of the comments and to illustrate how the themes were grounded in the data, excerpts from participants are quoted.

4.3 WHAT ARE MALAY CHILDREN'S UNDERSTANDING OF THEIR PARENTS' CANCER; ITS CAUSES, EFFECTS, IMPLICATIONS AND CONSEQUENCES?

Most parents reported that while they had informed their children about their diagnosis, very little information, if at all, was provided to their children. They realized that their children were the least informed about the parent's experience and management of cancer treatment. They voiced their concern about the lack of resources providing information to their children. Once parents had voiced their concerns, the researcher solicited the opinions of children. The children agreed that coping and trying to understand their parent's cancer experience was difficult and sometimes overwhelming as a lot of incidents, treatment activities, role changes and the recuperation process came as a surprise.

One of the findings of the research suggested that participants made sense of cancer through their experience, observations and beliefs. Unlike published medical terms, "cancer" was described and explained as having components made from physical, emotional, sensory and spiritual experiences, observations and beliefs. This affected how cancer was perceived, treated (medically and reactively) and ultimately overcome. This has implications in the context and content of information, its design, accessibility and relevancy to children.

References sourced through the Internet and brochures provided medical definitions of the word “cancer” that were verbose, used complex language structures and were written in a language that the participants were not fluent in. Excerpts are presented in Table 4.7.

Table 4.7 Medical definition of the word “cancer”

SOURCE	DEFINITION
Malaysian Oncological Society	“Cancer is defined as the uncontrolled or unregulated growth of cells. The word is derived from “crab” in Latin” (Malaysian Oncological Society, 2004, para. 3).
National Cancer Society of Malaysia (NCSM)	“Cancer is a disease of the cells. These cells work to replace worn out cells, heal damaged cells and help in growth. Cells are regenerated by certain genes. When these genes grow or multiply abnormally and grow into a lump (tumor), it becomes cancer” (National Cancer Society of Malaysia, 2004, para. 1).
Datuk Dr Ibrahim Wahid, consultant oncologist and acting president of the Malaysian Oncological Society	“It (cancer) is a class of diseases in which a group of cells display traits of uncontrolled growth, invasion into and destruction of nearby tissues, and sometimes metastasis (spread to other locations in the body via the lymphatic system or blood)”. (Malaysian Oncological Society, 2004, para. 1)
World Health Organization (WHO)	“Cancer is a generic term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumors and neoplasms. One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs. This process is referred to as metastasis. Metastases are the major cause of death from cancer.” (**WHO,** 2004a, para. 1)
MedicalNewsToday	“Cancer is a class of diseases characterized by out-of-control cell growth. There are over 100 different types of cancer, and each is classified by the type of cell that is initially affected. Cancer harms the body when damaged cells divide uncontrollably to form lumps or masses of tissue called tumors (except in the case of leukemia where cancer prohibits normal blood function by abnormal cell division in the blood stream). Tumors can grow and interfere with the digestive, nervous, and circulatory systems, and they can release hormones that alter body function. Tumors that stay in one spot and demonstrate limited growth are generally considered to be benign.” (MedicalNewsToday, 2004, para. 1)

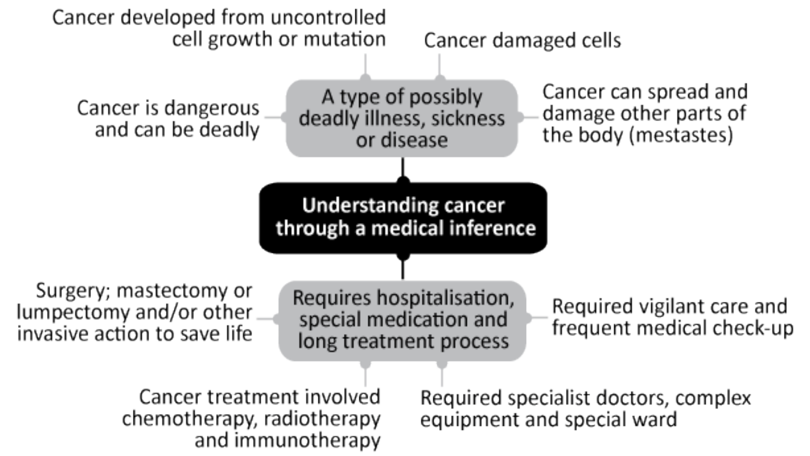
Unlike the medical definitions tabulated in Table 4.7, participants understood cancer in different ways. While older children readily provided some medical terms, most children and adult participants made sense of cancer through their experience, observations and beliefs. This is a global theme where participants conceptualised cancer as either one or a combination of the following organising themes; (i) by including a medical inference like including the word “chemotherapy” in their explanation of the cancer treatment process and side effects, (ii) by a description of the state of their parent being sick like describing their parent as experiencing “bodily aches and pains” which they perceived to be a symptom of being sick (iii) by mentioning the cause, either medically proven or perceived, of the disease like mentioning that too much stress was perceived to cause parent’s cancer.

4.3. i. Understanding cancer from “Medical Inferences”

A few participants, especially older children who performed duties as their parent's primary care-giver understood cancer as "An illness…", "A disease…" or "A sickness…". This included some medical term or medical-based inferences and their experience in a medical situation (for example, a visit or stay in the hospital). All participants used "illness", "disease" and "sickness" interchangeably instead of meaning three distinct health states or conditions. Unless otherwise clearly identified or clarified by the participants themselves, the two Bahasa Malaysia words of "*penyakit*" and "*sakit*" referred to "illness", "disease" and "sickness". This is because Bahasa Malaysia does not differentiate between the three English words whereby "*penyakit*" and in some contextual cases "*sakit*" can refer to the same or either state of having an illness, a disease or a sickness.

The thematic network Figure 4.1, illustrates concisely the key themes on which the word "cancer" was understood with a medical inference or a type of disease that requiring special medical treatment.

Figure 4.1 Thematic network diagram to understand "Cancer" as a medical inference



This generated an interesting discussion in which cancer was understood through the participants' medical knowledge base and observation of parent's treatment process in which participants had direct and frequent experience as a primary care giver. Cancer seemed to emerge as a term with medical connotations with a description of the development of cancer and the treatment process.

4.3.i.a. Cancer is "a type of possibly deadly illness, sickness or disease"

According to Figure 4.1, the theme ***"A type of possibly deadly illness, sickness or disease"*** pertains to the biological character and medically explained development of cancer in relation to the dangers posed to human life. This was an interesting phenomenon because when crossed referred, other than informing their children about their diagnosis, most parents communicated little information by way of how cancer developed and the treatment process. It seemed that contrary to their parents' actions and beliefs, in several instances children were more knowledgeable about cancer than what their parents presumed. This is evidenced in the following paragraphs.

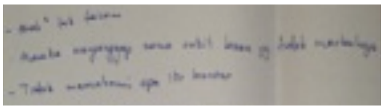
In contrast to parents perception of children's knowledge their children understood the seriousness of cancer as a disease or sickness that could cause their parent to die. Several children described their understanding of cancer as an illness through either illustrations or statements that included death, cell damage and metastases. These children were able to describe their experience and related their understanding of cancer to several medical terms and the process of recovering. Several of these children even cited their belief in the importance of treatment. In this, these children seemed to indicate some sensitivity to the parent's situation and their answers showed their effort in researching information about cancer. The following examples give a good idea of participants' responses.

For example, the parent in Family 8 said that;

> *[F8(P)]: We **did not know how to tell** the children, so therefore we **hoped** that they would **notice** and **understand on their own**.*

In addition to that statement, [F8(P)] wrote that she perceived her children as not being aware and not being able to understand the severity of her illness;

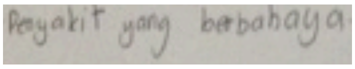
[F8(P)]:



*My **children do not understand** … They think that I only have a normal illness, not something that is dangerous … **They don't understand** what is cancer.*

When her children were asked, they said that they did notice something was different at home. Her 11-year old twins also said that they understood cancer as being a dangerous and deadly disease;

[F8(C2)]:



Penyakit yang berbahaya

*(cancer is) A **dangerous illness**.*

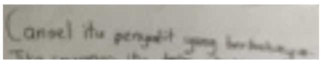
*[F8(C1)]: (cancer is) An **illness** … an illness that can **kill** mama*

This phenomenon was also evident in Family Three with the parent participant perceiving that her children were unaware of the possibility of her death from cancer:

*[F3(P)]: I **don't think** my **children know** that **cancer** can **kill** me …*

The account by this 9-year old [F3(C1)] contradicted her mother's belief:

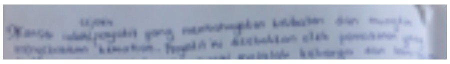
[F3(C1)]:



Cancel itu penyakit yang berbahaya.

***Cancer** is a **dangerous** disease … may lead to death.*

Her 12-year old sister [F3(C2)], wrote her understanding of cancer as a disease that endangered health and might cause death:

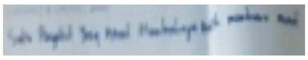


*(Translation: **Cancer** is a type of **disease** that endangers health and might cause **death**.)*

*[F3(C2)]: Ermm, **cancer** is a **sickness** that **damages** your health (pause)*
SUZIE: Ya … (indicating encouragement to continue talking)
*[F3(C2)]: Umm … and it **causes death**.*

A similar sentiment to [F8(P)] and [F3(P)] was recorded from the parent in Family One. [F1(P)] wrote cancer as possibly causing her death and said that she believed her children did not understand how deadly cancer could actually be:

[F1(P)]:



*(reading) I think it is a **very dangerous disease** that **can cause death.***

She explained that:

*[F1(P)]: … These **kids don't understand**. This thing (referring to cancer) is not fun and games. When the pain comes, God only knows. I am sitting alone thinking about **death** (sobs). **These kids don't understand** …*

However, contrary to [F1(P)]'s perception, all three of her children understood that cancer could cause death. This was evident from responses from the three children from Family One and [F1(C2)] response that related cancer to the possible consequence to their mother:

[F1(C3)]:

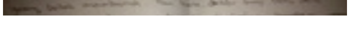
*(Cancer) is a type of **disease** that is also **dangerous**.*

*[F1(C1)]: … ha-ah **cancer** can **kill suddenly.***

*[F1(C2)]: **Cancer** is **dangerous** because it is **an illness** that can cause a very painful **death**.*

In instances when a parent participant had informed her children about how dangerous cancer could be, the children included parts of their parent's explanation in their beliefs about cancer. [F4(C1)], an 11-year old girl explained why she believed cancer was deadly:

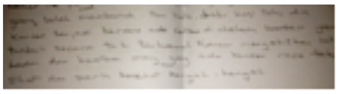
[F4(C1)]:



*Umm … My **mother** told me that **Cancer** is a **disease** inside the body, that we cannot see, that can **kill** …*

Another reason for children's perception about why cancer was deadly seemed to come from their belief that cancer had the capacity to damage other internal organs. Several children extrapolated the theme of cancer being a deadly disease as a disease that had an affect on normal cell development. These children seemed to understand that the development of cancer began at the cellular level and this cellular behaviour contributed to the damage in other organs. Excerpts indicated that children participants perceived that this damage was painful, made the parent feel unwell and could lead to their parent's death. This perception was evidenced with [F4(C1)]'s continued explanation of her understanding of cancer with the following:

[F4(C1)]:



*Umm, **Mother** said, her doctor told her that **cancer** develops because there are **cells** in the body that **grow uncontrollably**. **Cancer hurts** the body's **cells** and makes the person with **cancer** feel **unwell and need plenty of rest**.*

SUZIE: (indicating to continue)

*[F4(C1)]: Umm … she said that the doctor told her that **cancer** develops when a person's **cells**, inside the body, **grow out of control**.*

SUZIE: Do you know what cells are?

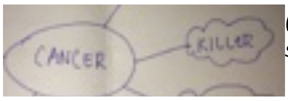
*[F4(C1)]: Yes, I learned at school that **cells** make up everything*

SUZIE: So what about what you said earlier, about cells that grows out of control?

*[F4(C1)]: When someone's **cells** in the body **out of control** … and (referring to what she wrote) it makes the person with **cancer ill** and **need plenty of rest**.*

[F5(C3)] specifically explained that cancer is a killer because cancer damaged cells;

[F5(C3)]:



*(Explaining drawing) **Cancer** means, the person who get's it must be strong and it's a **killer** …*

SUZIE: How so?

*[F5(C3)]: It's (cancer) a **killer** because **cancer damages cells** … it **kills cells** and then the **cells cannot work** and this **damage slowly** and can **suddenly kill** a person …*

SUZIE: How do you know this?

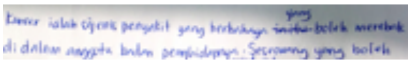
*[F5(C3)]: I saw **the dead cells** got sucked out of my mother after her operation … I saw the **black dead cells** being **pumped out** of a transparent tube that they put into her side …*

[F7(C2)] also attributed cancer to cell damage inside the body:

*[F7(C2)]:**Cancer** is because **cells** inside the body gets **damaged** … **kills** inside.*

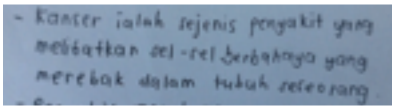
It seemed that for these children cancer was understood as a type of possibly deadly illness, sickness or disease because cancer was attributed to uncontrolled cell growth that could damage cells and lead to death. Children were also able to articulate that they understood cancer as having the ability to metastases. This is evident through [F2(C3)]'s writing:

[F2(C3)]:



*A **dangerous disease** that can **spread** inside the body of the person that has it.*

Her sister [F2(C4)] also wrote about metastases in her understanding of cancer:

[F2(C4)]: 

- Kanser ialah sejenis penyakit yang melibatkan sel-sel berbahaya yang merebak dalam tubuh seseorang.

*(Translation: Cancer is a type of **disease** that involves **dangerous cells** that **spreads** and **grows** in a person's body)*

*[F2(C4)]: . . . that can **spread** if not **treated,** the cancer **patient** can **die**.*

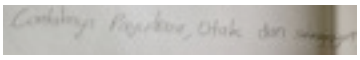
SUZIE: What do you remember about that?

*[F2(C4)]: Cancer is an **abnormal growth**. The **growth** can **spread** and **go to other places** in the body.*

SUZIE: (indicating to continue)

*[F2(C4)]: When the cancer **grows** and **spreads** it **damages** other things and I guess that because of this **damage, cancer** can **kill**.*

Interestingly, while according to MedicalNewsToday there were more than 200 types of cancers, most participants including parents identified cancer as a disease that developed and only affected the internal body. Cancer seemed to be more readily identified as affecting the breast, brain, lung and liver. For example, [F1(C3)] wrote that cancer is a dangerous disease based on its location;

[F1(C3)]: 

Contohnya Payudara, Otak dan [illegible]

*(Translation: For example **Breast, brain** and the **other areas**)*

*[F1(C3)]: (Cancer) A **dangerous disease** ... if you get it somewhere in your body ... like the **brain** ...*

SUZIE: What do you mean dangerous?

*[F1(C3)]: That's it. It's a **dangerous disease** ... if it is **inside the body** ... **the brain** ... can die.*

[F2(C4)]'s explanation of metastases also included cancer's spread to internal organs:

*[F2(C4)]: If the **cancer grows** from the **chest**, it can damage things in the **chest area**, like the **liver**, the **heart**, the **lungs**. It can be **damaged** and the person can **die**.*

Some parent participants, like [F4(P)], understood cancer as a cell-based disease that could spread and affected only a few areas inside the body:

*[F4(P)]: **Cancer** is **damage** in a person's **cells** … **inside** a person … these **cells** that are **damage** becomes a **cancerous lump** that has to be removed because if not, those **damage cells infect** other **cells** and **spread more damage inside** the body … inside areas like the **breast**, the **brain**, umm (pause) the **liver**, the **lung** (pause) … I think that's it. Those areas lah …*

[F5(P)] seemed the most knowledgeable parent and understood cancer as being a disease that affected a person internally and that cancer had the ability to either develop or spread to only a few internal organs:

*[F5(P)]: And then as you know kan everybody have **cancer cells** in their body, its just matter of active and inactive la. Ya, **cancer** is a **very deadly disease** because it is actually something that **damages** the way **cells** work and this cancer is very bad … it can **pass** on this **damage behaviour** to other **cells inside the body**. This **damage** can happen any time … just a matter of time and then when the **cells** get **damaged**, watch out, it can **spread, spread anywhere** and **so fast** …*

SUZIE: Where can it spread to?

*[F5(P)]: Oh, you know, like for me, from the **breast** and if I am not careful, if I did not go for surgery and treatment, the **cancer** could **spread** to my **lungs**, or **brain** or (pause) **liver** and then for sure, you are a goner. When **cancer** has **spread** like that, very difficult to treat.*

4.3.i.b. Cancer "Requires hospitalisation, special medication and long treatment process"

With reference to this theme several children included the codes "hospital", "treatment", "doctors", "screening" and "special medication". Children said that their parents required many trips to the hospital to check on their health status, specifically to find out if their parent was healthy enough to undergo chemotherapy and to assess their cancer status. For example, [F6(C1)], a 13-year old girl who was termed as a 'slow learner' by her parent, described cancer as an experience related to a hospital stay:

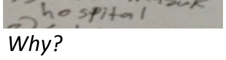
[F6(C1)]:

*(this is a) **Hospital**.*

SUZIE: Could you tell me why you drew this hospital?
*[F6(C1)]: Umm … mama always goes to this **hospital**.*
SUZIE: Why do you think so?
*[F6(C1)]: Umm … because she is always **sick**. **Every time** she has to go to the **hospital**.*
SUZIE: How often do you mean by every time?
*[F6(C1)]: Umm … **very often**. Like … **all the time**.*
SUZIE: Why do you think she has to go all the time?
*[F6(C1)]: She is **sick**, she goes to the **hospital** lah.*
SUZIE: Why is she sick?
[F6(P)]: La, I've already told you (child's name) …
*[F6(C1)]: Ya, ya … she has **cancer**, so when she **feels sick**, or **is sick** or not well, or **sick**, or she feels like she is **getting sick**, or she wants to make sure she's **not sick**, she has to go to the **hospital**.*

Children from Family Eight almost always accompanied their mother for her check-ups at the hospital and both her children's accounts mentioned this phenomenon with [F8(C1)] writing;

[F8(C1)]:



*(reading) **Frequently** go in and out of the **hospital.***

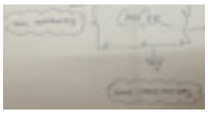
SUZIE: Why?
*[F8(C1)]: Umm … she (referring to mother) had to **check** up her **blood** (count) and had to **inject the cancer medicine**.*

F8(C2)] also agreed with this observation by saying:

*[F8(C2)]: U-huh . . . we **always** had to accompany her (mother) for her **medical check-ups**.*

[F5(C1)] related that cancer required special medicines with his drawing and explanation of cancer:

[F5(C1)]:



*(Explaining drawing) So, **cancer** has to take **chemotherapy** and **immunotherapy**.*

[F5(C1)] later added that cancer took a long time for his parent to recover from:

*[F5(C1)]: **Cancer** is not something like a normal fever or flu. Those you can get better in a few days. **Cancer** (pause) is so very different. It takes **a very long time to get better** … Months if not a whole year.*

His sisters [F5(C2)] and [F5(C3)] added more details to his observation:

*[F5(C2)]: I remember she (mother) had to wait about **two to three weeks** between her chemo because she had to have enough blood in her to help with the chemo.*
*[F5(C3)]: She had more than ten chemo cycles, so that easily became **… 30 weeks.** That did not include her radiotherapy and the time when she had fevers …*

Participants also drew or wrote their answers with the inclusion of their parent undergoing surgery, a biopsy, a mastectomy or lumpectomy. This is evident by Family One where all three children related cancer to activities conducted inside a hospital;

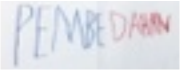
[F1(C3)]:

Cancer** means that the person has to go for an **operation

SUZIE: Is that what you drew here?
*[F1(C3)]: Ahuh . . . (indicating agreement) See the **surgeon***
SUZIE: So what can you tell me about this drawing then?
*[F1(C3)]: Umm . . . that person (with cancer) has to go for an **operation** to **check for cancer** (pause) Before he goes for the **operation**, the doctor **injects medicine** to make the area (to be operated on) numb.*
SUZIE: Who does this operation?
*[F1(C3)]: **A specialist doctor** . . . **a surgeon**.*
SUZIE: Why must this person go for an operation?
*[F1(C3)]: Umm . . . they have to **take out the cancer***
SUZIE: Why?
*[F1(C3)]: Umm . . . if not the person will **die** (from cancer)*

Her younger brother [F1(C1)] correlated cancer to surgery:

[F1(C1)]:



***Surgery**.*

SUZIE: Surgery?
*[F1(C1)]: Ahuh . . . See the **surgeon***
SUZIE: What for?
[F1(C1)]: (seems to think about it) Like what kakak (Older sister, F1(C3)) said (seeing a cancer specialist to remove cancerous growth)

[F10(C1)], a girl who was 6-years old when her mother was diagnosed, also understood cancer as something requiring surgery and a hospital stay:

[F10(C1)]: Ummi had to go to the ***hospital***
SUZIE: Why?
[F10(C1)]: She had to see a ***doctor*** *to* ***operate*** *on her . . .*
SUZIE: What for?
[F10(C1)]: Umm . . . ***throw away her rotten thing*** *inside her chest.*
SUZIE: What do you think happened?
[F10(C1)]: The ***doctor operated*** *her to* ***throw away the thing*** *and she had to* ***stay in the hospital*** *to get better.*

There appears to be an important difference for children who answered with a medical inference; it is suggested that the older the child, the more vocabulary they used, they formed more complex language structures and it seemed that they had a more complete understanding of cancer. It could be suggested that it seems from the above excerpts that age had an influence on how children form and expressed their answers. This phenomenon could be attributed to parents' perception on the suitability of certain information to be discussed with children of an appropriate age. As is evident from Family Eight, the parents confirmed that they did not know what to tell their then nine-year old twins about the mother's cancer:

[F8(P)]: We ***did not know how to tell*** *the children …*
SUZIE: Why?
[F10(C1)]: We just … I don't know (pause) I only thought of ***death,*** *that I could die any time, I was not ready to die (pause)* ***How do you tell your children*** *(pause) that you were going to* ***die****?*

In the case of Family Three, the parent said that she could tell her youngest less things about her cancer than what she could tell her eldest child:

[F3(P)]: I ***could not tell*** *[F3(C1)] the* ***same thing*** *as what I told [F3(C3)]*
SUZIE: Why?
[F10(C1)]: [F3(C1)] was (pause) nine years old at that time, she was ***too young*** *to understand about cancer.*

Similarly for Family Ten, the parent said she did not inform her daughter much about cancer because of her daughter's age:

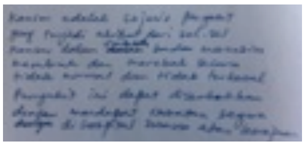
[F10(P)]: She was ***six years old*** *at that time.* ***What would she know****? Just started standard one, I* ***don't think she could understand*** *such a thing as* ***cancer*** *and* ***death****.*

Parent participants' assumption suggested a parallel with Kubler-Ross (1969, p. 6) where discussion about death is considered taboo and morbid, "children are excluded with the presumption and pretext that it would be "too much" for them.

A related finding was that besides age being a factor in the level of knowledge about cancer, at this stage a pattern seemed to emerge that the more knowledgeable a parent was, the more knowledgeable too was their children. This in part could be attributed to parent's information sharing attitudes and level of knowledge. This is because when cross referenced with parents' information seeking and sharing behaviour two patterns seem to emerge: i) that the more active a parent seeks information and ii) the more forthcoming a parent is about their treatment process and side effects, the more knowledgeable children appeared to be.

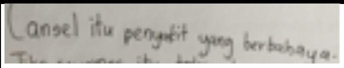
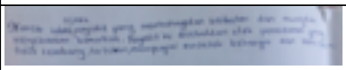
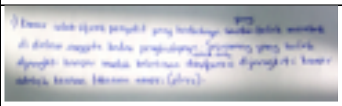
For example, Family One and Family Eight did not seem to use as many medical terms throughout the sessions and this was reflected in the discussions with their children. In the case of Family Three and Family Five, the more informed parent seemed to be more able and capable of contributing to their own children's understanding of cancer. Interestingly as well, the amount of cancer knowledge seemed to contribute to the behaviour of information sharing and inclusion within families. This phenomenon can be inferred through the several families. [F3(P)] for example wrote;

[F3(P)]:



(reading) Cancer is ***a type of disease*** *that develops as a result of* ***cancerous cells inside*** *the human* ***body*** *that* ***spawns*** *and* ***spreads*** *without* ***control*** *and* ***cannot be controlled*** *... This* ***disease*** *can be* ***cured*** *if receive fast* ***treatment*** *from private or government hospital.*

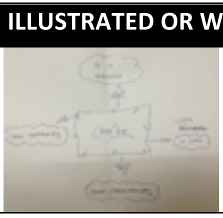
While [F3(P)] admitted to providing limited information, her children had reported their understanding of cancer using similar key words and codes. This is indicated below:

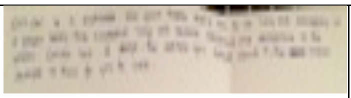
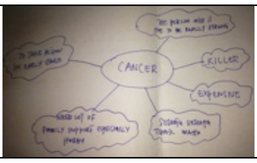
CHILD	AGE	WROTE	SAID
[F3(C1)]	9	 Cansel itu penyakit yang berbahaya.	***Cancer*** *is a* ***dangerous disease****.*
[F3(C2)]	12		***Cancer*** *is a* ***type of disease*** *that* ***endangers health*** *and might cause* ***death.*** *This* ***disease*** *is caused by* ***an unbalanced diet, emotional pressure, having familial problems*** *and etc.*
[F3(C3)]	15		***Cancer*** *is a* ***type of dangerous disease*** *that can* ***spread inside the body*** *of the person who has it. A person who has* ***cancer*** *is easily* ***fatigued*** *and one of the causes of* ***cancer*** *is* ***emotional pressure (stress).***

In instances of a more informed parent, as in the case of Family Five, children showed a higher degree of understanding cancer from a medical perspective. [F5(P)] said:

> *[F5(P)]: And then as you know kan everybody have* ***cancer cells in their body****, it's just matter of* ***active*** *and* ***inactive*** *la . . . Have to do* ***early detection****.* ***Early detection*** *can save lives and then undergo all the* ***treatment*** *. . .*

The children in Family Five illustrated or said the following:

CHILD	AGE	ILLUSTRATED OR WROTE	SAID
[F5(C1)]	13		*(Explaining drawing) From what I know,* ***cancer*** *is a* ***disease****. It can* ***kill****. So,* ***cancer*** *has to take* ***chemotherapy*** *and* ***immunotherapy****.*

[F5(C2)]	15		_**Cancer** is a **sickness**. **Overgrown tissue** that’s turn to be a **lump** and **excessive** in a person **body**. This **excessive lump** will become **cancerous** and **dangerous** to the person. **Cancer** has four stage. **The earlier** you **detect** about it, the **higher chances** is there for you to **cure**._
[F5(C3)]	*19		_(Explaining drawing) **Cancer** means, the person who gets it must be strong ... for those who aren’t strong, **antibodies** not strong, cannot survive the **chemotherapy** ... umm ... **chemo** and then **radio**, and **medicines** ..._

* [F5(C3)] was 17-years old at the time of mother’s diagnosis and the researcher included [F5(C3)]’s reports because [F5(C3)] was the primary care giver while she was still a child.

The belief in the importance of knowledge and information sharing was evident from the attitudes and belief by the parent in Family Five. [F5(P)] said that it was important for her children to be informed about cancer:

[F5(P)]: … My **children**, it is **important** for them to be more **knowledgeable**.

SUZIE: Why?

[F5(P)]: They really **need to know things** … they are of an age, my boy he is the youngest. He was umm (pause) 11-years old at that time, but even my boy he **must know about cancer** and **what I am going through**. He needed to know that even though I have cancer, **I needed to go through the terrible treatments to get better so that I can live longer**.

SUZIE: Why did you think that your children needed to be more knowledgable, even when your youngest was 11-years old at that time?

[F5(P)]: Aaa … (pause) **It is important for them to know what was going on, why** I was going for an **operation, what could happen to me** … it was important for them **to protect themselves from getting cancer**. Cancer is such a terrible disease that I want my children to be **safe** from ever getting **cancer** and do, they **must know how to protect themselves** (from getting cancer), **detect cancer,** especially my girls because in my case, the doctor said that my cancer is hereditary.

This phenomenon of associating cancer to a hospital stay, requiring surgery and the use of special medication were observations of children who experienced for themselves what it was like to either accompany their parent during medical check-ups or even in some instances throughout the duration of a hospital stay. Children participants accompanied their parent for surgery, blood tests, chemotherapy, radiotherapy and a number of related tests and medical check-ups that could be frightening, confusing and pose a health hazard to children.

4.3. ii. Understanding cancer from “State of Parent Being Sick”

Most children, understood cancer as a “State of Parent Being Sick” with direct observations and first-hand experience of their parents’ reactions to the side effects of their cancer treatment or what the children experienced as the effect of their parent being ill. Moreover, these children reported side effects of medication and treatments as one of the defining hallmarks of cancer. These side effects manifested physically as well as psychologically with children being able to observe and perceive how cancer affected their parent’s spiritual, mental and emotional state. The resulting codes from all participants’ self reports and illustrations helped to develop three themes of how children understood cancer, namely: physical side effects of cancer treatments, affects of side effects and, non-physical side effects of cancer and cancer treatment. The thematic network Figure 4.2 illustrated the key themes on which the word “cancer” was understood as a “State of Parent Being Sick”.

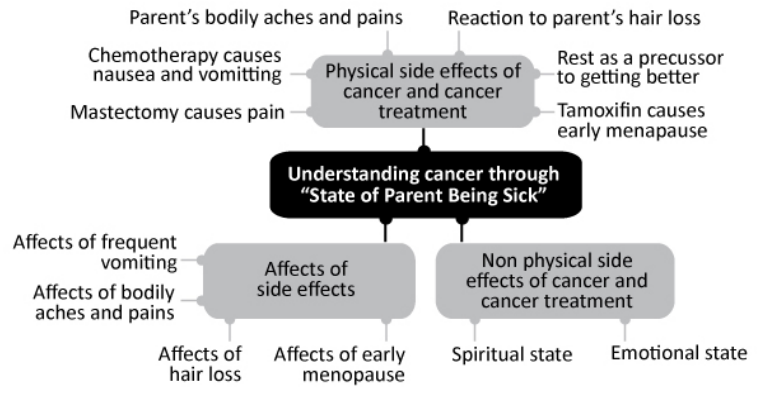


Figure 4.2 Thematic network diagram to understand “Cancer” as a “State of Parent Being Sick”

The results found in the thematic network were interesting. Contrary to published definitions of cancer as containing either scientific or medical terms (Table 4.7 on page 96), participants used a more descriptive manner of explaining cancer. The children participants’ descriptive definition of cancer was not surprising. Children participants seemed to develop their understanding of cancer by combining observations of parents while undergoing cancer treatments, decontextualizing available information into which that made the most sense to themselves and, their experience in caregiving. The descriptions of cancer suggested children participants more easily understood cancer through the “state of parent being sick”.

Observations during focus groups and children participants’ self-reports suggested that children noticed something was wrong or different about their parent at the onset of being informed of their parents’ prognosis. Children participants reported that their parents appeared to be “not normal”, a state of being that was different and not usual when talking to children previously. This change from their “normal” status could be attributed to how their parent felt at the time of information sharing. Almost all parent participants reported that they were either in a state of shock or disbelief. The parent participants were most concerned about the possibility of their perceived imminent death. This contributed to children participants’ assessment that something was wrong.

Children participants' reports seemed to indicate that the state of their parent being sick was very memorable. This is because most participants could clearly recall and describe vividly how sick they perceived their parent was. Children described this state through a general understanding of the symptoms of a person being sick such as feeling tired, needing bed rest, vomiting, feeling unwell, crying and unable to think. Central to this perception was the belief, supported by their parents' experience that the state of being sick was caused directly by cancer and the treatments. The long treatment schedule that included cycles of aggressive disease management and reduced symptoms, as well as their parent's unpredictable reactions to treatment, could have contributed to this perception and to how children made sense of their changed environment.

Observations of children participants and their self-reports suggested that learning was an active process in order to make sense of cancer and experiences. This seemed to support the principles inherent in Learning Theories; process of learning as a response to a stimuli or conditioned stimuli (Sherlin et. al., 2011, p. 293) and learning from experiences and observing the actions of others (Wilson, 2012, para. 1). It also supports principles from Cognitive Theories; children were "active builders of knowledge" (Papert, 1999, para. 3) and children's environment influenced the "way they communicate with others" (Carring, 2013, para. 1). Further understanding of this global theme is discussed in three related themes of a) Physical side effects of cancer and cancer treatment, b) Understanding cancer by affects of side effects, and c) Understanding cancer by Non-physical side effects of cancer and cancer treatment. These three themes are presented below.

4.3. ii. a. Physical side effects of cancer and cancer treatment

This theme was developed from discussions of issues raised by children participants. Children brought up their experience and observations about how their parents reacted physically to cancer treatments. These discussions encapsulated participants' understanding of cancer included the codes "mastectomy", "nausea and vomiting", "aches and pains", "being bald", "rest" and "menses".

Almost half of participants in the organising theme of "State of Parent Being Sick" included those words in their self-reports. These discussions were coded accordingly and formed topical headings of how children perceived the effects of cancer treatment such that: i)

Mastectomy caused pain, ii) Chemotherapy caused nausea, vomiting and hair loss, iii) Parent's bodily aches and pains, iv) Rest as a precursor to getting better and v) Tamoxifin caused early menopause. An indication about how this theme was developed is provided in the excerpts below.

Mastectomy caused pain

Several child participants connoted cancer by the pain their parent's exhibited post surgery. To some children, the pain from their mother's mastectomy was very memorable. For example, a girl [F2(C1)], who was eight years old at the time of her mother's diagnosis, responded in the manner as illustrated below:

[F2(C1)]:

*I drew mother in **pain**. Emak felt **pain** because cancer **hurts** emak.*

*SUZIE: It seems that in this drawing she felt **pain at her chest** area. Why is that?*

*[F2(C1)]: The **cancer** is there and she feels **pain** there (chest area).*

SUZIE: Why do you think she is in pain?

*[F2(C1)]: I think, mother is in **pain** because the doctor said that she had to **remove the pain** there. Like a toothache. If it is **damaged** and **painful**, it needs to be **removed**. When you do that, it is **painful.***

[F1(C3)], a girl who was 15 years old and [F4(C1)], a girl who was nine years old also mentioned post mastectomy pain as part of their understanding of cancer. [F1(C3)] said:

*[F1(C3)]: Uhuh, Mama's **cancer is pain** at the place where she was **operated** on.*
SUZIE: Where was that?
*[F1(C3)]: At her … **chest**, this side (referring to breast).*

and [F4(C1)] said:

*[F4(C1)]: Ya, cancer **attacked** her, umm, **breast** ...*

SUZIE: Could you describe that?

*[F4(C1)]: Umm ... it (cancer) **attacked** her, umm, **breast** and made her have **a lump** ... it was **very painful**, it had to be **removed***

SUZIE: How do you think she felt after she had it removed?

[F4(C1)]: Umm ... it (breast area) was still in pain

Chemotherapy caused nausea, vomiting and hair loss

Several children related cancer by how their parent reacted to chemotherapy, namely through nausea, vomiting and hair loss. Children wrote and talked frequently about their mother's nausea and vomiting and included a description of this side effect as part of their understanding of cancer. An illustrated example from [F2(C4)] follows:

[F2(C2)]:  *Uggh! Emak was **vomiting** all the time ... **cancer** means **vomiting** lah*

[F2(C2)] later added, "...you have to withstand nausea and the vomiting". Similarly, [F2(C3)] explained her drawing as a person with cancer vomiting;

[F2(C3)]: 

*Ya, I also remembered that (in response to [F2(C2)]). Always **vomiting**.*

This understanding of cancer and chemotherapy as the cause of parent's nausea was also mentioned by [F4(C1)];

[F4(C1)]: 
Ibu banyak muntah-muntah
*Ibu **frequently vomited** ...*

SUZIE: Why was this?

*[F4(C1)]: It was the **cancer** ... It was the **medicines** ... aaa ... the **chemo.***

Family Five also noticed the frequency of this type of side effect;

*[F5(C2)]: When she got **chemo**, my mother had to **vomit** it out so, that day she really **suffered** ...*

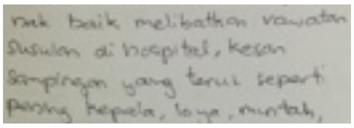
This was supported by a more detailed observation from [F5(C3)]:

*[F5(C3)]: My mother **vomited** from "maghrib" (at around 7:30pm) to midnight only, then after that she slept and the next day was better. But after taking **chemo** she **vomited** the whole night.*

Another child participant described vomiting as follows:

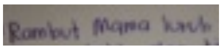
*[F6(C1)]: It (**vomiting**) was often, like she had food poisoning.*

Some parent participants also similarly described cancer from its side effects of nausea and vomiting. An example extracted from [F4(P)] indicated this:

[F4(P)]: 
nak baik melibatkan rawatan
Susulan di hospital, kesan
Sampingan yang teruk seperti
Pening kepala, loya, muntah,

*(reading) ... In order to be better, the treatment process involved follow-ups in the hospital, **side effects** that are terrible like headaches, **nausea, vomiting** ...*

Children also observed that other than nausea and vomiting, chemotherapy had the side effect of causing hair loss and in most cases, complete baldness. To varying degrees, participants noticed that hair loss was part of a parent's physical outcome of cancer treatment. The observation of this side effect is excerpted below:

[F3(C2)]: 
Rambut Mama luruh

(giggles) Mama's hair ***falling out*** *...*

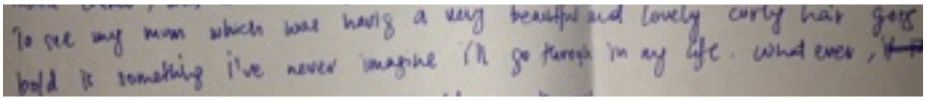
SUZIE: Okay, what can you tell about that drawing?

[F3(C2)]: The ***hair falls out****, and then ... it (hair) just* ***falls off*** *when you touch it.*

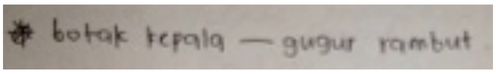
Other children, like [F6(C1)], [F10(C1)], [F5(C2)] and [F3(C4)] also equated cancer with either hair loss or parent becoming bald;

[F6(C1)]:(giggles) Her ***hair*** *got* ***less and less****, until it was* ***gone****!*

[F5(C2)]: Then her ***hair*** *didn't fall off little by little, it (hair) all* ***fell at once****.*


To see my mum which was havig a very beautiful and lovely curly hair going bald is something i've never imagine I'll go through in my life. What ever,

[F5(C2)]: (reading) To see my mum which was having a very beautiful and lovely curly ***hair*** *going* ***bald*** *is something I've never imagine I'll go through in my life.*

[F3(C4)]: 
botak kepala — gugur rambut

bald *head –* ***hair fell out*** *...*

Unlike children, parent participants discussed hair loss as an outcome of their treatment instead of equating hair loss as symptomatic of having cancer. These reactions are excerpted from [F3(P)], [F4(P)] and and [F5(P)]:

[F3(P)]: When you pull on it (hair), it just ***falls out****. You can just* ***rub the head****, no need to comb.*

SUZIE: When did that happen? Right after chemotherapy?

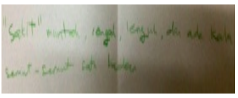
[F3(P)]: Eh, no, ***after*** *the* ***second chemo****. You can just rub the* ***head****, no need to brush. All the* ***hair dropped off****. (laughs)*

[F4(P)]: ***Hair falling off****, is* ***OK****, your body does not hurt, only your feelings.*

[F5(P)]: I had my basket (to collect hair fall), so I think four times my mother have to help me throw it out, I had that much ***hair*** *. . . No I'm* ***not worried*** *about my* ***hair*** *. . .*

Parent's bodily aches and pains

Several participants related cancer through the frequency of their parents' complaints or through their observations of either overt or covert show of pain. [F4(C1)], for example wrote that cancer meant that a parent was in pain in various locations and felt different kinds of pain;

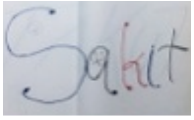
[F4(C1)]: 

*"****Pain****" like the* ***pain*** *when you frequently vomit;* ***restless pain****,* ***weakness*** *and sometimes like* ***pins and needles*** *throughout her whole body.*

SUZIE: What do you think caused this?

[F4(C1)]: ***Cancer****lah. This is what* ***cancer*** *does.*

Some children participants equated pain as someone having cancer. For example, the parent's physical pain was something that seemed to be central to [F1(C2)]'s understanding of cancer. This was evident in her excerpt;

[F1(C2)]: 
Sakit

(reading) ***Pain***

*SUZIE: In this picture, you wrote "**pain**". What do you mean by that?*

*[F1(C2)]: **Painful** because when there is **something foreign** in the body, that someone will **feel pain**.*

SUZIE: What is that 'something'?

*[F1(C2)]: **Something** that **should not be there**. **Something rotten** and **damaged** like mama said.*

SUZIE: How can that make people feel pain?

*[F1(C2)]: When it **grows**, it pushes other things aside and it uses the blood and meat to change into **rot**. That makes the place **painful**.*

SUZIE: How does that pain feel?

*[F1(C2)]: Umm, **very painful**.*

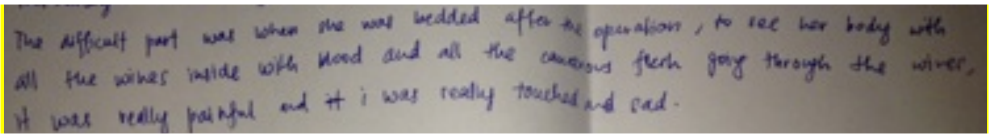
SUZIE: Painful because there is something growing inside you?

[F1(C2)]: Ahuh (nods in agreement).

SUZIE: So, what happens after the operation?

*[F1(C2)]: You're **in pain** because you had just been **operated on**.*

[F5(C2)] also included pain as part of her understanding of cancer:


The difficult part was when she was bedded after the operation, to see her body with all the wires inside with blood and all the cancerous flesh going through the wires, it was really painful and it i was really touched and sad.

*SUZIE: (referring to what was written) You wrote about " ... wires and it was really **painful**"?*

[F5(C2)]: Because when I saw my mother operate, with all the wires entering the body, and when the nurse takes it out, you can see the flesh that are cancerous coming out.

SUZIE: Oh it did?

*[F5(C2)]: Yeah. So when the doctor, nurse wanted to do it, they needed help, so they saw the wire like a telephone line entering her body. Like this (shows imaginary wire) this wire, enter my mother's body so every time the nurse will take it out. It looked **painful** and I know it was **painful**. My mother would say that her **side hurt**, her hands were **cold** and **felt numb**. Sometimes she said she **could not feel** her toes.*

[F2(C1)] described pain based on location and intensity:

[F2(C1)]: 

*(translation: **Very Painful!**) Emak felt **pain, everywhere**.*

SUZIE: Please describe that.

*[F2(C1)]: **Everywhere** lah. **Her hands, her feet, her legs** ... **headache** lah, **stomach ache** lah*

SUZIE: Please describe the pain.

*[F2(C1)]: She said felt **numb** in **her hands** and **legs** (pause) She said sometimes like **prickling pain of ants and needles** and then sometime like **throbbing pain** in her **head** ...*

Parents also recalled frequent bodily aches and pains; [F3(P)] and [F8(P)] said:

*[F3(P)]: We hear how others are affected by it; somebody get a **headache**, others felt **heaty** ... sharing experiences.*

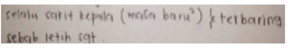
*[F8(P)]: At that time I had a **headache**, the noise (that children made) made it worse.*

These excerpts seem to indicate that both parent and children participants were unprepared for bodily aches and pains associated with the treatment and recovery process. Not only were both groups were unprepared for the varying types, locations and intensity of pain, they were also unprepared for the length of time their parent experienced pain and how long it took to alleviate those symptoms. Most parent participants relied heavily on their children for pain management with frequent and prolonged instances of massages. These parents associated children's support and assistance in this area as a form of care and showing love. However, the children disliked the frequency and duration of massaging. Two children from one family even indicated that the types and quantity of massage oils were enough to operate their own massage oil store.

Rest as a precursor to getting better

Several child participants related cancer by their parents needing frequent rest. Rest was needed as children believed that cancer made their parent feel unwell. For example, in Family Three:

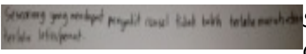
[F3(C4)]:



selalu sakit kepala (masa baru^{2}) & terbaring sebab letih sgt.

*(reading) Always had a **headache**, especially when she first came back from the hospital and she would lie down because she was **so tired** and felt **fatigued**.*

[F3(C1)]:



*Someone (pause) someone who has cancer cannot always be **angry** and **tired** or **fatigued** ... aaa ... if someone has **cancer**, the person who has **cancer cannot** (pause and then reading) **always be angry** because it could make that person **feel tension** ...*

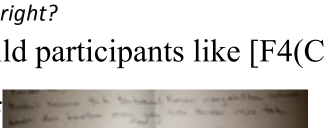
This was also mentioned by participants from Family 1, with [F1(C1)] and [F1(C3)]:

*[F1(C1)]: Aaa . . . mama says that she is in **pain**. **can't do work** (pause) have to **rest and lie down.***

*[F1(C3)]: After the **operation**, that person needs a lot of **rest**. Yeah, when you've been cut and have a **wound**, we **hurt** right?*

Other child participants like [F4(C1)], [F10(C1)] and [F5(C1)] wrote:

[F4(C1)]:



*... Cancer **hurts the whole body** and it makes the person with cancer **feel unwell** and need plenty of **rest**.*

*[F10(C1)]: Umm ... Ummi told me she was **tired** and **need to rest**. She's always **sleeping**. (shows irritation in face and voice intonation).*

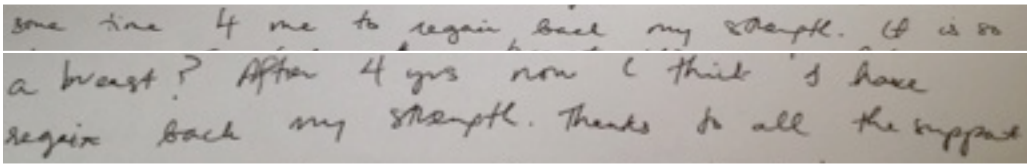
and

> *[F5(C1)]: ... then this **disease** makes my mum **feel weak**, and **tired** most of the time just because of she had to go through **radiotherapy 15 times** and **chemotherapy for 6 times** ...*

Throughout this thematic discussion, parents tried to respond and justify their rest. Most attributed the rest to their condition of symptoms of being sick, or as a side effect of treatments. According to [F3(P)]:

> *[F3(P)]: She (daughter) **does not understand**, I am already **sick**. The doctor asks me to **rest** because I am **not well**. When they (children) see me **ill**, they think it is **weird** or **odd**.*

and [F9(P)]:



some time 4 me to regain back my strength. It is so
a breast? After 4 yrs now I think I have
regain back my strength. Thanks to all the support

> *[F9(P)]: (reading) It **takes me some time** for me to **regain back my strength** . . . After four years now I think I have **regained back my strength**.*

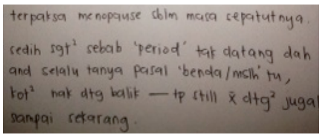
It seemed that all participants believed that rest was an important component to aid in parent's recovery from surgery and the toll of cancer treatment. Some believed that medications and post surgery resulted in parents being tired with complaints of severe fatigue and observation of frequent sleeping. However as evidenced above, several children had misconceptions about rest; they felt that the duration of their parents' rest was too long and severely limited parent's ability to contribute to the well being of the household and children. Parents were seen not behaving as normally prior to the cancer diagnosis.

Children participants did not understand mood swings or length of time that the parent was sick. They reported uncompleted housework and they observed that their parent appeared sad, stressed or being angry about something. In some instances these behaviour changes and apparently newly developed habit of resting throughout the day and into the night was unexplained and could not be accepted by children. This could be in part due to children's own experience of being sick or ill over a shorter period of time as opposed to parent's long cancer treatment cycles and effects. The periods of rest could also be part of parent's symptoms of depression that the children could not readily identify or describe.

Tamoxifin caused early menopause

Several child participants related cancer to their mother's symptoms of early menopause. The possible onset of early menopause was a side effect of chemotherapy and radiotherapy. This was especially noted in patients who took *tomaxofin* - a hormone-based medication that is believed to inhibit the growth of cancer cells in women with breast cancer. *Tomaxofin* either temporarily stopped menses or in some cases permanently induced menopause. The parent in Family Three was 42 years old when she experienced early menopause and her daughter [F3(C4)] wrote the following:

[F3(C4)]:



terpaksa menopause sblm masa sepatutnya.
sedih sgt^2 sebab 'period' tak datang dah
and selalu tanya pasal 'benda/mslh' tu,
kot^2 nak dtg balik — tp still x̄ dtg^2 juga
sampai sekarang.

*(reading) She had her **menopause early** and she was so **very sad** because her 'period' (menses) did not come anymore and she was always asking about that thing and that problem, hoping that it (menses) will come back, but still it has not come back until now.*

Other children, especially daughters who were primary care givers, seemed to know about cancer medications causing early menopause. This was evident from the accounts by [F4(C1)], [F5(C3)] and [F8(C2)].

*[F4(C1)]: Ya, I know about **menopause**. It is when a woman does not get her period. My mother has **menopause**, even though she told me it was **too early** for her to not have her period anymore.*

*[F5(C3)]: My mother told me and I read about **tamoxifin**. The doctors had to give her **tamoxifin** because it has a hormone-like substance that can help to stop the cancer but, that same hormone triggers her own hormones to start her **menopause**. So, whether she liked it or not, she had to go for **tamoxifin**. It's better she is alive.*

*[F8(C2)]: She (mother) felt **cold** one minute and then **hot** in another minute. She could not stand the cold temperature from the air conditioning in her bedroom, so I would have to accompany her to sleep downstairs where there is no air conditioning. It is so hot downstairs, but she (mother) can sleep through the hot.*

*SUZIE: Why do you think she felt **cold** one minute and then **hot** in another minute?*

*[F8(C2] ... She said something about **menopause**.*

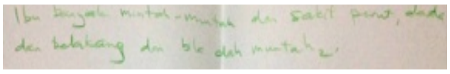
4.3. ii. b. "Understanding Cancer by Effects of Side Effects"

It seemed that the side effects of cancer treatment; most notably the nausea, hair loss, fatigued and early menopause, resulted in various reactions. This led to the development of the theme ***"Understanding Cancer by Affects of Side Effects".*** This theme was developed informed from discussions of issues raised by children participants about i) Effects of frequent vomiting, ii) Effects of bodily aches and pains, iii) Children's sympathetic somatisation to side-effects, iv) Effects of hair loss and v) Effects of early menopause. The themes contained participants' understanding of cancer that included the codes "reaction to vomiting", "alleviate pain", "losing hair", "housework" and "personal hormones". Approximately 36% of participants in the organising theme of "State of Parent Being Sick" included those words in their understanding of cancer.

Effects of frequent vomiting

Several participants made an inference that the vomiting contributed to some of the bodily aches and pains as well as to a loss of appetite. This phenomenon resulted in their parent losing weight and in some instances had teeth decay and body odour. [F4(C1)] wrote:

[F4(C1)]:



Ibu banyak muntah-muntah dan sakit perut, dada dan belakang dan ble dah muntah2.

*Ibu **... vomited frequently** and had **stomach ache, chest pain** and **back pain** when she **vomits** ...*

SUZIE: Yes?

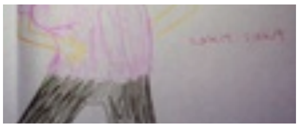
*[F4(C1)]: Umm ... Her **retching sounded horrible** (pause) it was **frequent** ... **smelly** and made her **cry***

SUZIE: Why was she crying?

*[F4(C1)]: I remember she said that it was **painful to vomit**.*

[F2(C2)] drew and said the following;

[F2(C2)]:



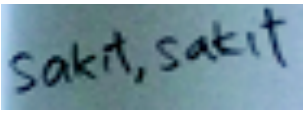
*She would **vomit** into a plastic bag, or hurry to the toilet. Sometimes, she won't make it and it was **disgusting** and **smelly**. **Made me want to vomit too. Yuck**.*

SUZIE: What is this you wrote here? (referring to "pain, pain')

*[F2(C2)]: Oh, her stomach was in **pain** and made her **vomit**.*

This was a similar reaction as what [F2(C3)] wrote:

[F2(C3)]:



sakit, sakit

(Translation: Pain, pain)

*SUZIE: Why did you write "**pain, pain**"?*

*[F2(C3)]: Huh, saw what she ([F2)C2)]) did, so I copied. (laughs) But I do remember Emak said she had **cramps**. Like **menses cramps**.*

and [F6(C1)] said;

*[F6(C1)]: I remember it (**vomiting**) **sounded bad**.*

Parents also informed the researcher about how vomiting affected them. [F2(P)] said:

*[F2(P)]: I knew that **chemo** had a **side effect** of **nausea and vomiting**, but I was **not prepared** for **how often** and **truly bad** it was . . .*

SUZIE: Could you describe that?

*[F2(P)]: It is correct that my children said it was **disgusting** and **smelly**. I was **vomiting** so much that the acids ate away at my **teeth** and I had to go to a **dentist** to **pull out** my **teeth**. It was **horrible**. Nobody told me about that.*

[F5(P)] said;

*[F5(P)]: Ya, I was **vomiting badly** after the second **chemo**. My **mouth smelled** really **bad** and next thing you know, I had **cavities**.*

SUZIE: (indicating to continue)

*[F5(P)]: You know, you are already **suffering** from the **chemo**, now you have **toothaches** on top of all the other **pains**. Hiya, terrible.*

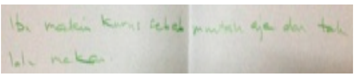
While [F10(P)] said;

*[F10(P)]: (laughing) I was a bit plumplah before cancer. I really **lost a lot of weight** from **vomiting.** Before (cancer) I had tried all kinds of diets, you know, but none of them worked. It took **chemo** and the **cancer** for me to **lose the weight**. I was **so skinny**, like **bones**. I was **afraid to look at myself**, you know, from being a bit plump to all of a sudden in a couple of months, **so thin**!*

SUZIE: What do you think about that?

*[F10(P)]: Well, it is **good that I got thinner**, but that's **not the way to get thin** lah. Not the way at all. So much **suffering** just to be **thin**? No lah. Now I just **control what I eat** and I am ok.*

Other than that, the medications also contributed to the drying of the saliva glands, which resulted in a temporary loss of taste buds. Several children participants believed that the frequent nausea and vomiting as well as a loss of taste buds contributed to a loss of appetite and dramatic weight loss. [F4(C1)] noticed this:

[F4(C1)]: 

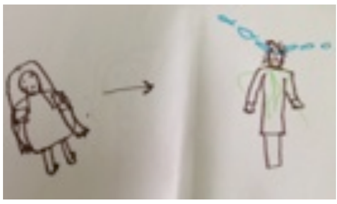
Ibu makin kurus sebab muntah aje dan tak lalu makan

*... Ibu **became thinner***

SUZIE: Why do you think she got thinner?

*[F4(C1)]: Because she just kept **vomiting** and **did not feel like eating (pause) lost her appetite.***

[F10(C1)] observed that her mother lost a lot of weight:

[F10(C1)]: 

*Ummi got so **thin** ...*

SUZIE: How did that happen?

*[F10(C1)]: She just **vomited** all her fat out.*

SUZIE: What is this green line here (referring to drawing)?

*[F10(C1)]: Ohh, that's her **yuck** (vomit matter)*

SUZIE: And what about this blue bubble-like drawing (referring to drawing)?

*[F10(C1)]: That's her **crying**.*

SUZIE: Why is she crying?

*[F10(C1)]: She's **crying** because that's what happens when you **vomit too hard**.*

[F8(C2)] also commented on her mother's weight loss;

*[F8(C2)]: She (mother) really became **thin***

SUZIE: Why do you mention that?

*[F8(C2)]: I don't know ... It was just she became very **thin**lah.*

SUZIE: Why do you think she became thin?

*[F8(C2)]: Umm ... she **could not taste anything** and so she **did not feel like eating**. **No taste**lah the **food**.*

To which her mother [F8(P)] responded that she could not cook because she could not taste if the cooking had enough salt or other flavours.

*[F8(P)]: Ya, that’s right. I **could not taste** anything. When **I eat, I taste nothing**.*

SUZIE: (indicating to continue)

*[F8(P)]: I **could not cook** like usual because when **I cook, I cannot taste** also.*

*[F8(C1)]: Ahuh (indicating agreement) It (mother’s cooking) **did not taste good** anymore.*

*[F8(P)]: That’s the difficult part. My family; my children and husband cannot understand. I am already so **weak**, you **cannot expect me to cook** too. I **cook** also **cannot taste**.*

SUZIE: How was this resolved?

[F8(P)]: Have to buy outside food lah.

It can be suggested that besides participants reacting to chemotherapy and other medications by vomiting, some participants reported their reactions to the vomiting itself. Several children associated the pain from vomiting as severe menses-like cramps that could induce crying from the pain. Other children participants remarked on how disgusted they felt. These reactions also developed an inference by children participants that the frequent vomiting resulted in their mother’s drastic weight loss and loss of taste buds.

Effects of bodily aches and pains

As a side effect of cancer treatment, most children participants readily observed that their parent was too ill to do normal housework. Children from Family Eight indicated that they “noticed that their parent was not well” and there was “something different at home”. The home environment changed with housework neglected and parents being unable to function normally. Several child participants reported that their parent’s bodily aches and pains resulted in an increase and frequency of chores that they had to do. The children were also burdened with more a mature role and responsibility for their parent’s welfare and health. This suggested that the children were ill equipped to deal with these tasks.

As an effect of parental ill health, some children helped their parents by increasing responsibility for home-related chores, while some did not. According to [F3(P)], [F5(P)], [F6(P)] and [F7(P)], said that their children, especially the older daughters; would “automatically” do what was needed, without being told or scolded into doing it. An excerpt from [F5(P)] exemplifies this affect:

*[F5(P)]: Even **my boy**, you know, he did the **housework.***

SUZIE: How did you get him to do so?

*[F5(C1)]: Most of the time, **he saw something that needed to be done, he did it** lah. Like **automatic**. Before cancer, no lah, but when I got cancer**, like automatic he did his part**. I did not have to ask him so much.*

However, [F5(C1)] responded that once his mother’s health improved, his chores were normalised:

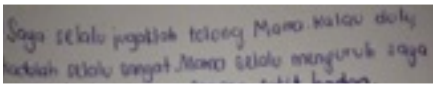
*[F5(C1)]: **Cancer**, can make someone **feel very weak**, a **disease** that can make **someone lose their strength**. And **not able to do anything***

SUZIE: What do you mean by not able to do anything?

*[F5(C1)]: I mean **carry stuff**, **anything heavy** ... Before (while mother was undergoing treatment) I do **ironing** now I don't. I learnt how to iron my school clothes from older sister. I had to iron them every time before I go to school, so it is something normal now. But, since my mother is better now, she irons my clothes. So, I don't have to iron so much anymore. So, everything, almost back to normal lah.*

To further evidence children's' changing roles and responsibilities affected by cancer treatment [F3(C2)] wrote;

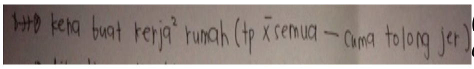
[F3(C2)]:



*(reading) I **quite often help** Mama. Last time (before diagnosis), not as often (laughed).*

Her sentiments were also experienced by [F3(C4)]:

[F3(C4)]:



kena buat kerja² rumah (tp x̄ semua – cuma tolong jer)

*(reading) Have to do **house chores**, but not all, just **help** in **some chores**.*

For some children participants, cancer was equated with having to do extra chores that they were obliged to take over from the ill parent. As an example [F10(C1)] claimed part of her understanding of cancer based on the chores she had to do.

[F10(C1)]:

*I drew **me sweeping** ...*

SUZIE: You don't look too happy there?

[F10(C1)]: Umm ... ya.

SUZIE: Why?

*[F10(C1)]: Umm ... **I don't like** lah.*

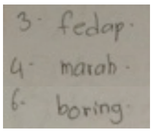
SUZIE: Why?

*[F10(C1)]: I **have to clean up** lah and sometimes OK, but sometime, I don't like.*

SUZIE: Could you tell me more about that?

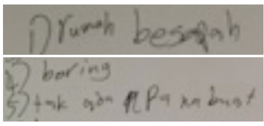
*[F10(C1)]: Umm ... She (mother) tells me to do it because I make the **mess** and the **house is dirty**.*

It was interesting to note that on the matter of house chores, unlike all the other families; Family 1 and Family 8 had clearly separated the gender roles. An excerpt from Family 8 exemplifies this separation of gender responsibilities by expecting [F8(C2)] – a girl to complete perceived "women's work" while her twin brother [F8(C1)] was not given or expected to perform any house chores. F8(C2)] wrote that she was fed-up and angry with the perceived unfair division of house chores based on gender differences that was practiced in her family:

[F8(C2)]: 
3 · fedap ·
4 · marah ·
6 · boring ·

Fed-up *(with doing the housework and twin does not have to) ...* ***angry*** *(because she had to do the housework while twin could play) ...* ***Boring*** *(with housework)*

[F8(C1)] claimed that the house needed cleaning and that he had nothing to do at home:

[F8(C1)]: 
1) rumah besepah
4) boring
5) tak ada apa nak buat

The ***house is messy*** *...* ***boring*** *(to stay home) ... (I have)* ***nothing to do ...***

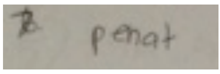
Their parent [F8(P)] had not realised gender bias and attributed this to her perception of gender roles: “He’s a boy, you can’t expect him to do the work”.

Children’s new roles in helping the parent to do their normal chores resulted in several children participants reporting that they felt tired from doing the extra work. This is evidenced by the following excepts from ([F5(C1)], [F10(C1)] and [F8(C2)]):

SUZIE: What do you feel about that (doing the work that parent used to do)?

[F5(C1)]: ***Tired****. Life goes on. Just accept to that fact.*

[F10(C1)]: ***Tired*** *lah*

[F8(C2)]: 
3 penat

... ***tired*** *(from doing the housework)*

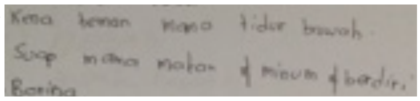
Since their parent was unwell, children, especially older children; had a prominent role as primary care-givers in the home environment. The spouse or husband was not mentioned in taking this role. [F5(P)] commented that if it were not for her children taking care of her, she did not think she would be alive today:

[F5(P)]: Thank God I have such lovely ***children****. If not for them, I would not be here today.*

SUZIE: How so?

[F5(P)]: Ya la, it was ***them*** *(children) that* ***told me*** *to continue with the treatment. It was* ***them*** *that* ***helped me, really helped me*** *when I was so sick.* ***They*** *give me* ***motivation****, you know, they tell me that I can do it (go through the treatment process).* ***They*** *told me, “You have to do it.”*

[F5(C3)] added that she and her siblings would take turns to accompany their mother to the hospital. When their mother was at home, they would also take turns to make sure their mother was all right or if she needed anything to help her feel better. As another example indicative of children’s role as primary care-givers, [F8(C2)] wrote down her roles in helping to take care of her mother:

[F8(C2)]: 

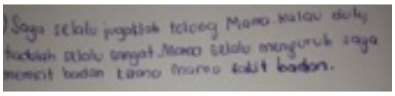
Kena temen Mama tidur bawah.
Suap mama makan & minum & berdiri.

(reading) I had to ***accompany her to sleep*** *downstairs (on account of not wanting to use the bedroom's air conditioning).*

SUZIE: (indicating to continue)

[F8(C2)]: ***Hand-feed mama*** *. . . and* ***help her drink and stand.***

In addition to increased house chores, children also were tasked to massage away parent's aches and pains. This seemed to occur as another affect of their parent's condition or cancer treatment. Not only did children do the parent's normal housework because their parent was feeling too ill or tired to do their normal chores, but children also helped to alleviate their parent's bodily aches and pains by massaging their parent when asked to do so. This is evident by an excerpt from [F3(C2)]:

[F3(C2)]: 

Saya selalu jugaklah tolong Mama. Kalau dulu
taklah selalu sangat. Mama selalu menyuruh saya
memicit badan kerana mama sakit badan.

(reading) I ***quite often help*** *mama. If before (cancer) not as often. Mama always asks me to* ***massage her body*** *because* ***her body hurts.***

[F2(C3)] commented about her bothersome role as a masseur on request, massaging in the following manner;

> *[F2(C3)]:* ***Massaging*** *is not difficult, it's just that it has to be done often.* ***I don't like doing*** *it. It's not that I don't want to help, but I want to do other things. It* ***smells****. It's* ***bothersome*** *. . . . it's* ***bothersome****.*

With reference to the task of massaging [F7(C2)] had this to say:

> *[F7(C2)]: Everyday had to* ***massage.*** *I want to watch TV but cannot enjoy it as I also have to* ***massage*** *her (mother). She had a* ***headache*** *and then had to continue with her* ***arms*** *and* ***hands*** *and then continue some more with her* ***legs****. It's like one time* ***massage*** *she said just for a moment, but a moment became 30 minutes, then 45 minutes, then had to do until she fell asleep!*

His brother [F7(C1)] said;

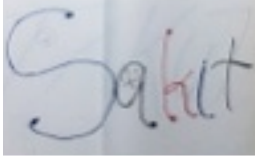
> *[F7(C1)]: The* ***house*** *would* ***smell*** *of* ***massage oil****. It smelled like some Indian temple. You name it, we had it. Minyak chap kapak for the head, Tiger balm for her back, Mestika for her arms and legs . . . umm . . something more expensive for her dry skin. I think that was from body shop.*

After which [F7(C2)] continued by saying, "We could open a massage oil shop!"

Children's sympathetic somatisation to side-effects

Another interesting phenomena emerged as children observed their parent either fearing or being in pain, they too felt sympathetic fear or pain. This seemingly transference of emotion and behaviour, identified as sympathetic somatisation; was described most notably by [F1(C2)]:

[F1(C2)]:

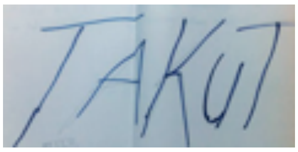


*I **fear** the **pain**.*

SUZIE: What about this person who is crying here and here?(referring to pictures in letter 'S' and 'a')
*[F1(C2)]: **Crying** because he's in **pain.***

This was also felt by [F1(C3)]:

[F1(C3)]:



*Aaa . . . **Afraid***

SUZIE: Is that a feeling of fear or fear of something?
*[F1(C3)]: Umm ... I feel that cancer is **scary** because it **feels very painful**.*
SUZIE: So, to you, you fear cancer because it makes people feel pain?
*[F1(C3)]: Ahuh (nods in agreement). I am **afraid of the pain**.*

After making the above statements, [F1(C3)] continued with the following drawing, emphasising the sympathetic somatisation affect.

[F1(C3)]:

*That's someone with **cancer**. He's **afraid** when the doctor **injects** (pointing to syringe) the cancer **medicine** or **painkillers** when he wants to be **operated** on.*

SUZIE: Ya?
*[F1(C3)]: Ahuh (nods in agreement). He **feels a lot of pain** at the place where there is cancer. So, when he sees the doctor at the hospital, the doctor says that at the place where he feels pain, it needs to be **operated** and **removed** so that he does not feel pain anymore. Umm . . . So, when the doctor **operates**, he feels **pain**, but the doctor **injects** (pointing to syringe) to give painkillers, it's not so painful. After the **operation**, that person needs a lot of rest. Yeah, when you've been **cut** and have a **wound**, we **hurt** right?*

Another child participant expressed a similar sympathetic somatisation affect. Through hospital observations, [F2(C3)] claimed that cancer is fearful, scary, and painful. [F2(C3)] became scared of staying in the hospital and injections:

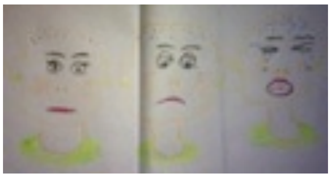
[F2(C3)]:

*Cancer is **scary** because you have to go for **an operation** ... erm ... **staying in the hospital alone**, **injection**, feel in **great pain** ... I **fear** having to go for an **operation**. Very **frightening** …*

SUZIE: Why do you feel that way?
*[F2(C3)]: . . . because it will be **painful**.*

[F2(C1)] said that she understood cancer was "a disease that is painful" while [F2(C2)] provided a more detailed description through her drawing and interview:

[F2(C2)]:



… ***in pain***

SUZIE: Please explain more about that.

[F2(C2)]: (pause) The first one is in ***a little pain*** *and can withstand it (the level of pain). The second one is in* ***great pain*** *and that is why there are* ***tears****. The last one is* ***in agony****, as if the* ***person can die from the pain****. That's why the person is* ***crying many great tears****.*

SUZIE: How did that happen?

[F2(C2)]: Well … (pointing to first drawing) She is ***not in too much pain*** *as the doctor is taking* ***a blood sample*** *to check if she has cancer.*

SUZIE: How do you know that?

[F2(C2)]: That's what mother said and she said that it ***pains*** *only a little bit.*

SUZIE: All right, please continue.

[F2(C2)]: (second drawing) ***In pain*** *because just after the* ***operation*** *…*

SUZIE: What can you tell me about how you think she felt in this picture?

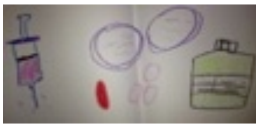
[F2(C2)]: I think the person with cancer is ***sad*** *too because there's something that isn't … right. She's* ***lost a breast****. She says that she is* ***not complete****. She's lost a part of her body. She's* ***embarrassed****.*

SUZIE: (indicating to continue)

[F2(C2)]: (pointing to third drawing) That's when ***the very painful pain*** *comes …*

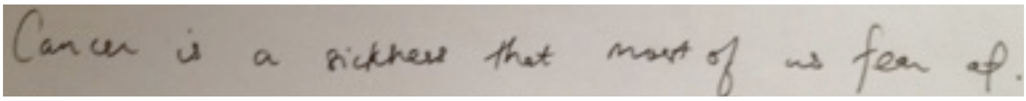
Based on her interview [F2(C2)] conceptualised that cancer and its treatment was painful and disfiguring. [F2(C2)] later expressed that she was frightened that she would have cancer as she could already imagine the suffering. The basis for this sympathetic somatisation affect was from her close observation of her parent's cancer treatment. In relation to the sympathetic somatisation affect, [F7(C1)] feared that the medication would not work. [F7(C1)] observed that his parent continuously took medication in various forms (pills, injections, creams, liquids) to treat the cancer but the benefits of the medication were not apparent. In fact, the parent seemed to get more ill. [F7(C1)] explained:

[F7(C1)]:



I **don't know how** *that (medication) helps. Seems to make you (mother)* ***vomit*** *all the time.* ***How can that*** *(medication)* ***help****?*

The sympathetic somatisation experienced by children participants was observed by their parents. Some parent participants commented and reiterated to their children about their pains and fears about cancer and cancer treatment. An excerpt from [F9(P)] evidences this:



Cancer is a sickness that most of us fear of.

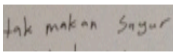
*[F9(P)]: (reading) **Cancer** is a **sickness** that most of us **fear of**.*
SUZIE Why?
*[F9(P)]: Because it is **very painful** and you can **die.***

The parent from Family Eight [F8(P)] said that she had in many instances complained about how cancer affected her:

*[F8(P)]: Ya, I have **complained** that this **cancer is killing me** ... it's just that I think I was in **so much pain**, that **I felt that I was dying**.*
SUZIE: How did your children respond to that?
[F8(P)]: Umm ... I did not really notice. (pause) I think they ignored me or just could not be bothered.
SUZIE: Well, [F8(C2)] since you took care of your mother most of the time, how did you feel about that?
*[F8(C2)]: **Sad ... afraid that she was going to die.***
SUZIE: When you felt that way did you think about cancer?
*[F8(C2)]: Yes. Sometimes ... **I am afraid of cancer**.*
SUZIE: Why?
*[F8(C2)]: My **mother said cancer was painful** and I am **afraid of pain from cancer** ... and a person with cancer can **die from very bad pain**.*

Interestingly, this fear of cancer transcended physical symptoms. Some children started eating fruits and vegetables in the belief that they will never feel pain from cancer. This is evidenced from [F8(C1)]:

[F8(C1)]:


tak makan Sayur

*(reading) **Not eating vegetable ...***

SUZIE: What about "not eating vegetable"?
*[F8(C1)]: My mother said that **if a person does not eat vegetables, they will get cancer**.*
SUZIE: So, what have you done about this?
*[F8(C1)]: Err ... **I eat more vegetables** lah. I **don't want to be in pain because of cancer**.*

Children from Family Five also began to eat more vegetables, believing that by doing so they will never develop cancer. The eldest child, [F5(C3)] reported that this attitude and belief was reinforced by their mother and her doctor.

*[F5(C3)]:Ya and then urmm when my mother got cancer, I learned that **we should eat a lot of vege**. Like cancer, **doctor says** if you want to **fight** it you have to **eat red things like carrot**, If you think of it, it's quite funny but colors in our food actually plays a role, tomato, carrot, so we have to eat all the colors.*

SUZIE:Was there other types of foods that you are careful about now?
*[F5(C3)]:And s**ome burnt things** like **satay** you have to be careful*

[F5(C2)] also believed in the role of diet:

*[F5(C2)]:... there are a lot of things that impacts and after you recover you tend to be **more cautious** about your **eating** and lifestyle, exercise and **diet has to be taken care of**. Don't eat things like fast food, satay, and then *coughs* dairy product, cheese, my favorite food was pizza, once or twice, now it's okay. It's just not nice eating in front of her although she says it's okay.*

[F2(C4)] believed that foods containing carcinogens caused her mother's cancer;

*[F2(C4)]:I know what **causes cancer**. I read and remembered that **cancer** is **caused** by **... not eating a good balanced diet** with **fruits** and **vegetables** ... I really think that her **cancer** is caused by some **carcinogen** that we were not aware of and we **ate** it. I **asked the doctor** and he said that could be the **cause**, so I believe it lah. It must be the **eating** of **foods** that are **unhealthy habits**.*

SUZIE:What did she used to eat?

*[F2(C4)]: Asam (preserved and salted dried plums), satay, KFC, very spicy foods, McDonalds, high cholesterol foods like grilled squid, prawns and mutton ... **Very little fruits***

To which her mother responded:

*[F2(P)]: Ya, that's what the **doctor said**. Most likely by what I **ate**. I really like asam and satay and spicy foods that had belacan (preserved fish paste). It was ... my meal was not complete without them.*

SUZIE: Did you share this information about the effect of your previous eating habits with your children?

[F2(P)]: Ha, yes. I did.

Effects of hair-loss

When the discussion about hair loss was raised, it seemed that children reacted with either one of two patterns: they felt the condition was weird and different or they wanted to show their support by offering to cut off their own hair too. Younger children (aged below 12 years old) indicated feeling uncomfortable with their parents' hair loss while older children, irrespective of gender; indicated their willingness to be bald in a show of solidarity. This is evident in the below excerpt of two participants who were 7 years old who expressed their discomfort. [F2(C1)] said:

*[F2(C1)]: **Cancer** is **scary** because ... **bald** ...*

SUZIE Why do you feel scared about your mother being bald?

*[F2(C1)]: Erm ... that **baldness** ... not scary, scary, but **funny scary** ... like **an alien** (shudders)*

[F2(C2)]: (giggling in response to sister saying mother looked like an alien)

[F2(P)]: Ya, none of them would touch my head when I had a headache and I asked them to help me massage my head.

*[F2(C3)]: Eee ... feels like a **weird** tickling feeling ...*

and [F10(C1)] drew and explained:

[F10(C1)]:

*... She did not have her 'Rapunzel' **hair** anymore. She became **bald** like some **ogre**.*

An 11-year old participant [F6(C1)] equated the loss of hair to the loss of feminine identity. As an effect of a parent's hair-loss, this particular child was scared that she would also lose her hair and not be a girl anymore. This is what the 11-year old said:

SUZIE: Ok. What about her becoming bald?

*[F6(C1)]: (giggles) Her **hair** got **less and less**, until it was **gone**!*

SUZIE: What did you think when you saw that she had no hair?

*[F6(C1)]: Ahyo! That was **scary**, like **alien**! I was **afraid**.*

SUZIE: Why were you afraid?

*[F6(C1)]: Mama **did not look like herself** and I was **scared** that I would **lose my hair too**. One day, I wake up and all my hair fall out, how then?*

SUZIE: How did you feel towards your mother when that happened?

*[F6(C1)]: **I pity her**. She had **no hair** and she had to **wear a scarf** even inside the house. I did not want to see her **bald**.*

[F6(P)]: But my hair grew back. See? So soft . . .

*[F6(C1)]: Yes, so, it's OK now. I was **worried** that she would be **bald forever**. That would have been **bad**.*

SUZIE: How so?

*[F6(C1)]: It is like . . . umm . . . **a girl must have hair**. If a girl does not have hair . . . you are not a girl anymore?*

SUZIE: What helped you to feel better about your mother losing hair?

[F6(C1)]: Umm . . . wearing the scarf. And I saw the hair growing back.

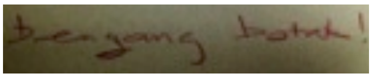
*[F6(P)]: Yes, she would **not touch my head** when I had a headache when I was **bald**. Even when the hair was growing, she did not want to touch it.*

SUZIE: Why?

*[F6(C1)]: I don't know. I think it would be **ticklish** and just **a funny feeling**.*

As another effect of hair-loss, some children participants were angry at the unfairness of it. They believed that a parent who was already in pain should not be 'punished' by going bald too. An 11 year-old participant, [F4(C1)] said:

[F4(C1)]:



be going botak!

*... I got **angry** that she became **bald**.*

SUZIE: Why was that?

*[F4(C1)]: Ya la, she was already in so much pain, so miserable like that, and then, she became **bald**. Angry lah.*

Older children, irrespective of gender; indicated their willingness to be bald when their parent lost hair to cancer treatment. In a family interview, children from Family 5 who were 11, 15 and 18 years old respectively remarked:

*[F5(C1)]: Her **hair** just **fell off**. One day got **hair**, the next, can **see the scalp** already.*

*[F5(C2)]: Then her **hair** didn't fall off little by little, it all **fell** at once.*

[F5(P)]: No lah, I had to throw my hair out four times. I had that basket ...

*[F5(C3)]: Ya, I remember. It was **horrible**. I **felt** so **bad**.*

*[F5(C2)]: Ya, we **all felt so bad** ...*

*[F5(P)]: My children, all of them, but especially the girls, all **offered to be bald**. I ask them "What for?", They said "to accompany me, so that I **did not feel bad** being the only **bald** one in the family."*

*[F5(C3)]: I think that's when we started buying her the **head scarves**.*

*[F5(P)]: Ya, my husband also asked me about my **helmet** (head scarf or turban), when we go out or when we have visitors at home, he would ask "Eh, where's your **helmet**?"*

To exemplify willingness to share a parent's experience, [F7(C2)] - a boy who was 15 years old told his father that he wanted to go bald. The boy had his head shaved to experience for himself what his mother was going through:

[F7(C2)]: Is that (becoming bald), that horrible? ... So I told Abah I wanted to cut off all my hair
SUZIE: Why?
[F7(C2)]: I just wanted to test lah ...
SUZIE: So, did you cut off all your hair?
[F7(C2)]: Ya ...
SUZIE: What did you think about that?
[F7(C2)]: Ermm ... a bit weird at first, my head felt so light. It was OK after a day or two. Not so bad at all lah.

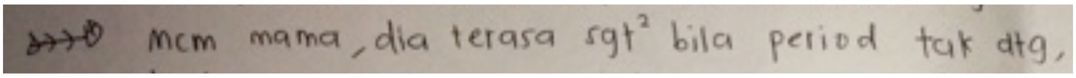
Effects of early menopause

This section provided results of the thematic analysis on "Affects of early menopause". In reference to this theme, children who were aware of the onset and reason for their mother's early menopause seemed to be very cautious with the issue. They were very careful on how they behaved when their mother was experiencing an angry episode. They were also careful not to inform her of their own menses cycles. According to [F1(C3)] and [F8(C2)]:

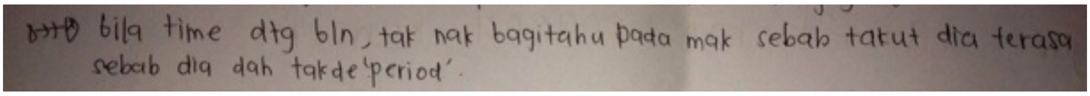
*[F1(C3)]: Yes, I know what is **menopause.** It is when you don't get your period (menses) anymore. Mama got her **menopause** because of the **cancer**.*

*[F8(C2)]: Ya, **menopause** is when you don't get your periods and you feel hot and cold and grumpy. I think that is why my mother is sometimes quick to get angry. She is getting her **menopause**.*

[F3(C4)] wrote the following regarding the affect of cancer treatment to her mother and herself:

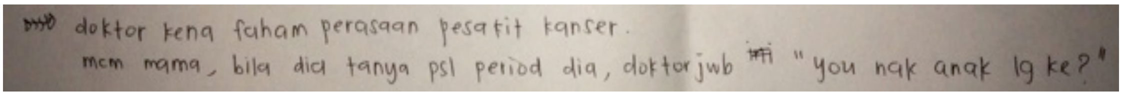

mcm mama, dia terasa sgt^2 bila period tak dtg,

*[F3(C4)]: (reading) Like mama, **she really felt upset** when her **period (menses) did not come** . . .*


bila time dtg bln, tak nak bagitahu pada mak sebab takut dia terasa
sebab dia dah takde 'period'.

*[F3(C4)]: (reading) When my **period (menses)** comes, I do not want to tell my mother because I am afraid that she might feel **upset** because she does not have her **period (menses)** anymore. (at 43)*

[F3(C4)] added that not only did children have to be aware of the mother's condition and her reaction to having early menopause, but doctors also had to be more circumspect;


doktor kena faham perasaan pesakit kanser.
mcm mama, bila dia tanya psl period dia, doktor jwb "you nak anak lg ke?"

*[F3(C4)]: The doctor must understand the emotions of a cancer patient. Like mama, when she asked about her **menses**, the doctor answers "Do you want more children?!"*

4.3.ii.c "Understanding Cancer by Non-Physical Side Effects of Cancer and Cancer Treatment"

The Theme "Understanding Cancer by Non-Physical Side Effects of Cancer and Cancer Treatment" was developed from qualitative discussions of two issues; i) spiritual state and ii) emotional state. The themes contained participants' understanding of cancer that included the codes: "prayer", "faith", "good deeds", "willpower", "Thanks to God" and "negative emotion". Approximately 21% of participants in the organising theme of "State of Parent Being Sick" included those words in their understanding of cancer.

Spiritual State

Several children noticed that their parent seemed to be more religious with marked frequencies in prayer, meditation, *zikir* (utterances) and recitations that included religious or spiritual references. After diagnosis, parent participants admitted to increased religious observance. Children participants reported an increase in their own spiritual activities. [F5(C2)] for example mentioned that cancer prompted a closer relationship with God:

> *[F5(C2)]: ... I think the **prayers helped**. My mother and all of her children, our families and friends all **prayed** for her **to get better**, to **not be in so much pain**.*

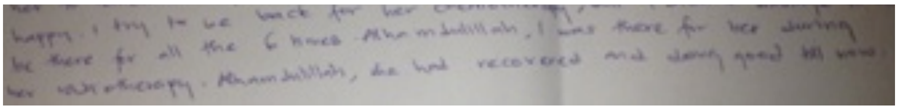
[F9(C1)] perceived that the diagnosis of cancer provided opportunities to perform religious good deeds. Some other children believed recovery from cancer treatment was dependent on spirituality. Their beliefs are excerpted below:

> *[F9(C1)]: ... **Cancer** means you get a chance to **be closer to God** ... People say that **cancer** can **kill**. It is **dangerous**. So, if you know that you will die, you get **a chance** to do **all the good things** that you were supposed to do.*

A children participant from Family Two, [F2(C3)], noted that parent's faith seemed to support her mother's willpower to overcome cancer;

> *[F2(C3)]:"I can see that mama fought this disease with **patience** and faced it with **perseverance**."*

This increase in religious practices seemed to influence children's own religious behaviour. Several children participants used "Thanks to God" for their parent's recovery as is exemplified by [F5(C2)] and [F7(C2)]:

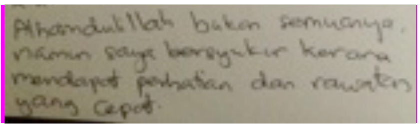


*[F5(C2)]:(reading) . . . **Thanks to God,** I was there for her radiotherapy. **Thanks to God**, she had recovered and doing good till now ...*

*[F7(C2)]:"**Thanks to God**, she is better."*

Parent participants also used "Thanks to God" in their accounts of the cancer experience. [F4(P)] wrote "thanks to God" in the following manner:

[F4(P)]:



Alhamdulillah bukan semuanya,
namun saya bersyukur kerana
mendapat perhatian dan rawatan
yang cepat.

***Thanks to God** . . . they did not remove it all (breast), still I am **thankful** because I was given quick attention and treatment.*

*[F3(P)]:Up until now, **thanks to God**, my cancer disease is getting better and my soul has become calmer.*

Patients also seemed to be more observant of religious doctrines, rituals and acts of faith as a mechanism to either cope with the diagnosis and treatment or as a means to overcome the disease entirely. Many patients commented that to them the word "cancer" was a test from God; citing either to test their faith, punish them for past misdeeds, or "telling" them that it was time to be more religious. Most of the parent participants pointed out that the fear of death or sudden death, being unprepared to face the afterlife and needing time to atone for their sins; as a reason for their more religious fervour. The following excerpts are evident of this theme:

F8(P)]: Cancer too has its reasons ...

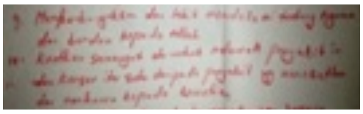
*F5(P)]: And then of course **religious** wise. But I didn't elaborate anything on the **religious** la but **religious** wise there's so many verses in our Qur'an that really help you out la. The only thing we are very very ... we ignore it we read but we ignore it. Because we don't understand, many translations*

After which [F5(P)] added;

*[F5(P)]: ... I always **pray to God** let me live to another 20-30 years, I will see you all (referring to children) graduated, get married, (laughs) ... **Thanks to God,** we always **pray,** like me and my cousin, we always **pray** urm ... none of the children got cancer, terminal disease la, that's what we believe.*

[F6(P)] wrote the following excerpt:

[F6(P)]:



*(reading) Frequent and more in-depth study about **religion** and **prayer to God** . . . **Strengthen** my **will** to fight this disease . . . **Cancer** is one of the **diseases** that is **frightening** and can lead to **death.***

It is to be noted here that contrary to Kubler-Ross (1969, p.8) belief, these children participants did not report blaming themselves for their parent's cancer. They did not seem to intuit or to internalise the reasons for their parental diagnosis as being a result of children participants' past misdeeds or wishes. Instead, the children participants suggested that cancer was a “Test from God” in which the ill parent and the rest of the family should increase the frequency of their religious practices.

Emotional State

Several children participants noticed that their parent exhibited several overt and covert negative emotional behaviours. Most of the child participants in this study did not know the cause of and could not figure out how to overcome their emotions, and so attributed cancer as causing the emotional upheaval in their parents. For example [F7(C2)] described her mother’s changed emotional state as follows:

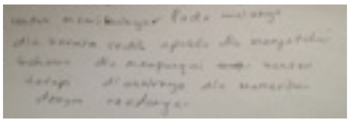
> *[F7(C2)]:Before **cancer,** my mother, she was not like this. She was much calmer, she did not **scold** us so much or **seemed upset** for little, little things. She was not **quick to anger** or ... she did not **stare off into space** and just **cry**. **Cancer** that did it.*

Other children were also able to recognise that their mother was in some sort of emotional distress. An example from children participants in Family One, Family Four, Family Six and Family Ten evidenced children’s capabilities to identify symptoms of emotional distress in their mothers.

> *[F1(C1)]: Mama is **boring**. She **does not let me do things,** like watch television or eat my favourite food. Mama is **always scolding**. **Boring** lah.*
>
> *[F4(C2)]: (when) She (mother) come out of the room, she would **start finding something is wrong with something**. So noisy.*
>
> *[F6(C1)]: My mother was not like before. When she had her cancer, she was **easily getting angry** and **very emo** ... **very emotional**. She can **cry** then she can be **upset** ... I don’t know lah, **very emo**.*
>
> *[F10(C1)]: She (mother) also became like a monster ogre ... (made shouting and grunting noises) She **shouted** and I don’t know ... she was always **mad** about something, the noise, so hot, baba (father) not being home ... there were just some things that made her **angry** almost every day. Really, (makes monster grunting and shouting noises) and then she threw things and then she cry because she broke her stuff.*

Several children identified their mother’s emotional distress and perceived that their mother was feeling worried or sad. F9(C1)] wrote:

[F9(C1)]:



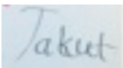
> *(reading) At first she felt **sad** when she found out that she had cancer, but at last she accepted it as it was.*

The depth of emotional distress was especially notable in Family One. The mother had tried to hide and control her emotions from her young children. Unfortunately, the attempt at concealment was not successful as her children noted her covert behaviour as indicative of emotional distress. [F1(C1)] wrote:

[F1(C1)]: 
Risau.
*(Pause) Mama said she's **worried**.*

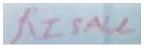
[F1(C1)]: About what?
[F1(C1)]: I don't know.

When his sister was asked about what she thought about her mother's experience, [F1(C2)] wrote and said;

[F1(C2)]: 
Takut
*Aaa, **I am not sure**. I think she's **afraid** to see the doctor again ... She's **afraid** if there is **anything else in her body** and have to **inject medicine**.*

SUZIE: She's afraid of being injected with medicine?
[F1(C2)]: Ahuh (nods in agreement)
SUZIE: Is mama afraid of injections?
[F1(C2)]: Ahuh (nods in agreement and laughs)

Similar to [F1(C1)], [F1(C3)] wrote and said;

[F1(C3)]: 
RISAU
*She (mother) felt **worried** and **sad**.*

SUZIE: Why do you think she felt worried?
*[F1(C3)]: (nervous laughter) **I don't know**. She just **looked worried**.*
SUZIE: How do you know she looked worried?
*[F1(C3)]: Umm, because **her face looked worried**.*


Sedih

SUZIE: Ok, what about the 'sad' that you wrote here?
*[F1(C3)]: Aaaa . . . she's (mother) **sad**.*
SUZIE: How do you know she's sad?
*[F1(C3)]: I see her **crying** and I ask why.*
SUZIE: What did she say?
*[F1(C3)]: She says she's **worried**. But sometimes she does not say why.*
SUZIE: But, you see from her face that she looks sad?
*[F1(C3)]: Ahuh (in agreement). Sometimes she does not have the **'mood'***
SUZIE: What do you mean 'Mood'?
[F1(C3)]: Does not want to go out. Does not tell stories like before.
SUZIE: Why is that?
*[F1(C3)]: (Shrugs shoulders) **I don't know**. She just doesn't have the **mood**.*
SUZIE: Hmmm. . . (Pause) Does mama always cry?
*[F1(C3)]: Umm . . . not always. I **hear** her from the room and have **seen** her **cry**.*

As mentioned earlier, children participants had the ability to realise and acknowledge that their parent was in some sort of distress. The children noticed from their parent's facial expressions and from overt or covert behaviours that the parents were upset, angered, worried or sad about something. However, these children could not identify the reasons for the distress and so made up their own reasons. Some of these reasons, as in the case of children participants from Family One mentioned earlier, were very different from the real concerns of the parent.

When the parent in Family One was asked about her emotional distress, she replied that she did not want the children to know what she was worried or sad about. She perceived that the cause of her worry or sadness would be too much for the children to handle. She did not want them to worry about her so much so that their education could be compromised. In further discussions, this particular parent admitted that she was worried that she would die soon. She was also worried that the children were not prepared for the possibility of her approaching death. In addition to that, she perceived that her children would not be able to care for themselves after her death.

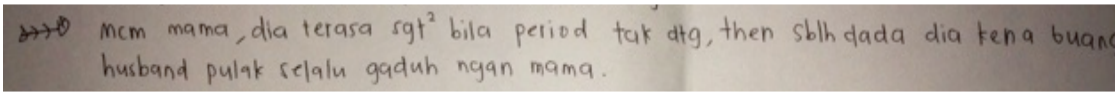
Even though most children participants could realise that their parent was experiencing emotional distress, they could not make precise inferences nor correct causation for those emotions. However, in a small number of instances where children participants were very informed and involved with their mother's care, children participants could make better inferences and more correct causation for their parent's emotional distress. This was evidenced in children participants from Family Five and in isolated cases for three other children: [F2(C2)], [F7(C2)] and [F3(C4)].

These three children participants perceived that a lumpectomy or mastectomy might have contributed to their mother's negative emotional state. These children specifically mentioned the loss of a breast that could possibly contribute to their parent's emotional upheaval;

*[F2(C2)]: I think the person with **cancer** is **sad** too because there's something that isn't . . . right. She's **lost a breast**. She says that **she is not complete**. She's lost a part of her body. **She's embarrassed**.*

[F7(C2)]:

*… well, when that (breast) hurts, someone must replace it lah … Well … that is a **woman** part. Man don't have that part.*



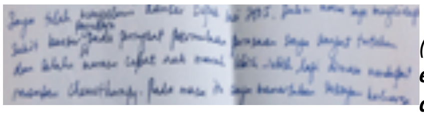
→ mcm mama, dia terasa sgt² bila period tak dtg, then sblh dada dia kena buan
husband pulak selalu gaduh ngan mama.

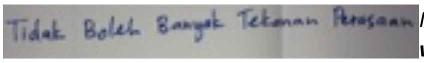
*[F3(C4)]:(reading) Like mama, she really felt **upse**t when her menses does not come, then because she does not have **one breast** (mastectomy), and husband always fights with mama.*

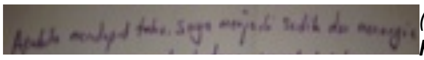
This phenomenon could probably be contributed to the fact that a mastectomy could be hidden and children did not readily identify breast loss as a contributor or trigger to their parent's emotional state.

Other than the few children participants mentioned above, most of the children who related cancer as an emotional state observed that their parent was upset for something that they could not identify. The children either did not know the cause of the emotional state or made their own guesses. Some made conjectures that the parent was afraid of injections, felt worried or feeling sad about something, or were easily angered for little or no reason.

Parents added to the qualitative discussion by reporting that cancer contributed to their emotional upheaval in various ways. Several parents acknowledged that chemotherapy contributed to them becoming temperamental while others cited a feeling of weirdness, not being attractive, and/or not being womanly when they experienced hair loss. [F3(P)], [F1(P)], [F6(P)] and [F8(P)] for example admitted the following:

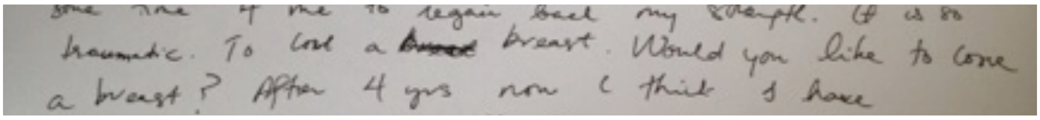
[F3(P)]:  *(reading) At first when I was diagnosed with breast cancer **my emotions** were really **under pressure** and I frequently **felt easily angered**, more so when I was undergoing chemotherapy.*

[F1(P)]: 
Tidak Boleh Banyak Tekanan Perasaan
*I do feel **emotional stress** because there is a lot on my mind. I am **worried** about the children…*

[F6(P)]:  *(reading) When I got to know, I became **sad** and **cried** ... It was **hard to accept** (losing hair)"*

*[F8(P)]:"It (hair) was all **gone**. You feel like some non-human ... you ask yourself, how will my husband react? How will my children react?"*

Parents who had a mastectomy responded as follows:


some time of me to regain back my strength. It is so
traumatic. To lose a ~~breast~~ breast. Would you like to lose
a breast? After 4 yrs now I think I have

*[F9(P)]:(reading) It is **so traumatic** (mastectomy). **To lose a breast**. Would you like to lose a breast?*

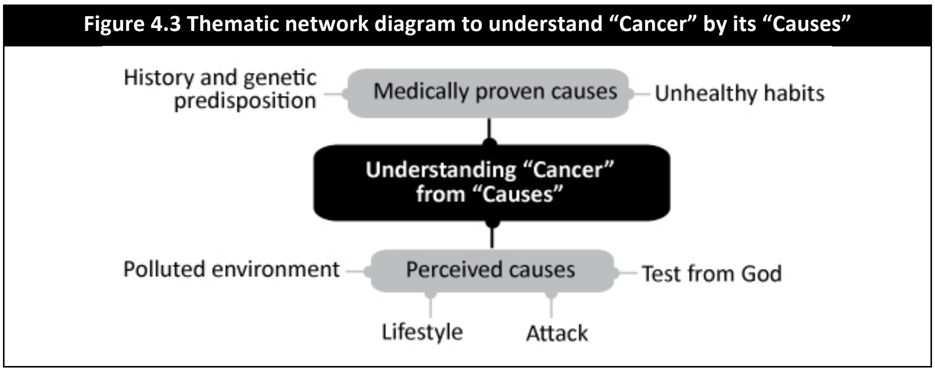
*[F8(P)]:I am a woman, **without one breast**. How can that still be (considered) a woman?*

*[F1(P)]:Ya, I **cry** and **cried**. I **did not want my children to see me cry** because it is **embarrassing for me** to tell them ... for them to know that I am **not a complete woman**.*

4.3. iii. Understanding Cancer from "Causes"

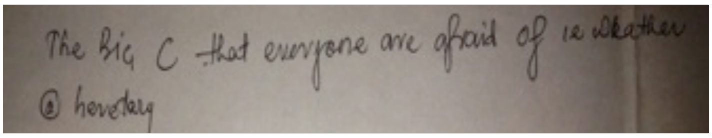
A few participants equated "cancer" as a sickness, an illness or disease caused by either one of two themes; medically proven cause or perceived cause. These two themes were developed from participant's responses that cancer was caused by either one or a combination of codes, being "history", "knowledge", "smoking", "pollution", "exercise", "stress", "food", "alien" and "God's test". This suggested that participants' knowledge about the causes of cancer were rather limited. Figure 4.3 illustrates concisely the key themes on which the word “cancer” was understood by its causes. This generated an interesting discussion in which cancer was understood through the participants’ knowledge of the causes of cancer and to a certain extent how to prevent cancer from developing.

Figure 4.3 Thematic network diagram to understand “Cancer” by its “Causes”



4.3.iii.a “Understanding cancer from medically proven cause”

The organising theme of *“medically proven causes”* was developed from participants who perceived cancer from the themes of “History and genetic predisposition” and “Unhealthy habits”. Most participants who responded in this manner seemed to be very knowledgeable about their situation and had good communication and information sharing practices within their family. This phenomenon was clearly evident in the case of Family Five where the parent had shared her knowledge of cancer being a family history with her children.


The Big C that everyone are afraid of ie whether
ⓐ heredetary

*[F5(P)]:**The Big ‘C’** that everyone are afraid of, for example weather due to **hereditary, environment of foods that we eat** ... But in my case doctor say reason is **hereditary** la ... because my **cousin** got it earlier than me two years. The difference is two years and we look like physical twin.*

This information-sharing attitude and behaviour seemed to result in children who were more aware of their parent’s health situation and more alert to health concerns for their parent and themselves. The statements by [F5(C2)] and [F5(C3)] evidences this.

*[F5(C2)]:Ya, **my aunt** (cancer survivor) always gave encouragement she always said it’s going to be fine ... when I thought of **my aunt**, okay, she’s made it through ...*

*[F5(C3)]:Our **cousin told us what to expect,** still, it is nothing like the experience yourself.*

[F5(C3)] later added her fear of getting breast cancer.

An account from a children participant in Family two, [F2(C4)], indicated cancer was caused by smoking, high stress and an unbalanced diet. She specifically believed that foods containing carcinogens could have caused her mother's cancer:

> *[F2(C4)]:I know what **causes cancer**. I read and remembered that **cancer** is **caused** by **smoking, high stress** and **not eating a good balanced diet** with **fruits and vegetables**. But, I also know that my **mother** does **not smoke** and she's a housewife, so I don't think her cancer is caused by **stress**. I really think that her cancer is caused by some **carcinogen** that we were not aware of and we **ate** it. I **asked the doctor** and he said that could be the **cause**, so I **believe** it lah. It must be the **eating** of those **unhealthy foods**.*

Her mother responded in the following manner:

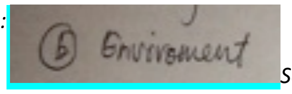
> *[F2(P)]:Ya, that's what the **doctor said**. Most likely by what I **ate**. I really like asam and satay and spicy foods that had belacan (preserved fish paste). It was ... my meal was not complete without them ... I was **very fat**, you see. **So fat** and I **really liked to eat**. So, that is what the doctor believes caused my cancer.*

4.3.iii.b "Understanding cancer from perceived cause"

The organising theme of *"perceived cause"* was developed from themes of "polluted environment", "lifestyle", "attack" and "test from God". Most children, irrespective of the extent and depth of their knowledge, seemed to be able to relate pollutants and a sedentary and unhealthy lifestyle as probable causes of cancer. Children and parents had either read or heard from people around them.

Polluted environment

Several children and parents readily equated pollution as a cause of cancer:

> *[F1(C3)]:I know that cancer is **caused** by the **dirty air** and **exhaust fumes from cars**. So, we must always be careful **not to breathe** that in because we breathe in air that can **cause cancer** in our **lungs ...** we can see the busses and the lorries with black fumes on the roads.*
>
> *[F2(C3)]:Teacher at school was teaching us during Bahasa Malaysia class that it's not just the **pollution** from **smoke**, it is also the **pollution** from **factories** that goes into our **rivers**. These **pollution chemicals** are eaten by the fish and then we eat the fish without knowing that the water was so **polluted** and then we develop **cancer**.*
>
> *[F5(P)]:*
>
> 
>
> ⑤ Envirement
>
> *So **environment** also, we take a look, we don't need to go so far, just go to Puduraya, we just stand there, what we can get from there? At Puduraya, what do you **inhale**, so I think there's also **possibility in risk cancer**. Probably. And then actually the government should pull more vigorously and to have **more public areas** that's **non-smoking**.*

Lifestyle

Several participants believed that cancer could also be caused by certain "Lifestyle" habits that included smoking, eating habits, sedentary lifestyles and work that is high stress. An excerpt from Family Five and children participants from Family Ten and Family Six indicates this.

[F5(P)]:And then actually the government should pull more vigorously and to have ***more public areas*** *that's* ***non-smoking****.*

To which her daughter [F5(C3)] added:

[F5(C3)]:Hiya, that is no point la ma, the people in the government also ***smoke*** *in* ***non-smoking*** *areas. It also has to start with them. No point the government come out with their anti-smoking campaign and clean air campaign if they don't enforce it. Once in awhile you read it in the newspapers or see in the news, but hiya, how many get away without the fine?*

[F5(P)]:(laughs) See, my daughter also knows that the situation of our ***environment*** *is not so nice. So easy to get cancer by just sitting out, waiting for the school bus ... I also I always advise him (son) to avoid friends who smoke, to avoid smoking areas, that's two advices to him, only that.*

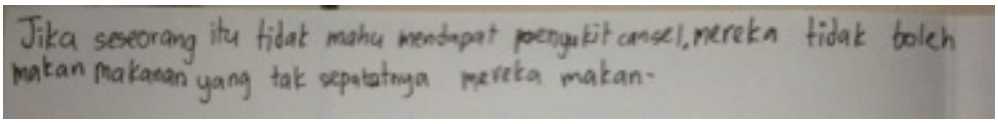
[F10(C1)] said:

*[F10(C1)]:****Smoking*** *is* ***smelly*** *and* ***causes cancer****. That is what Ummi tell me. It is not good, so if there is someone* ***smoking****, I must* ***move away*** *from that person.*

The belief of smoking causing cancer was also shared by [F6(C1)]:

[F6(C1)]:Humph! ***Smoking . . .*** *the person who smokes wants to get* ***cancer.***

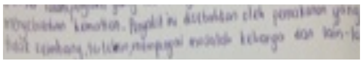
With eating habits, it seemed that many children and parent participants believed that an unhealthy diet was one of the main causes of cancer. [F3(C1)] wrote that people should not eat unhealthily:



Jika seseorang itu tidak mahu mendapat penyakit cansel, mereka tidak boleh
makan makanan yang tak sepatutnya mereka makan.

[F3(C1)]:(reading) If someone does not want to get ***cancer, they cannot eat what they are not supposed to eat.***

Other children believed that having an unbalanced diet and not eating enough fruits and vegetables caused cancer.

[F3(C2)]:  *...* *This* ***sickness*** *is caused by* ***unbalanced diet ...***

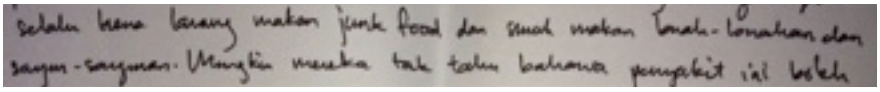
[F1(C1)]:Have to ***eat vegetables****.*

[F4(C1)]:It's because we don't ***eat*** *enough* ***fruits*** *and* ***vegetables****. Have to control lah, what we* ***eat****, like* ***junk food****, cannot so often.*

*[F6(C1)]:****Eat fruits*** *and* ***vegetables*** *lah to* ***not get cancer****.*

*[F7(C1)]:****Cancer means someone did not eat their fruits*** *and* ***vegetables****. Just like my mother (laughs), but now she does and she makes me eat it too so that I don't get* ***cancer****.*

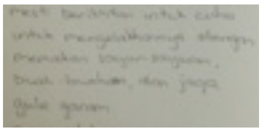
This sentiment of healthy eating habits seemed to be championed by most parents as in the extract by [F2(P)], [F4(P)], [F5(P)] and [F8(P)]:



selalu kena larang makan junk food dan suruh makan buah-buahan dan
sayur-sayuran. Mungkin mereka tak tahu bahawa penyakit ini boleh

[F2(P)]:(reading) I always stop them (children) from eating Junk Food and I ask them ***to eat fruits and vegetables*** *... because when you eat fruits and vegetables and don't eat junk food, you can* ***prevent cancer****.*

[F4(P)]:



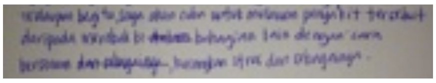
*(reading) We must attempt to prevent it (cancer) by **eating vegetables, fruits** and take care of our salt and sugars.*

*[F5(P)]:I always tell my children, health is very important, no point if you are very rich, but also very sick. So, they have to take care of their health and the easiest way to do that is by controlling what they **eat.** Each meal, must have **vegetables** and must have **fruits**. Very important to watch how often you **eat** meat. I mean, I like satay and I like KFC, but we have to control lah, once a month, should be OK, but better if more control on the food you take. Also, control sugars. You might be free from **cancer**, then you develop diabetes. That one also got problem.*

*[F8(P)]:Ha, when it comes to **eating**, I control my children now. The **foods** that we **eat** or **don't eat** can contribute to **cancer**. I have to force my children to **eat vegetables**. I don't care they say "yuck", they must **eat** it. I tell them this (eating vegetables) is to prevent **cancer**. You don't want to get **cancer**, suffer like me, you better **eat** your **vegetables**.*

Besides eating healthily, children seemed to understand that there was a link between a sedentary lifestyle and cancer as in the example written by [F3(C3)]:

[F3(C3)]:



*... I will try to fight this sickness from spreading to other parts (of the body) by **exercising**, lessen stress and such.*

[F1(C1)], [F2(C1)], [F3(C1)] and [F7(C1)] also seemed to believe that being active, participating in sports and outdoor play was important to prevent cancer:

*[F1(C1)]:**Exercise** is important to prevent **cancer**.*

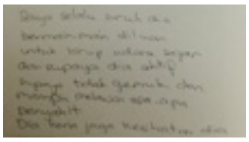
*[F2(C1)]:If we are lazy and don't go out to play, we can also get **cancer** because we stay home, watch TV and get **fat**.*

*[F3(C1)]:**I** listen to my **mother**. I go run and play outside with my friends. She said being inside the house all the time is not good. Can get **cancer**, so have to go outside and **exercise** by playing outside.*

*[F4(C1)]:My **mother** tells me that without **exercise**, people can get **cancer**. I got no problem with **exercise.***

It seemed that children were more willing to be active as opposed to changing their eating habits. Parent participants reported that they did inform their children about the need and importance of exercise. [F4(P)] for example wrote;

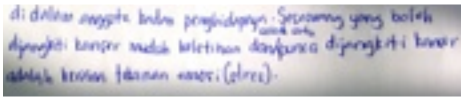
[F4(P)]:



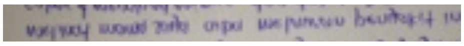
*(reading) I always tell my children to **play outside** to **breathe** in **the fresh air** so that they are **active** so that they **don't get fat** and can **fight off whatever illnesses**. They have to take care of their **health**.*

Another understanding was that cancer was caused by stress. Family Three and Family One wrote and discussed at some length about the effects of stress and how it contributed to their understanding of cancer. Excerpts of children participants from Family Three and the effects of stress are as follows:

[F3(C3)]:

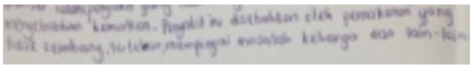


*... Somebody who can get **cancer** is someone who is easily tired and one of the **causes** of being infected with **cancer** is because of **emotional pressure (stress).***



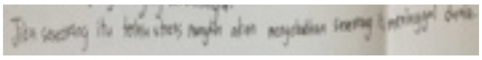
*... Most likely my mother is **stressed**.*

[F3(C2)]:



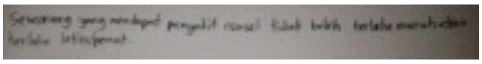
*... This **sickness** is caused by ... **pressure, family problems** and such like.*

[F3(C1)]:



*... If someone gets **too stressed**, maybe this will **cause** someone to **die**.*

[F3(C1)]:



*Someone with **cancer** cannot be **too angry** or **too tired**.*

Excerpts from Family One about stress are as below:

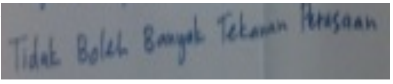
*[F1(C3)]:Her soul is too much **pressure. Very stressed**. This **stress** can **cause cancer** or make the cancer worse.*

*[F1(C2)]:She is sometimes **worried** about something. This is **stress** lah. Can make her **get angry** and when she is **angry** she can get **tired quickly** which **does not help her to get better**.*

*[F1(C1)]:She is **stressed**. I don't know why, but she said she was **stressed**.*

To which the parent wrote and explained;

[F1(P)]:



Tidak Boleh Banyak Tekanan Perasaan

Cannot** have **emotional pressure ...** have to control because **stress** and **emotional pressure causes cancer.** Don't want to make my **cancer** worse**.

Cancer seemed to emerge as a disease caused by not adhering to general health guidelines of eating a balanced diet, exercising, and lessen stress.

Attack

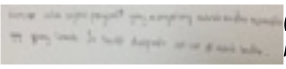
Some children participants overheard a discussion about cancer "attacking" a person. It seemed that in order to make sense of the "attack", children participants imagined a foreign or alien substance that attacked inside the body. This alien substance damaged a body internally and resulted in the development of cancer and subsequent damage to internal organs. A child, [F2(C2)] who was ten years old, drew that cancer was an attack by a dangerous disease inside the body:

[F2(C2)]:

*Mother told me, **cancer** is a dangerous disease that **attacks** inside her body, so I drew **diseases** that **attacked** the things in the body. Some of the diseases lost badly and some won.*

[F9(C1)] believed that cancer was a sickness that attacks an already unhealthy person:

[F9(C1)]:



*(reading) **Cancer** is a type of sickness that **attacks** a weak person's body ...*

SUZIE:What do you mean by that?

*[F9(C1)]:**Cancer** happens ... is **caused** by **something attacked** a weak person's body.*

SUZIE:What do you mean a weak person?

*[F9(C1)]:Somebody **not healthy** ...*

[F7(C1)] believed that cancer was the term for the damage caused by alien germs:

[F7(C1)]:

(explaining drawing) ***Cancer** is **a sickness** that happens when **some alien** thing, from **being dirty,** gets **in the body**. That's why I drew these alien things ... I think that **bad things** are purple in colour and I hate pink (sister likes pink) and I made the **alien** thing those colours. Like ... the evil witch in that movie, the dragon (referring to).*

SUZIE: Do you mean the evil witch in Disney's Sleeping Beauty?

*[F7(C1)]: Umm (indicating agreement) ... but also that movie ... the witch was short and she was fighting with that wizard man and he became **a germ** and she got sick?*

SUZIE: Do you mean the "Sword in the Stone" when Merlin fought Madam Mim?

*[F7(C1)]: Ha! (indicating agreement and starts to hum) That's it lah. The **alien germs** are purple and that pink.*

SUZIE: What do these alien germs do?

*[F7(C1)]: They **attack** the inside of the **body** (makes attacking noises) and then they **destroy** things inside and that **damage** is cancer ... I think.*

The excerpts above seemed to indicate that several children participants had heard about cancer attacking their parent and subsequently misconstrued that medical concept. It can be inferred that these children attributed an alien or foreign substance to causing damage inside the body. They believed that this damage was called cancer.

Test from God

It seemed that children heard lamentations that cancer was a test of their parent's perseverance, willpower and faith in the Almighty. They heard this collection of lamentations from either their parent or other family member or a member of their parent's cancer support group. They believed that God caused cancer as a test. An example of this belief is evidenced by a Figure drawn by [F2(C4)]:

[F2(C4)]:

*(explaining drawing) Cancer is **a test from God**. Why I say that, is that a person with cancer **is tested with their fear** … **with pain**, a lot of pain and all kinds of pain … see how you can perform prayers when you are **very tired** … umm … **test** you on how you are with the **nausea and frequent vomiting**, like if you are **patient** with this **test** … **lose appetite** to eat, so **test** lah. Last time you can eat anything, now with **cancer**, you can only **eat some food** and **foods that don't taste so** … and umm … **feel smarting pain** …*

SUZIE: Please explain a bit more on what you mean test with fear?

*[F2(C4)]: Well, with **cancer you know that you can die**. Soon. So, you are **tested** in … how shall I say? (pause) Are you prepared to die? Have you done enough to get to heaven? In a way, cancer lets you have that time to really, really be **more religious** before your time is up. Like if you had an accident and you died on the spot, you would not have had the time to say that you were sorry, with cancer you got the time lah.*

SUZIE: OK. What about this, "with pain"?

*[F2(C4)]: Umm … I notice lah, that **cancer** is **causing a lot of pain**. You get **pain** before you get into **surgery** and then **pain** when you **operate** to remove the cancer. And then, **all kinds of pain** lah.*

SUZIE: And so?

*[F2(C4)]: So … it is **a kind of test** to see lah. See **how you can stand the pain** and **what you do** when you are in pain.*

SUZIE: What about the next item that you wrote here? (referring to "tired")

[F2(C4)]: Well, cancer makes the person with cancer ***very tired****. So, sometimes even without cancer we get* ***too tired to pray****. So, with* ***cancer****, it is even* ***more of a test****lah, to see that even when you are very tired, very sick, you pray or not lah.*

SUZIE: And this? (referring to nausea)

[F2(C4)]: Oh, like I said earlier lah. ***Cancer*** *is about* ***always feeling nausea*** *and* ***always vomiting****. It is* ***disgusting****, it is* ***painful*** *… it is* ***smelly****.* ***God*** *will only* ***test*** *you to see* ***how you cope*** *with that lah … umm I guess the* ***lose appetite*** *is related too. Because when you feeling* ***nausea****, you cannot* ***eat****. You just* ***don't feel like eating****.*

SUZIE: How is that a test from God?

[F2(C4)]: Ya la, it's ***a test*** *because now* ***you cannot eat your favourite foods*** *lah. You just watch other people eating. (laughs)*

SUZIE: What about this last item, of feeling smarting pain?

*[F2(C4)]: Oh, I heard my mother saying that is what she felt and umm … sometimes she says "****this is a real test*** *…"*

In a separate interview, children participant [F5(C2)] had the same belief:

[F5(C2)]:"It must be ***a test from God*** *… Mother said it was* ***a test*** *for her and for us* ***to be better*** *Muslims and* ***better people****. She said that there were others who were in a worse state than us. We have a roof over our heads, plentiful food and all kinds of other stuff. What if she was sick with cancer and we were too poor for her treatment or if we did not have a maid? (shudders)"*

Even though [F7(C1)] had drawn an alien attack as causing cancer, he also believed that the attack was a test from God:

[F7(C1)]:Like ***a curse****. Like …* ***a test from God****.*

As mentioned earlier, the possibility of dying from cancer increased parent participant's spiritual state. This heightened spiritual state seemed to contribute to parents' belief that cancer was a "test from God". Parent participants cited cancer as either to test their faith, punish them for past misdeeds, or "telling" them that it was time to be more religious. Most point out that the fear of death or sudden death, being unprepared to face the afterlife and needing the time to atone for their sins as a reason for their more religious fervour. The following excerpts from [F1(P)], [F8(P)], [F9(P)] and [F10(P)] are evidence of this theme.

[F1(P)]:I have to do a lot of preparation, ***pray*** *… life and death is in* ***God's hand****. But we must still try to get better. So to me,* ***cancer is a test****. (pause) A* ***very difficult test****.*

*[F8(P)]:****Cancer*** *is not an easy thing to* ***suffer*** *through. You* ***really suffer, really miserable****, so it is like a* ***test*** *of one's* ***faith****, one's* ***perseverance*** *… to* ***test*** *your* ***belief*** *in* ***God***

[F9(P)]:Maybe it (my cancer) is ***God's punishment****? Better get punished in the world rather than in the hereafter. Over there, forever punished, on earth only a little time.*

[F10 (P)]:I know that is a ***challenge*** *by* ***God*** *…*

One parent participant [F4 (P)], reported that she had overheard someone saying that she was punished with cancer:

> *[F4 (P)]: Some people dared to say that I got **cancer** as a **trial from God** for whatever they imagined me as being "wild" when I was younger ... I say look to yourself first before you make such assumptions.*

In conclusion, this section reported that children participants understood cancer in various ways. Firstly, children participants defined cancer from an experience perspective. This was based on how cancer effected them on a personal level and how they observed the consequences of cancer to their ill parent. Older children participants who provided care and had more information, however, explained cancer using a medical inference. Secondly, children participants understood cancer as a type of possibly deadly illness, sickness or disease. These children participants did not differentiate the terms and used them interchangeably. This may be attributed to children participants' limited vocabulary or more broad understanding of nuances of illness and experience of being sick. Thirdly, a few children participants related that a person with cancer required hospitalisation, special medication and a long treatment process. They had several nuances of concern about parent being away from them and fear of hospital activities. Fourthly, most children participants recognised that their parent was sick from descriptions of physical and non-physical side effects of cancer and cancer treatments. Parent's bodily aches and pain, emotional state, hair loss, frequent vomiting, rest requirements and advent of an early menopause were recurring observational themes. Fifthly, a few participants formed causal reasons for parental cancer. Children participants suggested that cancer was caused by either medically proven causes or perceived causes. This included cancer as a "test from God".

It was evident that parental cancer contributed to new and, at times, frightening experiences. From overt and covert cues, these children participants realised that their parent was ill and formed their own beliefs about cancer, its causes and effects. Where evident of children participants' misunderstanding about cancer, a lack of information and children's limited ability to process and assimilate experience may be attributed. This supports findings by the American Cancer Society (2012a, para. 6; 2012b, para. 5; 2008, para. 5), Barnes et al. (2002, p. 213), Granet (2002, pp. 169-189), NCI (2012, para. 5-9), Scott et al (2003b, p.2) and Sweeney (2004, p.21). Children participants' contextual understanding and concept of cancer suggested that their information needs were varied and that children had more nuances of concern then previously documented. These findings were reported in the next section.

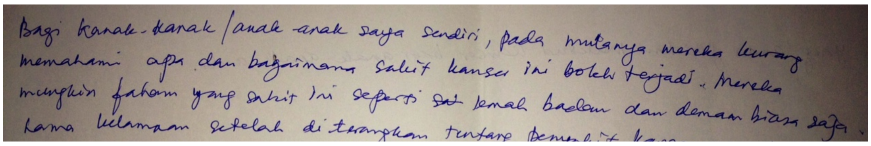
4.4 WHAT CONSEQUENCES DOES CHILDREN'S UNDERSTANDING OR LACK OF UNDERSTANDING ABOUT CANCER HAVE FOR THEM?

In reference to the second research question of "What consequence does children's' understanding or lack of understanding have?", it seemed that children's understanding of cancer were based on the attitudes of their information source towards information sharing. Children participants' own reactions to a health situation or stimuli, the relevance of the situation to children as well as the personal files (Kirkelas, 1983, p. 13) and information processing capacity of participants also influenced the quality, scope and depth of information that helped children to be prepared for how cancer impacted their lives. These attitudes seemed to shape children's experiences and understanding of cancer.

In order to show this relationship, this section was divided into subsections: i) Children participants' information-seeking behaviour, ii) Children participant's preferred source of information, iii) Attitudes to information sharing and, iv) The role of information for dependent children of cancer patients.

4.4.i Children participants' reactive information-seeking behaviour

Several parent participants indicated that they first believed their children were ignorant about cancer and its effects. However, contrary to their belief, children detected their parents' worry, fear, anxiety and a number of other emotive expressions that underlie their parents' changed behaviour and the disruption to 'normal' family dynamics. One of the more prevalent indications of children's' reaction to their parents' cancer depended on the information and cues children synthesized to come to terms with the diagnosis. It was noted by most participants that, over time and through reactions to the cancer experience and their information-seeking behaviour, children became more informed. This was evident from the excerpt of the parent from Family Three.



Bagi kanak-kanak/anak-anak saya sendiri, pada mulanya mereka kurang
memahami apa dan bagaimana sakit kansa ini boleh terjadi. Mereka
mungkin faham yang sakit ini seperti ~~sat~~ lemah badan dan demam biasa saja.
Lama kelamaan setelah diterangkan tentang

[F3(P)]: *(reading)For children, my own children, at first they did not really understand what and how cancer can develop. They might have thought that this sickness is just a feeling of weakness in the body and a normal fever. Aah. I thought that they did not understand. Actually, they do know.*

The manner and cues in which the information was given played a role in how children participants reacted to the diagnosis, unfamiliar health situation (for example first experience with effects of cancer treatments) and unfamiliar task (for example first experience at caring for oneself and/or ill parent and/or, younger sibling). It seemed that the extent of the information provided, manner, context, information source and the sources' psychological state and attitude to information sharing contributed to how children participants processed and made sense of information and instruction(s). For example, children participants' report on incomplete, unstructured and rushed news about parental diagnosis resulted in their feelings of shock, disbelief, denial and/or fear of the diagnosis. Some even thought the news did not make sense. The exchange of information by members from Family Two illustrated this:

[F2(P)]: *I called the girls to sit with me in the living room and I told them that the doctor checked me and that he said that I would need to go for an operation, a biopsy because he suspected that I might have cancer. It was something to check up on first, but I was already scared of dying and what would happen to my girls, they were so young still! So, I told them that they would need to take care of each other while I went for the operation.*

In a separate interview, her children reported that when their mother informed them about her diagnosis they did not know what to make of the news.

[F2(C4)]: *Emak had all of us sitting in the living room when she came back from seeing the doctor. She just told us that that we had to take care of each other.* ***I was confused****. Why did we have to take care of each other? More than usual?*

[F2(C3)]: *Emak told me at home that she has cancer and that because of that, we had to take care of each other.* ***OK?***

[F2(C2)]: *She was talking too fast and crying …* ***I really don't know what she was saying****.*

[F2(C1)]: *Emak told me at home that the doctor told her she had cancer.* ***I did not know what she meant ... what has that to do with me?***

In addition to the extent and manner of information provision, data explication suggested that children's reactions included the role of the 'self'. The health situation was compared against its relevancy to children participants. This is similar to Wilson's "person-in-context" in his "A Revised General Model of Information Behaviour" (1999, p.256), where it seemed that children participant's "self" was pivotal to children's information processing. Children participant's reactions seemed to also follow a similar process of accessing "personal files" as mentioned by Kirkelas (1983, p. 13) in the Kirkelas Model. "Personal files" here refers to the term first used by Kirkelas (1983, p. 13), to describe a storage collection of answers from a person's memory which can be recalled on demand and compared to their prior knowledge about cancer. Specifically, data explication suggested that children participants' reactions were based on how relevant their parent's health situation was to them and what they already knew or understood about cancer.

The children participants reported that when they were in a reactive state to a health situation or stimuli (for example witnessing mother's frequent vomiting), only then they felt or thought they required more information to rationalize the experience, cope or overcome the event. This implies that children participants' reactions acted as their triggers to information seeking. The excerpts below are evident of this phenomenon.

[F1(C1)]: *Each time after chemo, my mother would **"Uweek"**. After she **"uweek"**, I asked her why ...*

[F1(C3)]: *My mother, she was so "moody" ... I wanted to know why after cancer she became like that.*

[F2(C2)]: *Her (mother) **hair fell out**, it was **scary**. I was **so afraid** ... I wanted to know how come her hair did that.*

[F5(C1)]: *Before her (mother) cancer, **I knew nothing** (about cancer). Then when I saw how terrible cancer was, saw her dead cells being sucked out ... **I had to know more** ... **had to know** that she was going to be OK.*

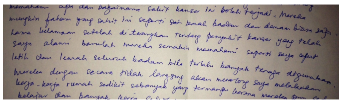
[F5(C3)]: *I saw how **terrible** my mother **suffered**. I **pitied** her. **I wanted to know how I can help her feel better, feel strong to fight the cancer.***

[F7(C2)]: *I don't want to get cancer. It is **very terrible. I must find out how to not get cancer and to make sure my mother does not get cancer again.***

[F10(C1)]: *How come I am staying at grandmother's house?*

Observations and self-reports seemed to indicate those children's reactions to a health situation or stimuli appeared to depend on individual capabilities and processing capacity. These individual capabilities were subjected to the 'self' that included variables in age, maturity, vocabulary, personality and attitudes that shaped participants' personal files. As indicated by the excerpts above, whichever reactions children perceived to be of most relevant to themselves or most important of their concerns, would then trigger their information seeking behaviour. Parent participant's observation in Family Two and Family Nine evidenced the result of children participants' information seeking in the excerpts below:

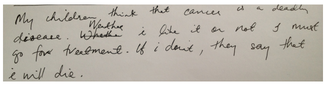
[F3(P)]:



memahami apa dan bagaimana sakit kanser ini boleh terjadi. Mereka
mungkin faham yang sakit ini seperti ~~sat~~ lemah badan dan demam biasa saja.
Lama kelamaan setelah diterangkan tentang penyakit kanser yang telah
saya alami barulah mereka semakin memahami seperti saya cepat
letih dan lemah seluruh badan bila terlalu banyak tenaga digunakan.
Mereka dengan secara tidak langsung akan menolong saya melakukan
kerja-kerja rumah sedikit sebanyak yang termampu bersama mereka
belajar dan banyak kerja

*They (children) may have thought that my **sickness** is like a **weak body** or a normal fever, but after I explained to them about the cancer I experienced, they increase their understanding ... like when I feel **fatigued**, they would help me do some of the chores ...*

[F9(P)]:



My children think that cancer is a deadly
disease. ~~Whethe~~ Weather i like it or not I must
go for treatment. If i dont, they say that
i will die.

*(reading) My children think that cancer is a **deadly disease.** Weather I like it or not, I must go for treatment. If I don't they say **I will die**.*

Central to this observation was that children participants seemed to engage in information seeking behaviours as a result of their reactions to an unfamiliar health situation or stimuli and to an unfamiliar task. It was noted that when children's reactions were normalized, their information seeking behaviour was differed. This "normalizing" was evidenced by [F5(C1)] and his parent [F5(P)].

[F5(C1)]: *I had to do some of the housework ... cleaning ... ironing ....*

[F5(P)]: *My son, my son also helped out. It was like 'automatic". They (children) saw that I was **too sick**, they "automatic" helped around the house. I did not have to tell them.*

[F5(C1)]: *Before her cancer, I did not help out so much. When she had cancer, I have to help her lah ...*

[F5(C1)] further explained that he had not known how to do the housework before his mother's diagnosis. He sought information from his mother and older siblings on how to iron his school uniform. He also reported that once he was familiar with doing housework, he did not seek more information. This behaviour suggests that for [F5(C1)], ironing his school uniform became a "normal" behaviour in which additional information on how to complete the task was not needed.

In concluding, data explication suggested that children participants' information-seeking behaviour was triggered by their reaction to the news about the diagnosis and health situation they had not experienced before. This was similar to some components of the 1983 Kirkelas Model (Kirkelas, 1983, p. 13) and similar to Wilson's 1999 "A Revised General Model of Information Behaviour" (Wilson, 1999, p.256). Children participants' reactions and their subsequent follow-up action(s) were influenced by the manner of information provision. The manner of information provision included how and the extent of the information provided, information source and the sources' psychological state and attitude to information sharing. The cumulative characteristics contributed (in various degrees of influence) to how children participants processed and made sense of their situation.

4.4.ii Children participant's preferred sources of information

According to the semi-structured interviews and responses to the "Information Source Questionnaire" Question 2, all children were informed about their mother having cancer. This was evidenced by the Participant Criteria (on page 71) and responses to Question 2 which is tabulated in Table 4.8:

Table 4.8 "Question 2: Who was the first person that told you about your parent's diagnosis?"

Answer option	Number of responses
The parent with cancer	15
The parent without cancer	3
Another family member	1
A neighbour or family friend	0
The doctor taking care of my parent	1
The nurse taking care of my parent	0
I noticed my parent was not well	2
I noticed that something was different at home	0

As an indication of children's awareness of illness among family members, two children participants asked about the health of their mother even before being told about her diagnosis. In follow-up discussions, both children participants (with validation by parent's report) indicated being informed after questioned about their mother's apparent ill health.

According to Table 4.8, children talked more to their mother, in varying rates of perceived success, than their father about cancer. This indicated that children preferred their mother as their primary source of information. This finding was further supported by the responses to Question 9 (If you needed more information, where did you get it from?) of the "Information Source Questionnaire". Most children participants knew where to obtain information about cancer. Children participants had several information sources; they used either an internal or external source or a mixture of both sources. The children participants reported both covert and overt direct observations of their parent, with some children describing the condition of their mother post surgery and during other cancer treatments. This was tabulated in Table 4.9.

4.9 "Question 9: If you needed more information, where did you get it from?"

Answer option	Number of responses
The parent with cancer	19
The parent without cancer	7
Another family member	10
A neighbour or family friend	4
The doctor taking care of my parent	16
The nurse taking care of my parent	9
The library	12
The Internet	15
I don't know	2

To increase children participant's options, they were allowed to select more than one answer. According to Table 4.9, most children participants responded that if they needed more information, they would ask their ill parent. The "attending doctor" had 16 responses, the use of the "Internet" had 15 responses, the "library" had 12 responses, "another family member" had ten responses and "nurses" had nine responses. The "non-sick parent" had seven responses and "neighbour or family friend" had four responses. Two children responded that their failure in obtaining information from their mother left them with no other recourse to information.

In addition to these answer options, children participants were also provided an option to add more sources of information. Three children participants indicated "Support group and

NCSM", three other children participants indicated printed materials ("daily newspaper", "Newspaper of magazine" and, "brochure that mother brought home"), one child participant indicated "Other people when we meet who had cancer" and, one child participant indicated "teacher who taught sports and health".

In comparing responses to Table 4.8 (on page 148) and Table 4.9, children participants preferred their mother as their primary source of information. This preference was also evident from the excerpts below:

[F1(C1)]: I always ask my mother first.
[F2(C1)]: My mama.
[F2(C2)]: (I ask) mama.
[F5(C1)]: I ask my mother
[F7(C2)]: I check with my mother first.

When asked why, children participants responded with a combination of reasons. Those reasons were accessibility, openness of communication and information from first-hand experience. Some of the excerpts indicating those reasons are listed in Table 4.10.

Table 4.10 Reasons For Preferring Information From Ill Parent

REASON	CHILDREN PARTICIPANTS' EXCERPTS	
Accessibility	*[F1(C1)]:Mama is at home*	*[F7(C2)]:I could always ask her (mother)*
	[F5(C1)]:She's (mother) right there.	*[F5(C3)]:I'm with her, so I ask her.*
	[F8(C1)]:Who else would I ask?	*[F8(C2)]:Just ask (mother)*
	[F3(C3)]: Because it is easy. Just ask her (mother) lah	
Openness of communication	*[F1(C1)]:Mama can answer herself*	*[F3(C3)]:She (mother) can tell me lah*
	[F2(C1)]:She (mother) can tell me how she feels	*[F7(C2)]:She (mother) will answer if she can*
	[F2(C4)]:She (mother) can tell me what she needs	*[F3(C2)]:Easier to understand and I get the answer faster*
	[F5(C2)]:She's (mother) always finding things about cancer and sharing it with us	*[F5(C1)]:I can ask my mother about how she feels*
Information from first-hand experience	*[F1(C3)]:Mama can tell me better how I can help her*	*[F5(C3)]:I can see what she needs, medicine or massage or water*
	[F2(C2)]:She is the one in pain.	*[F4(C1)]:My motherlah knows more*
	[F2(C4)]:She (mother) tell me straight away lah.	*[F7(C2)]:She (mother) tells us about all kinds of her pain*
	[F5(C1)]:Who else feel that way?	*[F8(C2)]:She (mother) will tell me what she feels and what I need to do*
	[F5(C2)]:She's (mother) experiencing the cancer … she is better to tell us about it.	

This preference was similarly reported by Kenrick (2009, pp.9-12).

Children participants’ responses were validated against parent participants’ version of Questions 2 and 9. Seven parent participants indicated that it was themselves who informed children about the cancer diagnosis. This is tabulated in Table 4.11.

Table 4.11 “Question 2: Who was the first person that told your children about your diagnosis?”

Answer option	Number of responses
The parent with cancer	7
The parent without cancer	1
Another family member	2
A neighbour or family friend	0
The doctor taking care of me	0
The nurse taking care of me	0
My children noticed I was not well	0
My children noticed that something was different at home	0

Recorded responses validated this preference as well:

[F1(P)]: *My husband and I felt that it was better that I told the children ... we thought that I would be able to tell the children in a better way. My husband … he did not know what to say.*

[F2(P)]: *It was not difficult to decide who to tell the children about the news. I always knew that I had to tell the children … It was difficult to think of what to say to them though.*

[F4(P)]: *It just so happened that my daughter was with me when I got the news. I think she did not hear what the doctor said. I was crying and so I had to tell her.*

[F5(P)]: *My eldest was with me when the doctor told me about it. I just broke down and tell her that I thought cancer was going to kill me soon. Later that day, I was calmer when I told my other children. I could not keep something like this to myself. It was important that the children heard about this cancer from me.*

As informed by the questionnaire and excerpts, parent participant preferred for their children to hear about the news from themselves rather than any other person or source.

In comparing children participants and parent participants’ responses to Question 9, it was found that there were a few differences. Similarly, to the children participants’ responses to Question 9, a majority of parent participants perceived that their children obtained cancer-related information from them first. However, parent participants perceived their children would seek information from the Internet secondly and their attending doctor thirdly. The fourth source of information was shared equally between the attending nurse, cancer support centres and their healthy parent. The library had three responses. Another family member and a neighbour or family friend had one response. Unlike children participants, parent participants did not indicate any other source of information. This may suggest that parent participants did not consider other sources such as printed materials as their children’s source of information. Table 4.12 summarises this.

Table 4.12 “Question 9: If your children needed more information, where did they get it from?”

Answer option	Number of responses
Me (parent participant who had cancer)	8
The parent without cancer	4
Another family member	1
A neighbour or family friend	1
The doctor taking care of my parent	7
The nurse taking care of my parent	4
The library	3
The Internet	6
Support Group/ cancer centre	4
I don’t know	0

Parent participants’ reasons for their perception of children’s preferences were also based on accessibility, openness of communication and information from first-hand experience. Some of the excerpts indicating those reasons are listed in Table 4.13.

Table 4.13 PARENTS’ PERCEPTION OF CHILDREN’S PREFERRED INFORMATION SOURCE

REASON	EXCERPTS	
Accessibility	[F1(P)]:	Easy for them to ask me because I am at home with them
	[F4(P)]:	They can ask me and I rather I tell them then they get some scary story from elsewhere
	[F5(P)]:	My children and I always talk. We are very close. The family bonding is very important
	[F7(P)]:	I am always with my children, so they can ask me when they feel like it
Openness of communication	[F2(P)]:	When I am not in pain or too sick, I talk to them (children)
	[F3(P)]:	They have always asked me things. So, asking me about cancer is ‘normal’
	[F5(P)]:	I always tell my children about what is happening and I try to give them as much information as I know how
	[F7(P)]:	Can ask me. But, not sure if I give them the right answer.
Information from first-hand experience	[F1(P)]:	The children really need to know what I am going through. They need to know how serious cancer is so that they can prevent cancer from happening to them.
	[F4(P)]:	Ya lah, who else can tell them what I am going through?
	[F5(P)]:	It is important that my children now about cancer and what I go through. They need to know from me. That way, they don’t become too afraid of what is going to happen.
	[F6(P)]:	I tell themlah when I am in pain and need their help.

It is to be noted that there is no indication of this preference for only information about cancer (as the mother was the person directly affected by the disease) or if it was participants' family dynamics to communicate illness in the family as a process flow from mother to child(ren).

In continuing the discussion about preferred information sources, as indicated in Table 4.8 (on page 148), children participants reported the second most preferred information source was the attending doctor. Children asked questions from the attending doctor when they perceived that their questions were not satisfactorily answered. When these participants were asked why, most children participants reported that they did this because of the perception that parents' doctor was the most knowledgeable about cancer and its treatment options. They cited the doctor's status as a specialist for this reason. Statements by [F1(C1)], [F1(C2)], [F1(C3)], [F2(C4)], [F3(C3)], and [F5(C3)] evidences this.

[F1(C1)]: Ask the doctor

[F1(C2)]: Ask the specialist

[F1(C3)]: I asked the doctor attending mama, why mama had to be operated. I ask him because he was the one operating her and he should know more about what has going to happen to mama and if she was going to be in pain.

[F2(C4)]: If my mother cannot answer, I was told to ask the doctor.

[F3(C3)]: My mother said that the doctor knows best

[F5(C3)]: I would say, after my mother, I would ask the doctor. The doctor has been dealing with cancer for many, many years. The doctor must know more about her situation and why she was suffering.

Unlike children participants, parent participants perceived that their children would seek information from the attending doctor as the third most likely information source (Table 4.9 on page 149). Parent participants perceived that their children would ask the attending doctor for more information if the parent could not or were unable to satisfy their children's questions. The attending doctor was perceived to be the next best source for information whereby the doctor was considered to have more medical-based knowledge. These excerpts evidenced this:

[F8(P)]: I did not know what to say. It should be the doctorlah who gives the information to my children. They can ask when he checks me in the hospital

[F5(P)]: And then, the doctor … he should have all the information about cancer and what is going to happen. He is the specialist after all. He should help patients inform their children.

[F9(P)]: Doctor is the person who should tell my children what will happen to me. I don't know what is going to happen, so what can I tell my children?

[F1(P)]: The doctor is the one who should inform us of what is going to happen.

This suggested the attending doctor played an important role as an information source. It was noted in discussions that almost most parent participants felt that doctors and other health practitioners should inform patients and their families about the treatment process, how cancer developed and what they could experience in the burden of care. Further discussions resulted in the general belief that other than providing a diagnosis about the progression of the cancer treatment, doctors could play a more informative role to better help patients and their families to cope with the cancer experience.

[F1(P)]: The doctor is more knowledgeable and has seen many, many people suffering from cancer. At the very least, the doctor should give some tips on what to eat so that patients don't suffer from nausea so much. I found out about fasting a day before chemo from another patient. Not the doctor.

[F2(P)]: I think the doctor would be better to tell my children about cancer and what I was going through. I believe that way, I would not have made my children afraid and confused.

[F3(P)]: Where I know that cancer would give me such a bad experience? I read about it a bit, but the doctor has seen and heard people complaints. The doctor should share that information. Just spend some more time so that we can be better prepared, you know?

[F7(P)]: I feel that the doctor should listen more, share more information about what was in store. I had to experience and be afraid for dying from the chemo before I found out that what I was feeling was 'normal'. My children were also afraid that I might die from the chemo, not from the cancer. He could have saved us a lot of anxiety and fear.

[F8(P)]: I really did not know what to say to my children. I really needed the doctor to help me with what to tell my children. I think I gave my children the wrong information.

[F9(P)]: If the doctor told my children that they needed to help me out, help me rest to get better, I think that I would have less problems explaining to my children and less problems in getting them to understand my situation.

However, children and parent participants, as similarly reported by Back et al. (2005, p. 164), Blum and Sherman (2010, p. 245), Chiu and Wistow (2002, p.2), Christ and Christ (2006, p. 199), DuBenske et al. (2009, p, 721) and, Finch and Gibson (2009, p. 214) information and discussions with doctors were less forthcoming.

According to answers in Table 4.8 (on page 148), the third most popular source of information for children participants was the Internet. Children participants reported that they solicited information from the Internet when their first two information sources could not or would not provide satisfactory answers. This is evident from the statements by [F7(C2)], [F8(C2)], [F5(C3)], [F3(C3)], [F3(C4)] and [F5(C3)].

[F7(C2)]: I go to the Internet when my mother cannot answer.

[F8(C2)]: Sometimes my mother does not know how to answer. So, I think the Internet can do that.

[F5(C1)]: The doctor was really busy and did not seem to want to answer my questions. So, I went to the Internet.

[F5(C3)]: I can get the information easier from the Internet … my mother looked too sick to bother

[F3(C3)]: I was afraid to ask the doctor. I did not know how to ask him. I can search the Internet for what I need, I think.

[F3(C4)]: I asked my mother about how something really become infected with cancer. She said that she could not explain, so maybe the Internet could.

[F5(C3)]: *As the eldest, I needed to find out more information on how I can make my mother less in pain and how to be strong for my siblings.*

It is to be noted that at the time of this stage in the research, access to the Internet was limited. The use of the Internet for more information was similar to that reported by Brashers et al. (2002, p. 260) and that access to the Internet was limited (Brashers et al., 2002, p. 265).

Comparatively, as indicated in Table 4.9 (on page 149), parent participants perceived that the Internet was the second preferred information source for their children. Parents believed that the Internet could provide answers to whichever questions that they could not or were unwilling to answer. In most instances, parent participants instructed their children to look in the Internet for answers.

[F1(P)]: The Internet has a lot of information … but I have to translate them as it is in English. A bit difficultlah like that.

[F2(P)]: Ha-ah, sometimes I get them to learn about cancer from the Internet.

[F4(P)]: The Internet can have a lot of information, so, I ask my children that if they have questions and I just cannot answer them because I am too sick or whatever, just look up the information they need on the Internet.

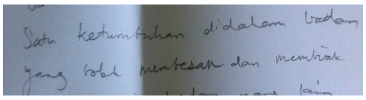
[F5(P)]: Ya, the Internet has a lot of information, but I noticed that a lot of it is in English, very high-level English and a lot of medical things. Very hard for the children or even me to understand. But, the information is there. It is a matter of being lazy to look through and read all that information.

[F8(P)]: Hiya, sometimes, you don't feel like talking. You are in pain, so, the best is to get them look it up for themselves. We have Internet, so they have to figure things out on their own already.

[F9(P)]: You know, sometimes there are questions I just don't have the answers to. I tell my children to look up the Internet because I want them to learn how to use it, other than to play games or whatever. The Internet is information highway, you know. So, they got to learn how to use it.

Other sources of information were secondary overheard discussions with or between other family members, doctors and members of the support group they attended with their mother. Other than the questionnaire, some children participants solicited information from the media, most notably from magazines or from brochures and booklets about cancer. For example, [F2(C3)] responded that she remembered reading about cancer from *"Wanita"* magazine and that cancer was a growth inside the body;

[F2(C4)]:



Satu ketumbuhan didalam badan
yang boleh membesar dan membiak

*(reading) It is a **growth** in the body that can become bigger and spread …*

SUZIE: How do you know about this?

*[F2(C4)]: Read it in 'Wanita' magazine. Cancer is **dangerous** as it can lead to **death** because of a **growth** in the body …*

It can be concluded that children participants' information source was firstly their ill parent, secondly the attending doctor and thirdly the Internet. Parent participants' perceived differently; their children's preferred information source was firstly their ill parent, secondly the Internet and thirdly the attending doctor. Data explication suggested that children participants' preference for information sources were based on their perceived accessibility to the information source, the degree or attitude of open communication and the scope and depth of cancer knowledge of the information source. It can be suggested that while children participants had other information sources, they preferred to interact and solicit answers face-to-face from the source with first-hand experience. However it is to be noted that since the parent with cancer was also the mother, it was unclear if this preference was limited to cancer or if it was pervasive for other matters and situations. This specific phenomenon was not further investigated, as that scope was not relevant to the research questions.

4.4.iii Attitudes to information sharing

Another finding from those questions was that the personality, psychological state, "personal files" (Kirkelas, 1983, p. 13), knowledge of cancer as well as attitudes to information sharing and to overcoming cancer were variables that limited or controlled information sharing and the outcome for quality and in-depth information. It is to be noted that while children participants indicated their source preference, the degree of information needs met differed. These variables were evident by how satisfied children participants were with the information.

Attitudes to information sharing from the parent participant to their children were identified from a combination of answers from the "Information Source Questionnaire" and three specific questions during session three: 1) What were children participants' reactions to the way they were informed about their parent's cancer? 2) Was the information enough for children participants to understand what was going to happen to their parent and, 3) Was the information enough for children participants to understand what was going to happen to them? In exploring those answers, participants corroborated their assessments with anecdotal reports of their experience relevant to the posed questions. The next paragraphs provide an insight to the attitudes of parents when sharing information about cancer to their children.

1) What were children participants' reactions to the way they were informed about their parent's cancer?

Children participants were asked how they felt about the way they were informed about their parent's cancer. This was done through Question 5 from the "Information Source

Questionnaire". They were provided with six response options: 1) the information was too rushed, 2) the information was too confusing, 3) I did not understand the information, 4) the information was too short, 5) I had to ask again and, 6) I don't remember. Most children participants did not understand the information that their parent was giving to them. Five children participants indicated, "The information was too short". Four children participants indicated that they felt the information about their parent being diagnosed with cancer was either "too rushed" or they "had to ask again". Two children participants indicated, "the information was too confusing" and one child participant indicated that he did not remember how he felt about the way he was informed. This was summarised in Table 4.14.

Table 4.14 "Question 5: How did you feel about how you were informed?"

Answer option	Number of responses
The information was too rushed	4
The information was too confusing	2
I did not understand the information	6
The information was too short	5
I had to ask again	4
I don't remember	1
Other response	5

Five children participants contributed other responses to this question.

[F3(C1)]: I had to have it (mother informing about diagnosis) repeated because maybe at that time I did not understand.
[F3(C2)]: I was shocked because I never thought about such a thing (that mother might get cancer).
[F3(C4)]: Because at the beginning I did not believe what I was told. Moreover, my mother had never displayed any symptoms, but I did notice that she was sometimes listless. But, the news was a real shock and surprise.
[F4(C1)]: I had to ask what they ment that they only suspected, not yet confirmed, that Ibu had cancer
[F7(C2)]: I did not understand why she had to go for an operation

Further discussions provided four main attitudes to how information should be shared with children. Firstly, children wanted to know what was going on:

[F1(C2)]: How to help my mother … how to make her feel better.
[F3(C3)]: I wanted to know so that I would get the latest update about my mother.
[F4(C1)]: I had to ask what they ment they ment by "suspected" that Ibu had cancer.
[F5(C3)]: So that we as children know what needed to be done and how to face cancer.
[F7(C2)]: How come she had to go for an operation?

Secondly, children felt that on the onset, the information provided to them first about their parents' diagnosis was "too rushed" and "too short".

[F1(C2)]: She (mother) told us very fast that her words ran together and I really could not make out what she was saying.
[F1(C3)]: Yeah, she talked too fast … I did not know what she said at first.
[F6(C1)]: When they left me to go to the hospital … they said she (mother) had cancer. That was all they said.

Thirdly, another reaction was that the information was too confusing and they did not have enough information to help them understand the health situation.

[F3(C1)]: I asked again because maybe at that time I did not understand.

[F5(C1)]: I saw those things … tubes sticking out of her …

[F7(C2)]: I remember saying "huh?", what is "cancer"?

[F10(C1)]: Why was she (mother) so sick?

Fourthly, children needed information that was relevant to their own well-being:

[F1(C1)]: Who was going to take care of me?

[F2(C4)]: She (mother) just told us that that we had to take care of each other. Huh? I was confused. Why did we have to take care of each other? I mean more than usual?

[F6(C1)]: So busy getting her (mother) to the doctor … don't forget me.

[F7(C2)]: So, what will happen to us?

[F10(C1)]: Ibu told me that I had to stay at grandmother's house because she had to see the doctor to check if she had cancer. I did not know anything else.

Older children reacted with shock and fear and so they requested more information to ally their fears and help them cope:

[F1(C3)]: How to help mama, what could I do?

[F3(C4)]: Because at the beginning I did not believe what I was told. Moreover, my mother had never displayed any symptoms, but I did notice that she was listless. But, the news was a real shock and surprise.

[F5(C3)]: I am the eldest, so I need to know and be strong for my siblings.

[F8 (C2)]: Is she going to die? Soon?

Pursuant to this inquiry, four parent participants responded they too felt the information they provided to their children was "too rushed". Three parent participants thought that the information was "too short". Two parent participants reported that their children had to ask again and one parent did not really remember what she said to her children as her husband informed them about the diagnosis first. These responses suggest that there were four main attitudes to parent's information sharing. Firstly, while the parent felt that children should be informed about their diagnosis, they did not know what to say and how to inform their children about the diagnosis. Excerpts evidencing this are:

[F4(P)]: I did not have enough information to tell them. I was praying that I did not have cancer.

[F5 (P)]: I felt that my children needed to know that I had cancer. It was important, but at first I did not know what to say … how should I tell them that this cancer could be my killer?

[F7 (P)]: My husband told the children

[F8 (P)]: I did not know what to say. It should be the doctor who gives the information to my children. They can ask when he checks me in the hospital

Secondly, the parent with cancer was not prepared to share information about their diagnosis to their children:

[F1 (P)]: *Ya. I know that there is a cure for cancer. It's just that I have to endure and be patient. I do feel emotional stress because there is a lot on my mind. I am worried about the children. I have to do a lot of preparation, pray. I told them that I had cancer but I did not give them any explanation. I was just thinking about that I would die … I really did not know how to say …*

[F2 (P)]: *I really was not prepared to tell them more.*

[F8 (P)]: *I did not know what to say. It should be the doctorlah who gives the information to my children. They can ask when he checks me in the hospital*

Thirdly, the parent with cancer wanted to protect their children from any news or situation that they perceived could cause their children to be upset. This is evidenced by:

[F3(P)]: *Yes, telling my children about me having cancer was important, as I knew they would be upset that I would be in the hospital a lot. I just wanted to tell them enough for them to not be too worried about me being away from them. I did not want them to be afraid.*

[F6(P)]: *I just quickly said that I had cancer and that my children had to take care of each other and that they were old enough to look out for each other … that way they knew everything will be OK.*

[F9(P)]: *I was scared and I only thought to tell my children that I was sick. I could not handle them being scared too.*

[F10(P)]: *At that time, I did not tell her too many details. Why make her upset when it was not confirmed yet?*

These response were similar to the findings by Brashers et. al. (2002, p. 264), Breastcancer.org (2004a, para. 1) and Rolinson (1998, para. 4).

Fourthly, literature review suggested that the psychological and emotional state of an information source could influence the manner and context in which information is shared or provided (National Cancer Institute, 2012b; Kirkelas, 1983). Data explication suggested that in situations of high stress and concern about possible mortality, these parent participants were unable to share coherent or meaningful information to their children. The following excerpts evidence this:

[F2(P)]: *At that time (sharing information about diagnosis) I was just so upset you know? So…upset … heartbroken … so sad … I could not say to my children anything …*

[F3(P)]: *You know... facing death so suddenly, it is like you blank out. There's nothing in your mind …*

[F8(P)]: *Yes la, I was so very worried about dying... so very worried. It's like you can't think … can not say what you want to say (to children) when all that you think about is you can die anytime from cancer.*

These responses were evidence that information source's character, information sharing attitudes and psychological and emotional state can be either an enabler or barrier to information sharing.

In conclusion to this section, children participants reactions suggested that they wanted information that was easy for them to understand. This further suggested that cancer information should use language and age appropriate information. Children also wanted information sessions that were properly planned with information that was not "too rushed" nor "too short". Children also need needed information that was relevant to their own well-being, to ally their fears and help them cope with the diagnosis and the challenges they faced.

Parent participants' attitudes to information sharing and the psychological and emotional state of information sources influenced the manner and context in which information was shared or provided.

2) Was the information enough for children participants to understand what was going to happen to their parent?

Parents were asked, "Was the information enough for your children to understand what was going to happen to you?" They were provided with five response options: 1) more than enough, 2) enough, 3) just about enough, 4) not enough and, 5) not enough at all. Seven parent participants indicated that the information was insufficient: Parents from Families One, Three, Five and Ten responded that the information was "not enough" and parents from Families Two, Four and Eight responded that the information was "not enough at all".

Family Five had the most open and accessible information sharing experience. However, both the parent and the children participant groups indicated that information was "not enough". Other than Family Five, the parents in families One, Three, Seven, Nine and Ten also seemed to contribute to the body of cancer knowledge within their families. In hindsight, some parents acknowledged that they did not share enough information. The information about cancer was provided with varying success. An example can be extracted from the comment by F3(P) and F8(P):

> *[F3(P)]: There were told in an incomplete manner and with very litte details.*
>
> *[F8(P)]: I should have taken more time and thought about what to say … but at that I did not know what to think, I was really afraid.*

Only three out of ten parents indicated that the information was sufficient; the parent from Family Nine responded "more than enough", the parent from Family Six responded "enough" and the parent from Family Seven responded "just about enough". Interestingly, when analysed against their children, only children who were not considered as care-givers responded in a similar manner. 12 children participants responded of having enough information to understand what was going to happen to their parent. One children participant indicated that the information provided was "more than enough" for her to understand what was going to happen to her mother. Three children participants indicated "enough" while eight out of 2 children participants indicated that the information provided at the onset was "just about enough". Six children participants responded that information about being diagnosed with cancer was “not enough” to provide children with information to cope with the changes as a result of the diagnosis. Four children participants responded that information about the diagnosis was “not enough at all”.

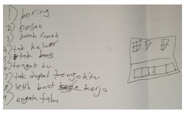
Further comparison was made. Out of the four male children participants, three responded that they assessed the information provided to them as sufficient to understand what was going to happen to their parent (two male children were five to nine years old and, one male child was ten to fourteen years old). Only one male child participant indicated that the information was insufficient. He was nine years old with a parent who did not share information about her diagnosis, cancer treatment and experience.

In analysing their families, the male child participant from Family Five exemplified the most open and accessible information about cancer between the ill parent and the children. He responded that the information provided by his parent and information that he solicited subsequently was “enough” for him to understand what his mother experienced. This response was also evident from his report:

> *[F5 (C1)]: Ya, I knew what she was going through. She was always telling me things, what was happening and when her next appointment was.*

The other male children participants were from Families One, Seven and Eight. Where information was somewhat open and accessible, two male participants from Family One and Seven indicated that the information provided by their parent and information that they solicited subsequently was “just about enough” for them to understand what their mother experienced. The male child participant from Family Eight however, responded that the information provided was “Not enough at all” for him to understand what his mother was going to experience. This response was also evident from excerpts of his drawing:

[F8 (C1)]:



(reading) 1) Boring, 2) Bored, 3) Stay home, 4) Don’t go out, 5) Not “Best”, 6) Watch TV, 7) Can’t watch too much TV, 8) Tired from doing work … 9) I don’t know …

When asked to clarify if he was informed about how his parent’s cancer could effect him, he answered, “I did not know, I did not know anything.” This particular statement directly corresponded to the attitudes to information sharing of his parent. The parent’s information attitude was closed and inaccessible. She acknowledged that she did not share information equally between her twin son and daughter.

Further analysis of these male children participants resulted in an understanding that they were not tasked with the responsibility as a care-giver. They were also not the eldest among their siblings. It seemed that culture, birth order and gender might influence information dissemination, roles and responsibility during a health crisis or situation. This was similar to the report by Scharlach et al. (2006, p. 135).

In looking at the data for female children participants, the results were markedly different from the male children participants. Out of the eighteen female children participants, nine (50%) responded that they assessed the information provided to them sufficient to understand what was going to happen to their parent. These female children were represented in all of the age groups. Further data explication suggested that for female children birth order played a part in how information about cancer was disseminated. All female children participants were provided with more information. It seemed that female children were expected by family members to be more caring and play a more visible and responsible role than their male siblings. In addition to that, the self-reports and responses seemed to indicate that information was provided to female children participants depending on their role and age: older female children care-givers were provided with more information than younger female children care-givers.

Pursuant to the severity or burden of task and information provision, an analysis of family groups was compared against age. The data suggested that age had an effect on parental information sharing: only older female children in the 15-18 years' old bracket who were also care-givers were provided with "enough" information for them to better understand or cope with their new tasks. This assertion was supported by the care-giver role in Family Five. The eldest child participant, who fit the profile of information recipient of being female as well as in the older age bracket, was deemed by her parent as being more capable to carry out the tasks of a care-giver compared to her younger siblings. As such, this particular child was provided an amount of information that was commensurate with the perceived needs of her new responsibilities. Her younger siblings were provided with "just about enough" information to understand what was going to happen to their parent. An excerpt of this attitude to information needs and information sharing is provided below.

[F5(C3)]: As the eldest, I must know what is going on so that I can be there for my mother … help her in whatever way I can. She cannot face this cancer on her own, she needs people, family, her children, it is important for me to be there for her and for my sister and brother. I needed information on how she can get better, what she can or cannot eat. I need to be with her when she goes to the doctor, when she had her operation, I was there you know.

[F5(C2)]: We did take turns taking care of her and making sure that she was OK, relieving her of her aches and pains, but I think, my older sister did most of the jobs that needed, the care.

[F5(C3)]: Ya, I know my mother needed care and help, and I did help as I could. I don't mind helping out, she just have to tell me. I'll get to it … a bit later lah, but I get to it.

This phenomenon can be considered as a consistent behaviour of parent participants as it was found that younger female children participants who were also the eldest sibling and a care-giver reported that they did not have sufficient information. This was further evidenced from reports by the eldest female child care-giver in Families Two, Three, Seven and Eight.

[F2(C3)]: What was going to happen during her surgery? I did not know and no one would tell me.

[F3(C4)]: I wanted to know what caused cancer, what cancer really meant, how to go through cancer … can cancer really kill? What does that mean?

[F7(C2)]: How long was the operation … how come she had to go for the operation?

[F8(C2)]: What is cancer? Why did my mother get it?

Data suggested that when female children participants were younger than 14 years old, they were provided with information that they considered was "not enough" or "not enough at all" for them to understand and cope with their parents' diagnosis even though they played a role as a care-giver and were also responsible for their younger siblings. Furthermore, parents as an information source believed that age was an important criterion for information sharing. When parents were asked, they responded in one of two ways: one that they felt young children may not be able to comprehend the information given or the illness itself and two that they wanted to protect their children from experiencing negative emotions of worry, sadness, grief, depression and fear of the parents possible demise. However, the parent participants' objectives were not entirely realised. Most children participants solicited information to comprehend the situation they were in and all of the children participants exhibited, in varying stages, the negative emotions their parents wanted to protect them from.

3) Was the information enough for children participants to understand what was going to happen to them?

Relevant to the inquiry of children's understanding, was the question if children had sufficient information to understand how cancer could effect them during their parent's cancer treatment. This was answered through Question 6 from the "Information Source Questionnaire". Both participant groups were asked if they thought that children participants had sufficient information for them to understand what could happen to them. Eight parent participants indicated that the information was insufficient: Parents from Families One, Two, Four, Seven, Eight and Ten responded that the information was "not enough" and parents from Families Five and Nine responded that the information was "not enough at all". It was interesting to note that even though the parent from Family Five shared the most information, she considered that her children did not have enough information for them to understand what was going to happen to them.

It can be reported that only two out of ten parents indicated that the information was sufficient; the parent from Family Three and Six responded "enough". Interestingly, when analysed against their children, only children who were not considered as caregivers responded in a similar manner. These responses suggest that children participants had unmet information needs.

For this inquiry, one children participant said the information was "more than enough" for her to understand what was going to happen to her. Six children participant responded that the information was "enough" and four responded that the information was "just about enough" for them to understand what was going to happen to themselves. Five children participants responded "not enough" and six of them responded "not enough at all". Cumulatively, 11 children participants reported that the information about what could happen to them was sufficient for them to understand what could happen to them with their parent's diagnosis. While this data suggested that an equal number of children reported that they had sufficient or insufficient information, further analysis identified that the responses were dependant on the children participants' perceived relevance of the disease to themselves and individual capacity in their caregiving role. A comparison between age, gender and care-giving role was conducted to further analyse this data.

Three male children participants responded that the information provided to them was sufficient for to understand what was going to happen to them (one male child in the ten to fourteen years old age bracket responded "enough" while two male children in the five to nine years old bracket responded "just about enough"). Only one male child participant who was in the ten to fourteen years old age bracket indicated that the information was insufficient. The three male children who responded in the sufficient information category were not the eldest children nor were they considered a caregiver. Specifically, they were not asked or instructed to help out with care-giving tasks that significantly changed their previous roles and responsibilities. This phenomenon seems to be a cultural norm that influences how parents allocate care-giving tasks and is evident in the excerpt below:

[F1(P)]: *You can't expect him ([F1(C1)]) to help out? He's a boy …*

[F4(P)] *My boy was … (pause) 11 years old at that time and really, you don't give boys to do women's work.*

[F5(P)]: *Ya, I tell my son, but you know … somethings you can't expect him to do.*

[F7(P)]: *My boy was so young at that time and needed to study for his exam and I did not want to disturb his concentration.*

[F8(P)]: *Well, boys just don't do house chores and cleaning and helping mothers to get up. Boys are not supposed to do those things … of course I get my girl to help out, girls are supposed to do that.*

The male children participants responded as below:

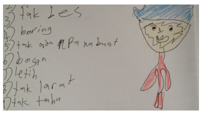
[F1(C1)]: *Ya, I know that my mother has cancer. So?*

[F5(C1)]: *I help out a bit … when I feel like it. Its not so bad, doing more of the housework because my mother is ill. It just needed to be done. I knew she would get better and then I won't have to do the work anymore.*

[F7(C1)]: *Well, my mother told me that because she was sick, she could not cook my favourite dishes and I could not watch television shows that were too loud … it got boring, but I know that my mother was not well. That's a pity, but that's OK.*

The male child participant who responded "not enough at all" came from Family Eight. He indicated that the information provided by his parent and information that he solicited subsequently was "not enough at all" for him to understand what was going on. This response is also evident in excerpts of his drawing:

[F8 (C1)]:



3) Not "best", 4) Boring, 5) Don't know what to do, 6) boring, 7) I don't know

When asked to clarify if he was informed about how his parent's cancer could affect him, his answer was "I did not know, I did not know anything". This particular statement directly corresponded to the more closed and inaccessible information about cancer as confessed by his parent. Specifically, she acknowledged that she did not share information equally between her twin son and daughter.

[F8(P)]: *Ya, I don't tell my boy anything much. Now my girl, my girl, I told her more about taking care of me and what needed to be done.*

In looking at the data for female children participants, the responses were markedly different from the male children participants. Unlike majority of the male children participants, about half of the female children participants assessed the information they received was sufficient for them to understand what was going to happen to them. Even when all female children participants were provided with more information about caregiving, they did not have sufficient information to understand how cancer could effect them. Further analysis suggested that for female children birth order played a part in how information about care-giving information was disseminated. While parent participants indicated that older female children care-givers were provided with more information, many female children participants felt that the information was still insufficient to help them cope with the changes in roles and responsibilities they now faced.

Out of the eighteen female children participants, only one responded that the information provided to her was sufficient. She was the youngest in the family and was six years old when her mother was diagnosed with cancer. Even though she indicated her willingness to help, all of her family members considered her too young to be given care-giving tasks or household chores. Five female children participants responded that the information provided to them was “enough” for them to understand what was going to happen to them. It is to be noted that for this assessment, a female child participant from Family Five responded thusly and justified her response because of the open and accessible information-sharing attitude of her mother. “Not enough” and “not enough at all” had five responses each.

It seemed that for the eldest female child, providing care, age and extent of caregiver tasks had an effect on parental information sharing about the impact of parental cancer to children. This may be attributed to the role these children participants had and parental perception of these children’s need for more information. However, all of the female children participants who were caregivers indicated that they did not have sufficient information for them to understand what would happen to them. The female children participants from Families One and Five had “just about enough” information however, they too still actively sought more information from their ill parent as well as from other sources to clarify whatever issues arose from care-giving tasks. The assessment of having insufficient information was especially true for children participants who were the main caregivers from Family Two, Six, Seven, Eight, Nine and Ten.

There was a markedly different perception about the scope and extent of information that parent participants were willing and/or able to share with their children about care-giving tasks. It seemed that parent participants did not provide constructive assistance to help their children cope with their new responsibilities and tasks on top of the other skill sets and concerns they were required to develop as growing children. The excerpts below are some evidence of this phenomenon.

> [F1(C3)]: *I had to be in charge, but it was difficult. I know she was sick, but I would have liked to know how long she was going to be sick … I remember thinking: I had to take care of her, who will take care of my younger siblings? I cannot: I also have school, homework, exams …*
>
> [F2(C3)]: *How do I take care of my health so that I don't get cancer too?*
>
> [F3(C4)]: *What about me? Who was going to take care of me?*
>
> [F5(C3)]: *There were so many things that I needed to find out for myself, especially foods for myself.*
>
> [F6(C1)]: *I needed to know what was cancer and how to overcome it.*
>
> [F9(C1)]: *How do I ask my parents?*
>
> [F10(C1)]: *How to make Ibu not scold me so much?*

It seemed that while parent participants solicited their female children's assistance in varying degrees, they were not as forthcoming and/or constructive in providing information to their children about what exactly needed to be done and how best to perform those tasks. As a follow-up, parent participants were asked about this finding and the unmet needs of their caregiving children. When asked about the lack of information sharing, parent participants thought to protect their children from information they perceived to be upsetting.

> [F1 (P)]: *I was worried about dying and I did not want them to be sad …*
>
> [F2 (P)]: *I did not want them to worry so much. They were still too young to understand … it would be a burden on them … their mental … they could not take it.*
>
> [F3 (P)]: *Telling someone that you might die very soon, is not something easy. It was hard to say that … I did not know what to say … how to say so that they don't become too upset. It was hard for me to control my own emotions, you know … it would be harder to have them be out of control upset.*
>
> [F4 (P)]: *No, I don't think my children should know everything I went through. It was just terrible. Nightmare. I don't want them to go through that … I do want them to take care of themselves better, eat a healthy balanced diet …*
>
> [F7 (P)]: *No lah, if they worry, they cannot study …*
>
> [F8 (P)]: *I thought that my children could figure out by themselves. I don't need to make them scared.*
>
> [F10 (P)]: *I did not want my children to be afraid of everything … or crying all the time about me.*

However as reported before, the parent participants' objective of protecting their children from being upset through a lack of information sharing was not successful.

Another reason was that in most cases the parent was unaware of their children's unmet information needs. This could be attributed to the self-report of parent participants who said that they were more concerned with the impact of cancer to themselves.

> [F1(P)]: *Really? I did not notice that at all …*
>
> [F2(P)]: *I should probably have made a schedule of chores …*

> *[F3(P)]: You know, when you go through cancer yourself, you just can't really see how people are suffering along with you. I know that I did not want to burden my children, did not want them to be very sad … upset that I will die tommorrow instead of a long time for now so that is why I did not tell them much. But, I think, now that I look at it, my children seemed a bit more grumpy and unhappy. I did not notice it so much, but there were some signs … you just ignore it, because those are little things, compared to you dying at anytime, what's a little mumbling?*
>
> *[F7(P)]: I was very afraid of dying and I just follow whatever the doctor planned for me. I was not thinking of what more my children need, more so information for them to better understand cancer. You know, I don't think I really noticed how my cancer changed their life. I know that they choose better foods to eat, but it did not really register to my mind … how my cancer affected them.*
>
> *[F8(P)]: When I was confirmed, I really did not tell my children much. I did not know what to say, so how can I say anything?*
>
> *[F10(P)]: No, I love her a lot … she helped me the most … why did you (daughter) think that way?*

Another reason for parents being unaware of their children's unmet information needs could be attributed to cultural norms' of roles for female children. It seemed that in these families, female children were assumed able to "automatically" figure out and actually behave as a care-giver as and when needed. This assumption seemed to be tasks which evolved from the traditional belief that tasks for household chores, like cooking and cleaning, as well activities that required more emotive support or input was "women's work". The subsequent delegation of care-giving tasks constitutes a gender-based phenomenon that was relegated to daughters as a non-negotiational aspect of their roles within the family construct. In line with the participants' cultural beliefs, care-giving tasks are a women's prerogative and as such may have strongly or "automatically" influenced the parents to readily identify care-givers in their families as being the eldest female child if the mother becomes unwell.

In this, most parents seemed to be unaware about how their cancer could affect the normal roles and responsibilities of their care-giving daughters. They seemed to expect their daughter caregivers to somehow "automatically" knew what needed to be done without tutelage or with a minimum of direction and supervision. The addition of care-giving tasks was perceived to be a cultural norm: female children were expected to multi-task care-giving in addition to other tasks and responsibilities. This was evidenced by:

> *[F1(P)]: I told my eldest, my girl, that she needed to help out more now … help me in whatever.*
>
> *[F2(P)]: I always have to explain what I actually needed, it was very tiring … so yes, I scolded them a lot, but really, these things should be "automatic" by now.*
>
> *[F3(P)]: They should know by now what needed to be done.*
>
> *[F4(P)]: Well yes, children should sooner or later learn to be more independent …*
>
> *[F5(P)]: Ya, you know my children, they "automatically" knew what to do, to help me around the house. My girls would take turns looking after me, they figured that out on their own without me saying so. My eldest, she has been a big help. She just does what I tell her very well. I no need to tell her so much what to do.*
>
> *[F7(P)]: They aren't like us in Malaysia, we have extended family, for them only take care of themself. Parent and grandchildren they already feel like the in-law, are interference into their life as they live with them. So, in Malaysia, our culture, our family, even young children, especially the girls in the family, take care of each other.*

It also seemed that in several instances the parents, either the ill parent or the healthy parent, had "subcontracted" their children to carry out tasks in which their doctors advised them to do. This is specifically evidenced in the excerpts by the parent from Family Three, Five and Family Seven. They indicated that because they could not do a certain action, they had their daughters do it for them.

[F3(P)]: The doctor said that I would be vomiting as a side effect and so, I was told to drink lots of water. I don't like the taste of water, so my daughter flavoured it with lime or gave me glucose water every time after I vomited. I just could not swallow ordinary water so my daughter made sure I drank so that I would not be dehydrated and get sick worse. I would scold her if the water tasted like 'normal' water. (laughs).

[F5(P)]: And then, she helped me with my medicines … she made sure I take it on time. Even the vitamins and supplements, she made sure that I have enough. She will tell her farther to buy some more if I was running low.

[F7(P)]: I don't know … I just followed what the doctor told me to do. If I could not do it, I would get my daughter to do it for me. Who else would care for me?

Furthermore, the data suggested that this phenomenon is also a result of the ill parent being reticent to ask for help from their children who was not of the same gender.

[F1 (P)]: Ish, no … I cannot ask my son to help me to do those things … like help me to go to the toilet.

[F6 (P)]: I cannot have my boy look at me bald. That is too … wrong …weird.

[F7 (P)]: Where can my son see me underdressed in the hospital? That's not proper.

[F8 (P)]: I was embarrassed to ask my son.

Within the cultural norms of the participants, there was a sense of familial obligation for children, more than spouses, to be responsible or at the very least be helpful, towards providing home care for an ill parent. Female children participants, especially the eldest daughter and irrespective of being younger than the eldest son, (as in the case of Family Four, Six, Nine and Ten who did not participate in the research) were "automatically" thrust into the role of care-givers, seemingly as a continuation of tasks relegated under the purview of "women's work". However, while care-giving seems to be considered an integral component of "women's work" by most participants, several children participants said:

[F1(C3)]: Ya, it is important to help my mother to get better. I'm the eldest girl, it is my job.

[F2(C3)]: I feel that it was not fair … I had to do most of the taking care, but I was told that as a girl and the eldest in the family, I had to those things, so, weather I like it or don't want it, I just have to do it. My father and mother told me so.

[F4(C1)]: My older brother? He just did his thing. He only does what my mother sometimes tells him to do. She has to ask him nicely. She does not ask me nicely … well sometimes … she's not very patient with me … I get scolded a lot when I don't know what she wants or don't do things fast enough. She needs to have more patience.

[F5(C3)]: As a girl, it is important to be able to take care of your parents, especially your mother. She gave birth to you, she went through a lot for you. The very least you could do is to help care for her when she is so down … And as a child, I think I had to be strong because if my mother is already sick and I'm sad, so it's like I want to give her strength.

[F5(C1)]: I help, I don't mind helping. Things needed to get done. I know that I need to learn these things because my mother tells me that who knows if I get a wife or daughter that needs such care and help. But, I'd rather not. I'm lazy … (laughs) besides my sisters are there to do those things.

[F6(C1)]: That's just how things are? My older brother does not do these things …

[F9(C1)]: My older brother? No, my mother said he cannot be depended on to help her …

[F10(C1)]: My mother says that I have a gentle touch, so I have to help her because she was in pain and did not have the energy to do things.

The children participants were asked to list tasks that they had done. The eldest female children participants had 35 tasks. Younger female siblings had 17 tasks and male siblings had nine tasks. The scope of tasks for the eldest female children participants was the most varied in three categories of household chores, care-giver tasks and other tasks. Some of these tasks required a certain level of specialised skill sets that these children participants were neither well informed, prepared nor educated to accomplish. This is listed in Table 4.15.

Table 4.15 List Of Tasks For Children Care-givers

TASKS	ELDEST FEMALE CHILD	OTHER FEMALE CHILDREN	MALE CHILDREN
A. Household chores			
Preparing food for the family	✓	✓	
Purchasing food for the family	✓		✓
Setting a meal for the family	✓	✓	
Clearing and cleaning up after a meal	✓	✓	
Cleaning the house	✓	✓	✓ (sometimes)
Laundry	✓	✓	✓ (sometimes)
Minor house repairs			✓
Moving furniture to make way for wheel chair or providing support posts for parent to move inside the house	✓	✓	✓
B. Care-giver tasks			
Accompanying parent to the hospital or clinic	✓	✓	✓
Accompanying parent for a hospital stay	✓		
Accompanying parent to sleep in a more comfortable area in the house	✓		
Helping parent to change clothes	✓		
Helping parent to move around in the house	✓	✓	✓
Feeding parent and monitoring nutritional intake	✓		
Monitoring consumption of medication	✓		
Identifying health issue(s) and providing solution(s)	✓		
Relieving bodily aches and pains	✓	✓	✓
Cleanliness of "sick" room	✓		
Management of parent's nausea	✓	✓	
Holding up parent and providing containers when parent was too ill to vomit in the bathroom	✓	✓	
Supporting parent to go to the toilet	✓	✓	
Changing the bed	✓		
Preparing clothes	✓	✓	
Collecting parent's hair	✓		
Cutting parent's nails	✓		
Being with the parent in free time	✓	✓	
Listening to parent's complaints	✓	✓	
Praying for the parent to get better	✓	✓	✓
Remembering or taking down notes on doctors' instruction or advice	✓		
Coordinating parental care among siblings	✓		
Ensuring parent is presentable to receive visitors	✓	✓	
C. Other tasks			
Monitoring siblings' homework	✓		
Taking care of ill siblings	✓		
Entertain and provide for guests	✓		
Management of new familial diet	✓		
Management of new lifestyle changes	✓		
TOTAL NUMBER OF TASKS	**35**	**17**	**9**

Children participants indicated they needed information to understand what they were doing, why they were doing so and for how long they had to carry out those tasks. The excerpts below evidence this.

[F2(C3)]: How do I help my mother get better? Taking care of her was scary … what could I do?

[F3(C4)]: Those side effects of cancer, I really was not prepared to see my mother vomiting so bad and her hair falling out! What more would happen to her?

[F4(C1)]: How come ibu took so long to get better?

[F5(C3)]: Oh when my mum got it, I felt it was important for me to know what was going on, to know if my mum was going to be OK, what she needed, to know what need to be done lah, to be alert. Their changes in their body? I would like to have known the types and treatments that has to be done … you know, the medicine, treatment and food that my mother could eat or not eat … and then as the oldest child, I think I have to be strong so that I can advise my siblings on what to do and what not to do, and tell them not to be sad. Because my father is the one who is sad.

[F8(C2)]: How can I help my mother? I just don't know … I can't think of how. She (mother) tells me to think of how to help her, but … I don't know … its difficult …

These children participants reported being overwhelmed by their new tasks, roles and responsibilities. They did not have sufficient information to carry out the duties that were expected of them. This is evident from the excerpts below:

[F2(C4)]: I have to be in charge of the house? I was only 13 years old you know and I have three younger sisters.

[F4(C1)]: I thought that there was a possibility that I had to accompany Ibu to stay the night at the hospital, but I had school and Ayah had work the very next day. I did not know what was going on.

[F5(C3)]: I had to figure things out on my own … We had to get to the hospital, but we did not have a car and we had to take a taxi to get to the train station. I had never done that on my own before.

[F6(C1)]: Can't she say thank you once in a while?

[F7(C2)]: I didn't know what was happening until Emak had to go to the hospital.

[F8(C2)]: It is always me who had to help out. My twin brother did not.

[F9(C1)]: How long was I supposed to do this?

Some were also worried of contracting cancer as they thought that cancer was a communicable disease. This is evident from the excerpts below:

[F3(C4)]: Is there a chance for a child to develop the same illness or sickness if it is not genetic?

[F8(C2)]: What is lung cancer? Since cancer can spread, will I get that? Cancer in my lungs?!

[F9(C1)]: I did not want to be in the same room with her. I did not want to get her baldness.

This was a concern reported by McCue and Bonn (2003, p. 48-49).

These excerpts and the data tabulated in Table 4.15 (on page 169) suggested that female children care-givers often received little support and lacked appreciation from their ill parent and other family members. This could be attributed to the perception that care-giving tasks were considered a domestic and *de facto* duty for females within a family construct and reflective of a cultural norm; female children participants in these families did not need to be thanked nor appreciated for doing something considered "normal" and not extraordinary.

[F1(P)]: Nothing special.

[F4(P)]: It's normal what.

[F8(P)]: *It so simple; just get the plastic bag (to vomit in), make sure the clothes are clean, give me the medicine … not too difficult is it?*

[F9(P)]: *That's how it is usually.*

[F10(P)]: *What's so difficult? Can't I ask you (daughter) to help? That's too much if you cannot help me out even a little for simple things. You could see me in pain, so you should do something about it.*

4.4.iv The role of information for dependent children of cancer patients

The data suggested that information was vital for the children participants to cope, understand and adjust to their roles as care-givers. Two polarities existed about children's assessment of how sufficient information was provided to them. When information sharing was open and accessible, with an active dialogue or discussion about a health situation, participants reported an experience that had positive outcomes. Conversely, when information sharing was closed and inaccessible, participants reported an experience that had negative outcomes.

The polarities, either positive or negative, seemed to be dependent upon attitudes to sharing information (openness and accessibility) experienced by children participants. This attitude of information sharing suggests influences by the reaction, relevance of a health-based situation or stimuli and personal files (personal collection of synthesized information and experience organised within an individual's mental capacities as termed by Kirkelas, 1983, pp.9-14 and Wilson, 2012, para. 1 belief in an individual's ability to learn from experiences and observation of others), in order to make sense of their specific "world", situation, environment or experience (Dervin, 2003, p. 270) of participants.

Positive outcomes in children's understanding of cancer were reported in instances where cancer-related information was more readily shared between the parent participant and their children. Both participant groups reported an increase in love, patience and understanding of roles and the importance of the cancer care continuum. It also seemed that when information-sharing attitudes were open and accessible participants reported willingness to adhere to new tasks. Children participants were more patient and willing to conduct chores than prior to the cancer diagnosis. Both groups of participants also reported an increase in the care, knowledge and adherence to diet and lifestyle changes. There were also indications of an increase in religious practices. It seemed that the diagnosis and eventual treatment of cancer had a positive impact in changing lifestyle patterns for the better.

Negative outcomes in children's understanding of cancer were reported in instances where cancer-related information was considered closed and inaccessible. Information was either not provided to children participants or did not meet a specific information need. Children participants made a self-assessment that the lack of information was insufficient for them to overcome the challenges they experienced. The consequences of this attitude to information sharing were that children exhibited some types of negative behaviours and seemed to lack understanding about cancer and its treatment. Both participant groups reported an increase in negative psychological changes in how children reacted to their experiences and the situation they were in. Children participants reported a decrease in love, patience and empathy toward their parent. They also indicated decreased understanding of the importance of the cancer care continuum. Some even indicated a degree of repugnance toward care-giving tasks.

Specifically, parent participants perceived that their children did not understand new roles and tasks. They also indicated that their children exhibited decreased patience and willingness towards those tasks. The interviews suggested that children who were less informed about their parent's cancer and the treatment and prevention strategies felt resentment and forced to adhere to diet and lifestyle changes. However, unlike positive outcomes form information sharing attitudes, there was no indication of negative changes toward religious practices. The subsequent sections provide evidence of these two polar outcomes.

4.4.iv.a Positive Outcomes

There were positive outcomes to children's understanding of cancer in families where attitudes to information sharing were open and when information sources were considered accessible. Data suggested that children participants identified openness to information sharing as an attitude of their preferred information source. An "openness to information" attitude was an important element that contributed most to the children participant's ability to question and receive information about parent's health situation and children's role in the family.

In the case of Family Five, the open and accessible attitude of the parent participant was instrumental for the children participants' understanding and subsequent attitude towards cancer and their new circumstances. The following are excerpts of this attitude:

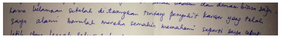
[F5 (P)]: *… I could not keep something like this to myself. It was important that the children heard about this cancer from me.*
[F5 (P)]: *My children and I always talk … The family bonding is very important.*
[F5 (P)]: *I always tell my children about what is happening and I try to give them as much information as I know how.*
[F5 (P)]: *It is important that my children know about cancer and what I go through. They need to know from me. That way, they don't become too afraid of what is going to happen.*

From the excerpts above, it can be suggested that the parent justified her information-sharing attitude as a mechanism in which her children may be better prepared for the cancer treatments' side effects and outcomes. In addition to that, she thought that the information was important to allay her children's fears of what might happen to them while she was undergoing treatment. Even though this parent was the most forthcoming about cancer and her medical treatments, she still reported that information provision and sharing was insufficient.

Other than Family Five, the parents in families One, Three and Four also seemed to contribute to the body of cancer knowledge within their families. This is evidenced by:

[F1(P)]: *Yes, I did tell my children about what is cancer and that I could die from it. But I don't think they really understood what I was saying. I told them cancer was dangerous, that it could kill me one day and so they also have to take care of their health … eat healthy foods, don't be in so much stress.*

[F3(P)]:



dan demam biasa saja.
Lama kelamaan setelah di terangkan tentang penyakit kanser yang telah
saya alami barulah mereka semakin memahami seperti saya cepat

… after awhile, after I explained to them (children) about cancer and what I experience or go through, they begin to understand more, like why I am easily tired …

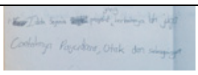
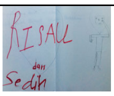
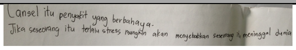
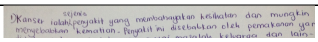
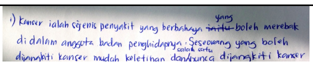
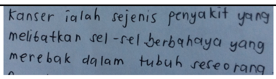
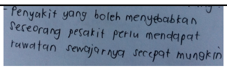
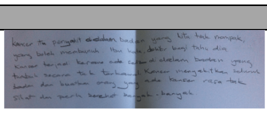
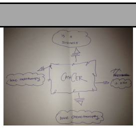
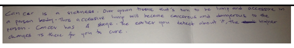
[F4(P)]: *I had followed a seminar on cancer by NCSM. They showed how to do self-examinations. I showed my daughter how too.*

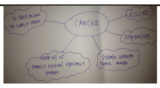
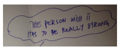
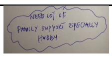
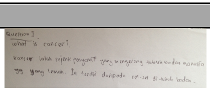
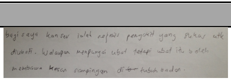
Specifically, further data explication found several outcomes that the researcher considered as successful information sharing markers. The outcomes were categorised into themes as 1) Children participants' reaction to cancer and cancer treatment, 2) Children's reaction to changes in familial dynamics and, 3) Children's reaction to changes in lifestyle which included children participant's indication of increased care, knowledge and adherence to changed diet and lifestyle changes as well as increased observance of religious practices. An explanation of these categories is provided below.

1) Children participants' reaction to cancer and cancer treatment

When information sharing was open and accessible, children participants' responses indicated that they had a better understanding of cancer, its causes and the cancer treatments. They were better able to provide a definition of cancer with the use of some medical terms and they were able to describe their experiences when their mother was undergoing treatment. It seemed that since these children participants had more knowledge and was more involved with their parent's treatment and recovery process; they exhibited an increase in love, patience and empathy toward their ill parent. Other than a more positive reaction towards the ill parent, children participants' responses indicated that they increased their understanding of the importance of the cancer care continuum. Excerpts are presented in Table 4.16.

Table 4.16 Successful information sharing markers - children participant's reactions to cancer and cancer treatment

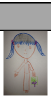
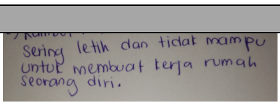
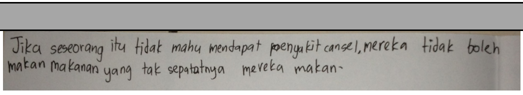
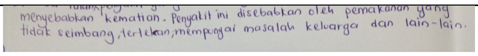
PARTICIPANT	REACTIONS TO CANCER AND CANCER TREATMENT		
	Indicated an understanding of cancer, its causes and the cancer treatment.	Indicated an increase in love, patience and empathy toward ill parent.	Indicated an understanding of the importance of the cancer care continuum.
Family One			
C2	 Cancer was a dangerous disease that Mama had. It made her very sick: vomitting and in pain a lot.	 I love Mama even she had cancer. I knew that she was in pain and she was afraid.	Mama needed rest so that she could get better.
C3	 Cancer is a dangerous disease that can spread. Example: breast, brain and other areas.	 I knew that she was worried and sad.	I understand that cancer is a dangerous disease if not taken care of.
Family Three			
C1	 Cansel itu penyakit yang berbahaya. Jika seseorang itu terlalu stress mungkin akan menyebabkan seseorang itu meninggal dunia Cancer is a dangerous disease. If someone is too stressed, maybe that person will die from it.	 Mama's hair fell out. I pitied her. No hair, was embarrasing for her.	Had to make sure that Mama was not so stressed.
C2	 1) Kanser ialah sejenis penyakit yang membahayakan kesihatan dan mungkin menyebabkan kematian. Penyakit ini disebabkan oleh pemakanan yan Cancer is a type of disease that is dangerous to health and can cause death.	I have to help her get better.	Important for her to get better by resting and taking care of what she ate.
C3	 i) Kanser ialah sejenis penyakit yang berbahaya ~~iaitu~~ yang boleh merebak di dalam anggota badan penghidapnya. Seseorang yang boleh dijangkiti kanser mudah keletihan dan salah satu punca dijangkiti kanser Cancer is a dangerous disease that can spread inside the body of the person who has cancer ... very painfull and must go for surgery to remove the cancer.	Mama was in a lot of pain, terrible pain	Mama needed for us to be quite and help to relieve her of her aches and pains. She also had to eat baby food because it was hard for her to swallow.
C4	 Kanser ialah sejenis penyakit yang melibatkan sel-sel berbahaya yang merebak dalam tubuh seseorang Cancer is a type of disease that involves dangerous cells that spread inside someone's body.	Cancer makes me angry, the person who gets cancer, I pity.	 -Penyakit yang boleh menyebabkan seseorang pesakit perlu mendapat rawatan sewajarnya secepat mungkin A disease that requires proper treatment as soon as possible. Doctor must understand how a patient feels.
Family Four			
C1	 Cancer is a disease inside the body, that we can not see, that can kill. Mother said, her doctor told her that cancer develops because there are cells in the body that grow uncontrollably.	When my mother was grumpy or seemed angry, I told myself that the cancer and the pain made her feel worse, so I should be more patient. It makes the person with cancer ill and need plenty of rest.	It was important for my mother to get plenty of rest and healthy food so that she could get well faster. Less pain.
Family Five			
C1	 Cancer is a sickness. It kills. So, in order to not die, the person with cancer must go for chemotherapy and have radiology. That is very expensive.	I saw all the black things from her body being sucked out, it was bad and she was in pain even though she tried to hide it. It was difficult for her to lie down properly because she had to have a tube coming out for the side of her body to drain the black things out. That was so pitiful and sad.	Cancer was very difficult to recover from. It was not like a fever or flu. She really needed to rest and eat well so that she could get better.
C2	 Cancer is a sickness. Overgrown tissue that's turn to be lump and excessive in a person's body. This excessive lump will become cancerous and dangerous to the person. Cancer has four stages. The earlier you detect about it, the higher changes (chances) is there for you to cure.	It was terrible for me to see her suffer so bad and it must have been worse for her to go through the treatments. The vomiting was painful, she lost her beautiful hair, and she did not have energy because of all the vomiting and just did not have the appetite to eat at all. When I imagine that happening to me, it is very frightening.	Her cancer was really bad. She could have died from the cancer treatment, but she must, I insisted she must, go for the chemotherapy and then the radiology. No joke, she needed to get the treatments so that she could beat this cancer.

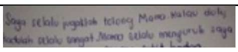
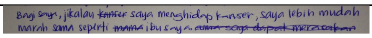
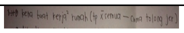
C3	 Cancer is a killer. It is expensive to treat. It is something that no one wants to get. To take action in early stage.	THE PERSON WITH IT HAS TO BE REALLY STRONG NEED LOT OF FAMILY SUPPORT ESPECIALLY HUBBY Cancer, the person with it has to be really strong. Need a lot of family support, especially from hubby.	She needed to be well hydrated because the doctor said that her frequent vomiting would make her lose water and she could get sicker without water.
Family Nine			
C1	Question 1 what is cancer? kanser ialah sejenis penyakit yang menyerang tubuh badan manusia ~~yg~~ yang lemah. Ia terdiri daripada sel-sel di tubuh badan. Cancer is a type of diesase that attacks the human body that is weak. It consists of cells in the body.	bagi saya kanser ialah sejenis penyakit yang sukar utk diubati. Walaupun mempunyai ubat tetapi ubat itu boleh membawa kesan sampingan di ~~b~~ tubuh badan. She (mother) expereinced a lot of suffering but she successfully overcame it. At first, she felt sad that she had cacner, but she eventully accepted it.	Cancer is a terrible disease. Somebody with cancer must really be taken care of well because that person cannot do it on his or her own. They need a good family support to help them get better and to help them do things because their body was just too weak.

2) Children's reaction to changes in familial dynamics

When information sharing was open and accessible, children participants' responses indicated that they had a better understanding of the reasons for their new roles and tasks. Most children participants reported their knowledge that their parent was too ill, too tired or recovering from cancer treatment to complete their 'normal' tasks. The children participants' acknowledged that a sick individual was unable to carry out tasks or strenuous activities and was required plenty of rest in a less stressful environment so they could get better. In acknowledging illness, fatigue and parent's health situation, children participants also reported their willingness to take on the previously 'normal' tasks of the ill parent.

It can be suggested that these children participants' were more empathic in the tasks and roles their ill parent carried out before. While children participants, most notably in the case of the eldest female children participants, were tasked to carry out care-giver tasks or other household tasks, they indicated that they understood why they were had to do so. When these children participants reacted to a new health situation, their ill parent was open to discussion, was willing to share information and was patient when instructing their children on care-giving tasks. Excerpts are presented in Table 4.17.

Table 4.17 Successful information sharing markers - children participant's reactions to changes in family dynamics		
	REACTIONS TO CHANGES IN FAMILIAL DYNAMICS	
PARTICIPANT	Understood new roles and tasks.	Patient and willing to help
Family One		
C2	I always helped Mama.	Have to eat vegetables and eat fruits.
C3	I always helped Mama, I asked her if she needed my help.	It is important to look after our health. We have to be particular about our eating habits. Less fried chicken.
Family Three		
C1	Sering letih dan tidak mampu untuk membuat kerja rumah seorang diri. Mama's was always tired and could not do the housework alone. I helped to bring food to my mother when she was in the hospital.	Jika seseorang itu tidak mahu mendapat penyakit cansel, mereka tidak boleh makan makanan yang tak sepatutnya mereka makan. If someone does not want to get cancer, they cannot eat foods that they should not eat.
C2	If someone gets cancer, it takes them a long time to get better, so I have to be patient.	menyebabkan kematian. Penyakit ini disebabkan oleh pemakanan yang tidak seimbang, tertekan, mempunyai masalah keluarga dan lain-lain. Cancer is caused by an unbalanced diet, stress, having family problems and others. So, in order to not get cancer, we have to eat a balanced diet, have less stress and not fight in our family.

C3	 Saya selalu jugaklah tolong Mama. Kalau dulu [illegible] selalu sangat. Mama selalu menyuruh saya [illegible] I quite often help Mama. Last time (before diagnosis), not as often (laughed).	 Bagi saya, jikalau ~~kanser~~ saya menghidap kanser, saya lebih mudah marah sama seperti ~~mama~~ ibu saya. ~~[illegible] saya dapat merasakan~~ If I had cancer, I would be quick to anger too. So, I try to help my mother without making her angry.
C4	 ~~[illegible]~~ kena buat kerja² rumah (tp x̄ semua – cuma tolong jer) Have to do house chores, but not all, just help in some chores	Cannot fight in the family because that will cause everyone to be stressed and then they also might get cancer. Changed eating habits to eat more healthy.
Family Four		
C1	Ya, I have to help around in the house, on top of doing well in exams.	It was OK. My mother could not do the work because she was too sick from the treatment.
Family Five		
C1	She really needed to be taken care of and we really needed to help her in any way we could. I pitied her and I know when she was angry, I had to be patient because sometime I was the one who did not do the things she wanted me to do. But I know better now.	Cancer really made me understand that my mother would not be there for me forever and if I don't want anybody in my family or future family to not get cancer, then I have to make sure we eat healthily and no smoking.
C2	My mother was very strong in facing her cancer. She could have given up ... because she could do it, I knew that I too must be patient and her in any manner that I could ... She was smelly from her vomiting, but that was OK because that tells me the medicine was working and that she would be alive another day.	Ya, I am careful of what I eat. I eat more vegetables now and I loved Pizza, but I don't eat so much of that now. I also know that I need to get my vitamins because if I get sick, my mother could easily get sick from my germs and that would take her longer to get better.
C3	After telling us what she wanted, she didn't really need to tell us again. I wanted to be sure that she was not stressed out about what needed to be done. She just needed to concentrate on getting better.	Ah. And then as the oldest child, I think I have to be strong so that I can advise my siblings on what to do and what not to do, and tell them not to be sad. Because my father is the one who is sad.
Family Nine		
C1	Cancer treatments have side effects on the body and it makes it very hard to do other things. The body was just too tired. So, I understand that I as a duaghter, have to help my mother to do things. Who else would do these things?	My mother told me that: a clean house helps to make a sick person become better, faster. So, since I love my mother and I cannot see her suffer and be in pain for so long like she had, I made sure the house was not so bad.

An additional finding was that parent participants talked about their perception of how their children were able to contribute to their care, a task that they never thought their children could carry out. They were able to "grow up" and behave responsibly towards their parent, themselves and to look out for each other. They also learned new skill sets, of which they could put into practice independently.

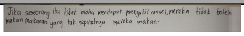
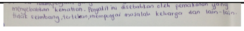
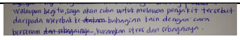
3) Children's reaction to changes in lifestyle

When information sharing was open and accessible, children participants' reacted positively in that their responses indicated an increase in the care, knowledge and adherence to their changed diet and lifestyle. The children participants were able to establish the relationship between diet, stress and a sedentary lifestyle to cancer. These children participant's repeated their parents' belief in eating a healthy balanced diet as a means of preventing cancer. Most children participants started to eat multivitamins and made healthier food choices. They also started to eat more fruits and vegetables and were less frequent to eat fried foods, especially fried chicken.

The older female children participants acknowledged the new diet and lifestyle changes as a positive change in their lives. They reported being more conscious about what they ate and their ill parent ate. Non-care-giving children participants indicated that the changes were something they considered as “good for them” and beneficial. However, it was unclear if those changes were imposed from the parents’ health circumstance or if it was their own inclination.

According to Table 4.18, other than diet and lifestyle changes, these children participants recorded an increased observance of religious practices. Both groups indicated often throughout the course of the session that they were thankful to God for being able to overcome the challenges of being a care-giver; the parent participants observed their children praying more regularly while children participants themselves believed in the power of prayer to help heal their ill parent. There was no in-depth discussion about religion, however, it was noted that children participants frequently thanked God for reducing the scope and depth of their parent’s side effects to the cancer treatments and prolonging their life.

Table 4.18 Successful information sharing markers - children participant’s reactions to changes in lifestyle

PARTICIPANT	REACTIONS TO CHANGES IN LIFE STYLE	
	Increase care, knowledge and adherence to changed diet and lifestyle changes.	Increased observance of religious practices.
Family One		
C2	Have to eat vegetables and eat fruits.	I pray that Mama got better.
C3	It is important to look after our health. We have to be particular about our eating habits. Less fried chicken.	I always pray that Mama got better … so that she won’t be in so much pain or so worried.
Family Three		
C1	 Jika seseorang itu tidak mahu mendapat penyakit cansel, mereka tidak boleh makan makanan yang tak sepatutnya mereka makan. If someone does not want to get cancer, they cannot eat foods that they should not eat.	I prayed every night before I go to sleep for God to make my mother stop crying and being in pain.
C2	 menyebabkan kematian. Penyakit ini disebabkan oleh pemakanan yang tidak seimbang, tertekan, mempunyai masalah keluarga dan lain-lain. Cancer is caused by an unbalanced diet, stress, having family problems and others. So, in order to not get cancer, we have to eat a balanced diet, have less stress and not fight in our family.	Thanks be to God she got better.
C3	 Walaupun begitu, saya akan cuba untuk melawan penyakit tersebut daripada merebak ke ~~dalam~~ bahagian lain dengan cara bersenam ~~dan sebagainya~~, kurangkan stres dan sebagainya. I would try to fight the disease from spreading to other body parts by exercising, reduce stress and etc.	Thanks be to God she is no longer in pain.
C4	Cannot fight in the family because that will cause everyone to be stressed and then they also might get cancer. Changed eating habits to eat more healthy.	I prayed that Mama would get better faster. I could not take it, seeing her in pain … getting scolded all the time … worried about upsetting her because I got my menses and she did not.
Family Four		
C1	She told that she maybe got cancer because she did not take care of her life before. So, because she loves me, I have to follow this new way of healthier life so that I don’t get cancer too.	Oh, yes. I prayed all the time. I prayed her hair would grow back long and lovely and that would make her happy. I prayed that she would not be in pain today.
Family Five		
C1	Cancer really made me understand that my mother would not be there for me forever and if I don’t want anybody in my family or future family to get cancer, then I have to make sure we eat healthily and no smoking.	Cancer really tested us. I prayed all the time for her life and for her to get better. Thank God we are still a family and that my mother has gotten better.
C2	Ya, I am careful of what I eat. I eat more vegetables now and I loved Pizza, but I don’t eat so much of that now. I also know that I need to get my vitamins because if I get sick, my mother could easily get sick from my germs and that would take her longer to get better.	Thank God she did not give up.
C3	Ah. And then as the oldest child, I think I have to be strong so that I can advise my siblings on what to do and what not to do, and tell them not to be sad. Because my father is the one who is sad.	Alhamdulillah, Thanks to God she is surviving and getting better and has her hair back. It even grew softer.
Family Nine		
C1	Yes, I know about cancer and how it can happen. So, I try to control not to eat unhealthy foods, to have a clean place, to be healthy.	Thanks to God!

4.4.iv.b Negative Outcomes

It was found that there were negative outcomes to children's understanding of cancer in families where attitudes to information sharing were closed and when information sources were considered inaccessible. Data suggested that children participants realised that when parents were reluctant to share information, they could not obtain satisfactory answers to their concerns about the parent's health situation and their role in the family.

When asked, parent participants indicated a number of reasons for not sharing information. As mentioned earlier (on page 6), some indicated that they were unable to communicate to their children, as they did not know what and/or how to inform their children. Some parents reported their own turmoil as a barrier to information sharing while some reported their need to appear "normal" to their children to ease children's fears and not disrupt the pre-diagnosis family dynamics. In the case for Family Eight, the closed and inaccessible attitude of the parent participant could be considered as a cause for the children participants' lack of understanding and subsequent attitude towards cancer and their new circumstances. The following excerpts indicated this:

[F8(P)]: We did not know how to tell the children … we hoped that they would notice and understand on their own.

[F8(P)]: I did not know what to say. It should be the doctorlah who gives the information to my children. They can ask when he checks me in the hospital

[F8(P)]: I really did not know know what to say to my children. I really needed the doctor to help me with what to tell my children. I think I gave my children the wrong information.

[F8(P)]: Hiya, sometimes, you don't feel like talking. You are in pain, so, the best is to get them look it up for themselves. We have Internet, so they have to figure things out on their own already.

From the excerpts above it could be inferred that the parent justified her non information-sharing attitude because of her not knowing how she may have shared information and what she could say to help the children understand her health situation and the changes their family would experience. She had also assumed that her children could "figure things out on their own". [F8(P)] added later that she came to realise that by not sharing her experience and not sharing information about her situation worsed the relationship between her children and increased the frustration and anger of her daughter on whom she expected to somehow already know what needed to be done.

[F8(P)]: She should know what to do already … I did not realise that she really didn't … that it was too much for her.

In the case of Family Six, the parent indicated that she did not know how to talk to her children about her cancer or how to alleviate care-giving tasks. Other than the inability to communicate, she also indicated that she was experiencing too much turmoil to have been able to share information with her children about her situation. Parent participants in Family Two and Family Seven echoed her sentiment of pain being a barrier to information sharing as well. An excerpt of this sentiment is provided below.

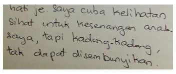
[F2(P)]: *Hiya, the pain, such terrible pain … you cannot think.*

[F6(P)]: *I guess it was just too hard for me to think. I cannot think of how to talk to them about it. They were much younger you know. How do you tell a six-year old things like that? At that time, I barely understood what I was going through myself. It was even harder to tell them and make them understand.*

[F7(P)]: *When you are sick, like I was, you can't think about anything else.*

In the case of Family Four, hiding a health situation was important to appear "normal" to her children and to not disrupt the family dynamics. This is indicated in the excerpt below:

[F4(P)]:



hati je. Saya cuba kelihatan
sihat untuk kesenangan anak
saya, tapi kadang-kadang,
tak dapat disembunyikan.

I try to appear healthy for the comfort of my children, but sometimes, I cannot hide it.

[F4(P)] *I really did not want my children to be too worried, or sad, or at anytime upset if they saw me in a sick condition … I knew that if I should them how very sick or in pain I really was, they would be more worried or upset.*

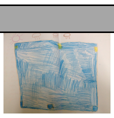
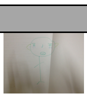
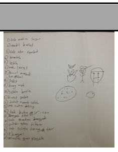
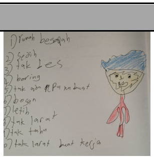
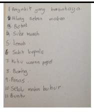
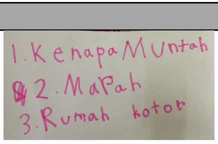
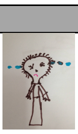
[F4(P)] *Well, when the children get upset, I fear that they cannot study. Can you study if you were very worried about your mother? No, right? So same here lah.*

However, parent participants' own admissions and children participants' reports contradict their parent's rationale for not sharing. Children participants indicated the result of not sharing information in several ways. Similar to **4.3.iv.a Positive Outcomes** (on page 180), the data found several following outcomes that can be considered as unsuccessful information sharing markers. The outcomes were categorised as 1) Children participants' reaction to cancer and cancer treatment, 2) Children's reaction to changes in familial dynamics and, 3) Children's reaction to changes in lifestyle which included children participant's indication of decreased care, knowledge and adherence to changed diet and lifestyle changes. There were no indicators of decreased religious practices. These outcomes are discussed below.

1) Children participants' reaction to cancer and cancer treatment

When information sharing was closed and inaccessible, comparative children participants' responses indicated that they had less understanding about cancer, its causes and the cancer treatments. They were less able to provide a definition of cancer; they hardly used medical terms and they described a more negative emotive and mental experience when their mother was undergoing treatment. It seemed that since these children participants had less knowledge but were still involved with their parent's treatment and recovery process; they exhibited a decrease in love, patience and empathy toward their ill parent. Other than that, children participants' responses indicated that they understood less the importance of the cancer care continuum. Excerpts indicating these negative outcomes are in Table 4.19.

Table 4.19 Unsuccessful information sharing markers – children participant's reactions to cancer and cancer treatment

PARTICIPANT	REACTIONS TO CANCER AND CANCER TREATMENT Indicated a lack of understanding of cancer, its causes and the cancer treatment.	 Indicated a decrease in love, patience and empathy toward ill parent.	 Indicated less understanding of the importance of the cancer care continuum.
Family Two			
C1	I think, mother is in pain because the doctor said that she had to remove the pain there. Like a toothache. If it is damaged and painful, it needs to be removed. When you do that, it is painful	She (mother) cannot take care of me as before. She (mother) can not be a true mother anymore."	My mother said she needed to sleep. But so long already ...
C2	Mama said that having cancer made her upset and cry. So, cancer is something that makes a person cry.	Cancer is the time when mother got very sick. She was sick for so long. She always asked to be massaged, she slept a lot and when she does not sleep, she just lied in bed.	Mother told me that the doctor injected her with medicine to fight the disease in her body.
C3	Like what older sister told me: cancer is dangerous because the patient can die.	I don't see why she cannot do things herself. She slept for most of the day anyway, so she should be OK already. Don't know whay she was still tired, all the time.	The doctor should take care of her.
C4	Cancer is a disease that is dangerous that you can get suddenly and it can cause death.	Why did cancer make my mother take so long to get better? We were not nurses to know how to take care (of a sick person).	Emak had breast cancer and she was sick for a long time and she had to be treated at the hospital and operated on and injected with medicine so that the cancer would not spread.
Family Six			
C1	 Cancer meant that you have to stay in the hospital alone for a long time.	 I did not like my mother being sick. She cried because she became bald and her bald head scared me.	A scary sickness that took a long time to get better from. I don't know why.
Family Seven			
C1	Cancer means, the person who's not strong cannot survive the medicine.	I think her sickness was troublesome ... I had to do my own things.	Why did it take her a long time to get better?
C2	Something in body grows too big and that thing kills the person.	Yes, I pitied her, but ... I don't know. She was sick for a long time, I was sick of it.	Uggh! Always the vomiting that I had to clean up ... the smell ... the gagging, made me want to vomit too.
Family Eight			
C1	 1) Not eating vegetables, 2) Not caring, 3) Bald, 4) Vomit, 5) Tired, 6) Not having energy, 7) Going to the hospital very often, 8) In pain, 9) Spitting bile, 10) Always lying down, 11) Not able to go out, 12) Always staying at home, 13) Don't like noise, 14) Not switching on the air-conditioning, 15) Frequently sleeping, 16) Seldom eating, 17) Sitting on the bed, 18) Watch TV infrequently, 19) Day dreaming, 20) Vomit into a plastic bag.	 1) The house is messy, 2) Sad, 3) Not "best", 4) Boring, 5) No hair, 6) Boring, 7) Tired, 8) Fatigued, 9) I don't know, 10) Too tired to do housework	Why did it take a long time for her to get better? Why was it so boring?
C2	 1. A dangerous sickness, 2. Loss of appetite, 3. Bald, 4. Likes to get angry, 5. Weak, 6. Headache, 7. Purplish nails, 8. Lying down, 9. Heaty, 10. Always eating porridge, 11. Can't think	 (laughed) Mama was not happy that she did not have hair. The cancer ... and the medicine were too strong. All her hair fell. (laughed)	Too long for her to get better.
Family Ten			
C1	 1. Kenapa Muntah 2. MaRah 3. Rumah kotor 1) (Why did cancer) make her vomit? 2) (a person with cancer is) Angry, 3) House becomes dirty.	 She became bald like some orge.  She cried because she got very thin.	I don't know.

2) Children's reaction to changes in familial dynamics

When information sharing was closed and inaccessible, children participants' responses indicated that they understood less the reasons for their new roles and tasks. Even though most children participants reported their knowledge that their parent was too ill, too tired or recovering from cancer treatment to complete their "normal" tasks, they could not relate the severity of their parent's disabilities to carrying out "normal" and pre-diagnosis tasks. This could indicate that parent participants did not share sufficient information for their children to understand their new roles and tasks. It can be inferred that these children participants' were comparatively less empathic in the tasks and roles their ill parent carried out before, even though they complained about the difficulty in carrying out those very tasks themselves. The lack of information seemed to contribute to these children participants being unable to relate to the suffering and inability of their ill parent.

In addition to that, when these children participants reacted to a new health situation, their ill parent was not open to discussion, was not willing to share information and was impatient when instructing their children on care-giving tasks. These children participants did not have sufficient information and found it difficult to develop the necessary skill sets as a care-giver. Children participants reported that they did not know why or understand why they had to do tasks and some reported no prior knowledge or tutelage of carrying out some tasks, especially care-giving tasks. They reported being scolded or that their parent was angry when tasks were not carried out in the manner that the ill parent would have done. This lack resulted in the children participants being less willing to take on the responsibilities as a caregiver.

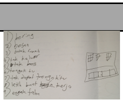
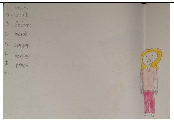
Parent participants talked about their perception of how their children were unable to contribute to their care. The behaviour of these children participants seemed to give credence to their parent's belief. An excerpt from Family One indicated this:

[F1(P)]: *These kids don't understand. This thing(referring to cancer) is not fun and games. When the pain comes, God only knows. I am sitting alone thinking about death (sobs). These kids don't understand . . .*

Tasks were carried out in various degrees of success. Parents and younger siblings expected 'normal' tasks of parents to be carried out in a similar manner as was performed by the ill parent before the diagnosis. As indicated earlier, some parents hoped their children would take on their 'normal' tasks as a matter of course or 'automatically' without instruction of specific tutelage. In instances when children participants failed to perform in the same manner, both participant groups reported that children participants were scolded and berated.

Children participants acknowledged that their parents' 'normal' tasks were often difficult, time consuming or tiring. Care-giving tasks were even more so. The children were less cooperative, less willing to contribute to care-giving and household chores and showed negative attitudes that were not as discernible prior to their parent's diagnosis. The children participants seemed to reluctantly learn new skill sets, of which they would rather not repeat when the ill parent became healthier. Excerpts indicating this are presented in Table 4.20.

Table 4.20 Unsuccessful information sharing markers – children participant's reactions to changes in family dynamics

	REACTIONS TO CHANGES IN FAMILIAL DYNAMICS	
PARTICIPANT	**Did not understand new roles and tasks.**	**Impatient and less willing to help**
Family Two		
C1	I have to help around the house, but not so much because I am the youngest.	I am the youngest and smallest. I cannot do … things
C2	I help a bit, but my older sisters do more. I just have to take care of my self and my younger sister. Like hold her hand when we walk to class.	I don't know how to do those things. My older sisters do. I help when my mother tells me to do or to follow what my eldest sister order me to do.
C3	Yes, but, I am not the oldest. The eldest have to do evrything. That's how it is.	My older sister is stronger, taller and born first. So, she has to do the work. I just help when my mother tell me.
C4	It is not fair that I have to everything. Why me?	These tasks were diffucult. I could not do them on my own.
Family Six		
C1	Yes, I know she was always in pain, but all the time and everyday? Hiya, I am not the maid to do everything.	I can help, but mother was always in a bad mood so I don't want to do any work now. Always scolding because something is always not right.
Family Seven		
C1	No … I don't know why I had to do the work.	My sister does the work lah. I don't know how.
C2	It was always me who had to do the cleaning and taking care of my mother.	It was difficult and took a lot of time. It got tiring and troublesome and no freedom.
Family Eight		
C1	 1) Boring, 2) Boring, 3) Stay at home, 4) Can't go out, 5) Not "best", 6) Can't watch television, 7) Tired doing housework, 8) I don't know (why)	My sister is the girl, she is supposed to do those things
C2	 1) Afraid, 2) Sad, 3) Fed-up, 4) Angry, 5) Silent 6) I cannot tell anyone), 6) Boring, 7) Tired	Girls have to do the taking care. I don't know why, when it comes to cancer, the husband or the brother always don't care. It was unfair … I had to do eveything all the time. I have to figure things out on my own and I cannot even ask how to do something. I am supposed to have known already. How? I am always scolded.
Family Ten		
C1	 I don't like … I have to clean up lah and sometimes OK, but sometime, I don't like. Tired.	Ummi told me she was tired and needed to rest. She's always sleeping. (shows irratation in face and voice intonation) She tells me to do it because I make the mess and the house is dirty.

3) Children's reaction to changes in lifestyle

When information sharing was closed and inaccessible, children participants' reacted negatively in that their responses indicated a decrease in the care, knowledge and adherence to their changed diet and lifestyle. The children participants were less able to establish the relationship between diet, stress and a sedentary lifestyle to cancer. These children participant's reluctantly followed their parents' belief in eating a healthy balanced diet as a means of preventing cancer. In some cases, their reluctance was conveyed through anger at their parent or the forced lifestyle change. In others, their reluctance was conveyed through disgust towards eating vegetables. This is indicated in Table 4.21

Table 4.21 Unsuccessful information sharing markers- children participant's reactions to changes in lifestyle

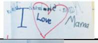
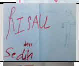
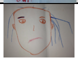
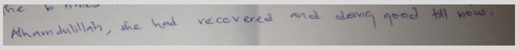
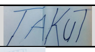
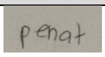
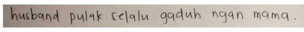
PARTICIPANT	REACTIONS TO CHANGES IN LIFE STYLE
	Decrease care, knowledge and adherence to changed diet and lifestyle changes.
Family Two	
C1	I don't like the green food
C2	(puts hands over the mouth when sisters talk about eating vegetables)
C3	I don't like to eat fruits and vegetables. I can vomit
C4	Forced to eat fruits and vegetables because if not we get cancer. I always have to scold my sisters to eat them. Sometimes they spit it out and start gagging. So, we all start to gag and end up not eating.
Family Six	
C1	Boring … Angry. I cannot eat KFC, no Pizza, no more McDonalds. I only want to eat it once in awhile, not all the time…
Family Seven	
C1	Just like my mother, no salt no sugar so, taste no sugar. Have to eat vegetables, Yuck.
C2	Umm, I don't like it. Boring … fed-up. I get enough exercise from all the work I do at home. My food also has to control?
Family Eight	
C1	Boring. Not the same as before, not "best".
C2	Fed-up. I have to follow, but nobody else does. Not fair.
Family Ten	
C1	Have to eat more vegetables. I don't like vegetables … I have to be more quite because Ummi would get a headache and it would take longer for her to get better. Very hard to behave and be a good girl.

In addition to the information sharing markers, children participants also exhibited emotional reactions to their situation and the health status of their parent.

4.4.iv.c Children's emotive reactions to their parent's cancer.

An inquiry was made to assess children's emotive reactions to their parent's diagnosis and subsequent behaviour. Children participants own reactions toward several overt side effects and care-giving tasks were explored. Data collected and analysed from interview questions, observances and the questionnaire provided information about children's reactions. It was found that irrespective of their parent's attitude to information sharing, children participants exhibited several emotive reactions.

The children participants picked up non-verbal cues from their parents about how cancer affected them. This ability belied the intent of their parents to protect them from emotional distress. There were two polarities to children's emotive reactions to cancer and care-giving tasks: positive and negative emotive reactions. The basis for categorising children participants' reactions is provided in Table 4.22.

Table 4.22 Basis for categorising children participants' positive and negative emotive reactions		
POSITIVE REACTIONS	**CHILDREN'S RESPONSE**	
Increased love	*[F1(C2)]:*	 *"I love Mama even she had cancer."*
Increased care	*[F1(C3)]:*	 *"I knew that she was worried and sad."*
Increased empathy	*[F3(C1)]:*	 *"Mama's hair fell out. I pitied her. No hair, was embarrassing for her."*
Increased religious observance	*[F5(C2)]:*	 Alhamdulillah, she had recovered and doing good till now. *"Alhamdullilah, she had recovered and doing good till now."*
NEGATIVE REACTIONS	**CHILDREN'S RESPONSE**	
Decreased love	*[F8(C1)]:*	*"… she (mother) could not take care of me as before"*
Decreased care	*[F8(C2)]:*	*"The cancer … and the medicine was too strong. All her hair fell. (laughs)"*
Decreased empathy	*[F7(C1)]:*	*"I don't know how that (medication) helps. Seems to make you (mother) vomit all the time. How can that help?"*
Feared cancer and cancer treatments	*[F2(C4)]:*	*"Cancer is dangerous as it can lead to death because of a growth in the body that can spread if not treated, the cancer patient can die."*
Feared parental death	*[F5(C3)]:*	*"I have to make sure my mother fights this cancer, if not I fear she will die."*
Feared pain	*[F1(C3)]:*	 *"I feel that cancer is scary because it feels very painful."*
Feared hospitals and health tools	*[F1(C3)]:*	 *" … afraid when the doctor injects (pointing to syringe) the cancer medicine or painkillers …"*
Feared parents' hair loss	*[F6(C1)]:*	*"Ahyo! That was scary, like alien! I was afraid."*
Feared losing own hair	*[F9(C1)]:*	*"I did not want to be in the same room with her. I did not want to get her baldness."*
Disgust towards parent when ill	*[F2(C2)]*	 *"Uggh! Emak was vomiting all the time. She would vomit into a plastic bag, or hurry to the toilet. Sometimes, she won't make it and it was disgusting and smelly. Made me want to vomit too. Yuck."*
Worried about getting cancer	*[F8(C2)]:*	*"Since cancer can spread, will I get that? Cancer in my lungs?!"*
Resented new tasks and changes to family dynamics	*[F8(C2)]:*	 *"I felt so tired of helping mak and being with her all the time and of doing the housework"*
Resented non caregiver sibling(s)	*[F8(C2)]:*	*"My brother doesn't do anything about his own mess."*
Resented father	*[F3(C4)]:*	 husband pulak selalu gaduh ngan mama. *"… and husband always fights with mama."*
Felt tired, frustrated or overwhelmed by care-giver tasks	*[F8(C2)]:*	*"… I really don't like how she (mother) did not seem to get better and that I always have to help her. She (mother) hardly ever asks my brother. It is not fair. Always, I have to do the work and still I get scolded and cannot rest to watch television, but my brother, he can play soccer and make a mess. I look out for mak and I also have to clean up after him. This cannot be. It makes me so … fed-up and so angry!"*
Resented new health and lifestyle changes	*[F7(C1)]:*	*"Just like my mother, no salt no sugar so, taste no sugar. Have to eat vegetables, Yuck."*

This indicated that children experienced emotional reactions to cancer and care-giving. In families where the information-sharing attitude was more open and accessible, children participants reported more incidences of positive emotional reactions and exhibited their love, care and empathy. However, where the information-sharing attitude was more closed and inaccessible, children participants reported more incidences of negative emotional reactions and exhibited those emotions in many ways. This is tabulated in Table 4.23.

Table 4.23 Children Participants' reactions to parental cancer and care-giving tasks

	POSITIVE REACTION				NEGATIVE REACTION															
CHILD PARTICIPANT	Increased love	Increased care	Increased empathy	Increased religious observances	Decreased love	Decreased care	Decreased empathy	Feared cancer & cancer treatments	Feared parental death	Feared pain	Feared hospitals and health tools	Feared parents' hair loss	Feared losing own hair	Disgust towards parent when ill	Worried about getting cancer	Resented new tasks and changes to family dynamics	Resented non care-giver sibling(s)	Resented father	Felt tired, frustrated or overwhelmed by care-giver tasks	Resented new health and lifestyle changes
FAMILY ONE																				
C1				✓		✓	✓	✓		✓	✓	✓		✓						✓
C2	✓	✓	✓	✓				✓	✓	✓	✓	✓								
C3	✓	✓	✓	✓				✓	✓	✓	✓	✓	✓		✓	✓	✓		✓	
FAMILY TWO																				
C1				✓				✓		✓	✓	✓		✓						✓
C2				✓				✓		✓	✓	✓		✓						✓
C3				✓				✓				✓		✓		✓				✓
C4				✓				✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
FAMILY THREE																				
C1	✓	✓	✓	✓				✓	✓	✓	✓	✓								
C2	✓	✓	✓	✓				✓				✓		✓		✓				
C3	✓	✓	✓	✓				✓		✓		✓			✓	✓				
C4	✓	✓	✓	✓				✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
FAMILY FOUR																				
C1	✓	✓	✓	✓				✓				✓		✓	✓	✓	✓		✓	✓
FAMILY FIVE																				
C1	✓	✓	✓	✓				✓	✓	✓	✓			✓						
C2	✓	✓	✓	✓				✓	✓	✓					✓					
C3	✓	✓	✓	✓				✓	✓	✓					✓				✓	
FAMILY SIX																				
C1				✓		✓		✓		✓	✓	✓	✓	✓		✓	✓		✓	✓
FAMILY SEVEN																				
C1				✓	✓	✓	✓	✓		✓		✓		✓		✓				✓
C2				✓		✓	✓	✓		✓	✓	✓	✓	✓		✓	✓		✓	✓
FAMILY EIGHT																				
C1				✓	✓	✓	✓	✓		✓	✓	✓		✓		✓				✓
C2				✓		✓	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓	✓	✓
FAMILY NINE																				
C1	✓	✓	✓	✓				✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	
FAMILY TEN																				
C1						✓	✓	✓		✓	✓	✓	✓			✓	✓		✓	✓
TOTAL	11	11	11	22	2	7	6	22	9	19	15	19	7	14	9	14	9	4	10	12

According to Table 4.23, even though children participants exhibited positive reactions, they still felt several negative emotional reactions. When side effects of cancer were overt and visibly startling, like hair loss and frequent vomiting, all children participants reported some degree of fear. The difference was that these children had fewer incidences in the extent, scope and frequency of negative emotions. They seemed less afraid of parental death, felt less disgust toward their parent when the parent was ill and did not feel as resentful of the health and lifestyle changes. Information sharing and interaction mitigated or lessened the negative emotional reactions. This was recorded in families One, Three, Four, Five and Nine.

Children participants assimilated different meanings to their parent's behaviour. This resulted in many misunderstanding and resentment between children participants and their parents. However, this phenomenon was not investigated thoroughly because this specific exploration was beyond the scope of the research questions. For children participants who were caregivers, the fear of parental death, hospitals and health tools as well as hair loss seemed to provide signals that the parent's condition was deteriorating. These fears contributed to feeling overwhelmed with care-giving tasks and resentment towards their other siblings and healthy parent. They also experienced symbiotic fear of pain, hair loss and were worried that they would get cancer too. This contributed to their increased fear of cancer. In summary, the role of information for dependent children of cancer patients was explored through two polars of positive and negative outcomes. This was discussed against five variables of 1) parent participants' attitudes to information sharing, 2) outcomes of information sharing, 3) consequences: children's reactions to cancer and cancer treatment, 4) consequences: children's reaction to changes in familial dynamics and, 5) consequences: children's reaction to changes in lifestyle. This is tabulated in Table 4.24.

Table 4.24 What consequence does children's understanding or lack of understanding have?"

	POSITIVE	**NEGATIVE**
Attitudes to information sharing	Open and accessible information	Closed and inaccessible information
Outcomes	Positive and indicates understanding of cancer	Negative and indicates lack of understanding of cancer
Consequences: Children's reaction to cancer and cancer treatment	• Increase in love, patience and empathy toward parent. • Increased understanding of the importance of the cancer care continuum.	• Decrease in love, patience and empathy toward parent. • Decreased understanding of the importance of the cancer care continuum.
Consequences: Children's reaction to changes in familial dynamics	• Understanding new roles and tasks. • Increase in patience and willingness towards burden of care.	• Does not understand new roles and tasks. • Decrease in patience and willingness towards burden of care.
Consequences: Children's reaction to changes in lifestyle	• Increase care, knowledge and adherence to changed diet and lifestyle changes. • Increased observance of religious practices.	• Resent and feel forced to adhere to changed diet and lifestyle changes. • No indication of negative change towards religious practices.

The excerpts of transcripts from this section and data explication suggest that information was vital for the children participants to cope, understand and adjust to parental diagnosis and their role as caregivers. A lack of information resulted in three main reactions: 1) Children exhibited emotional distress and children had less understanding about cancer, its causes and treatment, 2) Children practiced misguided health and lifestyle changes and, 3) Children reacted negatively to new tasks and responsibilities.

4.5 WHAT INTERVENTIONS MAY BENEFIT CHILDREN AND ENABLE THEM TO COPE WITH THEIR PARENTS HAVING CANCER?

An integral part of this research was to find out what children participants wanted to know. The data for this research objective was obtained through Question 8 (“If you needed more information, what kind of information did you want?”) from the “Information Source Questionnaire” and through individual interviews in session four that further expounded children participant’s responses. In order to relate to the health situation that children participants experienced, their parents’ observation on this inquiry was also solicited.

As evident from narratives and findings, these children participants had unmet needs. The unmet needs generated co-development of suggested interventions that may better relate to children’s information needs and information seeking behaviour. It was anticipated that at least one of the participants’ suggested solutions could relate better to the required needs and abilities of children to make sense of their circumstances. Another outcome was that the solutions might bridge complex medical terms and definitions to match the abilities of children. An additional outcome was that these solutions might mitigate some possible negative experiences of future children and their families.

The inquiry provided ten options of responses: nine variables that were anticipated and one open-ended variable that allowed children participants to self-report. The open-ended variable was important because while children participants might concur with the anticipated information needs, they could either elaborate on the existing nine variables that were anticipated responses or they could report unanticipated aspects of children’s information needs. These unanticipated aspects could arise from the children participants’ culturally different demographics than have taken place in previous studies.

Among the nine anticipated variables, the top three information needs of care-giver children participants were: i) What will happen to my parent, ii) How I can help and iii) Food and diet. Among the three variables, the open-ended question had the most number of responses from both caregiving children participants and other children participants. Contrary to the previous indications of several children participants who indicated that they had sufficient information, it was found that the open-ended question provided an opportunity for most children participants to elaborate on their concerns in a constructive manner. Their responses contributed new knowledge and nuances to the types of information that children of cancer patients might require in order to make sense of their new situation and to cope with the challenges they faced. This data was collected from the second and third focus group sessions. Participants were presented with a list based on the issues they raised and/or discussed. The is as summarised in Table 4.25:

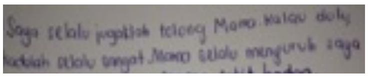
Table 4.25 List Of Participants' Issues Raised and/or Discussed

PARTICIPANTS' ISSUES		
LANGUAGE PREFERANCE		
Written: Bahasa Malaysia	Verbal: Bahasa Malaysia	
CANCER SPECIFIC INFORMATION		
Definition of Cancer	Definition of Disease	Types of Cancer
Is cancer dangerous?	Is cancer contagious?	Cancer detection
Treatment process flow	List of possible side effects of cancer treatment	Cancer prevention
Why does cancer take a long time to recover from?	Why does chemotherapy cause vomiting?	Why does chemotherapy cause hair loss?
How to ask parents about cancer?	How to tell children about cancer?	How to tell children about diagnosis?
FORMAT		
Interaction with ill parent	Interaction with healthy parent	Interaction with attending doctor
Interaction with other children in a similar situation	Interaction with counsellors at cancer centres	Talks at school
Comic book with problem-solving setting	Reference book with many pictorial references	Easy-to-read guide book
Dramatised story of a family with cancer	Dramatised problem solving situation	Reality television of coping with cancer in the family
Magazine article	Newspaper article	
CHILDREN'S CONCERNS		
How to care for a cancer patient	List of possible ways to help parent with cancer	List of possible changes to familial roles
How to take care of self	How to take care of younger siblings	How to talk to parents about the parents' cancer experience?
Assurance of continuation of care and love towards the child	How to talk to parents about what made the parent upset	How to talk to parents about what made the child upset
How children can show their care towards the ill parent	Why are household chores unequal	Why girls have to do more care-giving tasks
Why is father less helpful / less supportive?	How to approach ill parent when the ill parent looks bad/disgusting/not normal	How to not be scolded often
Why is ill parent emotional?	How to make ill parent to be less emotional	How to calm ill parent when ill parent is angry or upset

From here, it was found that children participant's information needs were more varied than previously anticipated. Children participants reported many types of unmet information needs, in particular were cancer information and caregiving support. Participants then cast votes on which of the items were the problems they had the most concern. In exploring these children participants' information needs, the priority information problems were put into the context of themes and in order of descending importance, were identified information needs relevant to their concern of accomplishing care-giving tasks, explanation for parent's recovery from cancer, how to instigate an interactive dialogue about their concerns and, how to prevent cancer. These detailed responses were similar across family groups. It is to be noted that since the sample size was too small and findings indicated that the distribution of responses across subgroups were too skewed to a specific response, no statistical assessment will be presented. However, an indication of children participants' responses will be made to illustrate and support findings accordingly.

4.5.i Accomplishing care-giving tasks

Most children participants indicated that they were willing to help their parent recover from cancer as well as to support their parent by temporarily taking the responsibility of household tasks and caring for younger siblings. Most of these children participants understood that they had a responsibility to help out and most were willing to help as indicated by a children participant:

[F3(C2)]:  *(reading) I **quite often help** Mama. Last time (before diagnosis), not as often (laughed).*

*[F5(C1)]:Ya, my mother, she could not do the (house) work for a while. I had to **help** out too, had to learn how to iron my own clothes.*

*[F5(C3)]:Ya la, I have to **help** her. Somethings you just have to do.*

The open-ended question allowed for children participants to further elaborate on this variable. It seemed for these children participants and their family dynamics, having to take care of their ill parent and filling in for the ill parent for the care of younger siblings was a culturally imposed "automatic" task that could be attributed to their role as the eldest female child. Some parent participants indicated that they had assumed their children would "automatically" know what to do to carry out household tasks and care-giving tasks. However, the open-ended question inferred that contrary to parent participant's belief, their children did not know how to "automatically" carry out the said tasks, as they had no proper tutelage or supervision. Most of these children participants did not know how to help or how to offer help. In addition to that, children participants had more limited capacity and capabilities than their parents. Children participants indicated that other than care-giving tasks, household chores that were previously the responsibilities of the mother were considered difficult. This difficulty seemed to be a result of these children participants' inability to carry out the said tasks in the same manner as their parent. Several children participants indicated this:

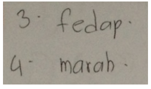
[F1(C3)]: *How to help mama?*

[F5(C3)]: *As the eldest, I must know what is going on so that I can be there for my mother … help her in whatever way I can. Ya, I know my mother needed care and help, and I did help as I could. I don't mind helping out, she just have to tell me. I'll get to it … a bit later lah, but I get to it.*

These children participants reported their feelings of frustration, tiredness, anger and thoughts that the tasks were beyond their abilities or overwhelming. In some instances, children participants also wanted parent to realise that tasks were not distributed equally and that the tasks were not commensurate with the physical abilities or capacities of the specific child. They had complained that the scope of tasks and the distribution of responsibilities were unequal among siblings. This was indicated as:

[F4(C1)]: *I thought that there was a possibility that I had to accompany Ibu to stay the night at the hospital, but I had school and Ayah had work the very next day. I did not know what was going on.*

[F8(C2)]:



3· fedap·
4· marah·

Fed-up *(with doing the housework and twin does not have to) …* ***angry*** *(because she had to do the housework while twin could play) …*

[F10(C1)]:

I drew me sweeping … I have to clean up lah and sometimes OK, but sometime, I don't like. Always have to clean. I am not a maid (domestic helper) you know.

Parents were requested to instruct or ask without shouting or being angry. For example, children participants said:

[F5(C1)]: *Must she scold?*

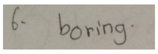
[F6(C1)]: *Just say what needed to be done. Don't have to be angry or shout.*

Despite these limitations and the manner in which tasks were delegated, children participants were still expected to carry out tasks in the same or similar manner as their parent. Children participants were also concerned about the ability of their parent to resume their prediagnosis "normal" tasks. It seemed that, in some cases, the burden of care and responsibilities for household tasks was a series of activities that was prolonged throughout their mother's recuperation. In the case of the parent from Family Nine, this time frame stretched to four years from the date of the cancer diagnosis. Pursuant to that situation, children participants felt that it was important for parents to realise that they did not want to take on tasks indefinitely. Children participants needed to know how long their help was required. They specifically wanted their parents to realise that taking on those tasks could not be a continued expectation of them. They wanted information as to how much longer the parent would be indisposed and if the family dynamics of household chores and responsibilities would be "normalised". Some children participants wondered:

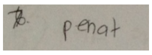
[F1(C3)]: *I had to be in charge, but it was difficult. I know she was sick, but I would have liked to know how long she was going to be sick … I remember thinking: I had to take care of her, who will take care of my younger siblings? I cannot: I also have school, homework, exams …*

[F5(C1)]: *I mean carry stuff, anything heavy ... Before (while mother was undergoing treatment) I do ironing, now I don't.*

[F8(C2)]:



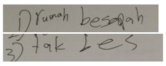
6. boring.



8. penat

*... **Boring** (with housework) … ... **tired** (from doing the housework)*

[F8(C1)]:



1) rumah besepah

3) tak Les

*The **house is messy** ... Not "best" (mother did not provide the same care as before diagnosis) … Felt like a long time for her to get better.*

4.5.ii Explanation for parent's recovery from cancer

The findings indicated that many care-giver children participants were concerned with how cancer impacted their once-healthy parent. They were concerned with what would happen to their parent throughout the cancer treatment process and recovery period. Children participants, especially care-givers, were in close proximity to their parent when side effects of cancer treatment manifested. In accordance with the care-giving tasks listed earlier, these care-giver children participants witnessed and experienced first-hand their parents' hair loss, bodily aches and pains, onset of nausea and frequent vomiting. Many children participants did not know about the possible side effects and so were not prepared to witness and help parents recover from said side effects. For example, when asked to expound to what extent the care-giver children participants were concerned about their parent, several children participants explained:

[F5(C3)]: *Oh when my mum got it, I felt it was important for me to know what was going on, to know if my mum was going to be OK, what she needed, to know what need to be done lah, to be alert. Their changes in their body? I would like to have known the types and treatments that has to be done … you know, the medicine, treatment and food that my mother could eat or not eat … and then as the oldest child, I think I have to be strong so that I can advise my siblings on what to do and what not to do, and tell them not to be sad. Because my father is the one who is sad.*

She cannot face this cancer on her own, she needs people, family, her children, it is important for me to be there for her and for my sister and brother … I need to be with her when she goes to the doctor, when she had her operation, I was there you know.

[F2(C4)]: *The doctor and my mother said that cancer caused my mother to be in pain. The chemo medicine also made her be in very bad pain. What kind of pain? How much pain was she in? She was in pain all the time, what happened to her when she had to go for chemo? Really, what was going on? How come cancer and chemo made her feel pain? Oh, she had all kinds of pain …*

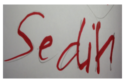
[F8(C1)]: *"Uweek!" into the plastic bag. Each time she came back from the hospital … all the time … for days … I don't know why … it sounded as if she would die from vomiting.*

Other than the side effects of cancer treatment, the open-ended variable provide insight on what other issues were relevant to the children participants' concern toward their parent.

Most children participants, regardless of their role as care-giver or non-care-giver, recognized that their parents exhibited new and extraordinary behaviour after diagnosis. These behaviours were very different from their parent's "normal" behaviour. Parent participants informed the research that their abnormal behaviour could be attributed to the fear of death and the concern for children's care. These concerns impacted the mental and emotional well being of the ill parent and, as a result, the ill parent exhibited the abnormal behaviours children participants remarked on. While parent participants tried to hide or disguise their turmoil, children participants could still decipher the covert non-verbalized cues as something was wrong or something was out of the ordinary.

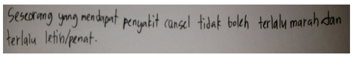
Children participants detected their ill parent as feeling sad, worry, anger, stress, frustrated and not in the "mood". Even though children participants at times misconstrued the parent's true mental or emotional expression, they nevertheless were concerned about their parent's health status, recovery time and pain management. For example, several children participants explained:

[F1(C3)]:  RISAU *She (mother) felt **worried** and **sad**.*
SUZIE: Why do you think she felt worried?
*[F1(C3)]: (nervous laughter) **I don't know**. She just **looked worried**.*
SUZIE: How do you know she looked worried?
*[F1(C3)]: Umm, because **her face looked worried**.*


Sedih

SUZIE: Ok, what about the 'sad' that you wrote here?
*[F1(C3)]: Aaaa . . . she's (mother) **sad**.*
SUZIE: How do you know she's sad?
*[F1(C3)]: I see her **crying** and I ask why.*
SUZIE: What did she say?
*[F1(C3)]: She says she's **worried**. But sometimes she does not say why.*
SUZIE: But, you see from her face that she looks sad?
*[F1(C3)]: Ahuh (in agreement). Sometimes she does not have the **'mood'***
*SUZIE: What do you mean **'Mood'**?*
[F1(C3)]: Does not want to go out. Does not tell stories like before.
SUZIE: Why is that?
*[F1(C3)]: (Shrugs shoulders) **I don't know**. She just doesn't have the **mood**.*
SUZIE: Hmmm. . . (Pause) Does mama always cry?
*[F1(C3)]: Umm . . . not always. I **hear** her from the room and have **seen** her **cry**.*
SUZIE: So, mama does not want other people to know that she cries?
[F1(C3)]: I guess so.

[F3(C2)]:

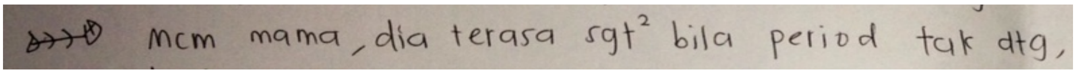


Seseorang yang mendapat penyakit cansel tidak boleh terlalu marah dan terlalu letih/penat.

Someone (pause) someone who has cancer cannot always be ***angry*** *and* ***tired*** *or* ***fatigued*** *... aaa ... if someone has* ***cancer****, the person who has* ***cancer cannot*** *(pause and then reading)* ***always be angry*** *because it could make that person* ***feel tension*** *... that means, I have to make sure I don't make her feel so tension. If not will take longer to get better. That's what she (mother) said.*

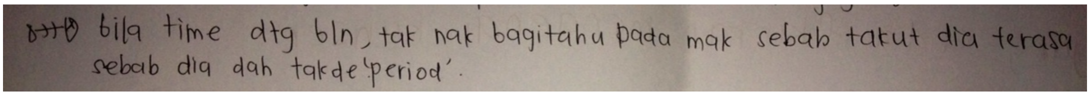
F10(C1)]: She (mother) also became like a monster ogre ... (made shouting and grunting noises) She ***shouted*** *and I don't know ... she was always* ***mad*** *about something, the noise, so hot, baba (father) not being home ... there were just some things that made her* ***angry*** *almost every day. Really, (makes monster grunting and shouting noises) and then she threw things and then she cry because she broke her stuff.*

In addition to that, the data seemed to indicate that these children participants wanted to limit the frequency and extent of their parents' outburst. They also wanted to mitigate the impact of those outbursts to themselves. It seemed that for these children participants, they recognized that their parent was upset about something. Children participants reacted by seemingly wanting to analyse for possible causation(s) and took steps to limit or stop such emotional behaviour from their parent. In several cases, children participants reacted to a situation by processing causation-and-effect on their own because their parent was inaccessible to share information. This reactive behaviour of children participants is exemplified by this response:



mcm mama, dia terasa sgt² bila period tak dtg,

[F3(C4)]: (reading) Like mama, ***she really felt upset*** *when her* ***period (menses) did not come*** *. . .*



bila time dtg bln, tak nak bagitahu pada mak sebab takut dia terasa sebab dia dah takde 'period'.

[F3(C4)]: (reading) When my ***period (menses)*** *comes, I do not want to tell my mother because I was afraid that she might feel* ***upset*** *because she does not have her* ***period (menses)*** *anymore.*

4.5.iii How to instigate an interactive dialogue

The data indicated that most children participants did not know how to instigate an interactive dialogue with either parent about their cancer-related concerns. As indicated earlier (on page 180**)**, in most cases it seemed that the ill parent was not accessible or open to an interactive dialogue with their children as they were either too ill or concerned with other matters. In addition to that, several parent participants seemed to consider that the concerns raised by their children were trivial in comparison.

[F3(P)]: You know, when you go through cancer yourself, you just can't really see how people are suffering along with you. I know that I did not want to burden my children, did not want them to be very sad … upset that I will die tomorrow instead of a long time from now so that is why I did not tell them much. But, I think, now that I look at it, my children seemed a bit more grumpy and unhappy. I did not notice it so much, but there were some signs … you just ignore it, because those are little things, compared to you dying at anytime, what's a little mumbling?

This is an interesting finding that cancer patients and their families have a greater level of sophistication than the other assumed. Members of both participant groups underestimated the sophistication of the other group's information needs, information seeking behaviour and abilities to process information. This suggests that each group of participant should not underestimate the sophistication of the other. This phenomena infers that the medical practitioner could be guilty of an overly simplistic representation or view of the person who has cancer and the affect of cancer to patients' children. Similarly, patients have this same perception towards their children. It was also found that younger children participants, perhaps limited by their latent-age[10] developments construed their parents' experiences and concerns in a simplistic view.

This attitude of the parent participants made it very difficult for children participants to talk about their concerns. It could be inferred that the parent participants' attitude resulted in children being unable to judge which of their concerns were considered important enough to solicit answers or reassurances. Another response was that children participants felt too afraid to ask either parent for fear of upsetting their parent or fear of being scolded. Several children participants said:

[F4(C1)]: When my mother was grumpy or seemed angry, I told myself that the cancer and the pain made her feel worse, so I should be more patient. But, I don't know … I don't know what made her that way. It is very confusing. Sometimes before seeing the doctor, she would look like she was afraid? Worried? I don't know, exactly. I could not ask her.

[F4(C2)]: (when) She (mother) come out of the room, she would start finding something is wrong with something. So noisy.

[F6(C1)]: Eee … afraid to ask her. I have to see her "mood" first.

[F7(C2)]: Before cancer, my mother, she was not like this. She was much calmer; she did not scold us so much or seemed upset for little, little things. She was not quick to anger or … she did not stare off into space and just cry. Cancer that did it.

In exploring their responses, it seemed that these children participants did not know how to broach their information needs and concerns to their parents. An analysis of these children participants' reports suggested that they wanted to be informed about the implications of a cancer diagnosis for their lives. Specifically, children participants were very concerned about their sense of personal well-being. Their perspective of cancer was that the loss of their parent's care due to the cancer proved to be detrimental to the amount of time, scope as well as extent, of care extended to children participants when their mother was unable to function

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[10] According to Kornreich et al. (2008, p. 65), in most paediatric studies children are further grouped as latent-aged children or adolescents. Latent-age as defined by Kornreich et al. (2008, p. 66) is pre-schoolers and school aged children, between five years old to early puberty (11 years old), with mental capabilities operating in a concrete mind-frame somewhat limited to talking about their experiences through partial use of symbolic and abstract language. Furthermore, it was understood that the age bracket acts a natural border, as these children would have different cognitive capacities, abilities to process information and make sense of their world compared to adolescents.

"normally". Most children participants indicated that they were concerned with what would happen to them when their parent was away or too ill to care for them. This was a prominent concern of most younger children participants. For example, several children participants wrote or said:

[F1(C1)]: (wrote) 1. Who will take care of me?, 2. What is to be done about the love of me? and, 3. How to go for walks and to the playground without mama?

[F1(C3)]: (wrote) 1. How long will mama be sick?, 2. Her sickness (should not) hamper her love and show of love and, 3. Who will take care of my younger siblings?

[F2(C1)]: (wrote) 1. Who will take care of me?, 2. How can I be with emak? (I cannot sleep with emak) and, 3. How can I make her feel better?

[F2(C2)]: (wrote) Ayah was always busy, so how will we get food?

[F2(C4)]: I have to be in charge of the house?

It is to be noted that most older care-giver child participant did not respond to the variable of "What will happen to me". Rather they were concerned with the welfare of their younger siblings. In the interest of time, and due to the limitations of this research, this phenomenon was not fully explored. It could be interesting to understand if this trait could be culturally imposed or a natural inclination of the participants' culture whereby self-sacrifice or putting others first is taught or proscribed to the role of eldest daughter. The younger female children participants seemed to confirm that phenomena as they did not exhibit that trait. Older female children were given the most care-giving responsibility.

The children participants were also concerned about the impact of cancer on their ill parent. Even though several parent participants believed in protecting their children from news or events that could potentially be upsetting by not sharing information, children participants were very involved in their parent's recovery. Parent participants erroneously assumed that their children did not care or love them. Several parent participants commented that their children did not appear to care for them anyway and as such did not require more information other than the cancer diagnosis. This is evidenced by:

[F1(P)]:If my children loved me, they would know what to help me with.

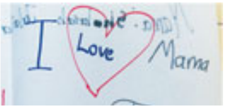
[F8(P)]:Ya, I have ***complained*** *that this* ***cancer is killing me*** *... it's just that I think I was in* ***so much pain****, that* ***I felt that I was dying****.*

SUZIE:How did your children respond to that?

[F8(P)]:Umm ... I did not really notice. (pause) I think they ignored me or just could not be bothered.

[F9(P)]:Haiy … when you get cancer, you want the people who say they love you to show how they love you. You and them, don't have much time. You must show love. If not, I can not tell...

However the children participant's revealed otherwise. This is evidenced by the different declarations and show of love children participants responded to their parents' error:

[F1(C2)]: 

I love Mama even she had cancer.

SUZIE: *Well, [F8(C2)] since you took care of your mother most of the time, how did you feel about that?*
[F8(C2)]: Sad ... afraid that she was going to die.
[F9(C1)]:My mother told me that: a clean house helps to make a sick person become better, faster. So, since I love my mother and I cannot see her suffer and be in pain for so long like she had, I made sure the house was not so bad.

One explanation for this contradiction between the two participant groups was that the parent participants had not realised that the children participant's reticence in providing care and support was because the children participant's did not have sufficient information to provide such care and support. Another explanation could be that children participants were erroneously assumed to be able to "automatically" provide care without tutelage and supervision, and as such, did not require information to carry out tasks.

Several children participants indicated that they wanted to be more involved, if only they could be provided with more meaningful and relevant information to cope with the changes and challenges they faced. Several children participants indicated in the open-ended question that they would like to have known how they could help their mother to get better. For example, several children participants indicated:

[F1(C3)]: How to help mama? I didn't know.
[F2(C2)]: Do I stay with her at the hospital to keep her company?
[F2(C3)]: How to help emak get better.
[F3(C1)]: I want to learn how to cook because one day mama will not be able to cook ... how (else) can I help mama? I want to know more about cancer because I want to help my mother.

4.5.iv How to prevent cancer

Further discussions with children participants suggested that children wanted to know what caused cancer and why cancer happened to their parent:

[F3(C4)]: What causes cancer, what does cancer really mean ... how to go through cancer ... can cancer ... kill?
[F5(C3)]: My mother looked healthy ... I was shocked you know. How could this happen? Why her?
[F6(C1)]: Need to understand how cancer can happen, why my mother got this sickness and not another person.

The excerpts above formed the sentiments of the children participants. Further data explication showed that these children participants thought that their parent was healthy and so, the cancer diagnosis was unexpected. A possible contribution to this perception of health was that the ill parent had not shown any signs of being sick (e.g., feverish, headache, runny nose) before the diagnosis, had never smoked (to their knowledge) and was perceived to have eaten more healthy then the children.

It was found that children participants concept of “being sick” included having a fever, headache, runny nose and bodily aches. Some included nausea, vomiting and purging. However, according to these children participants’ since they did not notice those symptoms of “being sick”, their parent could not have possibly developed cancer or, in some children participants’ perception, contracted cancer from elsewhere. This suggest that children participants had the ability to recognise that a family member was sick, however they were unable to form correct correlations to their parent’s cancer diagnosis.

The lack of knowledge about cancer symptoms could be attributed to the children participants and their parent’s attitude to information about cancer and the belief that cancer was only a possible consequence of smoking. Even though materials about cancer were made public, participants indicated that they thought cancer was a health situation that would not affect them. Thus, information about cancer was generally ignored as being irrelevant or shunned as a means of disassociating the self from the stigma of cancer. There were reports of patients being shunned because of taboo and the superstitious belief in the power of certain words, most notably in “cancer.” In this, several participants remarked that having visible cancer information amounted to the perception of others that said person is confirmed to have cancer and should be avoided, as the general thought is that cancer is a dangerous and contagious disease. As reported by several parent participants, having a visible representation of cancer information was tantamount of admitting having the disease and community members who see this would shy away or is too inquisitive of said person’s health status.

It seemed that children lacked information about what causes cancer. Children participants seemed to be well informed about smoking and its cancer consequence. However, children participants perceived that having no known history of parental smoking or alcohol consumption, parents could not have developed cancer from those factors. Children participants’ reported reacting with confusion and fear upon being informed of parental cancer, because it seemed that their previously held beliefs and preconceived understanding of cancer did not corroborate with their new situation. Some could not accept the diagnosis as they had perceived their parent was healthy enough to not have developed the disease.

The children participants seemed to be concerned about eating habits. They seemed to think that eating the correct foods would contribute to their parent's return to health.

[F5(C3)]: I needed information on how she can get better, what she can or cannot eat.
[F7(C2)]: A sick person has "special" food to get better.

They and their parents seemed to think the volume of healthy foods, especially vegetables, consumed corresponded directly to cancer prevention. Children participants indicated that their ill parent had eaten healthier and more vegetables than them, but apparently not enough to have entirely prevented cancer. Children participants said:

[F2(C1)]: I brought vegetables for my mother to eat at the hospital
[F2(C2)]: Eat more fruits and vegetables to get healthy
[F3(C2)]: Eat vegetables (to prevent cancer)
[F8(C1)]: Have to eat lots of vegetables
[F8(C2)]: Ya, must always have vegetables each time (to eat)

Parent participants seemed to have informed these children participants that vegetables played an important role in preventing cancer. Most insisted that each meal should be accompanied by at least one vegetable dish.

[F1(P)]: Vegetables are very important. Does not matter if you eat it as a salad or a cooked meal. Nowadays you also have instant spirunella drinks …
[F2(P)]: I make sure my kids, I force them, they must eat vegetables, if not they get cancer like me.
[F5(P)]: Need to eat vegetables. They have antioxidants to prevent and fight cancer, you know … but must also include the colored vegetables like tomatoes …
[F9(P)]: Eat more vegetables. They are good for you.
[F10(P)]: Must have vegetables

While most medical studies indicate that consumption of vegetables for its cancer prevention and cancer recovery properties, most of these participants seemed to have the mistaken belief in the role of vegetables as the main method for cancer prevention. This suggests that participants' knowledge about the causes and prevention of cancer was limited in scope, as they seemed to be only aware about the consequences of smoking and the role of vegetables. In conclusion, children participants thought that interventions informing them of: i) how to accomplish caregiving tasks, ii) explanation for parent's recovery from cancer, iii) how to instigate an interactive dialogue with the ill parent and iv) how to prevent cancer, were priority information needs. Nuances of information relevant to those priority information needs corresponded to challenges and difficulties children participants faced. The scope and depth of information seemed to correspond to children participants' age limitations, knowledge base and concerns for their own well-being and the well-being of their ill parent.

4.6 PARTICIPANT’S SUGGESTED INTERVENTIONS

Another component of the research was to explore participants’ strategies and suggested information solutions. These responses might contribute to possible future intervention mechanisms. Responses from Stage Four of the methodology (refer to page 78), where children and parent participants discussed and identified key information needs, were utilised. The vetted themes were voted in order of importance and were reused for participants to plan strategies and/or solutions. Subsequently, Stage Five (refer to page 79) of the methodology explored participants’ strategies and suggested information solutions from the voted key information needs. All participants were tasked to reflect on the information problem, plan and, propose strategies they thought could best help resolve the said problems.

The key information needs (in order of descending importance) were i) how to accomplish caregiving tasks, ii) explanation for parent’s recovery from cancer, iii) how to instigate an interactive dialogue with the ill parent and iv) how to prevent cancer. Participants’ suggestions were solicited per family. Suggestions were compared to other family groups, organised thematically and arranged based on preference of participants. The result was divided into three key themes: i) language preference, ii) topics and, iii) the medium in which children participants preferred to receive information. Topics were further differentiated from children participants’ concerns and cancer specific information. This is summarised in 4.26 List of Participants’ Suggestions.

Table 4.26 List of Participants’ Suggestions

LANGUAGE PREFERENCE		
Written: Bahasa Malaysia	Verbal: Bahasa Malaysia	
TOPICS: CHILDREN’S CONCERNS		
Easy to follow guide on how to care for a cancer patient	Easy to follow guide on how children may help parent with cancer	Explain list of possible changes to familial roles
Easy to follow guide on how to take care of self	Easy to follow guide on how to take care of younger siblings	Easy to follow guide on how to talk to parents about the parents’ cancer experience?
Easy to follow guide on how to get assurance of continuation of care and love towards the child	Guide for parents’ expectation of children’s’ abilities as a care-giver	Guide for parents to be aware of children’s needs
TOPICS: CANCER SPECIFIC INFORMATION		
Explain how is cancer dangerous	Explain treatment process flow	Explain why side effects happen
Explain why ill parent may get emotional	Explain how children can cope with side effects	
INFORMATION MEDIUM		
Interaction with ill parent	Interaction with healthy parent	Interaction with attending doctor
Interaction with other children in a similar situation	Interaction with counsellors at cancer centres	Talks at school
Comic book with problem-solving setting	Pictorial reference book with easy to understand explanations about cancer	Easy-to-read guide book

4.6.i Language Preference

The desk-based research and reports from participants indicated that most cancer-related information in Malaysia was presented in English. However, all participants indicated that they preferred for cancer information to be conveyed in their mother tongue of Bahasa Malaysia. Participants' language preference is provided in the excerpts below:

[F1(C3)]: I ask my mother in Bahasa Malaysia.
[F2(C1)]: I can't speaking. (speak English well).
[F5(C3)]: We can speak English, it's just that BM (Bahasa Malaysia) it's easier to understand.
[F7(C2)]: My English so-so.
[F8(C2)]: You (researcher) ask in BM (Bahasa Malaysia).

Other than the excerpts, another indication of this preference was that the majority of this research was conducted in that language with the researcher requiring to transliterate exploratory questions and situations in order to generate responses from children participants. It was also observed that information sharing among participants was mostly conducted in Bahasa Malaysia; children participants asked questions and conveyed their concerns in Bahasa Malaysia. The desk-based research, as well as participants' reports, indicated that what little information that was presented in Bahasa Malaysia was a direct translation, as opposed to transliteration, of English-based information. This created contextual understanding. Furthermore, participants reported that the information was about cancer in general and did not address children participants' needs. Several leaflets and brochures requested for patients to solicit more information from their doctors. However, participants reported that doctors were not forthcoming and helpful. This resulted in children participants soliciting information from other sources. This was corroborated in responses to the questionnaire and throughout discussions in focus groups.

As mentioned earlier, children participants indicated that their main source of information was their parent who was diagnosed with cancer. When cancer-related terms were in English or sounded medical-scientific, these children participants would solicit further explanation by requesting for a translation. This could be attributed to the fact that, while English Language is taught in schools, most children participants have not developed a higher-level of English language competency. Furthermore, they have a rather limited-school based vocabulary that does not include familiarity with cancer-related words and contexts. This was also reported earlier on page 91.

Answering and translating information became the responsibility of these parent participants who found it to be a difficult task.

[F1(P)]: Eh, its difficult to translate
[F7(P)]: I don't want to translate (from English into Bahasa Malaysia).
[F5(P)]: We are in Malaysia. People need to understand that we mostly speak in Bahasa Malaysia. Where can have information, cancer information, so high-level English for people like us? I can understand, but, you know, most of the people with cancer, like the people in the villages, cannot understand anything in English. Cannot even pronounce some words, how can they know what is cancer like that?

These parent participants, who also had limited English-based and medical-based vocabulary either translated wrongly or poorly, or presented the information in a context that children may have found to be more confusing, more frightening or unsatisfactory.

[F3(P)]: How to say? I say hair fall out because of medicine. Then they think all medicine do that. Where got all medicine do that? See? Got problem. My children always say they don't understand what I am trying to explain to them. Sometime I think they say that to tease me.
[F8(P)]: Oh? Is that what it meant? I thought that second-hand smoking meant by second time you smoke, you sure get cancer.
[F9(P)]: (English) is difficult to story (tell) my children in Bahasa Malaysia. Too much thinking for me. I just said the "doctor said so".
[F10(P)]: I don't know what to "story" to them. I think for sure, I gave them the wrong information now. (laughs)

Most parents gave up explaining their situation by justifying that their children would not understand anyway, it was not the business of their children to know, or the information and its implications would be too frightening and upsetting for their children.

[F2(P)]: Sure they don't understand. Too younglah, their minds, too young. Simple things cannot do, want to understand cancer? No lah.
[F4(P)]: Why they want to be too busy about it? Not like they can do much, right?
[F8(P)]: Eh, I did not know what to tell them. (too me) Cancer is very frightening; you think my children could take it aa?
[F9(P)]: I don't know how to tell them about cancer without them crying or thinking that I will die tomorrow. Difficult to say … difficult to decide how and what I can actually tell them.
[F10(P)]: Eh, no … I don't tell them everything. I don't want them to be upset. They needed to focus on their studies.

Since parents and their children often develop a bond that allowed each to be familiar with the other's behaviours and capabilities, it may seem obvious, that at some point, the parent should be the main source of "right" information that is timely, appropriate and acceptable for children to understand or make sense of the health situation they face. This could lead to more satisfactory reasoning for both the children and parents' actions and understanding about acquired responsibilities.

However, in a situation of illness most parent participants indicated that it might be beyond their abilities to maintain their responsibilities consistently. This is especially so when it comes to information sharing of English-based information whereby the parents themselves have to first process and understand the information correctly before reiterating it into something more appropriate and relevant for their children. These parent participants reported that the information provided to them was mostly about how cancer developed and some mentions about dietary advice. Some information was also provided about treatment options and side effects. This information was however mostly in English, and the severity of possible side effects and the complexity of the cancer treatment process often gets lost in their personal ability to translate information from English into Bahasa Malaysia.

It can be suggested that, since relevant information in Bahasa Malaysia were not sufficiently available, doctors were less forthcoming about information sharing and that, as cancer patients' own English language aptitude was limited, both parent participants and children participants' concerns and questions remained largely unanswered.

4.6.ii Topics

As presented in Section 4.5 (on page 188), reports and suggestions from participants indicated that these children participants were interested in a range of topics. The range suggests that prior to diagnosis, these children participants knew very little about cancer.

[F1(C1)]:	*I did not know.*
[F3(C3)]:	*I thought that only people who smoked got cancer. My mother never smoked, but she got it too.*
[F5(C1)]:	*Before, it was like cancer, what was that?*
[F5(C2)]:	*I heard that yeah, cancer could kill, but so? I did not think it could happen to my mother … I did not really want to know about cancer before.*

These children participants also knew very little about the cancer treatment process and avenues from which they might solicit more information or help in specifically coping with their changed circumstances.

[F3(C2)]:	*When we visited our mother at the hospital, we always bring vegetables and fruits for her to eat … because you need vegetables and fruits to make you healthier.*
[F4(C1)]:	*Afraid to see her bald.*
[F5(C3)]:	*As the eldest, I needed to know what could be done for my mother … We did not know how her cancer would be treated, what the side effects were. How to help her?*
[F8(C1)]:	*Not "best" anymore.*
[F8(C2)]:	*How to help mama?*
[F9(C1)]:	*How to make ibu not scold me so much?*
[F5(C2)]:	*I heard that yeah, cancer could kill, but so? I did not think it could happen to my mother … I did not really want to know about cancer before.*

While not surprising however this indicates that better information and intervention methods are needful. This suggests that there are information gaps and children participants' have concerns post parental diagnosis. These gaps further provide an indication about the extent and scope of information needs.

It was found that parent participants informed their children about their diagnosis but then did not share enough information about the cancer treatment, possible side effects and the possible changes children would experience. Other than the diagnosis, most children participants reported that they needed significantly more information. This was evident when their ill parent returned home and the children could experience for themselves how difficult and painful recovery from cancer could be.

Children participants reported their experiences with how their parent's cancer affected them. They had various reactions to the side effects of the cancer treatment, most notably to the frequent vomiting, hair loss and parents' complaints about bodily aches and pain. Children participants also noticed their parents' changed behaviours and this included either hearing or seeing their ill parent crying. Parent participants were not forthcoming about the behaviour changes and several children participants either misconstrued, or wrongly attributed, the causes. Examples of this phenomenon were reported on page 189. In addition to that, most children participants, especially older female children participants who were care-givers, indicated that they needed information on how to accomplish care-giving tasks. Some of these unmet needs were reported on page 167.

Even though children participants were aware of where they could obtain information (parents, the Internet, cancer centres, the attending doctor), most information sources either did not acknowledge these children participants' questions and concerns, or perceived that the information requested was not commensurate with the abilities of these children participants to understand cancer-related information. At times, the information was judged to be too upsetting, confusing or frightening for the children. These findings contributed to the children participants' issues and concerns being largely ignored or unanswered. This, in turn, could have negative repercussions towards these children participants' understanding and concepts about cancer, as well as other issues that could be detrimental or could impair the development of a nurturing family dynamic and good social construct.

4.6.iii. How to instigate an interactive dialogue

The children participants and their parents suggested several methods by which children may communicate their information needs. The parent participants suggested several possible strategies children might use when approaching their parents to talk about their relevant concerns.

4.6.iii.a. Strategies from parent participants

Some parents were unaware about their children's attempts to ask them questions regarding cancer, the parent's health status and even how tasks needed to be done. Some parents also conveyed that they felt that their children seemed uncaring and did not want to understand the parent's challenging situation. It was made clear in the course of the research that these parent participants' perceptions were not entirely true as they heard and observed for themselves that their children did care and wanted to know more about cancer, the parent's health situation and how they may help support the parent in times of illness. In addition to that realisation, several parent participants subsequently acknowledged their ignorance about children's cues of emotional distress or request for parental attention or action. This was similarly reported by Buchwald et al. (2011, p. 229), Barnes et. al. (2000, p. 479) and Rait and Lederberg (1990 p. 589).

Above and beyond the information problems, the parent participants were unaware that their children needed more than just information about cancer and their illness. These children participants wanted cues that would help them to understand and believe that they were still an important element and concern in their parents' lives when the parent was ill. These parent participants also had not realized that children exhibit and express their concerns in different ways than adults. For example, some of these parents also remarked that their children had exhibited inappropriate behaviour; it was only during the research that they realized that the said behaviour was their children's way of communicating their responses, emotions or opinions. This suggests that parents (either the ill parent or the health parent) and information providers (preferably the attending doctor) may need help and support. This suggestion is similar to findings by Finch and Gibson (2009, p.214) where "parents are seeking help" to what and how to share information.

In acknowledging this shortcoming, several parent participants suggested that a list of situational settings that depict verbal and non-verbal cues of children's reactions could be provided. They believed that this list could help them to be more alert and to better identify the needs of their children. Parent participants thought that a good strategy was to encourage interactive dialogues with their children. They thought that the discussions would help them bond with their children, provide first-hand experience about cancer and perhaps mitigate some challenges or problems in the family. The following evidences this:

[F1(P)]: *Yeah, it is always better to be able to talk to the children. I tried before, but it was difficult when all you think is death and … maybe the children don't care…but, I now think talking with them, telling them I love them, asking them what is their problem…maybe that is better than isolating myself and hoping for the best … (not) for my children to just know (what to do and what parent experience)*

[F4(P)]: *Hmmm…my daughter is right … I should see more what she needs … not that she is a busy body to know but more … err…to how to help me…and how I can help her to understandlah.*

[F5(P)]: *Talking about cancer is not an easy thing … especially when you don't know what to tell your children exactly…but you know, talking is way to be closer to the children, what you call … bond. You don't have too much time left to be with your children, so perhaps take the time and talk to them about this cancer, this killer so that they know more of what you go through, what they can do to prevent cancer from them … I advise this lah…go talk to your children about what you are going through. I think, I believe this helps them to ummm…to understand what you are going through, what you can and cannot eat…why I nag them to take care of their health …*

[F8(P)]: *I think this talking with them (children) will help to stop them fighting. Maybe be more alert to what is happening … show a little more concern that they argue gives me a headache, makes me more upset and sad .. and so… don't argue so that I don't get more stress from them…that way can help me and perhaps that way, I don't get mad so easily with them.*

Two parents even remarked that an interactive dialogue could also be a platform in which they could be motivated to look outside of their self as a cancer patient and be more in tune with the developing needs of their children who still required their love and care.

[F7(P)]: *I see … I can understand now. This really makes me think about them, more than just me, alone you know? I really did not think that my children needed me in that way. It's not so much about who is being selfish … just that you know, children still need their mother even if she was ill.*

[F8(P)]: *Ya, I think, there was a …phase in every cancer sufferer's time that they are very concerned about death and if they will be there for their family for a long time or a short time. So, while one is very … distressed about this cancer killing us, we must still open up and ….Talk …talk about it with the children so that they can more understand. So that they know that you still love them. Saying you love them is not enough … I get it that as a parent, we cannot ever forget this very important thing of also showing our love and concern to our children. You know, no matter what, at the end of the day, these children don't know anything else … anything other than that their mother or father loves them. Anyway, that's what I now think. I really did not know before. I was not … sensitive to these things … of the children's needs of me as a mother.*

Another suggestion was for parent participants to be provided with relevant information that presented the impact of cancer to their families. These parent participants believed that if they were provided with culturally relevant information, then they would be more aware and better equipped about how to react and handle to issues that their children could develop or experience from observing their parent's recovery process. When verbal or non-verbal cues become apparent, parents would be better able to recognize its emergence and its trigger. This may help parents to assimilate those factors and suggested approaches to better assuage their children's information needs. In this, while parent participants acknowledged that each child had different personal files, triggers and reactions, they agreed that a guide on the possible reactions to cancer and the methods to address those reactions could have helped them to overcome the problems their children reported even before said problem became unmanageable. These suggestions could help prompt parents to identify behavioural cues and to prompt an interactive dialogue when a problem arises.

4.6.iii.b. Strategies from children participants

The children participants' reports seemed to indicate that they understood that their parent was too ill to carry out "normal" household chores (on page 121). They also understood that cancer affected how their parent behaved and interacted with them. In acknowledging this, children participants indicated that they required assistance in communicating or informing their parent when tasks become overwhelming, unevenly distributed, an unexpectedly long burden or when parental expectations could not be met. These children participants wanted information that would help them interact with the ill parent, the healthy parent, attending doctor, other children in a similar situation and with counsellors at cancer centres. They also indicated that they wanted someone to conduct a talk at their school, so that not only they could be better informed about cancer, but so too could their friends and peers.

In developing solutions on how children could instigate an interactive dialogue, these children participants suggested that information be provided to them with topics to discuss with their parent. Children participants co-developed a list of topics that related to their concerns. This is presented in Table 4.27 below.

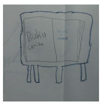
Table 4.27 Children Participants' Concerns

TOPICS: CHILDREN'S CONCERNS		
Easy to follow guide on how to care for a cancer patient	Easy to follow guide on how children may help parent with cancer	Explain list of possible changes to familial roles
Easy to follow guide on how to take care of self	Easy to follow guide on how to take care of younger siblings	Easy to follow guide on how to talk to parents about the parents' cancer experience?
Easy to follow guide on how to get assurance of continuation of care and love towards the child	Guide for parents' expectation of children's' abilities as a care-giver	Guide for parents to be aware of children's needs
TOPICS: CANCER SPECIFIC INFORMATION		
Explain how is cancer dangerous	Explain treatment process flow	Explain why side effects happen
Explain why ill parent may get emotional	Explain how children can cope with side effects	

According to these children participants, these topics required information sharing strategies that provided information that were simplified, easy to follow and in a manner that would help children participants to solicit information that was appropriate to their age, capacity and capabilities.

As a follow-up to these ideas, it was found that, for these children participants, they preferred to verbally solicit information rather than to read information. As reported earlier (on page 148), children participants preferred to ask their ill parent or mother for more information. This preference for face-to-face discussions was similar to findings by Kenrick (2009, pp. 9-12). When face-to-face discussions were not possible, children participants indicated that they were still willing to read information that was pictorial. The children participants suggested for information to be presented as a comic book or as a pictorial reference book with easy to understand explanations about cancer or as an easy-to-read guidebook. These preferences were indicated through a number of drawings as illustrated as well as through session five as presented below.

[F1(C1)]:



Story book like "Conan" (Inspector Conan style)

[F1(C2)]:

Comic book

[F3(C2)]: *Maybe comic book? … Yes, yes… I think comic book. Err … easy to understand.*

[F5(C1)]: *I don't like to read (laughs), but if the information was in a … a comic, than OKlah, I read. It is easier to read … not too many words and the pictures can already tell the story. Look at the picture, can already understand what is happening.*

[F9(P)]: *Comic book, I think because easier to understand and remember … and if forget, can still look for it and remember it again.*

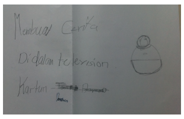
Pictorial-based information was an important distinction from textual-based information. Children participants provided the reason of ease of reading and pictures conveying information (as opposed to textual information) was more attractive, interesting and facilitated understanding. All four male children participants informed the research that they did not like to read. The following evidences this:

[F1(C1)]: *Read? Ishk!*
[F5(C1)]: *I don't like to read (laughs) …*
[F7(C1)]: *I don't want to …*
[F8(C1)]: *No! (does not like reading)*

Most of the female children participants did not indicate their dislike of reading, but some did indicate their reluctance. These excerpts and observations suggest that the preference for pictorial-based information could be age-dependent and leverage the literacy skills of children participants. Another possible reason was cultural influences where reading was not cultivated among Malaysians. This was evidenced by the 2005 National Library Study reported by The Star Newspaper (8 August, 2006, Sunday Star edition). While Malaysia has a 93% literacy rate, the 60,441 children and adult survey respondents read an average of seven pages a day (including academic books) and cumulatively completed reading two books a year. 60% of respondents were aged 10-years old and above (The Star, 2006).

In addition to comics, children participants provided another suggestion for information to be provided through television or feature films.

[F1(C3)]:



Make a cartoon in television

[F2(C1)]: *I like to watch television, so … make a television showlah and show what is cancer and what happens to kids when their mother has cancer. I think that would be good.*

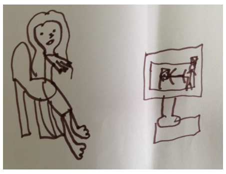
[F7(C1)]:

Show a story at the movies

[F7(C2)]:

Make a movie that shows the many, many medicines so that people will know not to get cancer unless they really want to eat all those medicines.

[F10(C1)]:



Watch a show with the operation so that people can understand that cancer is a dangerous sickness.

Similarly, children participants indicated that visual information was more attractive and easier to understand. Several children participants reported that it was easier to recall. The following evidences this:

[F1(C2)]: *More attractive*
[F2(C3)]: *I can just sit and watch (the information) easily*
[F3(C1)]: *I don't need to think so much.*
[F3(C3)]: *Yes, no need to think what a (unfamiliar) word means. Just see and can understand already*
[F5(C1)]: *Umm…more real…to see what happens, you know…not like when you read … so boring*
[F5(C4)]: *Seeing something is like … makes it easier to understand what is going on, instead of imagining the thing … like I imagine something else from what I read. This way, I can … more easily understand what is the matter … why something is like that … like how the cancer actually looks like inside …*
[F9(C1)]: *Easy to remember*

These mediums of information suggested that, when communicating to these children participants, face-to-face discussions and pictorial based information were preferred.

4.6.iv Timing of questions

Several parent participants indicated that children should be aware of when was the best time to ask questions about cancer. The "correct" timing of questions depended on the parent's health and mental state and if the parent was "busy" with an activity or chores.

[F1(P)]: Children need to see if it was the right time to ask questions.
[F3(P)]: When I say I have a headache, don't ask me questions. Wait for me to be better, then ask.
[F4(P)]: Look at the situation first, don't simply ask … like if I am talking to a guest or cooking, not appropriate time to ask your questions.

The timing for questions about the health situation was important so as to give the ill parent time to recover and regain their equilibrium. However, most children participants were not yet able to identify when the "correct" timing was to ask their questions. Furthermore, in some instances, it seemed that children participant's questions sometimes wrongly identified by him or herself as "not important enough" or "too upsetting to parent". In addition to this, contrary to several parent participants' responses, children participants thought that parents should be made aware of their children's concerns or fears about cancer when children face a health situation at the onset rather than after a prolonged absence of the health situation. This is because, according to several of the children participants, some of their questions were put aside and eventually forgotten while some of those questions were answered through children participants own observation and assimilation of information through their personal files and personal capabilities and skill sets. Whether the answers were correct, was a different matter.

As briefly indicated before, perhaps it makes better sense for parents to be playing the part as an information provider, using the experience and knowledge of their children's sensitivities and the distinctive ways they respond to different types of information. Parents often understand certain things about their children beyond what experts, such as physicians and teachers, can analyse and convey, because of the stronger bonds between the parent and child. Parents might also be able to judge what could be the most effective ways to approach different subjects and topics, based on how children have been responding to information "triggers" throughout their lives thus far.

Based on the observations and the responses throughout the study, it takes much more than to depend solely on the children themselves to decide on the optimal time, relevance, appropriateness, importance and other concerns of various levels and explicitness relating to cancer information. To support this, the children participants indicated their inabilities in accessing information throughout the cancer treatment processes their parents undergo. Responses suggest that the information should be provided to parents about their children's concerns, their information seeking behaviour and other behaviours that indicate children's difficulty in coping with their new roles, the effect of cancer and the changes in their home environments. Although there are multiple indications that parents make premature judgments that children would not understand anyway, perhaps in a systematic setting where there could be a third party asking the right questions, gathering specific information and ways to communicate strategically, with the main purpose of creating awareness to the children of parents with cancer, the right information, medium and optimal method(s) may be achieved.

It seems that, from these participants, information should be developed for both the parent with cancer and for their children. The findings indicated that while there were several overlapping information needs of these two groups, parents and children differed in the nuances and use of information. For example, while both sets of participants wanted to know about cancer treatments, some parents were very concerned with their possible imminent death while their children were concerned with how fast their ill parent could return to their "normal" health state and duties. Several children care-givers wanted to know how to accomplish tasks while several parents were not even aware that children needed such information as they had mistakenly assumed that their children either already knew what to do or could "automatically" carry out such tasks.

The separate information could address the different nuances of concerns reported from each group. In addition to that, the importance of familial communication and interaction, as evidenced throughout this research, may necessitate for the information to be cross-referenced or linked to the concerns of the other. Information relevant to specific individual needs would play an important role in encouraging the understanding about cancer. In addition to the suggestion, more information about cancer's impact to other family members could provide a more holistic understanding of how cancer effects family dynamics. It is hoped that, in this way, not only would some of the more pressing information concerns of an individual's be answered, the linked information could also support the development of the said individual's personal files and interaction with other family members who may experience other concerns.

4.6.v Doctor's role as an information source

The data reports that parents are the main information source, but both parents and children participants also indicated that the attending doctor could be more helpful in sharing information. Participants further indicated that doctors were viewed with respect as the authority and point of reference for medical matters. Participants from both groups specified that they “followed doctor’s instructions/orders/advice” as closely as possible and, other than seeking clarification, they followed the said instruction almost without question. However, the doctor’s status and authority seem to also result in a slight fear or shyness to ask beyond what had already been stated by the doctor.

This may contribute to the information problem whereby the actions or advice given by the doctor would remain only for the ill parent to understand and act upon, and not for the children to digest and to use in their everyday “duties” to help. Some children respondents indicated some attempts in asking the doctor, but the answers were often indifferent and unsatisfactory. Children were informed in a manner that did not contribute to their understanding, rather, contributed to more confusion and fear. These difficulties of doctors to communicate were reported by Fourie (2012, para. 15-19; 2008, para. 72).

Children participants’ actions of soliciting answers from the attending doctor suggested that they were genuinely concerned about the well being of their parent and wanted to find out what the treatment process involved. These children participants wanted to understand the process so that they could be of help or appear to be supportive of their parent. Doctors could be made more aware of children’s concerns because children care-givers were undertaking tasks that may not be within their abilities, capacities and skill sets. The information that doctors provide could help support children in understanding their new and challenging tasks and responsibilities.

The parent participants also thought that the role of doctors could be more than just to administer medication and monitor patients’ health. The extension of a doctor’s role as an information provider could be attributed to the parent participant’s perception of the doctor’s knowledge and experience of cancer. Parent participants reported having asked their doctors to clarify what would happen to them and explain the process so that they could in turn inform their children. However, acting as an intermediary to assimilate complex medical terms and process proved to be difficult. Parent participants thought that doctors should provide information to their children instead. In addition to that, parent participants felt that the doctors needed to communicate in a way that conveyed care and awareness of patients’ and their families' sensibilities towards cancer. Parent participants wanted specific information at a specific point in time or context. When it came to the assessment and use of information, participants were pragmatic and they only needed information that helped them to make sense of a situation they faced currently. This was because parent participants reported the immediacy of the current situation and its significance that triggered their reaction and information seeking behaviour. These phenomena suggest that information needs should be geared towards participants' experiences.

4.7 CONCLUSION

The results of data explication presented in this chapter answered the research's' aim and objectives to a certain extent. There were three main findings that were similar to the previously reviewed literature in Chapter Two:

1) Parent participants could not keep their cancer diagnosis a secret. This was similar to findings by the American Cancer Society (2012c, para. 2), Christ and Christ (2010), Kornreich et al. (2008) and the National Cancer Institute (2012b),
2) Children participants were aware that their parent was ill from mannerisms and visual cues. Similar to findings by the National Cancer Institute (2012a, 2012b, 2003e, p. 17), Finch and Gibson (2009) and Sweeney (2004, p.21), these cues contributed to children's' misunderstanding about cancer, cancer treatment, parents' experiences and expectations about children's' behaviours and,
3) Children participants' observations (whether correctly or wrongly interpreted) influenced the meanings they attributed to the said observations, what they experienced and how these observations were subsequently synthesized into their "personal files" (Kirkelas, 1983, pp. 9-13) and formed their "perpetual perceptual encoding" (Bettman et al., 1991, p.57).

However, narratives and participants' responses suggested that a lack of information has far reaching consequences to children and that cancer's impact was not limited to the emotional and behavioural problems reported by extant literature. Unlike previously reviewed literature in Chapter Two, data explication and observations suggested that there were more challenges children participants faced, nuances of information needs and, information seeking barriers then were previously documented. The reported prevalence for caregiving, the list of caregiving tasks and other concerns of children participants suggested that these information gaps, unmet information needs and problems provided meaningful and different perspectives about coping with parental diagnosis. This is discussed in Chapter Five in further depth.

This is reported through discussions to relevant aspects to precedent research and related theories. Chapter Five also reported on the implications of the study to children' and parental cancer's, information provisions and practitioners.

CHAPTER FIVE
DISCUSSION OF FINDINGS

This chapter provides in-depth discussions about the findings reported in the previous chapter. The discussions of findings, which address the research's primary objective and includes the implications of the study, is divided into three subsections: implications for information provision, implications of children's responses and implications for practitioners. In addition to this, a discussion of recommendations for each subsection will also be provided. This chapter concludes with a description of an information seeking process model that integrates findings and analyses of children participants' reactions to a health situation.

5.1 DISCUSSIONS OF IMPLICATIONS FOR INFORMATION PROVISION

This section discusses the implications of the research findings in relation to the Aim and Objectives of the research as first described in Chapter One of the dissertation. This section is further divided into five subsections: i) Information needs of parents, ii) Information needs of patients' dependent children, iii) Children participant's responses to parental cancer, iv) Children participant's experience in caregiving and implications for information provision, v) Implications for information provision by practitioners.

5.1.i Information needs of parents

Even though the focus of this thesis was children impacted by their parent's cancer diagnosis, part of the research was to also find out the experienced and situational context of information needs of cancer patients in Malaysia. As mentioned in Chapter One, in 2007, 44.35% of male cancer cases and 49.63% of female cancer cases occurred in individuals between 21 and 59 years of age (Omar and Ibrahim, 2011, pp. 28-29), which are considered the prime childbearing and parenting years. The Malaysian average was 2.5 children per household (*Kementerian Kemajuan Luar Bandar dan Wilayah, 2000*). This means that many cancer patients will have challenges with the disease and parenting at the same time (Weaver et. al., 2010, p. 4396). Moreover, it was found that significant to the participants' culture, children participants preferred and relied heavily on their parents to provide health relevant information. Knowledge about patients' information needs would help to better identify and understand how those problems or shortcomings contributed to the subsequent information needs of their children.

In addition to that, the Calman-Hine Report (Department of Health, 1995, p. 3) indicated that cancer's complications and the complexity of its treatment presents challenging, far-reaching and profound consequences. One of the consequences was for information to be more relevant to the needs of patients and family members (American Cancer Society, 2012; Kilicarslan-Toruner and Akgun-Citak, 2012; Chiou et al., 2009; Kornreich et al., 2008; Visser et. al, 2007; NCI, 2004; breastcancer.org, 2004; Scott et. al, 2003a, 2003b, 2003c; McCue and Bonn, 2003). This demand for relevant information, tailored to the needs of patients and family members, was observed in this thesis research.

The following paragraphs discussed the information needs of parents and provisioning of information for them in several ways. They are: a) parent participants' need for cancer information, b) challenges with cancer effects parenting, c) influence of ethnicity and culture, d) parent participants' information sharing behaviours, e) types of cancer information and, f) parent participants' awareness about their children's' caregiving.

5.1.i.a. Parent participants' need for cancer information

Similar to the research reported above, the participants reported that a lack of information about cancer, cancer prevention and treatment options contributed to many problems they and their children had with coping with the disease. Parent participants indicated their failure to access relevant information that would have helped them to understand better, cope and overcome the challenges they faced as patients and as parents requiring care from their children. Many parent participants reported that having information was important for cancer management from diagnosis, throughout treatment and during remission.

Guided by the literature review, observations and participants' self reports, the research in this thesis found that patients and their families wanted an information system that addresses "subjective experience" (Wilson, 1991, p. 701) with information provisions arising as solutions to people-centric problems and issues. Rather than providing information and methodologies to treat only the disease, this thesis research found, that for the most participants, sharing information about cancer covered a myriad of key themes.

In exploring these responses, the parent participants were more interested in how cancer developed and its possible impact to the family, how to mitigate the impact of the diagnosis, how to encourage and/or develop a supportive ecosystem for home-based care and how to overcome and/or prevent cancer's re-occurrence. Similar themes were reported by Weaver et al (2010, p.2) whereby cancer patients had "heightened distress related to worry about not seeing their children grow up, inability to perform usual parenting activities, the strain of multiple roles while ill …". This suggested that many more types of information were needed and that this information formed an integral component of the cancer care continuum. In a deeper analysis of the information needs, this seemed to be motivated by parent participants' need to be better informed about their situation, specifically about coping with side effects and, passing on information about cancer prevention to their children.

These nuances were different motives than reported by Sorensen et al. (2009, p. 272), Holman and Lorig (2004, p. 240-242), Zorbas (2003, pp. 529-530), Alpay et al. (2004, pp.1-2) and Griffiths (2000, p. 30), in which cancer patients indicated their greater interest in participating in decision-making. Most parent participants were considered passive information seekers because they readily accepted a course of cancer treatment as advised or recommended by their doctors and, were less involved in health decision making.

5.1.i.b Challenges with cancer effects parenting

Similar to findings by the American Cancer Society (2012c, para. 1), Bartlett (2010, p. 84), Lewis (2006, p. 23), and Barnes et al (2000, p.479), parent participants had difficulty in not only dealing with their own feelings and coming to terms with all of the implications of the disease but also in dealing with how their illness effected their children. Parent participants reported there were times when their fear of death, being tired from the effects of cancer treatments and not being in the "mood" limited their abilities to function normally in their parental role. According to Barnes et al. (2002, p. 209) and Lewis (2006, p. 21) cancer challenges impair parenting skills. The literature review provided a possible reason for this behaviour. According to Brashers et al. (2000, p. 63) cognitive capacity may be diminished when people experienced extreme stress or anxiety because of illness or medical procedures. According to Lewis (2006, p. 21) and Rait and Lederberg (1990, p. 589), these issues impaired parenting and placed children at risk for problems. Some patients were "unable to be the parent that they want to be and that they know they should be" (Lewis, 2006, p. 23).

The parent participants could not prepare their children, as they too were not prepared for the diagnosis. Some parent participants reported not being ready to talk about their situation; either they needed more time for sorting things out in their own minds before talking to their children or they did not know of how to talk with them about upsetting things. Some of the parent participants' narratives indicated their expectation for their doctors to inform their children or, they hoped their children would figure things out by themselves. Some of these challenges raised by parent participants were reported by precedent studies. According to Finch and Gibson (2009, p. 214) "parents are seeking help" about what and how to communicate to their children about parental cancer. This was similarly reported by the National Cancer Institute (2003a, pp.5-6) and Stuber et al. (2001, p. 187). Further report of parent's inability to communicate cancer diagnosis and cancer-related consequences was reported by Lewis (2006, p. 25); "parents say they do not know what to say or do, even when they can see their children's distress about the cancer". In other precedent studies, cancer patients reported feeling ill equipped to handle their children's potentially difficult questions (breastcancer.org, 2004; Scott et al., 2003b).

Similar to findings by Barnes et al. (2000, p. 479), the parent participants reported that informing their children about their illness and the modality of treatment was largely unaided. Many parent participants did not know how to inform and how much to provide. The parent participant's narratives suggested that their concern and hesitation was influenced by their fear of distressing their children, not knowing how to handle children's difficult questions and reactions and, the patient's own difficulties and ignorance about cancer and communicating bad news. These concerns could have contributed to the parent participants' preference for soliciting information from their doctors on how to inform their children.

This was contrary to findings by Connell and Crawford (1988, pp. 193-194) that ranked the order of patients' preferred information sources as: firstly, printed media; secondly, television; thirdly, informal networks of friends and doctors; fourthly, radio and lastly, organizations. Findings by Johnson and Meischke (1991b, p. 40-42) showed that when people solicited authoritative information, preferences were for: firstly, organizations; secondly, family and thirdly, media. However, in this research, many parent participants preferred their attending doctor first. The parent participants wished that their attending doctor was more forthcoming, helpful and sensitive to their needs.

5.1.i.c Influence of ethnicity and culture

While nuances existed as a component of the participants' ethnic experience, the key themes that emerged in part corroborated previous findings and theories as reported in the literature review. These finding builds on Chiu and Wistow's (2002, p.5) needs assessment project described in Chapter Two (refer to p. 25). They identified that many patients and their carers were unable to access information that took into account their vulnerability and ethnic social backgrounds. According to Scharlach et. al. (2006, p. 135) the influences of ethnicity and culture affected the use of healthcare services.

Ethnic and cultural factors influenced parent participants' attitude towards healthcare and dependency on their attending doctors and family members. According to the National Cancer Alliance (2002, p. 20-22), families of South Asian descent had significant roles in providing care. This, in part, may be attributed to Rowlands' (2005, pp. 16-21) findings that, in Asian families, it was acceptable for patients to be dependent and exhibit a passive attitude with regard their healthcare. Further, most health decisions were considered the onus of "respected elders": the attending doctor, the spouse and the patient's parents. In addition to this, this thesis research found that it was also acceptable for non-critical decisions to be carried out by the patient's eldest daughter. This phenomena was also reported by Chiou et al. (2009, p. 422) and Scharlach et. al. (2006, p. 135).

In another finding, by McCaffrey-Boyle (1998, p. 80-81) in Asian communities, people including those who were ill, were respected for being calm and serene and should not voluntarily disclose problems or concerns or outwardly show emotion. This attitude influenced the concern for others, even when sick, where individuals did not want to be burdensome or become an inconvenience. Hence, many needs were not communicated. The patient's own attitudes, influenced by their ethnicity and culture, contributed to their children's continued ignorance about cancer and difficulty in caregiving.

The cultural and religious factor of participants being Malay Muslims seemed to have implications in the attitudes to being ill and home care. Consistent with findings by Barnes (2012, para. 5-8), Yucel (2010, pp. 3-5) and Qadri (2005, p. 4), patience, prayers, determination to overcome the disease and, faith in healing were considered very virtuous and a form of piety. These attributes were considered very important values and many participants seemed to find religious activities as a therapeutic resource. According to Arifin (2009, para. 1-4), in Muslim families, there is the concept of "leaving up to God". Similar to the findings by Gatrad and Sheikh (2002, p. 526), many participants reported being *"redha"* (follow God's decision) when ill and this influenced their attitude and outward behaviours. Reinforcing Barnes' (2012, para 5) and Arifin's (2009, para 1-4) reports, participants felt cancer was an "*ujian*" or "*dugaan*"; a test of faith and belief in God's Greatness and Love.

Religious concepts of "*ruqya*" - spiritual healing (Qadri, 2005, p. 4-5), with the belief that there was "*taufiq*" (God's hidden reason) and "*hidayah*" (God's lessons) for them to experience cancer, seemed to also influence the parent participants' attitudes. Similar to the findings by the Boston Healing Landscape Project (Barnes, 2012, para. 5-10), parent participants believed that the cancer experience strengthened various spiritual and character development. Some strongly believed that being stoical and keeping faith in the face of illness was a psycho-spiritual imperative; this attitude would help pardon their past sins and could promote recovery. The parent participants reported an increase in their religious observances and this suggested that religion played an important component in the cancer care continuum. Pursuant to this attitude, many parent participants reported that they tried not to be emotional, by hiding their feelings, being more in control of their emotions, or hiding emotional outburst, such as crying in their bedrooms.

However, comparable to Crow et al.'s (2000, p. 149) report, it was found that patients' hiding needs or a situation makes it more difficult for health practitioners and family members to provide care effectively. This situation is made worse when, similar to findings by Weaver et. al. (2010, p. 2), Eden et al. (1993, pp. 160), Hogbin and Fallowfield (1989, p. 330), Northhouse and Northouse (1987, p.18-20) and Rosenbaum and Rosenbaum (1989, p. 91), distressed parent participants found it difficult to understand and remember information given during consultations. The parent participants regarded their doctor's recommendations as final decisions and offered little opposition, fewer questions and hesitancy in continuing with the course of the treatment. Parent participants reasoned this behaviour as adhering to the advice of their most trusted and experienced source of cancer information. Some indicated that while they had "mainstream" cancer information, their medical knowledge of cancer was very limited and so trusted their doctor's judgment implicitly. The lack of culturally relevant information and misinformation, either because of taboo, little interest, fear or because of myths, also contributed to their information seeking attitude.

It seemed because of the above beliefs, parent participants were more interested in obtaining information on how to cope with side effects and passing on information about cancer prevention rather than participating in decision making for their treatments. It is hoped that by identifying these ethnic and cultural influences and the nuances in which information needs arises from, would mitigate an already distressful situation. Similar to Weaver et al. (2010, p. 6) and Neuhauser and Krepps (2008, p. 377) it was found that understanding the characteristics and ethnography of patients and their families impacted by cancer was an important criterion towards recommending relevant interventions. As informed by parent participants and the observations, this thesis research found that some of the information needs for patients with dependent children builds upon the findings by preceding research for the importance of culturally relevant information about cancer, cancer treatment options and cancer prevention that were not conventionally "mainstream".

5.1.i.d Parent participants' information sharing behaviours

Parent participants who were more knowledgeable and participated more in their own cancer treatment, had more information and were more willing to share the said information to their children. Among the reasons for this was to better prepare their children for the side effects of cancer and how to care for the parent when at home. Some parent participants indicated that information sharing was also way for them to develop better relationships with their children; mitigating fears of death, changes to familial dynamics and helping children to understand cancer and its preventive measures better. This finding builds on the advice presented by the American Cancer Society (2012c, para. 5-7), Kornreich et al. (2008, p. 70), Visser et. al (2007, p. 142-143), Chiou (2009, p. 423) and Scot et. al (2005, p. 7).

Parent participants who did not share information, beyond the news of the diagnosis, realized and identified several information needs throughout the research process. Similar to a report by Barnes et. al. (2000, p. 479), these parent participants had the view that if doctors found difficulty in providing information, it was even more difficult for them to tell their children while coming to terms with cancer's implications to themselves. In exploring this experience, these parent participants shared that they did not know what to tell the children, when was the best time to inform them, how they may inform their children in a way that would be the least upsetting and how they could provide information that would reduce children's potentially difficult questions. These parent participants' reasoning seemed to be similar with Barnes et al's (2000, p. 480) report: parent participants avoided communication with their children to control or minimize what they perceived as children's difficulties. Also similar to Barnes et. al's. (2000, p. 481) findings, it seemed that these parent participants hoped to reduce the distress for themselves. This suggests that parents needed help in communicating about cancer and its impact to their family. Finch and Gibson (2009, p. 214) similarly reported this.

Similar to findings by Lewis (2006, p. 25), by the fourth focus group session, parent participants realised that the consequences of a lack of cancer information affected their children and their family dynamics. Most parent participants realized that they needed culturally-sensitive information on how to communicate to their children about the cancer care continuum. This included a language preference and the need for information about how to prepare their children for the parents' possible death, witnessing the side effects of cancer treatments and cancer prevention strategies that could be followed.

5.1.i.e Types of cancer information

It was found that to parents, having information about how to cope with side effects was important, especially when they exhibited an experience that children reacted to in fear. Parent participants identified their need for information on how to be prepared for severe vomiting, bodily aches and pains, hair loss, menopause and mood swings as being important with how they interacted with their children. Parent participants reasoned that advice about the potential consequences of side effects could have allowed them to better manage and prepare for children's reactions.

Information about cancer prevention was also a priority, because all parent participants shared that they did not want any other family member, especially their children to experience cancer first-hand. However, it was found that misinformation and myths were often deterrents in cancer prevention practices. Healthy eating habits of consuming more vegetables had the most opposition among children; the association between cancer prevention and eating copious amount of vegetables was not understood. A nuance of that information need was that parent participants reported that vegetables were not palatable and they required information on more palatable alternative foods.

Other than these two types of information, the focus group sessions resulted in parent participants' acknowledgment that they also needed information about how to identify their children's information needs and difficulties in coping with parental cancer. According to Weaver et al. (2010, p. 2), parents might not know the extent of the strain that children experience. Similar to Visser et al. (2007, pp. 140-141) findings, parent participants suggested that one of the reasons for their being unaware was that they experienced emotional and physical problems, which resulted in less attention for their children. Parent participants shared that they were very worried about their mortality and the future of their children. This affected their abilities to be alert to symptoms of their children's psychological problems and needs.

According to Weaver et al. (2010, p. 4), because children's health and function were closely tied to their parents, their well-being was also at risk. The children's' functioning was not as closely monitored as before the diagnosis and many symptoms and needs were unacknowledged. Most parent participants' were not aware about their children's problems. This reinforced studies by Weaver et al. (2010, p.4-6), Kornreich et al. (2008, p. 65) and Scot et al. (2003b, pp. 7-8) which has shown that parents may be unaware about their children's distress both during and after cancer and, that parents may benefit from professional services to help recognize and respond appropriately. The parent participants discussed that they needed information that would help them to identify their children's reactions and needs to ascertain if their children needed help in facing their new situation.

5.1.i.f Parent participants' awareness about their children's' caregiving

This research found that most parent participants were unaware that caregiving tasks, and the assumption for the eldest daughter to "automatically" take on such tasks and household chores, were difficult to accomplish. Children participants, while being willing to help, felt that the tasks were unreasonable and not age appropriate. Some children participants were responsible for a myriad of tasks that did not meet their skill sets, capabilities and physical abilities. These findings were similar to findings by Bauman et al. (2006, pp. 67-68) about children care-givers who provided personal assistive care for their HIV/AIDS parent in

Mutare, Zimbabwe and New York, USA. According to Bauman et al. (2006, p. 67), “children provided substantial personal care” that included “responsibility for cooking, cleaning, shopping and other household tasks”. In addition to this, according to Bauman et al. (2006, p. 68) children reported doing more than their mothers reported and, had too much responsibility that children reported reduced after-school and peer activities. The lack of parental awareness and their low perception of caregiving frequency was a phenomenon that was also evident in research conducted by Weaver et. al. (2010, p.6), Skovdal and Ogutu, (2009, para. 16), Becker (2007, p. 3) and in this thesis research.

Bauman et al. (2006, p. 56) reported that the amount of care provided was related to “maternal disability”. This was understood as the mother’s inability to take on her “normal” responsibilities due to illness. The studies by Skovdal and Ogutu (2009), Becker (2007) and Laird (2005) on African children who were caregivers provided anecdotal transcripts that seemed to agree with this assessment. However, a slightly different experience was found in this thesis research. As reported earlier (on page 119), the data suggested that, in line with the participants’ cultural beliefs, caregiving tasks were a gender-based prerogative and may have strongly or “automatically” influenced parents to readily identify caregivers in their families as being the eldest female child if the mother became unwell. It seemed that in participating families, female children were assumed able to “automatically” figure out and actually behave as a caregiver as and when needed.

Caregiving tasks seemed to be perceived as a cultural norm within parent participants’ familial and community structure. This parental assumption seemed to have evolved from the traditional belief that household tasks, caring and emotive support was “women’s work”. In the absence or illness of the mother, the subsequent delegation of caregiving tasks constitutes a gender-based factor that was delegated to daughters as a non-negotiable aspect of their roles within the family construct. Other than instructing and entrusting caregiving tasks, most parents seemed to lack information on how their cancer and their belief for “automatic care” could affect the normal roles and responsibilities of their children. They seemed to expect their daughter caregivers to somehow “automatically” know what needed to be done without tutelage or with a minimum of direction and supervision. The failure for providing a support system for young caregivers was similarly reported in Becker (2007, p. 11). Moore’s (2005a,

p. 2) study found that caring responsibilities for young carers "are most often provided without supervision or support".

The sophistication, understanding capabilities and realistic and/or unrealistic expectations of people about caregiving within the family was reviewed in previous literature (breastcancer.org, 2006; Fletcher et al., 2012, p. 387; Hermann, 2000; National Institute for Clinical Excellence, 2004, pp.25-27; Scott et al. 2003a, 2003b, 2003c). Both participant groups underestimated the sophistication of the other group's information needs, information seeking behaviour and abilities to process information. The parent participants had a simplistic view of how cancer effected their children and the extent of caregiving they provided. The children participants, perhaps due to their cognitive limitations, also construed their parents' experiences and concerns in a simplistic view. However, this underscores the expectations they have of one another and gives rise to the development of many problems as evidenced by observations and self-reports of participants.

The parent participants realized that they had placed challenging burdens and responsibilities to their young children. This acknowledgment developed from the parent participants' understanding that their children were more aware, had more knowledge than anticipated, were unfairly responsible for parent-assumed "automatic" tasks and more involved in caregiving than they previously assessed. Another significant finding was that parent participants realized how their children were affected by the cancer diagnosis. This contributed to their request for information on how to communicate to children about the cancer experience, what were age-appropriate tasks, developmental issues in children when faced with parental chronic illness, symptoms of children being adversely affected by the diagnosis and the co-development of recommendations for interventions.

In conclusion, patients' and their families' information needs and health seeking behaviour certainly merited further attention. These findings helped the research to identify the information system modality from patient to dependent children. This resulted in rich data about the problems in cancer information, difficulties in informing children and areas in which information provision may be strategically developed. A discussion about the information needs of dependent children of patients follow.

5.1.ii Information needs of dependent children of patients

This thesis' area of research was in an area that was considered by most studies as still being in its infancy (Fletcher et al, 2012, pp. 387-388; Hermann, 2000; National Cancer Alliance, 2002; Scott et al, 2003b). Specifically, the scope and focus of this thesis research has not been explored collectively by precedent research. Most previous research had not identified the specific information needs children wanted in order to help them make sense, come to terms with and to overcome their new environment and the health situation they faced. Most research also had not managed to identify and understand how children experienced their parent's cancer and the meanings that they attributed to cancer. Of significant interest to this research, there was very little information on the different consequences of parental cancer on children and the increasingly evident role that children played in their parents' well being while they were undergoing cancer treatment. It was found that children participants had many unmet information needs, had difficulty in accessing access information that would have helped them to understand better, cope and overcome the challenges they faced as young caregivers and, as children requiring care from their ill parent.

The following paragraphs discuss these findings in several ways. They are: i) children participants' need for cancer information, ii) types of information for dependent children of patients and, iii) the children participants' preferred source of information

5.1.ii.a Children participants' need for cancer information

The effects of parental cancer to children participants in this research suggest that the consequences of cancer and cancer-related information are far more needed and important than anticipated. In comparison, the current availability and presentation of cancer-related information (American Cancer Society, 2012a, 2012b; breastcancer.org, 2006; Hermann, 2000; National Cancer Institute, 2013, 2012a, 2012b, 2012d, 2006) suggests that the information needs for the children participants of this research were not met.

Children participants' information needs developed from findings about the consequences of a lack of cancer information, children participants' experience and their preferences. According to Scott et. al. (2003b, p. 1), while cancer created multiple problems for affected families, it has not been a common practice to share information and communicate to children about their responses. However, researchers, practitioners, patients and their family collectively believed that information played important and varied roles in helping them come to terms with cancer, make-sense of their new situation and provide more visibly supportive mechanisms in the cancer care continuum (American Cancer Society, 2012a, 2012b, 2012c; Leydon et. al, 2000; Sorensen et al, 2009; Scott et. al., 2003b; Schattner, 2002; NHS Effective Health Care, 2000 and NHS Executive, 1998). Evidences presented by Schulz and Sherwood (2008, p. 27), Kornreich et al (2008, p. 66-70), Christ and Christ (2006, p. 198-199), Kerr et. al (2003, pp. 424-427), Davis et al (2002, p. 134-135) and, Barnes, et. al. (2000, p. 480) further indicated that information was essential for people impacted by cancer to be more prepared for death, to be more knowledgeable about treatment options, feel less helpless, develop new skill sets and to feel hope.

Current information provision for the participants in this study seemed to be ineffective, inappropriate and less relevant to the information needs of children participants. All children participants reported that the many issues, challenges and difficulties they had could have been mitigated by digestible information that was relevant to their needs and cultural and/or religious imperative in providing home-based care. Children participants reported that health information available in Malaysia about parental cancer for children's needs were limited. The focus for cancer information was mostly on cancer eradication; information provision did not include much advice and information on the responses, psychological distress markers and needs of children impacted by their parent's diagnosis.

The children participants reported that access to published materials about the affects of cancer to dependent children were limited to materials in public libraries, cancer centres and their own abilities to access the Internet. It was found that these materials were not in their native language, had a noticeably complex grammatical structure, language and medical terms. This resulted in the information being regarded as difficult to read and understand which made the information less useful. Children participants also perceived the available information from non-Malaysian sources as not being culturally relevant and not addressing the nuances of participants' experience nor information needs. Locally published materials did not address dependent children needs. The information contained medical-based information that both children and parent participants deemed less relevant to solving problems in caregiving and the lifestyle changes children were challenged with.

Reports by the American Cancer Society (2012b), Fourie (2012), Christ and Christ (2010), Kornreich et al. (2008), Sweeny (2003) and findings from this thesis research found that withholding information and misguided unintentional twisting (or filtering) of the truth to protect children prevented appropriate support. Misinformation and children participants' own assumptions contributed to misunderstandings about the nature of cancer, cancer treatment, side effects and misguided cancer preventive strategies, which affected children participants' beliefs and attitudes towards the disease and their situation. Several children participants' definition of cancer, cancer causation and concept of cancer prevention were not commensurate with scientific medical knowledge. These experiences posed significant problems in supporting home-based recovery and, children participants' adjustments to the health situation, changing familial dynamics and adherence to a healthier lifestyle. Both participants groups reported many incidences that could have been better managed with relevant information provision.

Self-reports by children participants implied that whatever cancer information they managed to obtain shaped their lay knowledge and populated their personal files. This shaped their experience of health situations, their own methods and attitudes to information-seeking behaviours and capabilities in information synthesis. Myths about cancer, contradicting information about cancer prevention, confusion about the cancer treatment process, different expectations and, the evident adverse consequences to children have made information provision to children an important concern.

Contrary to reasons for withholding information, according to the American Cancer Society (2012b, para. 6), Stuber et. al. (2001, p. 187) and Sweeney (2003, p. 21), very young children understood that a parent was seriously ill, even if they are not directly informed. This finding accorded with Barnes et. al.'s (2000, p. 481) report that children have more potential to understand complex concepts of illness than was previously appreciated or anticipated. This was also suggested in the research by Skovdal and Ogutu (2009, para. 5-6), Becker (2007, pp. 3-11) and Scott et. al. (2003b, pp. 1-2). All children participants in this thesis research knew that their parent had cancer and even though parents feared full disclosure about their illness, the children were pivotal in home care and noticed symptoms of their parent being unwell. This experience reinforces findings by the American Cancer Society (2012a, 2012b), Weaver et. al. (2010), Skovdal and Ogutu (2009), Aldridge (2005) and Scott et. al. (2003b).

The situational context also reinforces Kirkby and Whelan (1996, p. 77) recommendations that the adoption of a family systems perspective in future research will further the understanding of how children and their families cope with medical procedures.

It was found that without timely and digestible information that was relevant to children participants' needs, they misconstrued and misunderstood the causation of cancer, treatment and prevention strategies. Similar to the literature review, these children participants depended on their imagination, fears and ability to synthesize information and experiences to explain the changes around them. In some cases of children participants' attempts to make sense of their mother's illness, this included wrong information and cancer myths that they believed to be true. The American Cancer Society (2012), breastcancer.org (2004) and the NHS (2000) for example, published several booklets and articles on why children needed to be informed. Weaver et. al. (2010, p. 1) wrote that there was a "large population of families from whom cancer may pose special challenges and for whom problem needs assessment and referral to resources are essential." The NCSM has seen 40 years of cancer's impact on families and concurs that children need to be informed and what may be expected of them (Somasundaram, 2004).

5.1.ii.b Types of information for dependent children of patients

According to data explication reported in Section 4.4 and presented in Table 4.26 (List of Participants' Suggestions, on page 201), children participants' wanted two types of key information. The first type was for cancer–specific information that covered 15 topics on cancer. They wanted to know the definition of cancer, definition of disease, the types of cancers, was cancer dangerous, was cancer contagious, cancer detection, the treatment process flow, a list of possible side effects of cancer treatment and cancer prevention. They also wanted to know why cancer took a long time to recover from, why chemotherapy caused vomiting and hair loss. They also wanted to know how to instigate discussions with their parent about their concerns.

The second type was for children's specific concerns. Children participants were concerned about 18 areas. They wanted to know how to care for a cancer patient, possible ways to help parents with cancer, possible changes to familial roles, how to take care of self, how to take care of younger siblings and how to talk to parents about their cancer experience. Children participants wanted assurance of continuation of care and love, they wanted to know how they could talk to parents about what made the parents upset or what made them upset. They had questions about how to show care towards their parent, why house chores were unequal, why girls had more care-giving tasks, why the father was less helpful or less supportive, how to approach a parent when they appeared bad/disgusting/not normal. Children participants also wanted to know what they could do so they were not scolded as often. The children participants asked why was the ill parent emotional, how could lessen it and how to calm the ill parent when angry or upset.

In addition to that, according to Weaver et. al. (2010, p. 6) and Aldridge (2005, para. 1-2), children have a right to age-appropriate information about medical conditions and access to services. This suggested for information provision to support the understanding about cancer that was not only commensurate closer to scientific and medical knowledge but to help children participants to make better sense of their situation as well. It was found that children participants had not known about their rights, what skill sets or tasks were conventionally age-appropriate and they had not known how to approach their parents with their difficulties. This resulted in children participants struggling to overcome the many challenges they faced, mostly alone and unaided. This implied that children participants' information needs should also include a guideline of age-appropriate tasks and strategies.

Children participants wanted information to be verbally communicated to them firstly by their ill parent or secondly from their mother's doctor. Most children participants indicated that they would like information that included attractive pictures to illustrate cancer information similar to a comic-book format. They wanted key information topics to be presented in a situational context or narrative construct. They provided reasons of attractiveness, situational relevance, handy reference and easy to digest information. Children participants also advocated for the information to be in Bahasa Malaysia so as to facilitate understanding and easy recall. Their information needs would necessitate for information provision to be commensurate with these findings.

5.1.ii.c The children participants' preferred source of information

Similar to the literature review, children participants also had different dimensions of concerns. Some were confused why and how cancer developed when they perceived that their mother had healthy habits. Children participants felt frustrated, bored and resented the frequency of hospital visits when they accompanied their mother. Some were concerned that cancer was contagious. Some even feared losing their hair if they became ill. Older children participants were concerned about the prolonged illness and how long they would have care-giving responsibilities.

It was found that information related to a health situation had a communication process flow from the source of the illness (i.e. mother) to the children; when children participants reacted to a health situation they often sought clarification and/or explanations or guidance from their mother. The children participants' preference for information sources was based on their perceived accessibility to the information source, the degree of open communication, and the scope and depth of the source's cancer knowledge. Similar to a report by Kenrick (2009, p. 12), participants preferred face-to-face interactions to seek advice and help with what they perceived as more complex problems that tends to focus on sensitive personal, emotional and health issues. First-hand experience was an important determinant as children participants perceived this source could provide them with more descriptive and recontextualiseed information that was relevant to their needs.

The most preferred information source allowed for face-to-face communication and information sharing. Many children participants indicated that face-to-face communication would help to clarify issues, mitigate concerns and, help them make sense of their health situation. Children participants perceived that this type of exchange was available from the parent who had cancer. An important component of this process was dependent on, and limited to, the information that their sources were able to provide. Parent participants reported that in most instances, they would have to translate, simplify and re-contextualize information in order to be commensurate with their perception of children's mental abilities and emotional threshold. They also had to "sugarcoat", filter or withhold some information. This experience reinforced Kornreich et al. (2008, pp. 66-69) and Kerr et al.'s (2003, pp. 425-427) report that clinicians did not provide "digestible information" and the said information had to be recontextualised to aid understanding.

This difficulty is compounded when parent participants often had to translate information from English into Bahasa Malaysia. Many concepts and terms were reported to have been lost in translation. Parent participants reported their difficulty and ignorance about scientific medical matters and felt that they were ill equipped to be information providers. Another nuance of this difficulty was that children participants solicited information mostly when experiencing a frightening or traumatic incident that required information to facilitate making sense of, or coming to terms with, the said situation. Parent participants reported that this information was not readily available. The consequences of this were evident in some of children participant's responses.

This implies that information provision would be required to meet children's information seeking process flow and how they react to a health situation. These experiences suggested that one alternative in providing information would be to educate and provide guidance to parents so that they could be better information providers with information that was more relevant to their family dynamics and needs. Another option would be the provision of information that was more digestible. Another perspective was for information to be provided that was independent of parental input.

The attending doctor was the second most preferred information source. However, the prevailing attitudes and beliefs of both parents and doctors were often deterrents to information sharing. Children participants also obtained information from a variety of other sources like the Internet, the library, another family member, the attending nurse or a neighbour or family friend. However, their ability to obtain satisfactory information from these other sources was with varied levels of success. They still reported having insufficient information to make sense of cancer and to cope with challenges they faced.

In conclusion, these findings and the advocacies presented in the literature review, influenced the belief that the information needs and health seeking behaviour of patients' dependent children certainly merit further attention. The myriad of myths, confusion, misinformation and evident adverse consequences to children has made informing children an important concern. These findings helped to identify the information system modality of patients' dependent children. This resulted in rich data about the problems in cancer information available to children participants, the difficulties they faced in obtaining information and areas in which information provision may be strategically developed. The cancer's impact on family members necessitated information provision that commensurate with their individual needs, skill sets and role in caregiving. Rowlands (2005, pp.16-21) believed that tailoring of such information allowed caregivers to better support patient and themselves. Following this discussion, a discussion about the children participants' responses to parental cancer follows.

5.1.iii Children Participants' Responses To Parental Cancer

The children participants in this study reported several reactions to their parent's cancer. This is discussed in the following subsections as: a) the children participants' emotive reactions, b) the children participants' cognitive responses and, c) the children participants' other responses.

5.1.iii.a The children participants' emotive reactions

Similar to Bauman et al. (2006, pp. 67-68) and Becker and Becker (2008, p.6), parent participants underestimated their children's emotional, behavioural and care-giving difficulties. In exploring the children participants' responses, it was found that they first reacted with fear, confusion and disbelief about their parental diagnosis because they had perceived that their parent was healthy; parents showed no lay knowledge symptoms and perceivably practiced healthy habits. Children participants had not anticipated the diagnosis among their immediate family members. They had not actively sought information about cancer and so were not prepared to deal with cancer's implications for their parent, themselves or how cancer effected their family. Beyond the knowledge about cancer possibly leading to death, they did not know what to expect about how cancer may effect their parent and themselves.

The children participants experienced emotional distress, challenging changes to their family dynamics, changes to their lifestyle and impaired functioning. Children participants were distressed about their parent's health situation and requirement for medical treatments, most notably hospital stays and side effects to cancer treatment that resulted in violent vomiting, hair loss and emotional outbursts. They feared parental death, hospitals, surgery, hospital stay and syringes. These children participants reported being worried of developing cancer, disgust at side effects, embarrassed because the mother became bald, anger at the unfair distribution of care-giving and household tasks and other reactive emotions to their situation.

Children participants were witness to their ill parent's experience. This resulted in some psychological stressors from witnessing their parent's anxiety and depression. Stress was reported because of parent's prolonged illness, not knowing what was going on, frustration and confusion of what to do to help parent get better, difficulty in accomplishing tasks and how to prevent cancer. Several younger children participants experienced separation anxiety. Some of the children participants felt sad. This was attributed to the possibility of the parent's death, empathy towards the parent's suffering, feeling unfair towards the uneven distribution of responsibilities, and frequency of being scolded.

Parent participants acknowledged that they were not aware about the extent of distress and difficulties in their children. According to Kirkby (1996, p. 65), "illness and hospitalization are stressful experiences for children and their families". Throughout the long recovery process, children participants experienced parents' reactions to cancer treatments and behavioural changes. These were significantly different then from before diagnosis. Irrespective of parents being afraid of their children's reactions, children already experienced unsettling cancer-related situations and a myriad of far reaching problems may develop which, in turn, may require complex interventions that were more comprehensive (American Cancer Society, 2012; Weaver et. al., 2010, p. 2; Thastum et al., 2009, p. 4031; Kornreich et al., 2008, pp.66-69; Aldridge, 2005; Scott et al.,2003b, p.1).

These findings give credence to the importance of understanding children's responses. These findings suggest that new modalities in developing and providing cancer-related information should be more responsive towards dependent children's' experiences, marginalised needs and strategies in seeking information.

5.1.iii.b The children participants' cognitive responses

The children participants were aware about their parent's cancer. The children participants, some as young as six years old, appeared to have the ability to generate and articulate (through drawings, writing and discussions) the cognitive association between cancer, symptoms of being ill and death. They were able to form and share their own sets of beliefs about cancer as a deadly disease that affected patients physically and psychologically.

The children participants reported that they perceived the state of parental health through non-verbal cues and behaviours. They saw parents' facial features and perceived their parents to be sad, upset or worried. However, they were unable to accurately identify the motives of the said expressions nor were they able to accurately identify and related an expression to an actual emotion. This contributed to children's confusion. Interestingly, the children participants' confusion seemed to strengthen the parents' conviction and perception that their children were less supportive or less caring than parents expected.

It was observed that the children participants' perception or reaction to a health situation and their role in caregiving seemed to trigger their information seeking behaviour. Similar to Lockwood and Manaszewicz's (2004, p. 632) belief, children's silence did not equate satisfaction with provided information or, a lack of questions. Rather it was evident that children understood that their present information system lacked the necessary support system and, that children lacked the knowledge of what to ask and when.

Children participants seemed to communicate better and more through face-to-face discussions and writing instead of drawing. This preference contradicted the research's originally assumption that these children would find drawing as a preferred and easier method to communicate their experiences. Drawings were tools or methods in which the children participants used to trigger or prompt story telling and opinions. It was found that drawing was not encouraged in these particular participants' families. Children participants responded with more anecdotal responses through their verbal and written communication instead.

As mentioned earlier, the children participants communicated and relied heavily on their mother for information. This was similar to the findings by Emmons (2004, para. 11), children tend to use sources first from that which is most accessible, and with personal experience as they were trusted and had a greater degree of success, even if the said sources did not provide the most correct or accurate information. However, the children participants' mother's own lay knowledge and subjective assessment of protection and suitable information often contributed to misinformation about cancer causation, development, diagnosis, treatment and prevention. It seemed that the misinformation and lack of age-appropriate explanations influenced what children participants perceived as truths and myths.

This further influenced their reactions, attitudes and the extent in which they believed parents' shortcomings or limitations were acceptable to them.

5.1.iii.c The children participants' other responses

The children participants did not blame themselves for their parent's cancer. Several children participants perceived that cancer was an "Act of God" and they praised their mothers' ability to persevere, maintain (or increase) faith in God and, to be stoic (in some instances). This attitude seemed to be influenced by a cultural imperative. This finding contradicted American Cancer Society's (2012b, para.20), McCue and Bonn's (2003, p. 50) and Kubler-Ross's (1969, p.3) belief that children blamed themselves or perceived that they contributed to parental illness. In addition to that, unlike Kubler-Ross's (1969, p. 4) belief, the anger that most children participants felt at having the parent being unable to gratify a need seemed to be targeted to the cancer, not to the parent specifically. Only two children participant, [F1(C1)] and [F7(C1)]'s anger was targeted to their mother for her impaired parenting.

Another effect of cancer was the disruption of family dynamics; it changed family routines and there were additional responsibilities for children. It seemed that when their mother was ill, many of her tasks became the responsibility of children participants. It is to be noted that the healthy parent, the father, had fewer care-giving tasks than his dependent children. Throughout the research, only two families mentioned the father/spouse as having accompanied the ill mother/wife for hospital visits. Some children participants remarked about the father's absence and some reported frequent fights between their parents. Some children participants thought that their parents might divorce because of the difficulty in coming to terms with the diagnosis, the difficulty and prolonged care required and the stigma of cancer. However, a follow-up discussion about spousal/father's role were not further elaborated because it seemed to be too sensitive or taboo a topic and it was not the focus of the research.

These findings suggested that patients' dependent children had more dimensions of concern. The children participants' reactions and responses indicated information gaps in current cancer information.

5.1.iv Caregiving: Experience and implications for information provision to children caregivers

Parental and community expectations for children's contributions and role in the face of parental cancer among Malay families had not previously been documented. In an effort to understand this experience, according to Bauman et al. (2006, p. 56), the amount of care provided was related to maternal disability, not child age, gender, or presence of other adults/siblings. The study by Skovdal and Ogutu (2009) on African children who were caregivers seemed to agree with that assessment. However, a slightly different experience was found in this thesis research. Unlike Skovdal and Ogutu (2009), Bauman et. al. (2006) and Rowland's (2005) reports, this thesis research discovered that the eldest female child was prominently more involved in decision-making and caregiving tasks than the husband or eldest son. The prevalence for patient dependency on the eldest female child included their responsibility for multi-tasked activities that included caregiving and household responsibilities and, decision-making for some cancer related treatment. These findings are discussed as a) prevalence of children providing care, b) cultural influences in caregiving, c) religious influences in caregiving and, d) consequence to caregiving.

5.1.iv.a Prevalence of children providing care

13 Malaysian children who participated in this thesis research played a significant caregiver role while nine children participants provided less significant caregiving. Children participants, especially the eldest female child were given caregiving tasks that in most cases were not age appropriate, not previously taught and had little adult supervision. Nevertheless, children were still expected to carry out both household and care-giving tasks "automatically". Children participants reported being overwhelmed and not being able to cope. These new challenging responsibilities was one of the most significant finding about cancer's effect on dependent children of cancer patients.

Children participants played an important role in caregiving and interacted more often and more closely with their ill parent. Part of this finding contributes to a greater understanding of children's informal caring roles and responsibilities. According to Becker (2007, p.23) "in western constructions of childhood, children are not expected (or encouraged) to take on substantial or regular caregiving responsibilities". "Childhood' was viewed as a 'special' or 'protected' phase and children should be safeguarded until they made the transition into adulthood (Dearden and Becker, 2000, p. 27). However, Frank et al. (1999, p. 1) reported that there were children who regularly took on caregiving roles and responsibilities. An estimated 65.7 million people in North America served as unpaid family caregivers (National Alliance for Caregiving, 2009, p. 4), and an estimated 174,996 children (Becker, 2007, p. 27) contributed through their caregiving.

Similar to Bauman et. al. (2006, p. 56), it was found that the children participants provided substantial amounts of personal care and children reported performing more tasks than their mothers reported. The children participants had household chores as well as caregiving responsibilities that required more mature and specialized skill sets. According to Aldridge (2005, para. 4), when parents were sick or disabled, "children undertook both domestic and emotional care responsibilities" that can profoundly impact children when caring was long term and disproportionate to their age and level of maturity. However, Aldridge's "range of duties" was not as extensively reported as this research provided. The children participants listed 35 tasks (listed in Table 4.15 on page 169) that included household chores, caregiver tasks and other tasks, many of which were not age appropriate and proved to be very difficult for the children participants to carry out.

Becker (2007, p. 32) reported that young carers roles developed because there was no alternative for families impacted by an illness. Becker (2007, p. 32) explained that the demands for, and availability of, informal care was because of a lack of available or affordable health and social care provision that necessitated children to provide caregiving to their parents. This thesis research found some ethnographic similarities, and one of the influencers for children participant's roles was similar to Rowlands' (2005, pp. 16-21) report whereby Asian cultures suggested more interdependent relationships where families become very involved in caring for the patient.

5.1.iv.b Cultural influences in caregiving

In addition to Becker's (2007, p. 30) findings, it seemed that, in participants' families, children were expected to take on caregiving responsibilities as a cultural and religious imperative. As Laird (2005, p. 462) observed, "failure to fulfil these responsibilities will attract censure and probably penalty both from kin and the wider community". Parent participants criticized the extent, frequency, sincerity, concern, care and, even show of love toward their parent when those tasks did not meet their expectations.

In line with participants' cultural beliefs, caregiving tasks were a gender-based prerogative and may have strongly influenced parents to readily identify caregivers in their families as being the eldest female child if the mother becomes unwell. According to Scharlach et al. (2006, p. 135), "culturally-defined values, norms and roles are major determinants of caregiving" whereby "Familism" was often cited as a motivating factor for expectations of providing care. Family specific values of mutual support, reciprocity, filial obligation and respect for an elder's authority influenced the caregiving quality and frequency.

The collective data suggested that, within the cultural norms of the participants, there was a sense of familial obligation for children (more than for spouses), to be responsible or at the very least be helpful, towards providing care for an ill parent. It seemed that in participating families, female children were assumed able to "automatically" figure out and actually behave as a caregiver as and when needed. In the case of children participants of this thesis research, cultural and religious factors seemed to impact on attitudes to caring for the ill and home care. This parental assumption seemed to have originated with their compartmentalism of "women's work". In the absence or illness of the mother, the subsequent delegation of caregiving tasks constitutes a "typical" gender-based phenomenon relegated to daughters. Some of these tasks required a certain level of specialized skill sets that these children participants were neither well informed, prepared nor educated to accomplish. This reinforces the study by Becker (2007, p. 30) that, caring responsibilities "are more intense … and are most often provided without supervision or support".

Reports by the children participants seemed to suggest that there were familial expectations for caregiving tasks to be repeated throughout the duration of their parent's long course of treatment. It also seemed that, in several instances, both the ill parent and the healthy parent, had "subcontracted" their children to carry out tasks in which their doctors advised them to do. This is specifically evidenced in the excerpts by the parent from Family Three, Five and Family Seven. Furthermore, the data suggested that this experience was also a result of the ill parent being reticent to ask for help from their children who was not of the same gender. Male children, irrespective of their age or order of birth were tasked with "manly" tasks and not similarly expected to carry out the caregiving and household responsibilities as their female siblings. This finding was similar to the expectations in African families reported by Skovdal and Ogutu (2009, para. 3) and in Asian families reported by Rowlands' (2005, p.19).

It seemed that while parent participants expected their female children's assistance, they were not as forthcoming and/or constructive in providing information to their children about what exactly needed to be done and how best to perform those tasks. Female children caregivers often received little support and lacked appreciation from their ill parent and other family members. As a follow-up, parent participants were asked about this finding. Parent participants indicated different scopes and extent of information that they were willing and/or able to share with their children about caregiving tasks. When asked about the lack of information sharing, parent participants implied that caregiving tasks were considered a domestic and *de facto* duty for females within a family construct and reflective of a cultural norm. This was similarly reported by Bauman (2007, p. 57).

Parent participants had not acknowledged, appreciated nor thanked their eldest female children for doing something considered "normal" and "unextraordinary." Some parent participants replied that their children's questions were not welcome because parents assumed their children should have already known how to accomplish said tasks. Some parent participants appeared defensive in those situations; they remarked that those questions allude to parent's own ignorance or shortcomings in educating their children about cancer and "automatic" skill sets. In most cases, the action of soliciting answers seemed to reinforce parent's belief that their children were too young, immature and unable to process and remember more complex information. However, contrary to this perception, parent participants still expected their children to be responsible for difficult caregiving tasks. This is an interesting paradox and suggests for more exploratory research.

5.1.iv.c Religious influences to caregiving

It was found that religion was an important influencer to children participant's attitude to caregiving and sharing information about their difficulties. Reinforcing the findings by Gatrad and Sheikh (2002, p.526), participants were Muslim families and would rather care for their ill family member. In the face of parental illness, all children participants reported an increase in their religious observances. Many participants seemed to find religious activities as a therapeutic resource.

Children participants considered their parent's diagnosis as their parent undergoing a "test from God". Several children participants reported that they believed cancer was an "act of

God" and that children were obligated to help their ill parent to overcome the disease. Rowlands (2005, p.19) reported that in Asian Muslims, care for the dying is "virtuous and promotes their own metaphysical readiness to meet God". As mentioned earlier (on page 215), in Muslim families, the concept of "leaving up to God" and being *"redha"* (follow God's decision) extended to caring for one's ill parent. Similarly, most children participants believed that being stoic and keeping the faith in God in the face of their parent's illness was a psychospiritual imperative; their care of their ill parent would help pardon their past sins and could promote recovery.

These beliefs in the face of illness were evident in transcripts of most participants of this thesis research. Since the religion promotes the concept of "*syurga di bawah telapak kaki ibu*" (heaven is under the feet of the mother), many children participants reported being *"redha"* in taking care of their ill mother and that this would help them get into heaven. Children participants also felt that their behaviour and care of the ill parent was a form of love as proscribed by the religion. Similar to the findings by the Boston Healing Landscape Project (Barnes, 2012, para. 5-9), children participants believed that the cancer experience strengthened various spiritual and character developments.

Also consistent with findings about parent participants and findings by Barnes (2012, para. 5-8), Yucel (2010, p. 3-5) and Qadri (2005, p.4) patience, prayers and faith in healing were considered virtuous and a form of piety whereby these attributes were considered very important values. Many children participants reported that similar to the behaviours of their parents, they too they tried being more in control of their emotions or hiding emotional outbursts. Some participants considered not complaining about their situation as a form of piety. When their ill parent became better, all children participants reported uttering "*Alhamdullilah*" (Thanks to God) for the recovery. It was noted that children participants did not perceive caring for their ill parent was their own test from God. However, many children participants seemed to find religious activities as a therapeutic resource for parents and for themselves when dealing with difficult tasks or situations.

It seemed that the practice of religion and cultural behaviours reinforces Weaver et al.'s (2010, pp. 2-3) report that past research has found children often do not speak up about their problems because they try not to overload or worry their parents who are already burdened by their own illnesses. Relevant to this finding was the understanding that a cultural imperative among children participants was for them to not ask too many questions, burden their parents with their concerns, manage and resolve difficulties on their own as a process of growing up. In another finding, by McCaffrey-Boyle (1998, pp. 80-81) in Asian communities, people were respected for being calm and serene and, may not voluntarily disclose problems or concerns or outwardly show emotion. These behaviours were evident in the research and it was difficult to solicit information from children participants as most would rather not be perceived as complaining, less pious, sharing family secrets or talking about matters that the family and community considered taboo.

5.1.iv.d Consequences to caregiving

According to Schulz and Sherwood's (2008, p. 24) and Pinquart and Sorensen's (2007, p.6) report, clinical observation and early empirical research showed that caregiving roles by adults could be stressful and burdensome. They elaborated that caregiving created physical and psychological strain over extended periods of time, was accompanied by high levels of unpredictability and uncontrollability, had the capacity to create secondary stress in multiple life domains, and frequently required high levels of vigilance (Schulz and Sherwood, 2008, p. 24). It was concluded that caregiving would be even more difficult for children.

However, Koerner et al. (2009, p. 238) reported that some caregivers experienced personal gains. Becker (2007, p. 25) reported that there might be some 'positives' associated with children being care-givers. He reported his previous finds (Dearden and Becker, 2000; Aldridge and Becker, 2003) that children care-givers exhibited "enhanced coping mechanisms; the development of life, social and other skills; maturity; a sense of purpose and closer attachments to people in their lives" (Becker, 2007, p. 25). Similar to Bauman et al. (2006, p. 63) both participant groups from this study felt children were more capable because of their responsibilities. Some assessed that they were more mature than their peers. In addition to this, and similar to the report by Skovdal and Ogutu (2009, para. 8), children constructed a positive identity as a young care-giver when they perceived that they were loved because of providing care and support to their parents.

Several children participants reported that they felt good about being able to care for their ill parent and they felt it was their chance to repay their parents' efforts in bringing them up in the world. These children participants also felt that they were “doing the right thing” and that they behaved accordingly as proscribed by religion. Their belief that caregiving would be rewarded with a place in heaven also acted as an impetus to continue to take care of their ill parent. This seemed to help them feel as if they were better prepared metaphysically to meet God after their own deaths. Similar to Rowlands’ (2005, p. 19) findings, the traditional values of “love, respect and loyalty to family elders” were evident.

In this it seemed that children participants had developed their own strategies in coping and overcoming challenges as caregivers. Even though children participants were still fine-tuning their skill sets, this development implied a level of maturity not readily observed among other children participants who were not primary caregivers. Both children and parent participants’ groups reported that these children care-givers appeared more mature than their peers and siblings, specifically in taking charge of the ill parent, younger siblings and the overall well-being of the family. It was reported that this assessment of maturity was well received by the children caregivers. However, these children participants felt that the burden of care was unfair, too difficult, not age-appropriate and impacted their own well being and development.

Parental perception and cultural and religious inhibitions created many difficulties for the eldest female children participants. These children participants reported being overwhelmed by their new tasks, roles and responsibilities. Many indicated they needed myriad of information types to help them cope and understand their new situation. They reported that they did not have sufficient information to carry out the duties that were expected of them. Some were also worried of contracting cancer as they thought that cancer was a communicable disease. In addition to that worry, similar to Weaver et. al.’s (2010, p.2) findings that other studies have found increased somatic complaints among children of all ages whose parents have cancer. Children participants indicated they needed information to understand what they were doing, why they were doing so and for how long they had to carry out those tasks. The data suggested that information was vital for the children participants to cope, understand and adjust to their roles as care-givers. These challenges infer that alternative solutions may be required.

In conclusion, the children participants as care-givers had myriad tasks that included household chores, caregiving tasks as well as tasks to support the well being of their family.

The children participants reported more tasks than their parents assumed. Some tasks were evidently difficult, not age appropriate and required specialized adult skill sets. They had to multitask over a long period of time, more than anticipated. Several children participants reported that they felt good about being able to contribute to their parent's and the family's well being; they reported feeling sad about the possibility of their parents' death and suffering to overcome cancer. They also believed that their caregiving was a way in which to communicate their love, support and care. It was also considered a religious and cultural duty. However, several children participants reported that their contributions were not acknowledged and they felt it was unfair for their parents to assume that children could "automatically" undertake caregiving and household tasks.

The above demonstrated the environment in which participants faced difficult challenges. This highlighted different ethnic experiences of children participants and the importance of understanding the implications for long-term care of people living with cancer and their families. These findings suggested that information provision needed to meet challenges that children faced. Pursuant to this and relevant to the focus of this thesis research, care-giving children participants wanted to have information predominantly about how to accomplish tasks; secondly, the effect of cancer treatments, and thirdly, how to prevent cancer.

In order to mitigate some of children participants' challenges, information may be independent of parental input. Another option was to educate parents on age-appropriate tasks and skill sets as well communication strategies to nurture better familial roles and appropriate responsibilities. Children participants also suggested the provision of easy-to-follow manuals in accomplishing household tasks and caregiving skills that was age-appropriate. These manuals may be in a comic-form, or illustrated to incite children's interest. A reality drama television programme or a feature film about some of the challenges of coping with parental cancer was also suggested. In addition to this, since religion and culture influenced children participants' reactions and expected responsibilities, information should also include the needs of Muslims in palliative and home-based care services.

These suggestions indicated that, similar to advocacies in the literate review (Archibald, 2000; Johnson and Meischke, 1991b; National Cancer Alliance, 2001; National Cancer

Society, 2012; Rowlands, 2005), changing the knowledge, attitudes and behaviours toward cancer was critical for preventive oncology and cancer control.

5.1.v Implications for information provision by practitioners

Many health care applications and administrators have realized how important information is to their industry and to people impacted by a health situation. As reported by Holman and Lorig (2004, p. 241), there was evidence for better health outcomes when "physicians' were attentive to patient's concerns and interests". However there has been very little research and development of systems to either encapsulate or minutely identify the myriad of ecosystems to tailor information to its end users (Bath, 2008, p. 505; Bergsma and Carney, 2008, p. 523; Bevan and Sparks, 2011, p. 26; Blackstone, 2012, p. 4; Blum and Sherman, 2010, p. 247; Wilkins et al., 2009, p. 528). The lack of knowledge from both practitioners and patients were a significant problem for preventive oncology and cancer control (Johnson and Meischke, 1991b, p.37). The findings of this research have implications for information provision by practitioners. This was discussed in several ways: a) the role of health practitioners and, b) list of cancer-related topics.

5.1.v.a The role of health practitioners

As mentioned earlier (on page 220), the sophistication, understanding capabilities and realistic and/or unrealistic expectations of people, suggests that the medical practitioner and information provider may similarly underestimate the scope and preference of cancer-related information needs for patients and their children. Holman and Lorig (2004, p. 242-243) believed that health practitioners needed to behave as "health partners"; not only medical-based management of patients but also as teachers in providing information to facilitate the patient's own management skills in assuring continuity and integration of care. Chiu and Wistow's (2002, p. ii) reported that Community Health Educators had the potential to facilitate information. The New York Academy of Sciences' report (Surborne and Zwitter, eds., 1997, p. 809) and a more recent report by Surborne (2013, p.4) concurred that doctors interacting with their cancer patients were considered important and integral to the continuum of care.

Some patients wanted to have as "much information as possible" about their illness (Schattner, 2002, p. 135). However it was clarified that for other patients, they only wanted information when it was good news, otherwise treatment options and other information was at the discretion of doctors to disclose (Butow et. al., 1997, p. 861; Jenkins et al., 2001, p. 49; Meredith et. al, 1996, p. 724). Other research reported that information regarding coping mechanisms and maintaining quality of life were priority information needs instead of detailed knowledge about the cancer itself (Leydon et al, 2000, pp. 909-913; Hassan and Hassan, 1998, p. 1153). Holman and Lorig (2004, p. 241) reported that patients were interested in having access to information concerning diagnosis and its implications, available treatments and the consequences and potential impact on patient's future; ways to cope with symptoms and, ways to adjust to disease consequences.

An example for organizational advocacy is the concept of tailor-made information packs that built upon the "person-based" principle. The NHS Effective Health Care bulletin (2000, p.3), reported their overview of 44 articles that "emphasized the importance of tailoring information to meet patients' educational background cultural orientation and general level of comprehension". According to Griffiths (2000, p. 16), this provided a strategic context for patients whereby the NHS is now expected to offer "appropriate, easily accessible and attractive information about … self-care for any illness … empower participation in health care decisions … a choice of high quality services … comparative information about waiting times and clinical quality." Griffiths further stated that clinicians were encouraged to provide "patient friendly" explanations and information "packs" that could be customizable (Griffiths, 2000, p. 16).

Relevant to the above reports as well as to findings by Chiu and Wistow's study (2002, pp.1-2), many parent participants in this thesis research felt that their doctors could have facilitated a better understanding about their health situation. Almost all parent participants felt that doctors and other health practitioners should inform patients and their families about the treatment process, how cancer developed and what they could experience in the burden of care. Further discussions resulted in the general belief that other than providing a diagnosis about the progression of the cancer treatment, doctors could play a more informative role to help patients and their families cope with their cancer experience. Other than being more medically knowledgeable about cancer with information that was culturally relevant, participants felt that their doctors should provide them with essential background information about cancer to better pass the information on to their children or care-givers at home. In co-developing interventions, parent participants recommended for their health practitioners to help them communicate information to their children, educate them on how to identify their children's information needs and difficulties in coping with parental cancer.

Somasundaram (2004) reported that patients and their families trusted their doctors as the most knowledgeable and experienced source for cancer information. This also proved to be true in the course of this thesis research. According to the participants, it was because of this belief that they readily identified doctors as having to not merely medical treat cancer, but to also provide information on a number of topics. Pursuant to this belief, the interaction between patient's and their doctors (notably information about side effects and how cancer may affects the family), affected how patients communicated and shared information with their children.

This was because parent participants' personal files and their extant knowledge pertaining to cancer information helped to shape and develop their children's own information seeking behaviour and needs. This was motivated by parent participants' acknowledgment that they lacked information on age-appropriate tasks and symptoms of children being adversely affected by the diagnosis. These findings implied that the information priority was on how to share information with children about the side effects of cancer and cancer prevention, and how to identify children's reactions and information needs. The justification for this relationship between the amount and quality of information of the parent with cancer and their children's own personal files and information needs was reported in section 4.4.iii (on page 152) and was evident by the questionnaire, self reports and observation obtained throughout the focus group sessions.

The children participants reported that for them, the second most referred source was the attending doctor. Children participants understood the medical role of doctors in helping their parents get better; however, they indicated that doctors and parents played a role in re-contextualising information so that children could better understand, be better prepared, cope and overcome challenges in caregiving. They asked questions from the attending doctor when they perceived that their questions were not satisfactorily answered. When these participants were asked why, most indicated their perception of the doctor as a specialist and being the most knowledgeable about cancer and its treatment options. It was noted, similar to the findings by Leydon et al. (2000), that even though information was considered an important aspect to healthcare, children were reluctant to ask doctors if they appeared “too busy”. Some children reported that their questions were ignored. The NHS Effective Health Care bulletin (2000, p. 4) recommended for peoples’ preferences for information and involvement in decisions to be considered; health practitioners to have communication skills training that provides higher priority on understanding patients needs’ and, for information to be tailored to the needs of patients. A justification was presented by Rowlands (2005, p. 20); “each patient’s beliefs, view of the world and their place in it will differ from that of the staff caring for them.” Rowlands (2005, pp.20-21) elaborated that holistic care involved empathic understanding of a person’s values, beliefs, culture, experience and expectations of healthcare. Rowlands (2005, p.21) added that education of healthcare professionals should also include communication skills so to facilitate better health outcomes.

Information practitioners will also need to play a more culturally-sensitive role and should be aware of the ethnography of cancer patients and their caregiving children. According to Jolicoeur and Madden (2002, p. 118) “simply providing information will not be enough … it must be accompanied by culturally sensitive persuasion and instruction to use them”. Bettman et al. (1991, p. 57) advocated “merely making information available may not be sufficient”. In an earlier work, Bettman and Kakkar (1977, p.239) proposed that when information is available and processable (easily understood and used), the information has increased utility. In the face of the inadequacies mentioned earlier, these advocacies were relevant to the research findings. Both groups of participants indicated their preference for people-centric exchanges of information to better facilitate understanding, rapport and adherence to cancer treatment and prevention strategies.

5.1.v.b List of cancer-related topics

The research found that children participant’s information needs were more varied than previously anticipated (Section 4.5, on page 184 and presented in Table 4.15, on page 169). There were cancer–specific information that covered 15 topics and there were children participants’ specific concerns that covered 18 areas. The top three information needs of care-giver children participants were: i) What will happen to my parent? ii) How I can help and iii) Food and diet.

The children participants seemed to be willing to help in caregiving (in various degrees). However, they indicated many times throughout the focus group sessions that they did not know how to do this. Thus, instruction on how to accomplish care-giving tasks was considered a priority information need. Children participants were concerned with how cancer impacted their once-healthy parent. Thus information providing explanations about cancer treatment modalities and the possible side effects of cancer treatments were important to the children participants.

Relevant to both of these priority information needs was the children participants' request for instruction on how to instigate an interactive dialogue with their ill parent. The data indicated that most children participants did not know how to talk with either parent about their cancer-related concerns. In addition to these concerns, children participants were also interested in knowing how to prevent cancer. They wanted to be informed about the implications of a cancer diagnosis for their lives and their sense of personal well-being.

As indicated in Table 4.25 (on page 189), the children participants preferred information in Bahasa Malaysia. Since most cancer-related information was in English and recontextualising information into Bahasa Malaysia was considered a difficult endeavor, participants' concerns and questions remained largely unanswered. The information gap is compounded with user's limited English language aptitude. This language preference implies that a new avenue for information provision existed. It also provided an opportunity for known and new information about cancer to be tailored into Bahasa Malaysia. This would be a positive step to support efforts in the cancer care continuum.

Both participant groups were interested in, and were willing to co-develop comic books or pictorial based information to tell a story about cancer experiences. Most children participants indicated that they would like information that included attractive pictures illustrating cancer information similar to a comic-book format. They provided reasons of attractiveness, situational relevance, handy reference and easy to digest information. For comic-books, the children participants specifically wanted more information about how to accomplish both household and caregiving tasks, how their parent's cancer may affect them and cancer preventive strategies. The children participants thought that the story telling angle could create rapport and easy referencing as the person-in-context is presented in a way that resonates better to them as information seekers.

In conclusion, children participants had more types of information needs than originally anticipated. These information needs corresponded to challenges and difficulties children participants faced. It is anticipated that if these nuances were addressed, information provision's utility would be increased by way of greater relevance, ease with which information can be processed, understood and used. An important outcome of this research was the development of a "Children's Reactive Information Seeking Behaviour – An Integrated Model" (Model). This assimilated participants' anecdotal reports and the researcher's observations on the nuances of information seeking triggers and behaviours and, how the children participants used information in order to make sense of their experience and concerns about cancer and parental well-being. The Model sought to provide an overview of the information-seeking and information synthesis process of children impacted by their parents' cancer diagnosis. The development of this Model is discussed in the next section.

5.2 SYNTHESIS OF FINDINGS: "CHILDREN'S REACTIVE INFORMATION SEEKING BEHAVIOUR – AN INTEGRATED MODEL"

It was observed that children participants' information seeking behaviour and information synthesis seemed to start from their reactions to a health situation and when they were required to do something about the said experience. This was evidenced by children participants' narratives about parent's biopsy, a mastectomy (either partial or whole), or when they experienced the first onset of the side effects of cancer treatments. This included instances when they experienced their parent's violent vomiting, hair loss, out-of-the ordinary bodily aches and pains, impaired parenting, seemingly unexplainable or irrational mood swings and, dependency for a myriad of tasks with which the children were unfamiliar, had no knowledge of or felt unable to accomplish.

When children adapted to the said health situation, they seemed to rely less on this information-seeking behaviour and information-synthesis; they had developed a more personally relevant and effective personal file to address a similar situation. They seemed to have developed their own strategies in coping and overcoming challenges as caregivers. Participants' narrative and research observations suggest that there was a specific process in information seeking behaviours and information processing for the children participants. Data explication resulted in an understanding of some of these behaviours. This contributed to the researcher’s development of the “Children’s Reactive Information Seeking Behaviour – An Integrated Model”.

The “Children’s Reactive Information Seeking Behaviour – An Integrated Model”

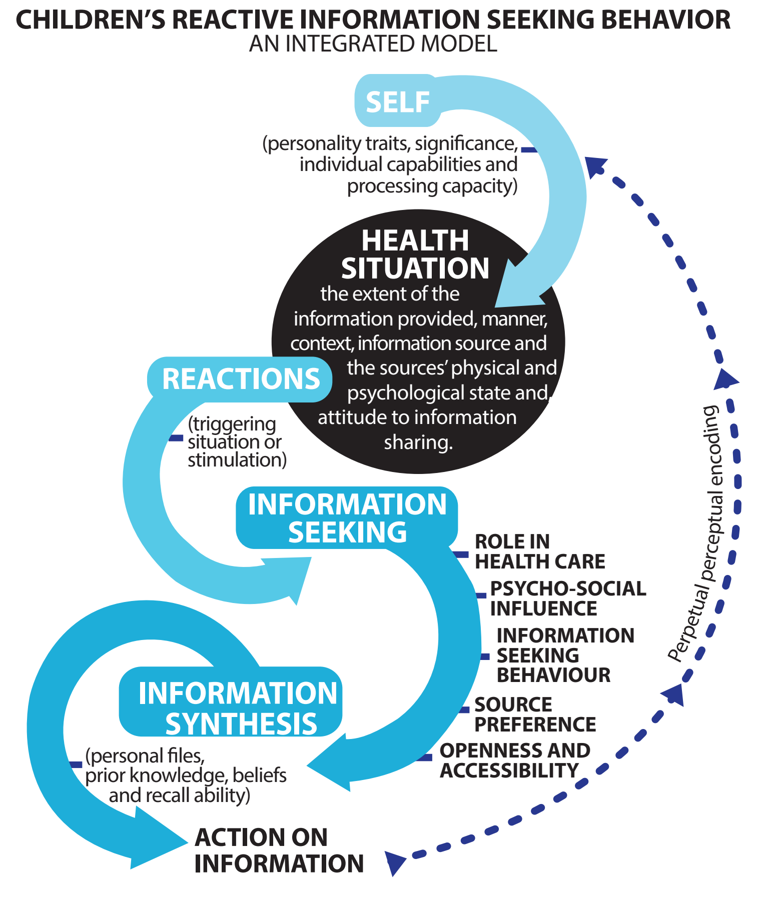
The “Children’s Reactive Information Seeking Behaviour – An Integrated Model” (Model) described children participants’ information processing flow. This included children participants as the “user” (termed as “self” in the Model), the health situation, the children participants’ reactions, information seeking, information synthesis and, action on information that subsequently forms a feedback loop. Some components were informed and built upon earlier findings by Finch and Gibson (2009), Wilson (1999), Dervin (2003), Krikelas (1983), Johnson (1997), Baker (1995) and Bettman et al. (1991). Other supporting components were influenced by Gallistel (2008), Kellman and Garrigan, (2009), Prince et al. (2005), Wilson and Walsh (1996), Belkin (1980), Ford (1980) and, Schutz (1967).

The Model is not infallible, but participants’ narrative and research observations suggested that the children participants’ process of information seeking began with a health situation or stimuli. Information was sought as a reaction to an unfamiliar, frightening or confusing health situation or stimuli. News of the health situation seemed to have been shaped and was influenced by several variables: the extent of the information provided, manner, context, information source and the sources’ physical and psychological state and, attitude to information sharing. These variables combined to influence children participants’ reactions to the said health event. This reaction resulted in an information trigger or triggers that either deferred or escalated the immediacy for children participants’ information need. After a situation presented itself, these children participants were prompted to find out more; either to make sense of the situation, to return to equilibrium, to provide support or to contribute in problem solving.

Children participants’ subsequent information synthesis depended on their information seeking behaviour and its outcomes. This included input from their preferred information source and the children’s own prior knowledge, beliefs and recall ability before an action on information occurred. Children participants replicated this process as a “Perpetual Perceptual

Encoding" (Bettman et al., 1991, p.57) of their newly obtained information, what information they already had, what they perceived to be of use and relevant to their situation and, subsequently will continue (or not continue) to use when facing either a new health situation, a similar situation, or a situation that they have developed familiarity with. Bonner et al.'s (1998, pp.68-74) inclusion of information behaviour activities (refer to page 16) and Wilson and Walsh (1996, para. 6, chapter 2) explanation of a belief-value matrix containing relevant images of objects or elements of past experience that can influence information behaviour (mentioned in Chapter Two, p. 17) expanded this concept. An overview of this process is provided in Diagram 5.1 while the original concepts is available in Appendix 9.

Diagram 5.1 "Children's Reactive Information Seeking Behaviour – An Integrated Model"



5.2.i "Self"

It was observed that the children participant's "self" contributed to how a health situation was perceived, their resulting reactions, their information needs and, their information seeking behaviours. This sense of "self" mirrored the researcher's understanding of the Information Universe illustrated in Diagram 2.2 (on page 18). The central concept of "user(s)" was the genesis of an information need, motive and seeking behaviour. User(s) have a goal or goals of interaction (learning or selecting) for their information needs and motives to be triggered. Their information requirements and their method(s) of interaction were strategized in order to meet or, satisfy or, answer the said information need. User(s) undergo a cognitive process to retrieve information from what is available or accessible to them from the information universe. Then, the user(s) utilised their influencing variables to make sense of the found or retrieved information.

Following this understanding, the sense of "self" of the children participants as "users", was central to the Model. "Self" included the personality traits, significance (in relation to self and situation) and, individual capabilities and processing capacity of children participants. Individual capabilities and processing capabilities is defined as the user's ability to make sense from information and its assimilation processes into knowledge that contributed to understanding. Other variables included age, maturity, vocabulary, attitudes, and existing knowledge and skill sets. Furthermore, the psychological state at the time of the health-related event also seemed to influence the experience of the health situation. This was shown at different times throughout the focus group sessions, especially when the children participants reported they were in shock, afraid, disgusted, angry, frustrated and confused. Examples are:

> *[F5(C1)]: When I saw all the black stuff coming out from her (mother, post surgery) I was so … disgusted and so shocked. I never knew inside (the body) can be like that … can not believe …horror … and horror for her … that was bad. Very bad …*
>
> *[F3(C4)]: Because at the beginning I did not believe what I was told. Moreover, my mother had never displayed any symptoms, but I did notice that she was sometimes listless. But, the news was a real shock and surprise.*

This sense of "self" was demonstrated most often when a health situation or stimuli may impact the children participants and their cancer parent (in varying degrees). For example, from an information gap standpoint, to the children participants' knowledge, their parents were non-smokers, did not exhibit symptoms reported in mainstream cancer information provided and, were perceived to be healthy. Cancer only happened to "bad people" or "unhealthy people". They had little or no information about how their parents would depend on them for care and the possibility of their changing roles in their family dynamics. It was clear that the children participants knew their parent had cancer. They perceived that death would be a fast and foregone conclusion. However, parent's prolonged life (beyond their lay knowledge expectation) confused the children:

> *[F2(C3)]:I thought cancer means, die already. It has been awhile since (diagnosis) … she's (mother) not dead yet.*

[F3(C2)]:She's (mother) had cancer for some time. Weird that she's still here. I mean, not to wish her to die so soon lah, but, I thought cancer, you die very quick …

SUZIE:How quick do you mean?

[F3(C2)]:Umm… I don't know … ummm…maybe… three months? You hear people saying that so-and-so did not have time … (cancer) was so quick … the person died already …

[F5(C3)]:Ya lah, you usually hear someone died of cancer … like three or four months (after diagnosis). No hope already. No chance to do anything. But, alhamdullilah lah, my mother she survived. Still going strong. I don't know why, maybe God, but, its good she is alive. So confusing lah, people say for sure die very quick, be prepared for her to die … like tomorrow, but look here, see, she's (mother) is OK. We just can not believe wholly what people say about death … about die from cancer so fast. This is in God's hands you know. Still very confusing…you pray and you hope … so-and-so said die in a few months, then someone else said die in a few days … haiyo … enough with the die now … what about will live for more? Live for many more months, years…

The children participants' existing knowledge about cancer (facts and/or myths) influenced their reactions. In an effort to understand this thought process and children participants' strategies in coping or overcoming their knowledge gap, it seemed that the children participants accessed their "personal files" (refer to page 143, adapting Kirkelas' (1983, p. 13) term of a person's stored or collected memory of answers from which can be recalled on demand and compared to their prior knowledge about a thing, event or experience) and their prior knowledge or "stock of knowledge on hand" (Schutz,1967, p. 222) to make sense of their experience. For example,

[F3(C3)]: I thought that only people who smoked got cancer. My mother never smoked, but she got it too.
[F8(P)]: I thought that second-hand smoking meant by second time you smoke, you sure get cancer.

"Self" influenced how the children participants perceived a health situation or stimuli, reacted to it and sought information to resolve the resulting states of information needs. From "self", the information seeking process moves to the "Health Situation" the children participant was confronted with. This is explained in the next subsection.

5.2.ii "Health Situation"

The "Health Situation" in Diagram 5.1 depicted the advent of the parent participant's health situation where the children participants were informed about the cancer diagnosis, surgery and cancer treatments. "Health situation" also described the onset of an unfamiliar event to the children participants; first exposure to parent's side effects to chemotherapy (for example: vomiting and hair loss), radiotherapy (for example: hospital procedures to prepare patient and darkened skin from radiotherapy burning) and, psychological and emotional reactions to the cancer diagnosis and cancer treatments. The reactions to a health situation were influenced by the extent of the information provided, manner, context and, the information source (including the sources' physical and psychological state and, attitude to information sharing) when the unfamiliar event occurred. These variables contributed to the children participants' understanding of a health situation or stimuli. Information or explanation that was too rushed and/or unclear confused the children participants, contributed to the development of misconstrued knowledge and misunderstanding of the said health situation.

Information source was included because literature review (American Cancer Society, 2012b, para. 5-9; Kornreich et al., 2008, pp. 64-65; American Cancer Society, 2001, p. 14) and research observations suggested that the information source's physical and psychological state influenced the scope, extent and attitude to information sharing. The extent of the information provided, manner, context and, the information source influenced information sharing was reported in 4.4.iii (on page 152). When information sharing was open and accessible, with an active dialogue or discussion about a health situation, the children participants reported an experience with positive outcomes. Conversely, when information sharing was closed and inaccessible, the children participants reported an experience with negative outcomes.

The term "unfamiliar event" described an event or stimuli in which the children participants had not encountered before. This was registered in the children participants' consciousness when they recognised a situation in which they had no prior experience and/or do not have a memory in which they may recall and/or access in which to be familiar with. Reactions to the said unfamiliar event are discussed below.

5.2.iii "Reactions"

"Reactions" was a component that included the children participant's emotive, behavioural and cognitive reactions to a health situation or stimuli. The children participants reported being shocked, confused, in disbelief, in denial and/or in fear of the diagnosis. They also reported feeling afraid, disgusted and worried about the onset of side effects. Some felt anger and frustrated about parents' behaviour and attitudes. These reactions followed experiences of the unfamiliar, frightening or confusing situation:

[F1(C1)]: Hoyoo… so scary when she vomit. Like everything (inside of mother) throwing up. Eeee, I don't want to be like that.
[F1(C3)]: So "moody" (referring to mother) ... don't want to tell us anything. That was so annoying.
[F2(C2)]: Her (mother) hair fell out, it was scary. I was so afraid ...

[F3(C4)]: I was so sad to see her crying … I never saw her cry like that before … so pity…
[F5(C3)]: I was so afraid of how loud her vomiting sound. It sounded so painful. It is like … I cringe … (shudders)
[F1(P)]: My children seemed confused when I told them I had cancer … It is like … the cancer … that I had cancer, did not register to them … or they did not know what cancer meant.
[F5(P)]: Yes, they (all children) saw me at the hospital and even though they seemed glad to see me, they did not come close. I remember asking them to come closer, but [F5(C1)] was shaking his head and getting close to my husband. Maybe he was afraid? Not sure he was afraid of me, all the strange tubes (drainage tubes) and machines, or what … I don't know
[F8(P)]: You can see from their (children) face … they were disgusted by the vomiting … by hair falling out and being bald … also, at times their face is like not sincere to help out … when have to help, they make a face …

The children participants also reacted behaviourally by overtly or covertly removing themselves from the situation, somatisation to the health situation (for example, gagging and vomiting when seeing, hearing or smelling a parent vomiting), or wanting to help but not knowing how (for example moving closer to the vomiting parent, but stopping mid way as unsure of how to help). This is evidenced below:

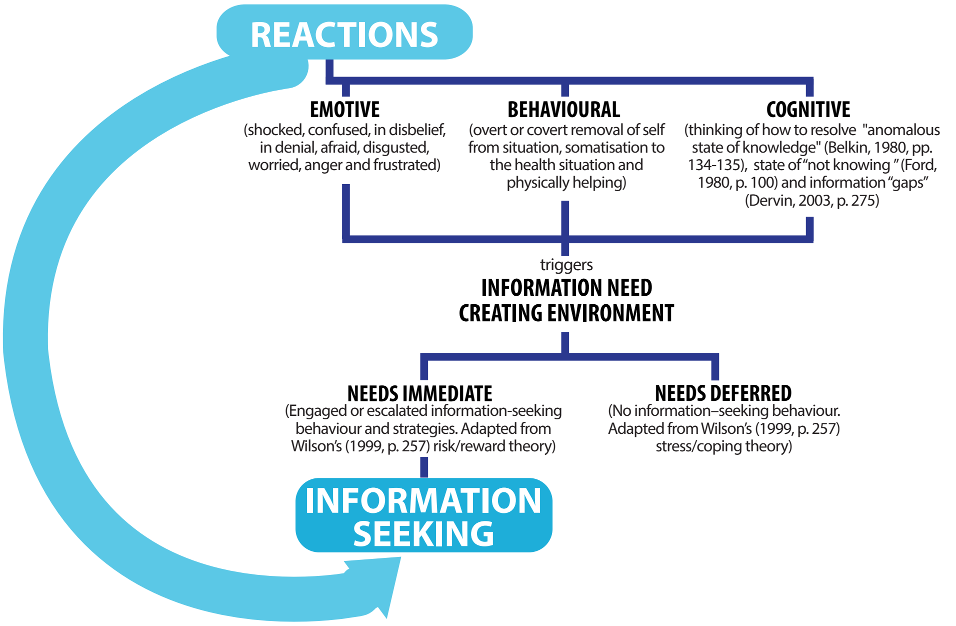
[F1(C1)]: When she (mother) uweek (vomit) I run away. I also uweek, uweek …
[F2(C2)]: Her (mother) hair fell out, it was scary. I was so afraid ...
[F3(C4)]: I also feel sad when she cries.
[F5(C1)]: Oh … I quietly go away… I don't want to hurt her feelings, but when she starts her vomiting … or being upset … I just get out of the way …
[F5(C3)]: I don't know how to help her. You like want to hold her, but not sure if that will make her more in pain or not …
[F7(C1)]: When I hear her vomit, I also want to vomit (giggles).

The children participants narrated thinking about what they did after their initial reaction to the health situation. This suggested cognitive reactions. For example:

[F1(C1)]: Why like that? (cause of mother's vomiting) I make sure I don't be like that.
[F1(C3)]: I thought … what can I do?
[F2(C3)]: So, (after she vomited) what now?
[F3(C4)]: What to do? What to do?
[F5(C1)]: I had to do some of the housework ... cleaning ... ironing ... I did not know how, how do I do this? But I have to find out lah.
[F5(C3)]: … you have to think lah, before you do something … How to solve this new problem. You think …what did she (mother) do before, how did she do it yah?
[F8(C2)]: Why have to do something that exact way? She (mother) never told me. Just scold when I do not do the way she did.
[F10(C1)]: Why was she bald? Why her hair fall out like that (in clumps) I don't want my hair to be like that. If I wake up and my hair like that (shudders) … what happened? Will it (hair loss) happen to me?

These narratives evidence Belkin's belief of the existence of an "anomalous state of knowledge" (Belkin, 1980, p. 135) and Ford's belief of an awareness of a state of "not knowing – or some conceptual incongruity or cognitive inadequacy" (Ford, 1980, p. 100). These narratives suggested that there were information "gaps" (Dervin, 2003, p. 275) in the children participants' efforts to makes sense of their experience. The children participants' reactions triggered an "information need-creating environment". This is defined as a matrix of variables that influenced the immediacy of an information need. Where information needs were deferred, no visible information–seeking behaviour was observed. Where information needs were immediately pertinent, the information seeking behaviour was escalated and the children participants engaged in various strategies to meet the said need. A diagram of this relationship is illustrated in Diagram 5.2 below.

Diagram 5.2: Relationship of reactions to a health situation to information seeking behaviour of the children participants



The concepts of information needs deferred and information needs immediate was adapted from Wilson's 1996 Model of Information Behaviour (Wilson, 1999, p. 257). Specifically, Wilson's (1999, p. 257) theoretical idea of stress/coping theory offered possible reasons for delaying, limiting or not engaging in information-seeking behaviour. Wilson's (1999, p. 257) theoretical idea of risk/reward theory and by extension, social learning theory offered possible reasons for source preference and solving information needs. While the Wilson 1996 model described macro-behaviour Wilson (1999, p.257), this component of the Model described observed generalised micro-behaviours of the children participants. It also described the relationship and process flow of the children participants' reactions and how those reactions (influenced by the health situation and the children participants' "sense of self") triggered information seeking behaviours.

5.2.iv "Information seeking"

From Diagram 5.1 (on page 252), the next component was "information seeking". This referred to the children participant's cognitive process of trying to make sense of an unfamiliar health situation. This process built upon Dervin's (2003, p. 270) "sense-making" term: how people "make sense of their everyday experience". This was evidenced by:

[F1(C3)]: So when she said "think for yourself" (what needed to be done) I had to figure how to do the housework she wanted me to do in the way she would have done it. But, she did not tell me how to do it and I never saw how she did it. It was very confusing. I am not her, but I have to do it (housework) like her, even though I have never done it before. Very hard for me to make sense of what I really needed to do lah.
SUZIE: What do you think she meant about "think for yourself"?
[F1(C3)]: It means think of she would do and do it like that way. When I think like that, then I understand. Then, I know what and how she actually wanted me to do it lah.

[F2(C4)]: When she (mother) said that the doctor will cut out the cancer from her, it did not make any sense to me … because how? They what…just take, I don't know, a knife and cut her? Cut her where? Must they cut? I then said "huh?". She showed me a cutting motion at her chest. So, understood after that she meant that the doctor had to cut a part, I think, of her chest area?

[F5(C3)]: When she was vomiting … I know that after a day or two after her chemo, she will get sick and start to vomit a lot. So I know that to help her, I needed to prepare the small bucket. And I know to make it easier to clean up, the bucket, I need to line it with a plastic bag. That way, I don't have to wash the bucket so often so that it does not smell worse. Another thing, I need to make sure the plastic bag does not have any holes. That happened before and it was … ughhh… vomit dribble everywhere that I had to clean up too. I guess the experience, thought me lah what to do in such a situation. I now know lah what to do.

[F6(C1)]: Need to understand how cancer can happen, why my mother had to get this sickness and not another person.
SUZIE: What do you mean that you need to understand?
[F6(C1)]: How to say this? Umm… my mother, she eats vegetables, she eats fruits, she does not smoke. So, how come she got cancer? Other people smoke, and yet they are healthy. Why did my mother get it (cancer)? I don't understand. I asked my mother and she said … sometimes it is God's will. God's test lah. Sometimes it happens because of just something wrong or rotten in the body and that rottenness is the cancer. How it happens.
SUZIE: So, now, what do you know about how cancer happens? What do you think?
[F6(C1)]: What I think? So, with what my mother told me … I think cancer happens because something in the body just became rotten. It became spoilt, it just became … does not work anymore lah. Then this rotten just becomes more rotten and becomes a bigger rotten thing and that is cancer lah. It is dangerous because this rotten thing can spread and cause pain and people can die from it. Especially if it spread to the brain, or the … heart?

[F7(C1)]: My mother said if a person does not eat enough vegetable, that person gets sick, gets easily tired like her and get cancer like her. So, if I eat vegetables, I won't get like her lah. That make sense to me lah, so I can follow that lah. If I eat vegetables, I won't get cancer.

For these children participants, the need to make sense of a situation, the need to resolve a state of "not knowing" and/or the need to fill an information "gap" became an information need. From this state, these children participants were prompted to find out more; either to make sense of a situation, to return to equilibrium, to provide support or to contribute in problem solving. This component also described the matrix of variables observed to have influenced the extent of information seeking. As mentioned in Section 2.2.ii (page 18), the type of information required depended on a specific problem, how the children participants sought information and the decision making process in order to resolve the said problem. In this Model, information seeking variables were the children participants' role in health care, psycho-social influence, information seeking behaviour and source preference. How the children participants perceive the openness and accessibility of information also influenced their information seeking efforts. These variables are explained below.

5.2.iv.a Role in health care

Children participants' initial reaction and the role they played in caregiving influenced the information trigger(s) that could either defer or escalate the immediacy for their information need. This was indicated in Section 4.4 on page 141. Children participants who were care-givers seemed to be motivated to solicit and synthesise information as a means to help care for the sick parent and to ease their task burdens. Children participants who were not care-givers seemed to be motivated to solicit and synthesis information to normalize their sense of well-being and to provide secondary support to their ailing parent and the family dynamics. Whichever reactions children perceived to be of most relevance to themselves or most important of their concerns, would then trigger their information seeking behaviour. When children's reactions were normalized, their information seeking behaviour were differed:

> *[F5(C1)]: Before (while mother was undergoing treatment) I do* ***ironing,*** *now I don't. I learnt how to iron my school clothes from older sister. I had to iron them every time before I go to school, so it is something normal now.*

5.2.iv.b Psycho-social influence

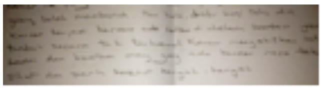
Children participant's psycho-social influence, interpersonal networks and meaningful dialogues were interrelated. This had important consequences on how information was sought and synthesized. The children participants appeared to utilise their individual capacity and processing capabilities to assimilate information from their reactions, personal files and information seeking behaviour. This was explicated from the children participants' narrative of learning new things about cancer and how they overcame the challenges of care giving. This was in line with earlier findings by Learning theorists that children learn through observing, modelling and cognitively processing the behaviour of others (Greig et al., 2013, pp. 31-32; Bandura, 1993, pp. 119-145). For example:

> *[F5(C3)]: I remember missing my mother's cooking. I missed eating her chicken rice. I tried cooking that on my own. The first time was a disaster. I remember that she cooked the chicken first, but I forgot how long it must be cooked. So, the chicken was undercooked, it was a bit bloody when I served it. Yuck! But, I tried again, I asked her where I did wrong, and I learned to make it better. Now, I can do chicken rice that is almost as good as hers!*

> *[F10(C1)]:*
> 
> *I took a broom and just swung the broom very fast (vigoursly) across the floor. So much dust! Dust got everywhere and I coughed and coughed. It was then I remembered seeing her (mother) moving the broom from one corner gently, gently … slow-slowly. Ah! When I did that, no more coughing so much.*

The children participants seemed to have learned from their experiences and modelled some of their behaviour by observing the benefits of certain actions of other people when applied to a similar situation. This supports Learning theories reported by Mineka and Zinbarg (2006, p. 11) and Wilson (2012, para. 1). Similar to Cognitive Theory principles (Greig et al., 2013, pp. 35-38), it was found that the children participants' individual capacity and processing capabilities to assimilate information was influenced and nurtured by their environment and cultural impetus. It was also evident that the children participants had the ability to develop their "own explanatory principle" (Papert, 1999, para. 3) when they lacked sufficient information or the skills to process information. For example:

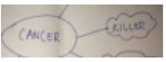
[F4(C1)]:



*Umm, **Mother** said, her doctor told her that **cancer** develops because there are **cells** in the body that **grow uncontrollably**. **Cancer hurts** the body's **cells** and makes the person with **cancer** feel **unwell and need plenty of rest**.*

SUZIE: (indicating to continue)
*[F4(C1)]: Umm … she said that the doctor told her that **cancer** develops when a person's **cells**, inside the body, **grow out of control**.*
SUZIE: Do you know what cells are?
*[F4(C1)]: Yes, I learned at school that **cells** make up everything*
SUZIE: So what about what you said earlier, about cells that grows out of control?
*[F4(C1)]: When someone's **cells** in the body **out of control** … and (referring to what she wrote) it makes the person with **cancer ill** and **need plenty of rest**.*

[F5(C3)]:



*(Explaining drawing) **Cancer** means, the person who get's it must be strong and it's a **killer** …*

SUZIE: How so?
*[F5(C3)]: It's (cancer) a **killer** because **cancer damages cells** … it **kills cells** and then the **cells cannot work** and this **damage slowly** and can **suddenly kill** a person …*
SUZIE: How do you know this?
*[F5(C3)]: I saw **the dead cells** got sucked out of my mother after her operation … I saw the **black dead cells** being **pumped out** of a transparent tube that they put into her side …*

Similarities to findings by Carring (2013, para. 2) that, "the behavioural patterns and environment children are introduced to … shape the way they will interact …" were found. The children participants' responses seemed to be influenced by a "zone of proximal development" (Coffey, 2009, para. 1; Thies and Travers, 2006, p. 14). This helped them learn new skills. For example, [F1(C3)] explained that she saw her mother asking the attending doctor questions and she copied her mother's behaviour to do similarly.

[F1(C3)]: I asked the doctor taking care of my mama, why mama had to be operated. I ask him because when my mama wanted to know something, she would ask him.

5.2.iv.c Information seeking behaviour and source preference

The different information-seeking behaviour modes as postulated by Wilson (1999, p. 257; 1996, para. 2, Chapter 5.1) of passive attention, passive search, active search and ongoing search were observed in the children participants. Excerpted evidences are:

Information-seeking behaviour modes	**Children participants' excerpts**
Passive attention:	*[F2(C4)]: Read it in 'Wanita' magazine. Cancer is **dangerous** as it can lead to **death** because of a **growth** in the body ... (Clarified with SUZIE, read about cancer before mother's diagnosis)*
Passive search:	*[F5(C4)]: Why did cancer make my mother take so long to get better? We were not nurses to know how to take care (of a sick person).*
Active search:	*[F3(C4)]: I wanted to know what caused cancer, what cancer really meant, how to go through cancer … can cancer really kill? What does that mean?*
Ongoing search:	*[F5(C4)]: Seeing something is like … makes it easier to understand what is going on, instead of imagining the thing … like I imagine something else from what I read. This way, I can … more easily understand what is the matter … why something is like that … like how the cancer actually looks like inside …*

The children participants indicated their use of either an internal or an external source (or a mixture of both sources) of information. The children participants reported both covert and overt direct observations of their parent, with some children describing the condition of their mother post surgery and during other cancer treatments. Children talked more to their mother (in varying rates of perceived success) about cancer. It was found that for these children participants their mother, who had first-hand experience, was their preferred source.

How information was communicated (the scope, language, manner and attitude of information sources) influenced the outcome of information seeking. This was reported in Section 4.4.iii (on page 152). The children participants' accessibility to their mother and how open she was to communication and information sharing had an important influence in the outcome of their information seeking. This influenced how children participants made sense of, coped with and, overcame challenges. In this, children participants seemed to be heavily dependent on the information and personal files of their mother. However, the information, personal files, attitudes and behaviours of their mother might not be as conducive to information sharing nor have sufficient quality and depth to provide accurate and relevant information that could normalize children's reactions to a health situation or stimuli. There was no indication of this preference for all discussions or specifically for cancer. Other sources of information were secondary overheard discussions with, or between, other family members, doctors and members of the support group they attended with their mother. Some children actively solicited information from the media, most notably from magazines or from brochures and booklets.

In conclusion, the "information seeking" component of the model was an activity or series of activities influenced by the children participants' role in health care, psycho-social influence, information seeking behaviour, source preference and how the children participants perceive the openness and accessibility of information. These variables combined to influence their subsequent information seeking and information synthesising behaviours before an action on information occurred. This relationship is illustrated in Diagram 5.3 below.

Diagram 5.3: Variables in information seeking among the children participants

Primary care giver Requires more types of detailed information

Not primary care giver Requires less information

Learning and cognitive abilities Builds upon findings by Greig et al., (2013, pp. 31-32), Bandura, (1993, pp. 119-145), Mineka and Zinbarg (2006, p. 11) and Wilson (2012, para. 1)

Social networks and culture Builds upon finding by (Greig et al., 2013, pp. 35-38), Papert (1999, para. 3), Carring (2013, para. 1 and 2), Coffey (2009, para. 1) and Thies and Travers (2006, p. 14)

Modes of information seeking behaviour (Wilson, 1999, p. 257; 1996, para. 2, Chapter 5.1) and information sources (external or internal or a mixture of both)

External Source Ill parent, support group, other people and published materials

Internal source Covert and overt observations of their parent and first-hand experience

Scope, language, manner, source and attitude of information source

More open and accessible was equated with perceived increase in understanding of sought information

The subsequent subsection explains the next component of the Model.

5.2.v “Information synthesis”

After the children participants sought information, they conducted an information synthesis. This was a natural progression and was reported by Wilson (2012; 2006), Johnstone (2004), Dervin (2003) and, Wilson and Walsh (1996). Information synthesis is defined as the point in which obtained information was synthesized with children participants’ personal files, prior knowledge, beliefs and recall ability in order to elucidate obtained information as a means of “making sense” of the said health situation. The data suggested that the children participants assimilated and synthesized new information and experiences that contributed to the development of their assumptions and additional knowledge about cancer. Some of the children participants repeated the beliefs of their information source and made those beliefs their own. In some cases, several children added more conditions and causation scenarios to their beliefs. For example:

[F5(C1)]:

*(Explaining drawing) From what I know, **cancer** is a **disease**. It can **kill**. So, **cancer** has to take **chemotherapy** and **immunotherapy**.*

This illustrated how [F5(C1)] made sense of his experience. However, later in the interview he added more conditions and causation:

*[F5(C1)]: **Cancer** is not something like a normal fever or flu. Those you can get better in a few days. **Cancer** (pause) is so very different. It takes **a very long time to get better** … Months if not a whole year… then this **disease** makes my mum **feel weak**, and **tired** most of the time just because of she had to go through **radiotherapy 15 times** and **chemotherapy for 6 times** ... **Cancer**, can make someone **feel very weak**, a **disease** that can make **someone lose their strength**. And **not able to do anything …***

To further explain information synthesis in the Model, this is where the children participants' experience and knowledge was combined (or processed to be easily understood and used: Bettman and Kakkar, 1977, p.239) into re-contextualised information about cancer that child participants could recall and utilize. This process seemed to influence their decision-making process and subsequent actions in caregiving tasks and cancer prevention strategies. It is to be noted here that the children participant's information synthesis could at times be flawed. As evidenced in the participants' self report, some of their resulting actions were a result of information that was misconstrued or misunderstood. An example of this is how a child participant described God testing her mother with cancer:

[F2(C4)]:

*(explaining drawing) Cancer is **a test from God**. Why I say that, is that a person with cancer **is tested with their fear** … **with pain**, a lot of pain and all kinds of pain … see how you can perform prayers when you are **very tired** … umm … **test** you on how you are with the **nausea and frequent vomiting**, like if you are **patient** with this **test** … **lose appetite** to eat, so **test** lah. Last time you can eat anything, now with **cancer**, you can only **eat some food** and **foods that don't taste so** … and umm … **feel smarting pain** …*

SUZIE: Please explain a bit more on what you mean test with fear?

*[F2(C4)]: Well, with **cancer you know that you can die**. Soon. So, you are **tested** in … how shall I say? (pause) Are you prepared to die? Have you done enough to get to heaven? In a way, cancer lets you have that time to really, really be **more religious** before your time is up. Like if you had an accident and you died on the spot, you would not have had the time to say that you were sorry, with cancer you got the time lah.*

And,

[F2(C4)]: Because when you feeling ***nausea****, you cannot* ***eat****. You just* ***don't feel like eating****.*

SUZIE: How is that a test from God?

[F2(C4)]: Ya la, it's ***a test*** *because now* ***you cannot eat your favourite foods*** *lah. You just watch other people eating. (laughs)*

A parent participant described her child's misunderstanding with the following excerpt:

[F10(P)]: I asked my girl to clean up after me. You know what happened?

SUZIE: What?

[F10(P)]: She didn't clean up la. I ask her how come la? You know what she said? (laughs)

SUZIE: What did she say?

[F10(P)]: I did not see you clean up (daughter referring to mother), so how to clean up after you clean? If already you clean, I clean up again, what for?

SUZIE: So, could you clarify what you wanted her to do?

[F10(P)]: I wanted her to help clean the crumbs I accidently left on the table. I was eating, but then I was coughing and feeling nausea, so a bit of food came out and fell on the table la. I had to go to the toilet quickly, so I ask her to clean up after me. She did not understand la.

Some of the flaws in the children participants' information synthesis (the misunderstanding and/or misconstrued of information) can be attributed to a few variables. These were: the children participants' lack of information and their limited ability to process what they experienced and assimilated. Similar to reports by Kubler-Ross (1997, p. 126), the children participants' narratives suggested that they made sense of information in ways that differed from adults. At times the children participants' misconstrued actual events or information and, their thoughts or reasoning did not make sense to others. This method of sense making was explained by American Cancer Society (2012a, para. 6; 2012b, para. 5) and Scott et. al. (2003b, p.2); that a lack of information contributed to children constructing their own explanations, which led them to "fantasize a worse situation than is actually the case". A better understanding of the variables and processes contributing to the children participants' understanding or lack of understanding about cancer and its consequences may provide insights into the development of information provisions.

The Model suggested that the children participants' "self", the health situation, the children participants' reactions and, information seeking variables are components of an information seeking behaviour matrix that influences and contributes to information synthesis required for their sense-making, resolving a state of "not knowing" and/or the need to fill an information "gap".

5.2.vi “Action on Information”

Following information synthesis, the new information provided an impetus for action. According to the Model, this is termed “Action on Information”. This referred to the process in which the children participants acted (or not acted) on obtained information to help them resolve their information need. This action also formed a feedback loop or a “Perpetual Perceptual Encoding” to help enrich children participants’ “self”, knowledge and personal files. 'Perpetual Perceptual Encoding” builds upon Bettman et al. (1991, p.65) perceptual framework and Bettman et al.’s (1998, p. 193) constructive consumer choice that described “decision making based on the principles of human perception” and an individual’s limited processing capacities. In a particular situation, a person can only process selected information that is most pertinent to their needs. This becomes “encoded” and the decision-making influencers undergo a perpetual comparison against alternatives and/or options.

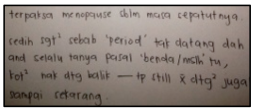
The term “encoding” built upon findings by Bettman et al. (1991, p. 62), Gallistel (2008, p. 19), Kellman and Garrigan, (2009, p. 55) and Prince et al. (2005, p. 1203). “Encoding” was the recognition of a symbolic memory attributed to a representation of an information or knowledge. In this Model, “encoding” was defined as the attached meaning structured by an individual’s understanding and representation of information positioned within the context of similar groups of information relevant to a particular problem solving process. The new encoded information formed an individualistic meaning that can be extracted, replicated and/or adapted to make sense of a future similar situation or requirement. Krikelas (1983, p. 9) referred this as a “continuously constructed cognitive environmental ‘map’ to facilitate the need to cope with uncertainty”. The continuity of processing information resulted in this Model’s, “Perpetual Perceptual Encoding” whereby a person evaluates (as needed) and perceives the encoded information’s value to resolve an information need. This encoded information contributes and builts upon prior knowledge. It behaves as a feedback loop and an indicator or prediction of success when compared to what worked (or did not work) before. This formed a new subset of the children participants’ experience and alternative and/or options to resolve information needs arising from the health situation. This cognitive process, similar to Krikelas’ (1983, p. 9) explanation of information processing, emphasised the importance of the children participants’ and their information sources’ memory.

The children participants continually evaluated their newly obtained information, what information they already had, what they perceived to be of use and relevant to their situation and, subsequently will continue (or not continue) to use when facing either a new health situation, a similar situation, or a situation that they have developed familiarity with. This information update seemed to help children adapt, cope and, at times, overcome similar challenges in caregiving. In situations that the unfamiliar, the frightening or the confusing was experienced again, the process was reactivated as a strategic means of resolving such issues. This process was evident throughout observations and self-reports of both groups of participants. Discussions about the side effect of *tamoxifin* and children participants' reactions to their parent's emotional distress exemplify this process.

Most children participants who were impacted by their parent's early menopause had not known that it could be attributed as a side effect of *tamoxifin*. Most parents had not known of this and they too were unprepared for changes caused by an early menopause. These changes seemed to escalate episodes of unjustified anger, unreasonable expectations and sudden changes to the attitudes, behaviours and psychological state of their mother. This had a spill over effect and children participants reported their reactions to their mother's distress. Female children participants seemed to cognitively process that the advent of an early menopause was an undesirable health situation to both their parent and themselves.

It seemed that when there was a high correlation to children participants' personal files, the advent of menopause and their reactions combined to motivate these children to find out more information. The children's reactions depended on how their mother exhibited symptoms, which were sudden changes to attitudes, behaviours and psychological states. Children participants' reactions to these changes began the process flow for information seeking; they sought out more information to clarify the reasons for, and make sense of, the said changes. The mother subsequently found out from her doctor that her symptoms was early menopause caused by *Tomaxofin*. She, in turn, translated and re-contextualized the information to her children. For example, the parent in Family Three was 43 years old when she experienced early menopause, and her daughter [F3(C4)] reported the following:

[F3(C4)]:

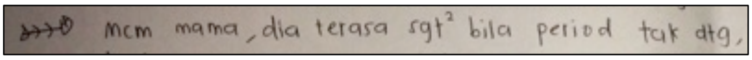


terpaksa menopause sblm masa sepatutnya.

sedih sgt^2 sebab 'period' tak datang dah
and selalu tanya pasal 'benda/mslh' tu,
kot^2 nak dtg balik — tp still x̄ dtg^2 juga
sampai sekarang.

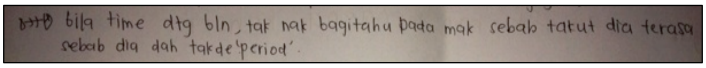
*(reading) She had her **menopause early** and she was so **very sad** because her 'period' (menses) did not come anymore and she was always asking about that thing and that problem, hoping that it (menses) will come back, but still it has not come back until now.*

Female children participants were very careful on how they behaved when their mother was experiencing an upset episode. They were also careful not to inform her of their own menses cycles. According to [F3(C4)], [F1(C3)] and [F8(C2)]:



mcm mama, dia terasa sgt² bila period tak dtg,

*[F3(C4)]: (reading) Like mama, **she really felt upset** when her **period (menses) did not come** . . .*



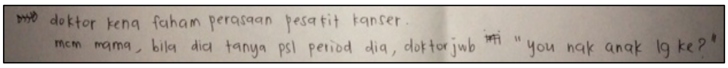
bila time dtg bln, tak nak bagitahu pada mak sebab takut dia terasa
sebab dia dah takde 'period'.

*[F3(C4)]: (reading) When my **period (menses)** comes, **I do not want to tell my mother because I am afraid** that she might feel **upset** because she does not have her **period (menses)** anymore.*

*[F1(C3)]: Yes, I know what is **menopause.** It is when you don't get your period (menses) anymore. Mama got her **menopause** because of the **cancer**.*

*[F8(C2)]: Ya, **menopause** is when you don't get your periods and you feel hot and cold and grumpy. I think that is why my mother is sometimes quick to get angry. She is getting her **menopause**. I know that I have to be very careful for her not to be angry.*

[F3(C4)] added that not only did children have to be aware of their mother's condition and her reaction to having early menopause, but doctors also had to be more circumspect;



doktor kena faham perasaan pesakit kanser.
mcm mama, bila dia tanya psl period dia, doktor jwb "you nak anak lg ke?"

*[F3(C4)]: The doctor must understand the emotions of a cancer patient. Like mama, when she asked about her **menses**, the doctor answers "Do you want more children?"*

This triggered children participants to evaluate and re-contextualize how their mother's menopause affected their 'self', either psychologically through interactions with the mother or physically in accomplishing caregiving and household tasks. Several of these children participants reported sympathetic sadness and empathy about the difficulties their mother faced. Some of these children participants understood that early menopause affected core bodily temperatures and that changing the temperature to suit the mother's well-being would result in her feeling better and less vocal about subsequent tasks. These children participants needed information about the possible affects of early menopause so that they may better protect themselves from their parent's reactions. Here, another outcome of the information seeking process was observed: by looking out for parental well-being, children participants' own well-being had better outcomes.

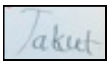
Another example of children's reactive information-seeking behaviour process was how children reacted to their parent's emotional distress. Even though parents tried to control overt expressions and behaviours, the children participants were aware that their parents were experiencing some sort of distress. The children participants generated and articulated their own cognitive associations between facial expressions, body language, and intonation and use of language. For example:

[F2(C2)]: *I think the person with cancer is* ***sad*** *too because there's something that isn't … right. She's* ***lost a breast****. She says that she is* ***not complete****. She's lost a part of her body. She's* ***embarrassed****.*

From visual cues, [F2(C2)] recognized her mother as feeling sad, which was unfamiliar event. She related her concern about this and sought more information. She recalled that at that time her mother had undergone a mastectomy. [F2(C2)] was cognizant that the loss of a breast contributed to the mother feeling incomplete and causing her mother to feel sad and embarrassed.

However, some children participants could not identify the reasons for parental distress and so made up their own reasons. Some of these reasons were very different from the real concerns of the parent. [F1(C2)] wrote and said;

[F1(C2)]:

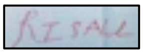

Takut

Aaa, ***I am not sure****. I think she's* ***afraid*** *to see the doctor again ... She's* ***afraid*** *if there is* ***anything else in her body*** *and have to* ***inject medicine****.*

SUZIE: *She's afraid of being injected with medicine?*
[F1(C2)]: *Ahuh (nods in agreement)*
SUZIE: *Is mama afraid of injections?*
[F1(C2)]: *Ahuh (nods in agreement and laughs)*

With regards to the above situation, the children reacted with their own feelings of sadness, worry and fear. The children participants' experience was processed in relevance to the 'self' and personal files. This experience influenced information synthesis and subsequent action. The children participants then reassessed the situation and came to their own conclusions about parental distress. For example:

[F1(C3)]:


RISAU

She (mother) felt ***worried*** *and* ***sad****.*

SUZIE: *Why do you think she felt worried?*
[F1(C3)]: *(nervous laughter)* ***I don't know****. She just* ***looked worried****.*
SUZIE: *How do you know she looked worried?*
[F1(C3)]: *Umm, because* ***her face looked worried****.*


Sedih

SUZIE: *Ok, what about the 'sad' that you wrote here?*
[F1(C3)]: *Aaaa ... she's (mother)* ***sad****.*
SUZIE: *How do you know she's sad?*
[F1(C3)]: *I see her* ***crying*** *and I ask why.*
SUZIE: *What did she say?*
[F1(C3)]: *She says she's* ***worried****. But sometimes she does not say why.*
SUZIE: *But, you see from her face that she looks sad?*
[F1(C3)]: *Ahuh (in agreement). Sometimes she does not have the* ***'mood'***

SUZIE: *What do you mean 'Mood'?*
[F1(C3)]: *Does not want to go out. Does not tell stories like before.*
SUZIE: *Why is that?*
[F1(C3)]: *(Shrugs shoulders)* ***I don't know****. She just doesn't have the* ***mood****.*

From certain cues, [F1(C3)] recognized her mother as feeling worried and sad. This was an unfamiliar event and triggered her various attempts to find out why. [F1(C3)] was cognizant that the cancer diagnosis contributed to her mother's worry and sadness. [F1(C3)] contributed her own thoughts as to why her mother behaved that way. This indicated that [F1(C3)] processed new information and observations into a construe of her own understanding. She further related that when she noticed her mother not being in the "mood", she would not disturb her mother. [F1(C3)] reasoned that by doing this, her mother would return to a calmer or happier state on her own. However, the parent clarified that her show of sadness was because she feared dying and her children being motherless.

Conclusions

In conclusion, the children participants have a process of reacting-information soliciting-information synthesis-action. The children participants' "self", own reactions to an unfamiliar health situation and, information seeking variables influenced their information seeking and synthesis process. This has implications for information provision that should address the children participants' observations and reactions to their parents' experience and, their own needs throughout the cancer continuum. Children could be equipped with age-appropriate information that described emotional markers, physical changes and disabilities more accurately. A list of possible scenarios that could trigger their parent's distress could be provided. The information could also identify culturally acceptable and unacceptable care giving tasks and behaviours.

The next chapter presents the implications and contributions of this research. It presents how the research findings contributed to the body of knowledge. The chapter provides an overview of the limitations and/or problems of the study. Lastly, the chapter provides implications for future work.

CHAPTER SIX
CONCLUSION

To the best of the researcher's knowledge, this research of identifying the information needs of dependent children of parents with cancer is the first in-depth qualitative and highly participative study. It investigated Malay children's perception of cancer and information culture; information needs, information seeking behaviour, barriers and enablers. The findings have the potential to mitigate some of the distress and challenges young children experience from their parental diagnosis.

In Chapter Two (on page 33), the Malaysian cancer endemic (Omar and Ibrahim, 2011, p.31) reported that in 2007, about 18,219 new cancer cases were reported and preference for home-based care may have affected some 14,860 dependent children[11]. At the time of the beginning of this research, no known intervention was tailored to the information needs of Malay children and their families to mitigate their difficulties, issues and problems existed. The available interventions for children had not provided information for dependent Malay children whose English language skills were less advanced and whose unique culture and religious observances contradicted some of the conventional wisdoms of children's role and expectations in care-giving. These wisdoms could not know of the myriad of problems and difficulties Malay children experienced and there could not be specific interventions and advice on how to help children become better informed. Information could not be tailored to their needs and circumstances. This resulted in children needs being largely unaddressed and this posed significant and a myriad of difficulties for these children and their families.

This research was considered difficult to undertake because the nature of cancer as a taboo topic among Malays, the cultural reticence to sharing information about health problems, the use of children as participants and the cultural and religious imperative of being stoic and patient in the face of illness presented challenges. The research managed to overcome some of these problems buy establishing rapport and trust as well as using a Participatory Action Research methodology that encouraged participants to be more open and forthcoming about their experiences. It was also useful to have had some experience in interacting with cancer patients and their family when previously employed by the National Cancer Society of

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[11] Calculated based on multiplying the number of child-bearing cancer patients with the average of 2.5 children per household (*Banci Penduduk dan Perumahan Malaysia, Jabatan Perangkaan, 2011)*

Malaysia, a very reputable cancer centre that providing not-for-profit services to disadvantaged patients and their families for more than 40 years.

The result was rich anecdotal data with ethnic and phenomena excerpts providing information about the nuances of the affects of parental cancer, several interesting and unanticipated findings, interesting participant suggested solutions, the implications for information provision and the development of a model of children's information behaviour and information synthesis in the face of parental illness. The research reports many information needs that may be utilized for children and their families to successfully make a critical transition in their lives.

The role of this chapter is fourfold. Firstly, to discuss conclusions from the key findings from the exploration of the information needs of children whose parent was diagnosed with cancer. These findings and their implications will be discussed based on the three research objectives mentioned in Chapter One. Secondly, to discuss several recommendations for information provision to dependent children of cancer patients. Thirdly, to discuss how these findings contribute to the knowledge and understanding of information problems, needs and provision. Fourthly, to acknowledge the limitations of this research and to discuss implications for further research.

6.1 CONCLUSIONS FROM RESEARCH OBJECTIVES AND THEIR KEY FINDINGS

The aim of the research was to understand children's information experience when they have a parent with cancer including their perception of cancer (for example, cancer is a dangerous disease) and information culture (for example, doctor's attitude to informing children); information needs (for example, how to care for a parent at home), information seeking behaviour (information sources, preferences and sharing attitudes), barriers (for example, low literacy) and enablers (for example, discussions with parents).

The study provided an insight and understanding of the consequences of parental cancer on many aspects of children's lives. Parental cancer impacted children's understanding about cancer, positioned children as care-givers and increased the importance of information provision. It should be noted that while there was no specific tool utilised to identify whether children experienced emotional cycles in assessing and accepting information about their situation, it was observed and self reported by participants that children experienced various emotional upheavals as a response to parental cancer throughout the different stages of treatment. These findings contributed to a better understanding of the context or environment, prevailing attitudes, culturally sensitive elements and objections within which information is communicated or nor communicated to children, what were children's challenges in care-giving and life changes; and if children experienced emotional cycles in assessing and accepting information about their situation.

Specifically, the study explored the lived experiences and reality of children whose parent has cancer, solicited their participation in identifying priority information needs and sought possible solutions to their information-needs problems. Through the three research objectives, this aim was achieved. In order to report these conclusions, this section is divided into i) Children's perception of cancer and their information needs, ii) Children's information culture, information seeking behaviour, enablers and barriers and, iii) Possible enablers and solutions to children's information needs problems.

6.1.i Children's perception of cancer and their information needs

The first research question "**What are Malaysian children's understanding of their parents' cancer; its causes, effects, implications and consequences?"** identified children's perception of cancer and their information needs.

6.1.i.a Causes:

It can be concluded that many children participants reported their belief that cancer was a dangerous disease in that it could cause death, cause a lot of many types of pain and, has a long and painful recovery. Most of the children participants seemed to believe that cancer was caused by exposure to a polluted environment, parents' unhealthy lifestyle and eating habits, an "attack" from aliens or something unknown, or a test from God. Older children participants seemed to have more knowledge about cancer's causation and only they reported their belief cancer had medically proven causes of either a history or genetic predisposition for cancer or from unhealthy habits. However, it was found that some nuances of these beliefs were repeated from myths and children participants' own misconceptions. For example, even though there were more than 200 types of cancers, children participants mentioned cancer as occurring only in the breast, lung, brain and throat. This indicated the extent of the children participants' prior knowledge. Children participants believed that cancer was either caught (from an alien attack or something unknown) or developed internally from damaged cells (as identified by older children participants) and this damage can spread to other vital organs and causes a lot of pain. Contrary to reports by the American Cancer Society (2012, para. 6-9), Kornreich et al. (2008, pp. 65-66), Visser et. al, (2007, pp. 683-694) and Greig and Taylor (1999, p. 78), these children participants did not worry that they might have caused parental cancer.

6.1.i.b Effects:

It can be concluded that children participants were affected by parental cancer. It was found that the diagnosis and treatment of a parent's cancer resulted in trauma, insecurity, stress and, psychological and behavioural problems. These effects were similarly reported by Thastum et. al. (2009, p. 4031), Lewis (2006, p. 21-23), Huizinga et. al. (2003, pp. 195-200), McCue and Bonn (2003, pp. 47-51) and Scott el. at (2003b, p.i-iii). Participants' self reports and observations taken during the focus group sessions recognized that children did fear parental death from cancer. Similar to reports by Kornreich et al. (2008, p. 64) and Greig and Taylor (1999, p. 155) children recalled and continued to be distressed, were frightened by unexplained changes and experienced anger. Similar to reports by the National Cancer Institute (2003a, p.18), it was found that children participants were afraid of staying or accompanying their mother to the hospital. They were afraid of syringes, the chemo port, taking blood, the MRI machine and other diagnostic tools. Some children participants identified that their mother was afraid of bad news during medical check-ups. Some children participants felt that the check-ups, while vital, was a boring and tedious experience. Children participants also exhibited differing degrees of feeling scared, guilty, angry, lonely, embarrassed, and not being able to cope or come to terms with their situation.

Similar to Davey et. al. (2005, p. 248), it was found that dependent children faced "psychosocial stressors" arising from the "threat of parental death … the temporary loss of the parent due to symptoms of the disease and side effects of treatment" and, "disruption of family roles and routines". It was also found that, similar to research by McCue and Bonn (2003, pp. 47), Barnes et. al. (1998, pp. 441), Fallowfield et. al. (1994, p. 448) and Maguire (1994, p. 1649), children participants also experienced psychological stressors from witnessing their parent's anxiety, depression, and other emotional difficulties. Similar to the reports by the National Cancer Institute (2003a, 2003b), Christ and Christ (2006, pp. 198-199), Kornreich et al.. (2008, pp.64-65) and American Cancer Society (2012a), parental cancer affected children participants' views of what was important in life; they reported changes in how they felt about themselves and asked about their own mortality.

However, in addition to these, children participants reported their anger and dislike of the disease as well as frustration and sadness about their cancer experience. Children participants reported difficulty in coming to terms with the side effects of cancer treatment and difficulty in witnessing how cancer affected their parent. Most children reported being afraid of cancer because of their fear of "painful" pain, the hospital, injected medicines and blood tests and, the possibility of their parent's death from the side effects of cancer treatment. These children believed that cancer caused frightful or alien-looking baldness in their parent, their somatisation affects and disruptive changes to the family.

Similar to reports by Visser et. al. (2004, p. 142-143) participants reported that not only did children experience distress to illness-related concerns but to also their sense of security. However, it was found that in addition to those experiences, children participants were very concerned about their family continuity. They were concerned that the stigma of cancer and/or toll from the burden of care could contribute to parental separation or divorce, polygamy and children's care by neighbors or distant family members. This could be in part due to their father's absence from the focus group sessions, some reports of parental arguments and children's observation of their father's lack of care-giving support and, children participant's overhearing distant relatives and neighbours' questioning their parents' marital status.

These findings indicate that cancer affected children in more ways than previously published. The findings and recommendations from Kornreich et al. (2008, pp. 64-66) indicated that parent's cancer can have a powerful psychological effect on children and that it was imperative to be more responsive towards children's experiences.

6.1.i.c Implications and consequences:

This research can be justified through three concerns reported by Brewer and Sparkes (2011, p. 283): firstly, there was a lack of models based primarily of what children experienced and self-reported. Secondly, little was known about the meaning and its construction that children developed and attached to their experiences and resources they accessed. Thirdly, there was a lack of understanding of how children processed their experiences in order to make sense and/or overcome the challenges they faced. The extensive literature review and the focus group sessions suggest that the children participants' emotional, behavioural and care-giving difficulties were underestimated. This research discovered that children participants faced many more challenges, had many more nuances of concerns and unmet information needs.

Similar to Kornreich et al. (2008, pp. 64-66) and Scott et. al. (2003b, p. 1-2), children participants reported that cancer disrupted living patterns, changed family routines, gave additional responsibilities and added to children's difficult self development issues. In addition to this, an important contribution from this research was that children participants seemed to struggle to "make sense" of their parental behaviours and to "make sense" of cancer's consequences. This affected children participants' familiar "normality" and "sense making" strategies. Children participants reported differences in parental care towards them, confusion about their parent's well-being, their status in the family and an increase in household tasks that most had not been previously taught. Children participants misconstrued parental illness and behaviour changes; most children, while recognising that a parent was unwell and feeling "upset about something" or "moody" attributed them erroneously. The introduction of healthier eating habits seemed to be a theme that children participants reported as most objectionable.

Another important phenomenon and significant contribution of this research that emerged was children participants' experience of a prolonged illness of a loved one. It was found that there were increasing cases of children providing care-giving support to their parents. This finding of prevalence was also reported by the Calman-Hine report (1995, p. 3), where the burden of palliative care was considered substantial. This was because technology advancements have lead to increased survival rates for cancer patients and prolonged home-based care. Cancer patients spend more time living in their own home than in a hospital or hospice (Joseph et al, 2009, p. 1; Gatrad and Sheikh, 2002, p. 526; Jenkins et al., 2001, p.48;

NHS Executive, 2011, p.1) because they felt more comfortable and secure at home and they did not want to be separated from family, friends, and familiar surroundings (Fives et al., 2010, p. 3; Hutchison et. al., 2010, p. 2). The escalating costs of medical care have also contributed to the increase in home-based care. This resulted in the growing prevalence of increased role and dependency of families, including young children being required to provide multifaceted care (Becker, 2007, pp. 30-32; Davey et. al., 2005, p. 247; Fives et al., 2010, p. 12; Given et. al., 2001, p. 213; Hutchison et. al., 2010, pp.1-2; Kenrick, 2009, pp. 8-12; Skovdal and Ogutu, 2009, para. 1-5). These phenomena were self-reported by both groups of participants.

It seemed that children participants were very important in their parent's recovery and they provided more caregiving than previously realised. Parent participants convalesced at home. Both participants group preferred home-based care and had considered hospital stays as very expensive, frightening and lonely. As a consequence, parent participants were heavily dependent on their children for at-home care. Children participants were more aware of health concerns and they developed new skill sets as they were exposed to numerous new health situations. After the diagnosis, children who were care-givers had greater understanding about the implications of chemotherapy, radiography and immunology in their mother's continued well-being. Children participants also repeated hearing the words "chemotherapy", "radiotheraphy", "tamoxifin" and various other medical terms. While they may not have understood the terms fully, they nevertheless were enriched by the medical vocabulary.

However, while home recovery resulted in the parent being more accessible, this also resulted in an increase in the tasks that many children participants reported were unfair and unacknowledged. Children participants took on prolonged care-giving roles that were complex and multifaceted. Older female children felt overwhelmed with their multitasking challenges as care-givers and household managers and, having to cope with all personal development issues without support or guidance. They reported feeling stressed by their failures and shortcomings in being unable to accomplish tasks expected of them.

A significant contribution of this research that emerged was a report of a list of tasks (on page 170) that the children participants provided. Most of these tasks seemed to require adult skill sets and the frequency, scope and duration of proving care was not age appropriate, found to be burdensome and contributed to children participants' trauma, insecurity, stress and, psychological and behavioural problems. Parents were reported as assuming the ability to recognise the need for a task and how to do a task properly was an "automatic" behaviour that they expected older female children to readily provide. Social ethnic and religious factors contributed to this belief. It was evident that these children participants and their families required information, advice and support to help cope with their realities.

Another important phenomenon and contribution of this research was that parents with cancer were mostly unaware about symptomatology and distress in their children and that they underestimated their children's emotional and behavioural difficulties. Children participants were frustrated with their parents' being unaware of children's difficulties and being unable to acknowledge children's contributions and care. In addition to this, similar to findings by Forrest et al. (2006, p. 998), it was found that parent participants sometimes misunderstood their children's reactions and underestimated the emotional impact or did not recognise the children's need for more preparation and age appropriate information about the illness and its treatment. Similar to findings by Lewis (2006, p. 25), children did not want to talk about their cancer-related worries, questions or concerns for fear they would further burden the ill parent and/or was wrongly perceived as the child being uncaring.

Without sufficient information, the children participants' reactions, limited abilities and skill sets in care-giving tasks and perceived lack of care or concern seemed to strengthen the parent participants' belief that children could not understand their cancer experience, were less willing to help and support the parent in time of need. The resulting parental admonishments compounded their children participants' experience of feeling less loving and engaging interactions. This strengthened children participants' perception of being less loved and cared for.

While some of these experiences were also reported by McCue and Bonn (2003, p. 47) and Barnes et al. (2000, p. 479-481) the extent of this phenomenon had not previously be documented among participant's ethnic group, had not identified particular children's experiences with difficulties in overcoming parental diagnosis, changes in family dynamics, care-giving tasks and, did not identify particular information seeking behaviour and information needs. In support of this, according to Lewis (2006, p. 24), knowing these difficulties will only serve to help design more effective programs, services, and interventions. Similar to indications by Macmillan Cancer Relief (2003, p. 6) and Chiu and Wistow (2002, p. ii), these phenomena resulted in the necessity and importance of information, advice and support to patients and their families throughout the duration of care. These findings and the advocacies reinforced the need for person-centric information provisions.

These findings achieved the research aim and contributed additional knowledge about the extent of the effect of parental cancer that included more documentation of psychological symptoms to children. It highlights the importance of first being aware of children's understanding of their parents' cancer, its causes, effects, implications and consequences in order to anticipate children's needs and to form recommendations for information provision. It also contributed new knowledge about what children understood about cancer, an understanding of the other ways in which children were affected and, the scope, variety and extent of care-giving tasks that children participants were expected to provide with little tutelage and adult supervision.

The children participants' experience suggests that the scope, depth and approach of existing intervention programs require new methods of information provision. These findings stress the importance of information provision to help children make sense of and come to terms with their new situation. It also helps patients, adults within these children's environments and information providers to better understand the myriad of difficulties that children have and the inappropriate burden of care they were responsible for. This advocacy for more inclusive and relevant research and intervention methods were also made by Christ and Christ (2006, pp. 210-211), Kornreich et al. (2008, p.70), Blum and Sherman (2010, p. 256), Northouse et al. (2012, p. 118) and Fourie (2012, para. 39). The situation is exacerbated when during the crisis of cancer the focus for cancer treatment was solely on cancer eradication and did not include advice and information on the responses, psychological distress markers and needs of children impacted by their parent's diagnosis.

In meeting the other components of this research aim, the above findings helped to identify several emerging themes about children's' reactions and information needs. This resulted in participants' rich anecdotal data that created the co-developed awareness and understanding of the many ways children are affected. It was also the basis for further exploration of children's information culture, information seeking behaviour, barriers and enablers.

6.1.ii Children's information culture, information seeking behaviour, enablers and barriers

The aim of the research was also achieved through the second research question: **"What consequences does children's understanding or lack of understanding about cancer have for them?"** which identified the information culture, information needs, information seeking behaviour, barriers and enablers.

It can be concluded that patients and their children made sense of cancer and their situation in varying ways and that children participants seemed to understand cancer mostly from their experience and observation; while their parent with cancer was the preferred source of information, children participants assimilated information from a variety of sources and used various strategies to cope with their situation.

Firstly, it was found that even though all parent participants' had informed their children about the diagnosis, most parent participants had various difficulties. This included dealing with their own feelings and coming to terms with all of the implications of the disease in addition to dealing with how it may affect their children. Parent participants reported being unprepared to provide more information, not knowing how nor the extent of information they should provide and, ignorance of how cancer may affect their dependent children. Parent participants shared that they did not want to upset their children and perceived their inability to discuss death, continuity of child's care, why they had cancer and the side effects of cancer treatment would make comprehension for children even more difficult. The result was that most parent participants were less forthcoming then their children required. Some parent participants indicated that they had hoped their children would realise their parents' health situation and needs on their own. Parent participants believed that their doctors could have played a role in information dissemination as they were perceived to be experts and authority on cancer and how it may affect patients and their families.

Secondly, children were aware about an illness in the family even without being directly told. Similar to findings by Skovdal and Ogutu (2009, para. 1-16), Becker and Becker (2008, p. 15), Kornreich et al. (2008, pp. 64-65), Scott et. al. (2003a, 2003b, 2003c) and the National Cancer Institute (2003a, 2003b), children sensed when something was wrong and were almost always aware of a change in their lives. It was found that children participants were within sensorial proximity of a chronically ill family member; accompanying ill family members on visits to the doctor, a hospital stay or home-based care where children were witness to side effects of cancer treatment and how their parents reacted to cancer physically and psychologically. This suggests that similar to findings by Forrest et. al. (2006, p. 998), awareness of cancer as a life-threatening illness existed among the youngest children they interviewed and that children suspected that something was wrong even before they were informed about the diagnosis. Similar to findings by breastcancer.org (2004b), this suggests that, for whatever reasons, parents' furtive hiding of cancer's effects on them could not entirely be kept a secret.

Thirdly, it was found that information played an important role in helping children cope with the psychological impact of their parent's cancer, as well as their own development and function as children and care-givers. Withholding information created complex and far-reaching problems for children and family dynamics. Other than the news about the diagnosis, most dependent children were not informed about how parental cancer may affect them. Lewis (2006, p. 21) found that not even family members helped children cope with the impact of the parental cancer in approximately 25% of younger children and 15% of adolescents whose mothers had cancer. Contrary to parent's practice of protecting family members (Hermann, 2000) by withholding information, not sharing information made it harder for children participants to understand cancer, parental difficulties, implication of cancer to themselves and how to cope with the many difficult changes and concerns in their life. This was similarly reported by Longfield and Warnick (2009, pp.10-12), breastcancer.org (2004), McCue and Bonn (2003, pp. 47-51), Brashers et al. (2002, p. 259), Granet (2002, p. 185) and Rees and Bath (2000, p. 372).

According to Longfield and Warnick, (2009, p. 12), these parental actions "do not avert a fearful situation", instead it "denies children's access to accurate information and appropriate emotional support". According to Kerslake & Rolinson (1996, p. 57), censorship of "adult" information is to maintain and protect the innocence of children and adolescence at the price of continued ignorance and relative information poverty. This was experienced by most of the children participants. Children participants misconstrued and misunderstood the causation of cancer and treatment and prevention strategies. Similar to recommendations by Scott et. al. (2003b, p. 2) and the American Cancer Society (2012a, para. 6; 2012b, para. 5), it was found that children needed information and support to help them construct personal and social meaning for illness and death, because without information children constructed their own explanations, misconstrued a health situation, and led them to fantasize a worse situation than was actually the case. According to the National Cancer Institute (2012, p.6), when children were not told the truth about an illness in the family, they "often depend on their imagination and fears to explain the changes" around them. This was found to be true. Also similar to Zahlis (2001, p. 1023), children participants had different dimensions of concerns and these concerns had not been previously documented. Some were confused about why and how cancer developed when they perceived that their mother had healthy habits. Children participants felt frustrated, bored and resented the frequency of hospital visits that they were forced to accompany their mother. Some were concerned that cancer was contagious. Some even feared losing their hair if they became ill. Older children participants were concerned about the prolonged illness and how long they would have care-giving responsibilities.

Fourthly, a significant finding of this research was the discovery of the information seeking behaviour modality of children when facing a health situation. It was found that before parental cancer diagnosis, children participants had little to no knowledge about cancer. It seemed that children participants' reactions towards parents' experience motivated children participants to seek information. It was only after the advent of a health event or situation in which children participant's recognized an information need and employed various information seeking behaviours to "make sense" of their experience which influences their subsequent actions. The most significant contribution from this finding was the "Children's Reactive Information-Seeking Behaviour" model which helps to explain information seeking behaviour that was triggered by children participant's reaction to a health situation.

The development of this model was a result of participants' self reports about their problems in the cancer information available to them. While there have been other efforts to explain information seeking behaviours, this model, and the findings that contributed to its development, helped to inform the research and to understand the realities faced by children who provided care. This understanding contributed to some of the research's anticipated themes about the nuances of children's difficulties, specifically the important role of information and its provision. This model helped to understand the attitude and process of information sharing to dependent children. This model also helped to understand how patients and their families solicit and synthesize information about cancer to make sense of, to understand and to overcome challenges. It also helped to identify several emerging themes about what motivated children to seek information and what information they thought was the most needful, when. This resulted in participants' rich anecdotal data that helped to develop an understanding of the ethnic landscape of participants that benefited the development of relevant and priority information needs for children whose parent has cancer.

Fifthly, it was discovered that providing information resulted in several positive outcomes that reported an increase in care, concern and the feeling of love to the ill parent. A clearly identified enabler were parents who were open and accessible to information sharing provided the most comprehensive and better understanding about cancer and provided the most help to children participants. Children participants felt more in control of their "world" by understanding more of what was going around them. They found lifestyle changes and challenges less difficult than their peers. Some children participants, especially older care-giving children reported that they felt good about discharging their duty in the time of their parents' illness and conveyed their sympathy towards the parent's suffering. They reported an increase in love and concern about parental well-being and each other. They also reported a greater and more comprehensive understanding about cancer's causation, treatment options, side effects and prevention strategies. However, their knowledge did not entirely dispel cancer myths and misinformation. Parents reported less adverse behavioural changes and less resistance in the development of a supportive home-based care and fewer problems in adhering to changes in diet and lifestyle. Some parent participants reported that they felt their children's behaviours were more mature, responsible and health conscious than their peers.

A clearly identified barrier was identified as parents who were closed and not accessible to information sharing. Children participants reported greater difficulty in coping, problem solving, empathic support and care for the ill parent. They felt fear, worry, angry, frustrated and disgust toward their situation and in some cases towards both of their parents. They had less understanding about cancer's causation, treatment options, side effects and prevention strategies. Most children participants believed in several potentially harmful cancer myths that could be potentially harmful to their own well-being and cancer prevention strategies. In addition, children participants were reported and observed to have many difficulties and problems; being uninformed raised the levels of anxiety and there were some indications of psychological distress among children participants. This was a possibility raised by Longfield and Warnick (2009, pp.10-12), Kenrick (2009, pp. 8-12), Lewis (2006, p. 21), Watson et. al, (2006) and breastcancer.org (2004). Specifically, according to McCue and Bonn (2003, p. 47), "Children whose needs are not recognized and addressed throughout the adult's medical crisis can suffer psychological consequences either immediately or later in their lives - even if that adult crisis is successfully resolved". Parents reported adverse behavioural changes and resistance in the development of a supportive home-based care and problems in adhering to changes in diet and lifestyle.

Sixthly, similar to potential barriers identified by Scott et al. (2003a) in meeting patients' information needs include: limited access to cancer practitioners, learning difficulties, cultural or language differences, or a failure by some practitioners to listen and respond to individual patients' concerns. For some participants, the failure of soliciting appropriate and timely answers from preferred sources have motivated them to utilise the Internet. However, as opined by Friedman and Hoffman-Goetz (2006, p. 370) and Neuhauser and Kreps (2008, pp. 371), Internet-based information was predominantly in English and this proved to be problematic for non-native speakers.

Another barrier was the low literacy skills of both participant groups. Children participants had lower literacy levels than their parents, however even parents indicated their dislike of reading. This and their academic qualification (Table 4.1 on page 86 and table 4.2 on page 91) contributed to the assessment of their low literacy skills. Participants reported their dislike of reading textual materials, particularly materials that included medical parlance, general health knowledge and admonishments for health care. Participants reported ignoring articles written about cancer and about other health concerns. This attitude was for both English and Bahasa Malaysia articles. Reasons for their dislike was "having to read", "too many words", "too difficult to understand", "gave me a headache" and "not interested".

After diagnosis, information in English was often ignored because participants acknowledged they had difficulty reading and understanding what was written. Several participants mentioned trying to make sense of pictures, failure of which resulted in disinterest or perceived success of which resulted in misconceptions. Several participants also mentioned that most of the provided information was contradictory, added to their confusion and not relevant to their needs. It was found that without timely and digestible information that was relevant to children participants needs, children participants misconstrued and misunderstood the causation of cancer and treatment and prevention strategies. These children participants depended on their personal files, rare opportunities for engaging discussions and their own abilities to synthesise information to "make sense" and explain the changes around them. In some cases of children participants attempt to make sense of their mothers illness included wrong information on cancer myths that they believe to be true. This resulted in children participants continued ignorance about cancer, its causation and treatment outcomes and, preventive habits.

It was found that the participants' general attitudes to health education were based on their needs; only in situations of illness would participants seek information. All participants acknowledged little or no knowledge about cancer before diagnosis. These phenomena helped to understand the various reported consequences of parental withholding of information and the limitations of current information provisions. However, similar to the findings by Forrest et. al. (2006, pp.998-1003), very little research has been done to mitigate this phenomena; it has the potential to impact millions of patients and their children. This understanding contributed to some of the research's anticipated themes about information problems and intervention. It also provided indications of key information needs in which information provisions may be developed.

6.1.iii Possible enablers and solutions to children's information needs problems

The third research question **"What interventions may benefit children and enable them to cope with their parents having cancer?"** identified possible enablers and solutions to children's information-needs problems. While patients and their families had several information source preferences, they reported feeling not having sufficient information to cope and overcome the challenges they faced. Children participants reported difficulty in soliciting information about cancer, their tasks and family disruptions as well as attitudes to information sharing that was not as open and accessible, discouraged timely and quality information exchange and synthesis.

It was found that current information provision seemed to be ineffective, inappropriate and less relevant to information needs of children whose parent has cancer. People affected by cancer do not always get the information that they need and are often confused about what is happening to them. According to Chiu and Winstow (2002, pp. 1-4), Neuhauser and Kreps (2008, pp. 372) and Friedman and Hoffman-Goetz (2006, p. 368-370), much information was inappropriate (i.e., information style and language does not commensurate with the needs of the target audience) and its dissemination was inadequate, uncoordinated and inefficient. This was found to be true. While the American Cancer Society (2012), breastcancer.org (2004), the NHS (2000) and other organizations published several booklets and articles to address some of children's needs, this research found that the accessibility, the English literacy and care-giving culture of the research participants identified information gaps and different information needs. This suggests cancer-related information, that was better informed about the nuances of Malay children's information needs, would offer more relevant support. Recommendations are provided in the following section.

6.2 RECOMMENDATIONS FOR INFORMATION PROVISION TO DEPENDENT CHILDREN OF CANCER PATIENTS

The recommendations that commensurate with the conclusions obtained from the research objectives and their key findings is organised through seven subsections. These are recommendation for: i) more information to be provided in Bahasa Malaysia, ii) specific topics, iii) open and accessible information sharing between patients and their children, iv) the delivery of information, v) the format of information, vi) the source information and, vii) information provision pathways.

6.2.i Recommendation for more information to be provided in Bahasa Malaysia

This recommendation developed from participants' experience in needing and wanting more information than they managed to receive and that most were unable to access information when they needed it. Information in Bahasa Malaysia was limited and difficult to obtain. The information style, medical language and topics did not meet their needs. Besides requiring information for themselves, parent participants had to censor and retranslate information into digestible information that was perceived to be commensurate with their children's abilities and roles in care-giving. Children participants' low literacy skills in English resulted in parent participants report of having to translate medical terms presented in English and re-contextualise information into more digestible and palatable information for their children. Parent participants found a lot of accurate information was lost in translation as they had difficulty with the language and that there was a lot of misinformation that may have contributed to some of their children's problem in understanding cancer's causation, treatment options, outcomes and preventive measures.

6.2.ii Recommendation for specific topics

A significant contribution was a list of specific topics for information provision. Specifically, participants reported information provisions to address the myriad of issues surrounding the communication and information about the cancer journey to dependent children who were care-givers were limited. Parent participants did not have clear and understandable information to share with their children about treatment options and outcomes from diagnosis and throughout the cancer journey. The information did not prepare patients on how important children were to their continued care at home.

Parent participants reported that they wished for information that would guide them on how to communicate to their children about what to expect and why they could not carry out their "normal" tasks. They wanted help in how to talk to their children about their possible death; how to prepare their children for a future without a parent, the limits of children's care-giving role and that they still loved their children even in the face of cancer. Parent participants also wanted information on what prayers and other religious activities they and their children could have performed to provide a sense of wellness to themselves and to each other. However, parent participants reported that hardly any of the information they obtained provided help in those areas.

Different from National Cancer Institute (2003) advocacy, another significant contribution was children participants' recommendation of two types of key information needs. The first type was for cancer –specific information. There were 15 topics of cancer-specific information in which participants were interested. Specifically, participants wanted to know the definition of cancer, definition of disease, the types of cancers, is cancer dangerous, is cancer contagious, cancer detection, the treatment process flow, list of possible side effects of cancer treatment and cancer prevention. They also wanted to know why cancer took a long time to recover from, why chemotherapy caused vomiting and hair loss. They also wanted to know how to instigate a discussion about cancer and the diagnosis.

The second type was for children's specific concerns. Children participants were concerned about 18 areas. They wanted to know how to care for a cancer patient, possible ways to help parents with cancer, possible changes to familial roles, how to take care of self, how to take care of younger siblings and how to talk to parents about their cancer experience. Children participants wanted assurance of continuation of care and love, they wanted to know how they can talk to parents about what made the parents upset or what made them upset. In addition to this, they had questions about how to show care towards their parent, why were house chores unequal, why girls had more care-giving tasks, why the father was less helpful or less supportive, how to approach a parent when they appeared bad/disgusting/not normal. Children participants also wanted to know what they could do so they were not scolded as often. This was related to children participants' questions of why was the ill parent emotional and how children participants may make their parent less emotional and how to calm the ill parent when angry or upset.

6.2.iii Recommendation for open and accessible information sharing between patients and their children

Parent participants who were more open and accessible to information sharing had dependent children who exhibited the least stress and emotional distress than dependent children of other families. Even though those children reported feeling sad about their current situation it seemed that there were still more able to cope with the new challengers and health situation they faced. These children participants indicated that they understood more of what was happening to their mother, how cancer treatment affected their mother's recovery and their role in providing her with care. They understood better and could explain more of how cancer developed and the importance of cancer treatments. Children participants from these families were more willing and supportive of their parent throughout their cancer treatment. They reported feeling empathy and concerned about their parent's well-being. These children were more patient, had lower anxiety levels and reported that they felt communication and the support mechanism within the family were improved. They took on household chores and care-giving responsibilities with less resistance and problems. The eldest female child felt that she was more matured than her peers and felt a sense of accomplishment in discharging her duties.

Similar to findings by Papert (1999, para. 1) and Given et al. (2001, p. 213) children participants did not behave and think like adults and are especially vulnerable in this context, more so when children were exposed and expected to provide multifaceted roles that lasted months and years. All children participants reported their failure in obtaining digestible information. Children participants reported the need for more information on a variety of concerns and topics. However, current information provision seemed to be ineffective, inappropriate and less relevant for these children. The failure in obtaining solutions from parents was reported. In most cases, these children participants also indicated that their most preferred information source was less forthcoming than they required.

In an effort to resolve parents' reticence, children participants turned to other sources. However, this was difficult because the information children obtained was still not sufficient to meet their needs. Children participants reported that written information from the Internet, books, magazines and booklets were too textual for their comprehension and interest. Children participants also reported difficulty with the language, the format was not attractive and, the information did not seem relevant to their specific needs.

6.2.iv Recommendations for the delivery of information

Similar to advocacies by Chiu and Wistow (2002, p. 2) participants thought that communication of information should be given with sensitivity, respect and with nuances of emotional support. Children participants reported that verbalized information was delivered in an insensitive manner; children participants were not listened to and the information did not help them prepare for and respond to difficult situations. Inappropriate delivery was found to incite children participant's anger, frustration and sadness and, contributed to their confusion, fear and despondency. Children participants lacked information that could help them prepare for and respond to difficult situations. This advocacy for better delivery of information was reinforced by Fives et. al. (2010, p. 12), Hutchison et. al. (2010, p. 2) and Chiu and Wistow (2002, p. 2).

It was found that the children participants had different information behaviour pathways. It was identified that reactions to health situations motivated children participants' information seeking behaviour. Their reactions affected why, how and when children required information. These children participants had to struggle with many issues and difficulties, often with very little information and adult supervision or support. The prolonged complex and multifaceted role children played required simplified and digestible information that was relevant to their situation. Without information sharing and avenues for discourse, children participants reported feeling confused, unappreciated, undervalued and unimportant, even though they played a very important role in their parent's recovery.

6.2.v Recommendations for the format of information

Participants preferred interactions and verbal communication about cancer information. The reasons were based on accessibility, openness of communication and information from first-hand experience. In the absence of interactions and verbal communication, cancer information should be pictorial-rich. Even though participants did not believe in drawing's abilities to tell a story about their experience or thoughts, they reported their preference for cancer information to be pictorial-rich as presented in a cancer reference book or a television programme. Parent participants were in favour of reality-based dramas or feature films. They rationalised that information presented in this manner would be more attractive, involving and encouraging follow-up discussion and empathy from their children about parental experiences. Parent participants also wanted information that was easily obtainable.

Children participants wanted information that was easily obtainable and attractively presented. Children participants were very keen for the development of a comic book. or pictorial-based reference or easy-to-read guidebook that was based on the 15 topics and 18 areas of children's concerns mentioned in earlier chapters and that addressed their concerns in care-giving, simple explanations about cancer and what more they could do in showing their love, providing support, care and comfort to their ill parent. Their solution also suggested a specific format of dramatizing a story of a family with cancer, dramatizing a problem-solving situation, or a reality television programme of coping with cancer in the family. More visual-based information was also preferred in magazine and newspaper articles. This implies that children may require information that simplifies relevant information that is presented in a more attractive format. This could encourage information synthesis and facilitate better understanding.

Both groups of participants wanted the information to also respect their language preference, cancer specific information needs, preferred information format and the identification of children's concerns.

As another possible solution, it is proposed that the information strategy may be recommended for the provision of information to be less textual and have less complex medical terms. For the reasons cited by participants, pictorial-based information would seem to be more attractive and easier to understand. In addition to that, cancer information should not be limited to oncological taxonomies but should also include solutions, advice and preparation for real experiences that address challenges to cancer patients and their families.

6.2.vi Recommendations for source of information

How information was communicated (scope, language, manner and attitude of information sources, format, attractiveness and accessibility) influenced the information seeking behaviour and its outcome. Specifically, children participants' accessibility to their mother and how open she was to communication and information sharing had an important influence in the outcome of their information seeking. This influenced how children participants made sense of, coped with and, overcame challenges. In this, children participants seemed to depend heavily on the information and "personal files" (Kirkelas' (1983, p. 13) a person's memory-based recallable collection of answers which can be compared to their prior knowledge) of their mother. However it should to be noted that, the information, "personal files", attitudes and behaviours of their mother might not be as conducive to information sharing nor have sufficient quality and depth to provide accurate and relevant information that could influence children's reactions to a health situation or stimuli.

Other than a preference for more open and accessible information sharing with parents, the attending doctor was the second most preferred information source. However, in instances where information was obtained from their attending doctor, most parent participants felt the information was too abrupt, confusing, not very informative, did not reassure them and used complex medical terms that did not contribute to their understanding. Participants suggested that the role of doctors in providing information could be more than to treat or cure cancer. This sentiment was similar to the advocacy by Miller and Zook (1997, pp. 66-72) that recommended for direct contact between care providers and physicians could provide information that was invaluable in providing home care for the patient, monitoring the patient's symptoms and advocating for the patient. It was believed that, similar to Forrest et al. (2009, p. 1002), general practitioners and hospital specialists, as well as nurses, were well placed to be able to help with these concerns and to be involved in discussions with the children. However, according to the children participants, they rarely experienced this very beneficial exchange.

Both groups of participants believed that doctors were pivotal in their understanding of the disease and how cancer may affect their lives. Doctors were trusted sources who were perceived to be experienced specialists who knew what they were doing and had first-hand experience with problems people faced with the cancer diagnosis. Parent participants thought that their doctor could have helped them to inform their children of what to expect and how their children might react to side effects. They would have welcomed simple guidance on how to announce the distressing news about cancer and how much information to share with their children. However, most parent participants reported that their doctors were less forthcoming in this area. They also reported that doctors appeared too busy to talk with them and dismissed their concerns for matters other than the treatment itself.

Children participants had trusted their parent's doctor to provide them with information of how to provide comfort, care and support as well whether they could contract the disease. They were ignorant about providing care and were concerned with their parent's diet, health and well-being. Hospital stays, blood checks, insertions of chemotherapy, radiotherapy and physiotherapy sessions were frightening and confusing to children. The prolonged hospital stay without information about parent's health status contributed to children's frustration and stress. However, most children participants reported that their doctors were less forthcoming in this area. Similar to their parent's responses, children participants also reported that doctors appeared to busy to talk with them and dismissed their concerns.

This finding suggests that doctors could have played a more proactive and positive role in children's understanding about cancer, treatment outcomes and preventive strategies. This was previously mentioned in page 49 of this thesis. With doctors' support, children participants may have had less frightening reactions, difficulty in experiencing parent's side effects and less ignorance and frustration in providing home-based care.

6.2.vii Recommendations for information provision pathways

One of the most significant findings, development and contribution from this research was the understanding of how to communicate and create information relevance to dependent children participants. The "Children's Reactive Information Seeking Behaviour Model" can provide significant insight into dependent children's information seeking behaviour and how information is synthesized into their "personal files" (Kirkelas, 1983, p. 13) to prepare them to either cope or overcome reoccurring health situations or problems.

This understanding provides an opportunity of identifying when information may be the most useful. It also provides insight into the development of the types and topics of information or intervention methods needed to mitigate children's reactions. In addition, this first reaction-based experience required the most depth of information; once there is familiarity in either coping with or solving a problem, reactions appear to normalize and less information was needed. Participants believed that timely, correct and digestible information not only helped to mitigate or dispel unknowns or problems, it also enriched children participants' personal files that contributed to more normalized reactions and subsequent behaviours.

Moreover, this understanding and its illustrated model provide an insight for information provision. Specifically, it may help information providers to tailor the availability and access to information when children may need it most. It may also help to facilitate greater understanding when the information pathways and information seeking behaviour is better understood; instead of generalized cancer information that may or may not reach its intended audience, information that understands how its users seek, synthesize and use information may create greater relevance and use.

In addition to that, the model indicates that children participants' receive information mostly from a trusted source that has had first-hand experience (as in the case of their mother) or the most experience (as in the case of the attending doctors). This suggests that information provision is based on verbal discourse that is depended on the knowledge base, "personal files" (Kirkelas, 1983, p. 13) and, attitudes of information sharing of parents or doctors. The implication to information provision infers that parents and doctors have a greater role in information dissemination than was previously realised. This phenomenon has implications on the scope, type and format of information that parents and doctors may re-contextualise when they impart information to children.

The model's contributions and the contributions of the rest of the research findings is discussed in the following section.

6.3 CONTRIBUTIONS

The findings of this research contributed new insights into the experiences of Malay children whose parent has cancer. The research identified these children's perception of cancer and information culture; information needs, information seeking behaviour, barriers and enablers. This section will discuss how these findings contributed to the knowledge and understanding of information problems, needs and provision. This research contributes to five different areas. They are: i) Contributions of the research methodology, ii) Contributions to ethnic-based information problems, needs and provision for dependent children of cancer patients, iii) Contributions to cancer information provisions, iv) Contributions to knowledge about children who were care-givers and, v) Contributions to Information Science models. These are discussed below.

6.3.i Contributions of the research methodology

This research adapted a Participative Action Research (PAR) approach in which to solicit participants' experience with the cancer information domain that was accessible to them. To the best of the researcher's knowledge, the use of an adapted PAR to explore the experience and information needs of children of cancer patients in this specific manner has not been conducted before. This suggested a new approach to conducting research with children about parental cancer. The line of enquiry, activities and method to obtain data from participants was very beneficial to the research. This forms an original contribution to research methodologies.

As opposed to other research methodologies, the Participatory Action Research (PAR) as introduced by Kemmis and McTaggart (1988) was utilised because it was evaluated as one of the few research methods that encouraged participants to be more forthcoming and provide their own experiences and insights into identifying problems, issues and needs of people and their children affected by cancer. In line with advocacy for information provision to correlate to the recipient's information needs (Johnstone et al. 2004, para. 38; Brashers et al., 2002, p. 263) with an emphasis on the process 'by which people become informed' (Dervin and Nilan, 1986, p. 16) and in resolving the problem of "effective and efficient interface between people and literature" (Saracevic, 1997a, p. 6), it was believed that cancer information should be developed in a way that allowed people to be "predisposed to use information effectively" (Davenport, 1997, p. 87) and that cancer information should be tailored to meet the needs of patients and their families (Kalbach, 2000, para. 47). Health campaigns and its advocacy by many organisations (WHO, American Cancer Society, The National Cancer Alliance, NHS Doncaster, NHS Scotland, Macmillan Cancer Relief, CancerCareConnection and NCSM) also have come to realize that human-centric information is an integral communication process to create greater relevancy, understanding and adherence to health advise. These collective beliefs informed the research for the necessity of a research methodology that would allow the research to be better informed about the nuances that constitutes needs, problems and possible solutions of research participants.

In addition to that, working with children necessitated a different approach to soliciting data. There were questions about how the research and seeking information could be made relevant, accessible and digestible for dependent children of cancer patients. This understanding contributed to the option for drawing as a means for children participants' self expression and platform to discuss their experiences and concerns. The option of drawing and narratives allowed for background knowledge to emerge and that information provisions would necessitate respect of children's information needs, processing capacity and skill sets. This methodology helped to inform the research and to understand the realities faced by children who provided care. This framework resulted in participants' rich anecdotal data that created the co-developed awareness and understanding of the information seeking-information synthesis process for families with cancer. It also encouraged participants to suggest solutions that may be more relevant in mitigating their problems.

Further, PAR allowed for participants and the research to "resolve uncertainties" (Shankle et al. 1999, para. 1-4) in the identification of information needs and the development of its suggested solutions. PAR enabled observations of participants' recognition of their information-based problems, their conscious effort to acquire information and their various information behaviours as defined by Read (2012) and Mok and Hughes (2004, para. 19). PAR facilitated an investigation of participants' nuance requirements for information that was reflective of their variables and cognitive process (Saracevic, 1997a, p. 6-8).

This adapted PAR resulted in rich anecdotal ethnic and phenomena excerpts of data and findings as cited interspersedly in this report. PAR was instrumental in the various anticipated and unanticipated findings, the development of themes and understanding of participants' lived experiences and, the identification of participants' myriad of needs. This method empowered participants by collaborative participation; acquisition of knowledge; and encouraged changes about their perception about cancer, its consequences and children as caregivers. This came about from participants' realization and identification of problems and shortcomings about their available cancer information, participants' experiences and expectations. Changes were evidenced when the parent participants were more cognizant of cancer's impact to their children and the consequences of a lack of cancer-related information. The parent participants were observed to be more open and accessible to discussing cancer and their children's concerns. The children participants had the opportunity to voice out their issues and concerns about care-giving, division of chores and accomplishing tasks, their well-being and the well-being of their parent. This change suggests an encouragement to discourse, information sharing and problem solving. The gradual realization of the affects of cancer to their children and family helped patients realize the importance of information and the important role their children played in their recovery. This also empowered children to solicit information and identify their needs in the face of care-giving and its associated problems. In addition to that, the methodology also helped in the development of suggested solutions and the model of children's information behaviour and information synthesis in the face of parental illness.

The adapted PAR helped to identify and establish the severity of the consequences of a lack of information to dependent children. It also helped to anticipate some of the information needs, problems and issues that participants faced when dealing with information sharing among themselves. It helped to identify and understand the pathway in which children participants solicit and synthesize information about cancer to make sense of, to understand and to overcome challenges. It also helped to identify several emerging themes about what motivates children to seek information and what information they thought was the most needful. It resulted in an understanding of the other ways in which children are affected. It helped to suggest the large scope in which the problems in information and its delivery may impact these children. The rich data reported conveyed the rigor and accurate description of participants' experiences to the extent of exhaustive inquiry. The versatility and scope of PAR as a methodology and an aid in resolving research questions in this research may become an inspired use for other research seeking to investigate, solve or better understand problems, motives and possible interventions for other health-based situations.

6.3.ii Contributions to ethnic-based information problems, needs and provision for dependent children of cancer patients

Findings about ethnic-based information problems, needs and provision for dependent children of cancer patients, are one of the original contributions of this research. To the best of the researcher's knowledge, this research is believed to be the first in-depth qualitative and highly participative study of the implications of cancer for dependent children of Malay cancer patients. It focused on young people's information seeking behaviour and information needs that had the potential to mitigate some of the distress and challenges young children experience from their parental diagnosis among Malay Muslims in Malaysia.

The nuances of cultural and religious imperatives to experiences in home-based care for these families contributed to the body of knowledge with a better understanding of the ethnic-based information problems, needs and provision for dependent children of cancer patients. It provided insights into children's abilities, their cognitive development, functional development, abilities in recognising facial expressions, care-giving expectations and skill sets in the face of parental illness.

This research obtained data and evaluated findings of how cancer affected dependent children in Malay Muslim families and this information has contradicted conventional wisdoms. Children were culturally expected to "automatically" undertake care-giving tasks without tutelage and with little or no adult supervision, even if the tasks were not age appropriate or were not commensurate with skill sets and physical abilities. The religious imperative also contributed to children's' and their families expectation of care and how children should be stoic, patient and pious. While children did not internalise cancer as their fault, they had attributed cancer’s development as parent’s test from God or as a means of paying for past sins. Patients similarly believed that. Both groups reported an increase in religious observances.

Cultural and religious practices contributed to personal beliefs and attitudes to information sharing of illness to dependent children. Malay Muslim children participants and their parents are a specific ethnicity of people affected by cancer who have not had interventions and anticipatory guidance to help them come to terms with a cancer diagnosis. Many nuances of the consequences of cancer’s diagnosis were discovered, some of which were unique to the cultural and religious imperative not only of patients but also in care-giving among these participants.

Other than medical efforts in overcoming cancer, parent participants seemed to also make efforts in increased religious observances and some reliance on traditional medicine. Parent participants reported an increase in their faith and frequency in prayers and increased practice in culturally-held beliefs in ensuring health and wellness. In their interactions with their children, parent participants admitted to hiding physical, psychological and spiritual side effects from their children. Even when it was apparent that keeping their experience a secret from children was futile, parent participants wanted to hide their hair loss, fear of their death, worry for their children’s future and practices of either repenting for their perceived sins or facing God’s test with perseverance.

Parent participants provided several reasons for this behaviour; some cited the belief in protecting children from potentially distressing information, their unwillingness to face difficult questions from children and the belief in being stoic and patience when ill. This behaviour resulted in less interaction and communication with children. This phenomenon seemed to contribute to children participants’ perception that they were less cared for and less loved. In the course of the research, parent participants seemed to realise that their behaviour did not help their children; observations and understanding of their children’s problems helped them to be more aware of the myriad issues their children experienced. This resulted in the co-development of suggested solutions.

While care-giving tasks among children seemed to have some similar practices among families of other cultures and religions, the nuances and frequency of the burden of care seemed to be unique and varied for these children participants. Within the cultural and religious ethnic, these children participants especially the eldest female child, seemed to be held responsible for many more household chores and care-giving duties than anticipated. Children participant's duty to their ill parent irrespective of age or skill appropriate was considered an "automatic" prerogative that had little adult supervision and tutelage. It seemed that this belief had somewhat contributed to children participants' contributions and difficulties being unacknowledged. It should be noted that the healthy parent, the father, had less care-giving tasks than his dependent children.

Children participants also increased their religious observances; they prayed for the health of their parent and for their parents' return of "normal" and acceptable behaviours. Children's roles in praying for the health of their parent and being religiously thankful for their parent's recovery was both a cultural and religious imperative. It should be noted that, unlike children from other cultures and faiths, most children participants perceived cancer as God testing their parent or as a means of atoning for a past sin. Contrary to what was anticipated from literature review of findings by National Cancer Institute (2003a, pp. 17-26; 2003f, pp. 17-19) and American Cancer Society (2012a, para. 20), none of these children participants internalised cancer as being caused by themselves. This was originally anticipated because the literature identified this as being one of children's central concerns.

This research has made aware experiences, difficulties and influencers to information sharing and attitudes about cancer that were not previously documented among Malay Muslim families. This has implications in what role cultural and religious imperatives have on information sharing, expectations of children roles and the information problems that may arise. It also indicates the difficulty to develop interventions for families with complex cultural and religious imperatives that may contravene conventional wisdom or medically and scientifically proved interventions.

6.3.iii Contributions to cancer information provisions

Findings about the consequences of cancer information (provision and its lack), an understanding of when cancer information was needed, parental role in cancer-related information provision among Malay families and, the type, scope and depth of topics that dependent children wanted to know were original contributions of this research.

Similar to Johnson and Meischke (1991b, p. 37), this research believed that the lack of knowledge from both practitioners and patients were a significant problem for preventive oncology and cancer control. This research made clear that cancer patients and their families seemed to have negative outcomes and consequences when there was a lack of cancer information. The children participants experienced distress and had misconstrued cancer's causation, treatment outcomes and preventive strategies. Comparatively, cancer patients and their families seemed to have positive outcomes and consequences when there was more cancer information. Children participants experienced less distress and had a better understanding of cancer's causation, treatment outcomes and preventive strategies.

In addition, this research helped to provide a practical approach in understanding the time of greatest information need and relevance. The time when information seemed to be more actively sought was at the onset of children's reactions to a health situation or stimuli. This implies that information might be provided a few hours before an anticipated event so that children may have the time to digest and recontexulatise the information to their future possible experience. Information can be provided just before administrating chemotherapy, radiotherapy, or immunology as side effects usually occur after an interval of time. Process and outcomes of surgical procedures, blood tests, MRI Scans and ultrasound scans can also be provided before children accompany or care for their ill parent.

The data suggests that information flows from a trusted source, in this case from either a parent who had first-hand experience, or from the attending doctor who has had a lot of experience with problems associated with the diagnosis. This suggests that the provision of information may need a two-pronged approach. Parent and doctors should be equipped with information that can be re-contextualised for information sharing. They should be made aware of information best practices and what strategies they may employ when communicating to children. Children may become informed through easily digestible and attractive information that was developed with respect to their information needs, role in care-giving and cognitive abilities.

In addition, this research contributed to the knowledge about the type, scope and depth of topics that dependent children seemed to want to know. The extent and nature of their specific needs had not been previously documented. The interesting findings in the analysis of the data poses new challenges in information provision and it provide insight into more relevant avenues for information provision. This would contribute in tailoring information, the development of cancer campaigns and prevention strategies.

6.3.iv Contributions to knowledge about children who were care-givers

This research found that children participants had greater importance in the care and recovery of their ill parents than was previously anticipated. It was previously unknown or undocumented that children seemed to be an integral variable in patients' recovery and continued survival from cancer. They had more responsibilities and carried out many more tasks than even their ill parents identified or acknowledged. The parents' impaired functioning, psychological distress for themselves and their children may have contributed to these phenomena. These finding form new knowledge and are original contributions of this research.

The majority of the burden of care was the responsibility of the eldest female child, irrespective of age, cognitive capacity, skill sets and physical abilities. The prolonged care, frequency of care and burden of responsibilities seemed to impair these children's functioning and development. This suggests the important role children play when there is an illness in the family. It also demonstrates the unfair burden children are "automatically" expected to accomplish. Their long and multi-tasked list provides an insight into the information needs of children care-givers. Without this research, little empirical evidence would have been available to communicate about children's problems in taking on specialised care responsibilities.

6.3.v Contributions to Information Science models

This research identified that information professionals of information science often assumed that users want, need, and use information and that many health-focused studies still addressed only formal information sources that mask the process of information seeking (Gray, 2003, p. 259). However, the literature review, as well as anecdotal accounts, necessitated for information to understand how children seek, synthesize and use information. The collective data and observations informed the development of a proposed model of children's information behaviour and information synthesis in the face of parental illness is believed to be a significant contribution. The resulting development of a "Children's Reactive Information Seeking Behaviour – An Integrated Model" was an original contribution of this research.

The model provided an overview process that identifies the time when information has a maximum impact and greatest relevance to the needs of children. It also indicates the information process flow from a child's reaction to an unknown, unfamiliar or psychologically distressing health stimuli or event. It indicated the child's possible motives or triggers in information seeking and their preferred source of information and the format in which information soliciting or exchange takes place. It also indicated the child's influences and role in health care, information seeking behaviour activities, source preference and perceived (and/or actual) openness and accessibility to information influencing how information is synthesized. This information synthesis added richness or reconfigured a child's collection of prior knowledge, beliefs and recall ability before an action on said information takes place. The obtained information and its attended action or inaction will then undergo a perpetual perceptual encoding. This was described in Chapter Five (on page 245) as a symbolic memory attributed to a representation of selected information that is continually evaluated against new information, prior knowledge, what they perceived to be of use and relevant to their situation and, subsequently will continue (or not continue) to use when facing either a new health situation. The result of the perpetual perceptual encoding influenced the child's sense of self. This sense of self includes personality traits, relevance, individual capacity and processing capacity in the face of illness. This was evident in how the children participants processed and used new information to resolve their information needs.

6.4 Limitations of the Study and Implications of Future Work

The review of the research project, its constituent empirical stages, and the research findings, enabled a critical evaluation of the rationale of the study. This assisted in the identification of weaknesses and/or limitations.

6.3.i The limitations of the researcher

The abilities of one researcher severely limited the ability to explore the methodology framework to its fullest potential. More data and the exploration of other interesting tangents (for example, the paradox of parental expectation of their children accomplishing tasks even without prior teaching and why children provide more care-giving compared to patients' spouse) could have been made with contributions from more researchers. There were many interesting findings, for example the expectations of children towards the role of their father in the face of mother's illness could have been further explored, but this was not possible.

The fieldwork had participation of 32 individuals with unique experiences and perceptions about cancer, its affects and implication for information provision. The verbatim transcription of participants in Bahasa Malaysia that was later translated into English and in some areas, recontextualised to reflect the researcher's understanding as the context of participants' meaning was limited by the thoroughness of the researcher. Data explication also included illustrated depictions of meanings and explanations by participants, the researcher's observation notes and, use of Bahasa Malaysia-English dictionaries and on-line translation applications. For example, *"sakit"* could either mean "in pain", "sickness", "illness" or "disease". Recontextualising data from these types of narratives prompted were new skill sets for the researcher and required the most time and effort. In hindsight, the limitations of the researcher would suggest for smaller number of participants (as in case studies) so that the research could be completed in a more timely manner.

6.3.ii Methodology framework

The framework was developed from an extensive literature review that used precedent findings and advocacies from information science, child psychology, methodological approaches and health studies. However, this resulted in prolonged data collection, data explication, analysis and interpretation. The three research questions of "What are Malaysian children's understanding of their parents' cancer; its causes, effects, implications and consequences?", "What consequences does children's understanding or lack of understanding about cancer have for them?" and, "What interventions may benefit children and enable them to cope with their parents having cancer?" resulted in the scope of the research being difficult to manage. 95 codes were derived from the discussions and according to the thematic analysis approach, a finite set of 20 anticipated and emerging themes was developed from data collected based. This was collected from five focus groups sessions with 32 individuals. There were too many different nuances and tangents that necessitated continuously refocusing and refining data collection and analysis.

In hindsight the research methodology framework would have been greatly simplified in that it would have fewer stages, have a more narrow scope and have more defined boundaries of research interests. The development of a three cycle, eight-step participative action research process would also have been made into a two-cycle process that would be easier to replicate for each family group. A more rigid research script would have been developed to better guide open-ended questions. This is suggested because it seemed that most participants, when became familiar with the researcher, tended to talk about non-research matters and went off on a tangent. For example, the researcher was asked about her father and the marriage status of her triplet sisters. The researcher had to constantly guide participants to address the research aim and objectives.

6.3.iii Line of enquiry

In addition to that, as evidenced by the data collection process, younger children required simpler phrasing of questions in Bahasa Malaysia to facilitate understanding and to encourage their responses. Most questions had to be reconetxtualised, either by the researcher or by the parent in order for children participants to understand the nuances of the enquiry and the freedom for them to respond. Most participants, even parent participants, were not familiar with inquires that required for them to answer from their experiences and observations. This was more so for children participants who it seemed were not often consulted nor solicited opinions from; they had hardly any experience in such engagement and method of discourse. Most continuously sought approval, permission or guidance from their mother or older siblings before responding.

In addition, the approach for offering alternative methods of responding to the research questions and enquiries were new experiences to children. The researcher found it surprising, that unlike advocacies of the literature review, most children did not prefer to narrate their experiences through drawings. Even with the option of drawing responses, children participants sought permission and some had to be encouraged by their parents to indicate their responses through drawing. Some reported that they did not know how to draw or felt that their drawings were ugly. It was thought that children participants' perception limited their freedom of expression in that manner. Parent participants indicated that they had discouraged their children from drawing, as they perceived it was a waste of time, could not possibly be of benefit to their academic and financial future and meant that their children were less academically inclined. This previous parental influence resulted in most children's perceived inability to draw and preference for writing down their responses, even at the expense of misspellings and misconstrued descriptions of their experience. The option to draw responses seemed to have placed undue pressure on children participants. In an effort to validate their written or drawn responses, the researcher solicited verbal narratives of their experience and intent as well as more explanation about their initial responses.

6.3.iv Limits of generalisability

The research presented phenomenological findings. This research was an effort to investigate the information needs and information seeking behaviour of a previously undocumented ethnography and in understanding how these families functioned in the face of parental cancer. However, the sample size and composition limited generalisability. This problem was similar to Pecchioni and Nussbaum's (2000, p. 324) study. However, the research provided insights into the experiences of 32 Malay Malaysians. These insights contributed to knowledge about cancer and the consequences of information to previously undocumented ethnic participants. This included the nuances of parental cancer's consequences to children and the information needs and information seeking behaviour of children and children who provide caregiving.

6.5 Further Research

The above discussion of the limitations of the research project assists the consideration of the implications of the study, for future work. Further research might include:

- The scope and extent of children's care-giving tasks were more extensive than previously realised. Research participated by many more children in similar circumstances may need to be conducted. This is to document prevalence and to develop a better understanding of what myriad of tasks children caregivers were responsible for. This knowledge would provide an indication for children's support systems.

- There needs to be more research on identifying possible strategies in communicating to children about parental illness and the information domains that may commensurate with children's age, cognitive capacity and physical capabilities. This is a very complex undertaking as there are many variables, however, findings by Kornreich et al. (2008, pp. 65-70), Christ and Christ (2006, p. 199-210), the American Cancer Society (2012a, para. 11-22) and Welch et al. (1996, pp.1415-1417) suggests that such an undertaking may contribute to a better understanding about how to provide cancer information to children and nuances of their cancer-related concerns.
- There needs to be a research to identify how parenting skills or functions are impaired from a cancer diagnosis and, how that impairment effects children. A possible result of such research would be an indication of the prevalence and extent of parental expectation for children to provide care. Another possible result would be the development of a guide to help parents more readily identify when their parenting skills or functioning was impaired and when expected tasks are not within the abilities of children to accomplish.
- There needs to be more in-depth research on the cultural and religious influence on family behaviour and expectations on the onset of a critical or prolonged illness. The role of faith and religious (Muslim) observances may provide a degree of hope and comfort to both patients and families. An empirical study, measuring these perceptions may be useful to gain a better understanding of care-giving motives, behaviours and needs. This could contribute to better interventions, guiding both parents and their children about care-giving roles and responsibilities.
- Future studies should include a longitudinal observation and documentation of families, specifically transitions of dependence and role of children, to develop a better understanding of the factors involved in successfully making critical transition in the family's life when dealing with chronic illnesses.

In addition to the possible future work relating to improving this research, the analysis of the information needs and information seeking behaviour of dependent children, context of children care-giving tasks, identification of possible intervention strategies to help mitigate or resolve children's information problems could be used for comparative purposes, in other countries. The differences in information problems and interventions for children care-givers across other cultures, religions and health circumstance need to be further investigated. For example, paradoxes of parental expectation of their children accomplishing tasks even without prior teaching and why children provide more care giving compared to patients' spouse among Malay families, were found. Majority of the current developments in interventions for children have been more from United Kingdom, Scotland, United State of America, Australia and other English-speaking countries where the attitudes to children taking on care-giving tasks may not be similar to the attitudes and needs of children in other countries.

Conclusively, it is generally expected that any further research advancements in this research area would include the refinement of this research methodology framework and to apply it into a similar area of research or different context. It would be interesting to develop a graphical solution as informed by the resulting data collection. It would be interesting to conduct an effectiveness study about this research methodology framework. In addition to that effectiveness study, it would also be interesting to test the effectiveness of "Children's Reactive Information Seeking Model" as an integrated model for identifying information needs, information seeking behaviour and information provision strategies for dependent children of cancer patients from a larger participant base, among other ethnicities and for other health-related concerns.

6.6 Conclusions

The extensive literature review and the focus group sessions evidences that the consequences of parental cancer to their children were underestimated. Specifically, it was found that information had an important role to help children face challenges in coping with the cancer diagnosis, reducing misconstructions and myths about cancer, understanding more about cancer's consequences to children's well being and, helping children to provide care for their ill parent. The existing literature about cancer and support mechanisms available in Malaysia had not met children's information needs arising from challenges in coping and caregiving. This problem was compounded when children participants' had difficulty in reading English-based literature and cultural and religious observances contradicted some of the conventional wisdoms of children's role and caregiving expectations. With some 14,860 dependent children (on page 30) affected by parental cancer in Malaysia in 2007 alone, information provision becomes an important concern.

The research's participatory approach identified that a better understanding of children's information seeking motives and behaviors, information processing pathways and sense-making was required. This understanding reinforced the need for person-centric information provisions that may provide opportunities for children to access more relevant information and appropriate support. This resulted in the development of a "Children's Reactive Information Seeking Behaviour- An Integrated Model". The Model informed about how children participants reacted to an unfamiliar health situation, how they seek information, what were the barriers and enablers to information seeking, how they synthesised information and acted on it. The identification of this process may facilitate greater understanding for information provision because when information pathways and information seeking behaviour was better understood, the resulting tailored information offered a higher likelihood of information relevance and use.

The model and the participatory approach resulted in recommendations for information provisions that respected children participant's' language preference, cancer specific information needs and preferred information format. In order to mitigate problems with translating information, medical terms and procedures from English, cancer information should be provided in Bahasa Malaysia. It was also recommended for information to be recontextualised into simplified information so that children could better understand treatment options and outcomes. This was especially important to help children understand caregiving instructions and tasks that were age appropriate. Parents were recommended to be more open and accessible to information sharing because it was evident that this contributed to children being less stressed, were more capable in coping and they had less difficulty in providing care. Children participants' preference for face-to-face discussions with parents and doctors contributed to the recommendation for interactions and verbal communication. When this was not possible, a pictorial rich comic book was a preferred alternative.

Other than the above findings and recommendations, the research contributed in five different areas by i) informing about an original research methodology adapting a Participatory Action Research method in order to explore the experience and information needs of children of cancer patients, ii) investigating ethnic-based information problems, needs and provisions for dependent children of Malay Muslim cancer patients, iii) reviewing cancer information provisions for children, iv) investigating tasks undertaken by children caregivers and, v) continuing to advocate for studies and Information Science models that were more user-centric. Information Science models and findings by Baker (1995), Bettman et al. (1991), Belkin (1980), Dervin (2003), Finch and Gibson (2009), Ford (1980), Gallistel (2008), Johnson (1997), Krikelas (1983), Kellman and Garrigan, (2009), Prince et al. (2005), Saracevic (1997), Schutz (1967), Wilson (1999) and Wilson and Walsh (1996) were integrated into the Model. This provided a novel way of presenting a more holistic Information Universe about the relationship between users, information needs and motives, information requirements, information behaviour and information seeking strategies.

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APPENDIX 1

Invitation to Participate
InqFE-v.04: English version
InqFBM-v.02: Bahasa Malaysia version

NOTE:

‘Invitation to Participate’ was developed in to two languages, English and Bahasa Malaysia with the code of InqFE-v.04 for the English Language version and InqFBM-v.02 for the Bahasa Malaysia version. The final version was printed on an A4 paper with one language on each side of the paper. The original document was developed in Adobe Illustrator. For perusal purposes, a .pdf version is appended for reference.

Dear Survivor,

NCSM would like to congratulate you on your strength and determination to survive cancer. Being a 'survivor' is more than merely finishing a course of treatment. You also had to relay on the help of others; doctors, nurses, spouse, children, cancer organizations and support groups. Having pulled through with their support, NCSM would like your help to help others triumph over cancer too.

NSCM would like to invite you and your family to participate in a study to identify what information would have helped you and your children to adjust to the many changes cancer brought to you. This study will help you understand the information and communication needs of your children who may require your assistance in coming to terms with your situation. It will also form recommendations and guidelines that will influence the development of information and education services by NCSM and will also feed into the national health and social welfare strategies.

Please take the time to answer this questionnaire and mail it back to NCSM, and should you be willing, an in depth research interview in the comfort and privacy of your own home. All information will be held in the strictest confidence and all participants are guaranteed anonymity.

Your and your children's views and experiences are important as they may help other people in a similar situation to face cancer with hope and determination to survive. If you do take part, you would have helped to make sure that the results of the study truly reflect the information needs of children impacted by their parent's cancer. Your participation might be the very spark that motivates them; with your help, they too can pull through.

National Cancer Society Malaysia
Loughborough University

INVESTIGATING THE INFORMATION NEEDS OF CHILDREN OF A PARENT WITH CANCER

'Cancer affects not only the individual with the disease but everyone and anyone connected to that person' (Granet, 2002, p. 169). This includes friends and family, particularly children. Besides coping with your diagnosis, medical treatment and its side effects, there is also the issue of your role as a parent and how your cancer affects your children. However, informing your children about what you are going through is not easy.

According to the National Cancer Institute (2003), some parents may not be ready to talk about their situation; they need more time in sorting things out in their own minds or they do not know how to talk about upsetting things to their children. However, when parents decide to withhold information it makes it harder for children to cope (Granet, 2002). Having their parents at the hospital can be scary to some young people. Most exhibit some degree of feeling scared, guilty, angry, lonely, embarrassed, and not being able to cope or come to terms with a parent's situation (National Cancer Institute, 2003). Some even fantasize a worse situation than is actually the case (Scott et. al., 2003).

How then should parents inform their children and what information do children need? The study holds the following objectives:

- To understand the children of cancer patients' information-seeking behaviour and information needs in Malaysia.
- To test information solutions that can help children to become informed.

Please help by filling out the questions below.

1.Please write your name and all of your contact details below, even if you decide not to participate so that the researcher will be able to compile the number of respondents. All information will be held with the strictest confidence.

Full Name: ______________________________

Mailing Address: ______________________________
____
____

Phone Number: ______________________________
E-mail address: ______________________________

2.Where and when were you diagnosed with cancer?
Place:
Month/Year: I don't remember:

3.What type, stage and location is your cancer?
Type of cancer: Stage of cancer:
Location of cancer:
I don't remember/know:

4.Where are/were you treated and under whose care?
Hospital Name:
Main Doctor:

5.If you are a parent, please indicate how many children you have and how old they are.

No. of children	Age	No. of children	Age
	1 mth - 6 yrs old		7 – 10 yrs old
	11-14 yrs old		15 -18 yrs old
	Over 19 yrs old		

6.Have you informed your child(ren) about your cancer?
Yes No

7.How useful do you think a guide on how to inform your child(ren) about your situation and how to prepare them for the possible side effects of your treatment would be?
Very useful Somewhat Useful
Not Useful Not sure

8.Would you be interested in helping to develop a solution to help parents like yourself to inform their children about cancer?
Yes No Not sure

9.If you were selected, and as the research is about what children want to know, would you allow your child(ren) to be involved?
Yes No Not sure

Thank you for taking the time to participate in this survey. Your responses may help in developing interventions for people impacted by cancer.

If you have any enquiries, please write to S.A.Mat-Saat@lboro.ac.uk or to mssuzieadina@yahoo.com or call at 012 603 4386.

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KAJIAN KEPERLUAN MAKLUMAT KANAK-KANAK BAGI IBU BAPA YANG MENGHIDAP KANSER

Kepada Survivor,

NCSM mengucapkan tahniah kepada anda di atas kekuatan dan kecekalan anda untuk memerangi kanser. Menjadi seorang 'survivor' bukan sekadar menamatkan kursus rawatan kanser. Anda juga telah terpaksa bergantung kepada orang lain seperti doktor, jururawat, suami/isteri, anak-anak, persatuan-persatuan kanser dan kumpulan sokongan. Memandangkan anda telah berjaya memerangi kanser dengan dorongan dan pertolongan mereka, NCSM ingin meminta pertolongan anda pula untuk membantu orang lain yang diimpak kanser supaya mereka sama-sama boleh memerangi kanser dengan jayanya.

NSCM ingin mempelawa anda dan ahli keluarga anda untuk mengambil bahagian di dalam sebuah penyelidikan untuk mengenalpasti apakah maklumat yang mungkin boleh membantu anda dan anak-anak anda untuk menyesuaikan diri kepada perubahan-perubahan yang disebabkan diagnosis kanser. Kajian ini akan membantu anda untuk lebih memahami keperluan maklumat dan cara berkomunikasi dengan anak-anak anda supaya mereka lebih bersedia untuk menerima keadaan baru anda. Kajian ini juga akan membentuk garis panduan yang akan mempengaruhi pembentukan khidmat maklumat dan pendidikan NCSM. Ia juga akan diserapkan kedalam stratagi kesihatan dan kebajikan sosial negara.

NCSM meminta jasa baik anda untuk meluangkan masa untuk mengisi borang ini dan sekiranya anda berminat untuk ditemuramah nanti. Semua maklumat akan dianggap sulit dan semua peserta dijamin kerahsiaan.

Pandangan serta pengalaman anda dan anak-anak anda amat penting kerana ianya mugkin boleh membantu orang lain yang diimpaki kanser di dalam keadaan yang mempunyai lebih harapan dan kecekalan untuk memeranginya. Sekiranya anda mengambil bahagian, anda telah menolong untuk memastikan hasilan kajian ini betul-betul mencerminkan keperluan maklumat kanak-kanak yang diimpaki kanser. Penyertaan anda mungkin mampu memberi motivasi dan menjana daya untuk mereka memerangi kanser dengan jayanya.

National Cancer Society Malaysia

Loughborough University

'Kanser bukan sahaja memberi kesan kepada pengidapnya tetapi juga kepada sesiapa yang mempunyai talian perhubungan dengan orang peseorangan itu' (Granet, 2002, p. 169). Orang-orang yang terlibat ini termasuk rakan-rakan dan ahli keluarga, terutamanya anak-anak penghidap kanser. Selain daripada mengatasi diagnosis, rawatan dan kesan-kesan sampingan, ada juga isu peranan anda sebagai seorang ibu atau bapa dan bagaimana kanser memberi kesan kepada anak-anak. Namun, memaklumkan anak-anak mengenainya bukannya sesuatu yang mudah.

Menurut National Cancer Institute (2003), sesetengah ibu bapa mungkin tidak bersedia untuk bercakap mengenai situasi mereka; samada mereka memerlukan masa yang lebih untuk meguruskan keadaan didalam minda mereka sendiri atau mereka tidak tahu bagaimana hendak berbicara mengenainya. Tetapi apabila ibu bapa memutuskan untuk tidak memaklumkan anak-anak, anak-anak mereka lebih susah untuk menyesuaikan diri (Granet, 2002). Bagi sesetengah kanak-kanak, ianya amat menakutkan untuk salah seorang ibu bapa mereka berada di hospital. Ada kanak-kanak yang mempamirkan rasa takut, bersalah, marah, kesunyian, malu dan tidak boleh mengatasi atau menyesuaikan diri dengan situasi ibu bapa mereka (National Cancer Institute, 2003). Malah, ada yang bertanggapan situasi ibu bapa mereka lebih teruk daripada keadaan yang sebenar (Scott et. al., 2003).

Bagaimanakah ibu bapa wajar memaklumkan kepada anak-anak mereka dan apakah maklumat yang diperlukan? Kajian ini berobjektif untuk:

- Memahami keperluan maklumat dan perlakuan mencari maklumat bagi kanak-kanak yang ibu atau bapanya meng hidap kanser.
- Menguji cadangan penyelesaian maklumat yang bakal terhasil daripada kajian ini.

Sila jawab soalan-soalan dibawah.

1. Sila tuliskan nama dan semua maklumat menghubungi anda dibawah walaupun anda tidak mahu mengambil bahagian didalam kajian ini kelak. Maklumat ini akan digunakan untuk merekodkan jumlah responden. Maklumat anda akan dijaga dan dijamin rahsia daripada diberikan kepada pihak ketiga.

Nama Penuh: ______________________________
Alamat surat menyurat: ______________________________
____
Nombor Telepon: ______________________________
Alamat E-mel: ______________________________

2. Dimanakah dan bilakah anda didiagnos menghidap kanser?
Tempat: ______________________________
Bulan/Tahun: ______________ Saya tidak ingat: ☐

3. Apakah jenis, peringkat dan tempat kanser anda?
Jenis kanser: ______________
Tempat kanser: ______________ Peringkat kanser: ____
Saya tak tahu/tak ingat: ☐

4. Dimanakah anda dirawat dan dibawah penjagaan siapa?
Nama hospital: ______________________________
Nama Doktor Utama: ______________________________

5. Sekiranya anda seorang ibu atau bapa, sila nyatakan berapa ramai anak-anak dan berapakah umur mereka.

Bilangan anak	Umur	Bilangan anak	Umur
	1 bln – 6 thn		7 – 10 thn
	11-15 thn		16 -18 thn
	lebih drp 19 thn		

6. Sudahkah anda memberitahu anak-anak mengenai kanser anda?
☐ Sudah ☐ Belum

7. Pada pendapat anda adakah sebuah garis panduan untuk memberitahu anak-anak dan cara-cara untuk menyediakan mereka untuk mengatasi kesan-kesan sampingan rawatan kanser berguna?
☐ Sungguh berguna ☐ Serba berguna
☐ Tidak berguna ☐ Tidak pasti

8. Adakah anda berminat untuk membantu merangka satu garis panduan bagi membantu ibu bapa lain seperti anda untuk memaklumkan anak-anak mereka mengenai kanser mereka?
☐ Ya ☐ Tidak ☐ Tidak pasti

9. Sekiranya anda dipilih untuk mengambil bahagian dalam kajian yang lebih terperinci, adakah anda sudi untuk mengizinkan anak-anak anda mengambil bahagian juga?
☐ Ya ☐ Tidak ☐ Tidak pasti

Terima kasih kerana meluangkan masa untuk mengisi borang ini. Respon anda akan membantu merangka bantuan untuk orang-orang yang diimpak kanser. Sekiranya saudara/saudari ada sebarang pertanyaan, sila hubungi saya di S.A.Mat-Saat@lboro.ac.uk atau mssuzieadina@yahoo.com. atau di 012 603 4386.

Resource & Wellness Centre
1st Flr., 66 Jln. Raja Muda Abdul Aziz
50300 Kuala Lumpur
T: 03 2698 7300 F: 03 2698 4300

APPENDIX 2

Participation Consent Form
Parent version (English and Bahasa Malaysia Version)
Child version (English and Bahasa Malaysia Version)

Participation Consent Form

Parent version (English Version)

RESEARCH TITLE

Information Needs of Children with a Parent with Cancer

RESEARCHER:

Mrs. S. A. Mat Saat,
Department of Information Science, Loughborough University

INTRODUCTION

This research aims to investigate the information needs of children with a parent with cancer. This research will bring about a the co-development of solutions to resolve specific information issues. The result of this research will then be refined and distributed to cancer-centric organizations to consider its employment as a method to help parents and children impacted by cancer.

YOUR INVOLVEMENT

This is a voluntary involvement. It is up to you to take part in this research. If you are interested in taking part, please keep ths document as part of the study's background information set: "Participant Information Sheet'. You may withdraw your involvement from this research at any time.

The researcher will give you a gurantee that all personal particulars will be kept a secret and will only be used for the express purpose of this PhD research. All data are protected from tresspass. Individual identities will be protected from all publications. All data will be destroyed when no longer used by this research.

Participants are asked to take part in all research sessions and to answer each section. The whole series will take about five hours to complete.

THANK YOU FOR YOUR COOPERATION

I understand the needs of the research and understand my involvement in the activities that will be undertaken. I am prepared to participate.

Name:

IC No.

Signature:

Participation Consent Form

Parent version (Bahasa Malaysia Version)

RESEARCH TITLE

Information Needs of Children with a Parent with Cancer

RESEARCHER:

Mrs. S. A. Mat Saat,
Department of Information Science, Loughborough University

PENGENALAN

Kajian ini bertujuan untuk menyiasat keperluan maklumat kanak-kanak bagi ibu bapa yang menghidap kanser. Kajian ini akan membawa kepada satu usahasama untuk menghasilkan cadangan-cadagangan untuk menyelesaikan masalah kekurangan maklumat yang khusus. Hasil kajian ini akan kemudian diberikan kepada pihak organisasi-organisasi kanser untuk dipertimbangkan kegunaanya sebagai satu cara untuk membantu para ibu-bapa dan kanak-kanak yang diimpak kanser.

PENYERTAAN ANDA

Ini adalah penyertaan secara sukarela. Terpulang kepada anda untuk mengambil bahagian dalam kajian ini. Jika anda berminat untuk mengambil bahagian, sila simpan kepilan ini sebagai maklumat latar belakang kajian. Anda boleh menarik diri dari kajian ini pada bila-bila masa.

Pengkaji memberi jaminan bahawa segala maklumat peribadi akan dirahsiakan dan hanya digunakan bagi tujuan PhD. Semua data dipelihara dari pencerobohan. Identiti individu akan dipelihara dalam semua penerbitan. Semua data akan dimusnahkan apabila tidak diperlukan lagi untuk kajian ini.

Peserta diminta untuk mengambil bahagian didalam sessi-sessi kajian serta menjawab semua bahagian. Kajian ini akan mengambil masa lebih kurang **5 jam** untuk disiapkan.

TERIMA KASIH ATAS KERJASAMA ANDA

Saya faham akan keperluan-keperluan serta aktiviti-aktivi yang akan dilakukan didalam kajian ini. Saya bersedia untuk mengambil bahagian.

Nama:

No. IC:

Tandatangan:

Participation Consent Form

Child version (English Version)

RESEARCH TITLE

Information Needs of Children with a Parent with Cancer

RESEARCHER:

Mrs. S. A. Mat Saat,
Department of Information Science, Loughborough University

INTRODUCTION

This research aims to investigate the information needs of children with a parent with cancer. This research will bring about a the co-development of solutions to resolve specific information issues. The result of this research will then be refined and distributed to cancer-centric organizations to consider its employment as a method to help parents and children impacted by cancer.

YOUR INVOLVEMENT

This is a voluntary involvement. It is up to you to take part in this research. If you are interested in taking part, please keep ths document as part of the study's background information set: "Participant Information Sheet'. You may withdraw your involvement from this research at any time.

The researcher will give you a gurantee that all personal particulars will be kept a secret and will only be used for the express purpose of this PhD research. All data are protected from tresspass. Individual identities will be protected from all publications. All data will be destroyed when no longer used by this research.

Participants are asked to take part in all research sessions and to answer each section. The whole series will take about five hours to complete.

THANK YOU FOR YOUR COOPERATION

I understand the needs of the research and understand my involvement in the activities that will be undertaken. I am prepared to participate.

On behalf of:

Parent's Name:

IC No.

Signature:

Participation Consent Form

Child version (Bahasa Malaysia Version)

RESEARCH TITLE

Information Needs of Children with a Parent with Cancer

RESEARCHER:

Mrs. S. A. Mat Saat,
Department of Information Science, Loughborough University

PENGENALAN

Kajian ini bertujuan untuk menyiasat keperluan maklumat kanak-kanak bagi ibu bapa yang menghidap kanser. Kajian ini akan membawa kepada satu usahasama untuk menghasilkan cadangan-cadagangan untuk menyelesaikan masalah kekurangan maklumat yang khusus. Hasil kajian ini akan kemudian diberikan kepada pihak organisasi-organisasi kanser untuk dipertimbangkan kegunaanya sebagai satu cara untuk membantu para ibu-bapa dan kanak-kanak yang diimpak kanser.

PENYERTAAN ANDA

Ini adalah penyertaan secara sukarela. Terpulang kepada anda untuk mengambil bahagian dalam kajian ini. Jika anda berminat untuk mengambil bahagian, sila simpan kepilan ini sebagai maklumat latar belakang kajian. Anda boleh menarik diri dari kajian ini pada bila-bila masa.

Pengkaji memberi jaminan bahawa segala maklumat peribadi akan dirahsiakan dan hanya digunakan bagi tujuan PhD. Semua data dipelihara dari pencerobohan. Identiti individu akan dipelihara dalam semua penerbitan. Semua data akan dimusnahkan apabila tidak diperlukan lagi untuk kajian ini.

Peserta diminta untuk mengambil bahagian didalam sessi-sessi kajian serta menjawab semua bahagian. Kajian ini akan mengambil masa lebih kurang **5 jam** untuk disiapkan.

TERIMA KASIH ATAS KERJASAMA ANDA

Saya faham akan keperluan-keperluan serta aktiviti-aktivi yang akan dilakukan didalam kajian ini. Saya bersedia untuk mengambil bahagian.

Bagi pihak:
Nama ibu/bapa:
No. IC:
Tandatangan:

APPENDIX 3

Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Research title : Information Needs of Children with a Parent with Cancer
Researcher : Mrs Suzanie Adina MAT SAAT

You are being invited to take part in a research. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Please submit your decision and the questionnaire survey by ______________. Thank you for your time.

1. Purpose of this Research

This research seeks to investigate children of cancer patients' information needs and information-seeking behaviour in Malaysia. This will lead to a definition of information content that meets children's information needs and the development of information solution(s) for the mutual benefit of adult cancer patients, their children and cancer centric hospitals and organisations.

The main aim of this research is to be informed about the information needs of cancer patients' children and to co-develop information solutions. The specific objectives are to:

a- Identify how children are informed about their parent's cancer.

b- Identify information gaps in children's knowledge about their parent's cancer experience through structured and observable activities.

c- Identify key information needs and information seeking behaviour of these children as a result of part –b-.

d- Collect suggestions from participants of how to address their information needs.

e- Co-develop a solution or a set of solutions to help parents and children communicate and inform more effectively about the situation.

f- Test the solution or set of solutions' effectiveness.

This is done by a series of structured activities and observing participants' behaviours in a controlled setting. There will be five sessions of two to three hours. Refreshments will be available for participants.

2. Participation Process

This section explains the process involved if you decide to participate in the research.

2.1 Why have I been chosen?
You had responded in a pre selection exercise (Inquiry to Participate form) and your specific responses fulfilled the research's selection criteria. This selection was based on proximity to NCSM, race and number of children in a specific age range.

2.2 Do I have to take part?
This is a completely voluntary participation. It is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

You are still free to withdraw from this research at any time without giving a reason after signing the consent form. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

2.3 Will my taking part in this study be kept confidential?

There is my absolute guarantee that personal information of all kinds of all participants in my PhD research, entitled 'Information Needs of Children with a Parent with Cancer' will be kept confidential and for the sole purpose of this research. All data will be secured against unauthorised access via a locked filing cabinet and password protected personal computer, and password protected folders. No individual will be identifiable from published results, without his/her explicit written consent. **Data, including all study notes and tape recordings are kept for seven years in a secure location, as part of the study record**. All data from which an individual is identifiable will be destroyed when no longer required for the purpose of the original research.

Precautions to minimize the risk of contamination and unauthorised access to data include ensuring all hardware is kept in a secure location with only the Researcher having access and handling rights; Coded references for identifying completed questionnaires (with codes retained in memory); Password protected files changed after every completed session; and 'read-only' protected files to eliminate contamination and manipulation of data.

If I wish to retain confidential information beyond the completion of the research, NCSM will be first made aware of the reasons for retaining the information and the circumstances in which this might be disclosed. The participant's consent to these arrangements will be recorded, in compliance with the Data Protection Act 1998 and the Access to Health Records Act 1990 on the protection of individuals with regard to the access, obtainment and processing of survey and interview data and on the movement of such data.

In the case of a tape or video recorder being used during the sessions or an interview, this information is included in the participant's information and consent form and that written consent is obtained. Recorded material shall be stored in a secure place for at least three years and will be treated as confidential matter. Any material submitted for publication will be anonymised before submission.

2.4 What will happen to me if I take part? And What do I have to do?

No medical examinations, drugs, or treatments will be involved. The research requires participants to recall knowledge/ experiences/ consequences of information or that require information that deals with their own unique needs and that occurred in the past 12 months.

All participants will contribute in **two ways**:

a- *Questionnaire Survey:* The purpose of this questionnaire is to investigate the specific objectives outlined in page one of this information sheet. The questions will inquire about the type of information, scope of information, accessibility of information, language of information and, text versus pictorial information. The survey will also help to develop the subsequent activities in the sessions.

Participants must complete all sections of the questionnaire. It will take approximately 15 minutes to complete and must be submitted to **Mrs Suzanie Adina bt. Mat Saat when the first session is concluded.**

b- Focus Group: The purpose of the focus group is to investigate the specific objectives outlined in page one of this information sheet. There will be five sessions of two to three hours of interactivity with other participants.

Session One: Includes introduction to the researcher and research objectives. There will be three activities, namely having participants i) answer the 'Participant Information Sheet', ii) sign the 'Participant Consent Form', iii) answer the earlier mentioned questionnaire survey. After this, participants will be instructed to form permanent focus groups.

Session Two: Intends to find out what children think about i) cancer in general and, ii) their parent's cancer specifically. This session is divided into two parts; a) involves drawing or writing out responses and, b) involves writing responses on sticky notes and rating issues on rate cards. All materials will be provided in advanced. Responses from the 'Questionnaire Survey' will be used to help inform the session.

Session Three: Intends to find out what information children want by getting responses through a brainstorming exercise. Members of each group will be invited to draw or write out ideas on sticky notes and A1-sized paper. Participants will then be invited to elaborate.

Session Four: Intends to solicit ideas to solve information needs as found out in Session Three. Participants will first rate needs identified in Session Three by priority. They then will be invited to discuss and draw or write out ideas on A1-sized paper. Participants will then be invited to elaborate.

Session Five: Intends to solicit responses on solutions co-developed by participants. Solution(s) will be rated and recommended for further development for researcher.

Additionally, in some cases, a participant may be approached for a private interview. Should you choose to be interviewed a session will be held between you and the researcher at a mutually appropriate time and place to discuss your insights and opinions. This is a short interview and will take between 10 minutes to 30 minutes to complete, depending on the number of questions or responses you may have. Please contact the researcher directly if you would like to be interviewed.

2.5 What are the side effects of taking part?

There are no negative side effects to this research, other than the possibility of recall of a lack of information and its consequences. This recall and subsequent retelling may serve as an opportunity to vent out suppressed emotions/feelings and as an opportunity to be 'heard'.

2.6 What are the possible disadvantages of taking part?

The main disadvantage of this research is to continue to allow children to be misinformed about cancer, especially what the cancer experience means to you and to them. Numerous studies have indicated that a cancer diagnosis creates multiple problems for affected families, including major changes in living patterns, roles and relationships (Scott et. al. 2003b). This can impair parenting and place children at risk for problems (Rait & Lederberg, 1990). Some of the documented problems are: emotional distress of varying degrees and varying kinds; feeling guilty or lonely or unloved; a feeling of inadequacy, unfairness and money/material deprivation that have been attributed to delinquent behaviour and other societal problems; miscontructing the causes of cancer and blames his/herself for the onset of the disease and fantasizing a greater cause and effect of the real situation.

2.7 What are the possible benefits of taking part?

It is hoped that this research will benefit all parties concerned with the problem of information provision to cancer patients and to the people who are affected by a cancer diagnosis nationwide. Foremost, a specific information provision strategy may be implemented that would, at the very least assist families in coping with the disease.

Secondly, the efforts of the government and cancer centres towards the management of cancer would be made more effective.

Thirdly, correct information about cancer risk factors and the experience of cancer would make it easier to self-identify cancer among the general populace. The earlier a cancer is found, the better chances for survival and the less traumatic the treatment process to the cancer patient and to his or her family members.

2.8 What will happen to the results of the research?

All participants interviewed will have the option to have their recorded interviews forwarded to them for confirmation prior to use in the research. When sufficient numbers of surveys and interviews are collected, the next process of the research will take place. The data will be analysed to identify the key information needs, information gaps, information preferences towards the development of a solution or set of solutions to generate an information provision strategy specific to the information needs of children with a parent with cancer in Malaysia.

Results of this research will be shared with Malaysian Government Hospitals and cancer centric organisations and will be submitted as PhD research work to the University of Loughborough, United Kingdom. Some findings of this research may be submitted for publication in journals.

2.9 Who has reviewed the research?

This research has been reviewed by the following:

- Dr. Mark Hepworth, Lecturer, Department of Information Science, Research School of Informatics, Loughborough University

- Dr. Derek P. Stephens, Director of Teaching and Learning, Department of Information Science, Research School of Informatics, Loughborough University

- Professor Charles Oppenheim, Professor of Information Science Department of Information Science, Research School of Informatics, Loughborough University

- Dr. Saunthari Somasundaran, Executive Director, National Cancer Society of Malaysia

3. Contact for Further Information

Mrs Suzanie Adina MAT SAAT
Department of Information Science,
Research School of Informatics,
Loughborough University,
Loughborough, Leicestershire,
LE11 3TU
United Kingdom

Tel: +44 (0)1509 223052
Fax: +44 (0) 1509 223053
Email: **S.A.Mat-Saat@lboro.ac.uk**

Puan Suzanie Adina MAT SAAT MAT SAAT
No. 8, Jalan P10C/2,
Presint 10,
Putrajaya
62250,
Wilayah Persekutuan
Malaysia

Tel: 03 8888 6979
Fax: 03 8888 6878
Email: **mssuzieadina@yahoo.com**

APPENDIX 4

Study Protocol

STUDY PROTOCOL

Investigating the information needs of children with a parent with cancer

By: Suzanie Adina MAT SAAT
Department of Information Science
Research School of Infomatics
Loughborough University

Summary

This research seeks to employ the tenets of 'Participative Active Research' (PAR) and through this phenomenological approach to investigate the information needs and behaviors of children with a parent with cancer. This will provide primary qualitative and quantitative data for the formulation of children's and the cancer patients' profiles, and investigate how participants seek information and what information they require to cope with the cancer diagnosis. This will subsequently enable the development and pilot test of a demographically sensitive solution to information and coping provisions for children's' information and coping provision as well as assist in the management of cancer incidences throughout Malaysia. In turn this will be of mutual benefit to the Ministry of Health towards health and healthcare promotion and to cancer patients and their children nationwide on coping with cancer and the tribulations that may occur as a result of the cancer diagnosis. This would simultaneously further the cancer agenda of many cancer centric organizations for managing and lowering the cancer incidence in Malaysia.

In order to obtain significant information, data from number of cancer cases of chosen hospitals and cancer organizations as well as in-depth observed controlled activities and interviews will be gathered from 2004 to 2007.

The following proposal outlines a research project with the key objective of investigating the information needs of children with a parent with cancer. It is a two-prong approach that first focuses on the information needs, information seeking behavior and information solution preferences of children. Secondly it focuses on the ability of the cancer patient parent to inform their children in a method and scope that both the parent and child can accept.

1. Introduction

This proposal outlines an investigation into the information needs of children with a parent with cancer, in particular the situational and environmental circumstances that provoke the information need and subsequent information seeking behavior. It is then hoped that through PAR a comprehensive standard of behavior will be established that will help in the development of tools or methods that would create information solutions to the problem of what information to provide, what is the scope and depth of information that children can accept and cope with as well as how to provide said information into an easily processed and accepted format that is also demographic sensitive.

For the purpose of this endeavor, this research is framed within the context of cancer support groups and will explore the experiences of children and their parents at the point of information provision during the parent's cancer journey. This project seeks to increase understanding the effects of a cancer diagnosis to the family unit and to indirectly the impact of cancer on society, building upon the Malaysian government's promotion of healthcare and 'Keluarga Penyayang' as well National Cancer Society of Malaysia's (NCSM) 40-year effort and public interest mandate for Cancer Awareness and Education.

This document outlines:

- The background and rationale of the project

- Important stakeholders
- The research aims and objectives
- The research methodology
- The researcher involved
- Appendix A: Selection of Participants
- Appendix B: Ethical Guidelines
- Appendix C: Benefits to Cancer centric organizations
- Appendix D: Benefits to cancer patients and their children

2. Background and Rationale of the Project

This project addresses the following:

- The number of cancer incidences
- The impact of a cancer diagnosis to the patient and their children
- The impact of information solutions

The number of cancer incidences

"Cancer is a serious global health problem" (Anandakumar, 2004, p.8). According to the World Health Organisation (2003), cancer is a growing public health problem around the world; in 2000 there were 10.1 million new cases in addition to 22.4 million people who are living with cancer and 6.2 million cancer-related deaths. By 2020 there could be as much as a 50% increase in new cancer incidences amounting to 15.7 million people who are newly diagnosed with the disease and the mortality statistics of 10 million cancer-related deaths. According to the inaugural Malaysian National Cancer Registry (2002) 26,089 cancers were diagnosed with an additional estimation of 10,656 cases that were unregistered. In 2003, the registry received 42,985 cancer notifications, a 64.80% increase to that of 2002 which was in part due to more diligent reporting of cases and the inclusion of cases from Sabah and Sarawak. Thus the first objective of the research is to investigate the prevalence of cancer incidences in chosen hospitals and cancer centric organizations by providing an account of the true state of affairs within a set time period. This would subsequently depict an overview of cancer prevalence and scope as well as guide the research's depth and complexity.

The impact of a cancer diagnosis to the patient and their children

Beyond the effect of cancer to an individual, cancer also impacts the spouse or partner, children and family members (Scott et. al, 2003a, 2003b, 2003c; McCue & Bonn, 2003; NCI, 2004; Somasundaram, 2004; breastcancer.org, 2004; Davey et. al, 2005) as well as friends and other people that the individual with cancer comes into contact. Like waves rippling out from a pebble cast into a still pond, 'cancer affects not only the individual with the disease but everyone and anyone connected to that person' (Granet, 2002, p. 169) and the potential of cancer affecting many more people is a high possibility (Somasundaram, 2004). In situations of critical illness like cancer, the need for information for the patient as well as to family members is increasingly evident (Scott et. al, 2003a, 2003b, 2003c; McCue & Bonn, 2003; NCI, 2004; Somasundaram, 2004; breastcancer.org, 2004).

Management of healthcare for critical illnesses and the people impacted by a critical illness diagnosis should be more than just archiving the incidence, locality and progression of the illness (National Cancer Alliance, 2002, International Union Against Cancer, 2004 and, Cancer Council Victoria, 2002). Patients and their carers require information about wellness, quality of life, how to cope with the effects of the diagnosis and how to prepare for role changes (Mooney and Blackwell, 2004, Kerr et. al., 2003 and Schattner, 2002).

Cancer diagnosis creates multiple problems for affected families, including major changes in living patterns, roles and relationships (Scott et. al. 2003b). Parents facing life-threatening illnesses and chronic health conditions are found to experience anxiety, depression, and other emotional difficulties (McCue &

Bonn, 2003; Barnes et. al., 2001; Fallowfield, Hall, Maguire, Baum & A'Hern, 1994 and Maguire, 1994). Parents worry about the future of those who will outlive them (National Cancer Institute, 2005).

The above issues can impair parenting and place children at risk for problems (Rait & Lederberg, 1990). After all, if doctors find it difficult to impart news of a cancer diagnosis, it would be even more difficult for parents to tell their children when dealing with their own feelings and coming to terms with all of the implications of the disease (Barnes, Kroll, Burke, Lee, Jones & Stein, 2000).

The types of impact listed here are common across all types and stages of cancer and serve as denominators of experiences of cancer patients. Some of the themes of the impact of a cancer diagnosis are as follows:-

Theme	Generalized experience of cancer patients	Generalized experience of children with a parent with cancer
Distress	Often feel emotional distress of varying kinds and degrees as a result of diagnosis. The distress may manifest itself in many ways, one of which through psycho-physiological reactions of which on one extreme, the individual may ignore the diagnosis and recommended treatment while on another extreme, the individual may suffer acute biological and emotional responses for an unforeseeable duration in which there have been reported cases of suicide.	Often feel emotional distress of varying kinds and degrees which in many cases are largely unnoticed or ignored. The distress may manifest itself in positive and or more often negative ways. There has been recorded instances of psycho-physiological reactions of delinquent behavior, distrust of health professionals and adult family members as well as feelings of powerlessness and lovelessness due to many factors, notably increasing reversal of parent-child roles, temporary loss of dependency of parent due to hospital stays and parental ill health, increased responsibility and burden of care.
Loss of mobility and independence	As a result of diagnosis and a side effect of treatment, patients usually exhibit loss of independence and mobility which has been demonstrated to add to the angst and frustration of a diagnosis.	Children are deprived of norms that is also compounded by role reversals and increased burden of care or feeling guilty / unloved / uncared for. There are reported cases of children dropping out of school to assist parents and to alleviate the home situation. However, this leads to more problems in the long run.
Financial Loss	Significant costs may result from a cancer diagnosis. These include costs for detection, treatment, hospital stay, diet, therapy, time off work, and increased insurance premiums. In the larger picture financial loss, for example through treatment subsidies will be recovered through taxpayers.	In the instance of a loss of a wage earner in the family will result in less discretionary income to provide children with necessities, education materials and will change the spending norm. A feeling of inadequacy, unfairness and money/material deprivation have been attributed to delinquent behavior and other societal problems. In the instance of financial loss due to the cost of care for a non wage earner, children still exhibit varying degrees of dissatisfaction of how money is spent. This has also resulted in various problems.
Psychological Scarring	Patients exhibit many different types of psychological scarring that are a result of the cancer journey and issues of their own mortality.	Many children who undergo exposure to cancer experience different, varying and in some cases multiple trauma induced psychological scarring that will be exhibited throughout their life. Most exhibit some degree of feeling scared, guilty, angry, lonely, embarrassed, and not being able

		to cope or come to terms with a parent's situation. Contrary to Sigmund Freud's belief that children do not feel grief, Granet (2002) observed that children do feel grief and that emotions vary with a child's age, and they are expressed in ways distinctively different from adult feelings of loss. This will have repercussions in the life and living habits of the child. According to Davey, Gulish, Askew, Godette and Childs (2005) children whose parents were diagnosed with cancer face significant psychosocial stressors. It exposes children, adolescents, and young adults to: (a) The threat of permanent loss of the parent to death; (b) temporary loss of the parent due to symptoms of the disease and side effects of treatment; and (c) disruption of family roles and routines.
Lack of Information	Lack of information has been a contributing factor to non adherence to cancer care and treatment as well as to outright rejection of undergoing diagnosis and treatment. This has also contributed to misinformation and reliance on unproven alternative medicine, treatments and well meaning advice which may be contradictory and counterproductive to treatment and survival. Most patients report that having information throughout their cancer care continuum would be beneficial for coping, adhering to cancer treatments and to survival.	In situations of critical illness, most children are marginalized and uninformed about the situation. Parents or other guardians rationalize that to withhold information is a form of protection. Moreover, illnesses and its treatments are perceived to be in the sole purview of adults. However, withholding information, even for the supposed good of the child or children, has been reported to be determinal for the child's well being. For example, reports have been made where the child miscontructs the causes of cancer and blames his/herself for the onset of the disease and fantasizes a greater cause and effect of the real situation.

As such, identifying the real impact of a parental cancer diagnosis as well as the core information needs and resulting information behavior of children may yield information vital for the continued health and wellbeing of the cancer patient and his children as well as improving the quality of services and communication of cancer care, awareness and education.

The impact of information solutions

"Information is the greatest gift"-- Cancer Patient (Gibson, 2004)

UK's NHS Department of Health developed a National Cancer Plan that stresses the role of information as a major component (DoH, 1997, 2000a & B). The National Cancer Alliance (2001) advocates that patients, families and carers should be given clear and understandable information about treatment options and outcomes from diagnosis and throughout the cancer journey. Leydon et. al. (2000) writes that over recent years, communication and information have increasingly been considered important in helping people to cope with cancer. According to Cancer Care Connection (2003), information is good medicine. It is also something that could help cancer patients fight and survive their conditions (Chiu & Wistow, 2002). However, according to Chiu and Winstow (2002), current information was seen as inappropriate (i.e., information style and language does not commensurate with target audience) and its dissemination was inadequate, uncoordinated and inefficient (i.e., a need to exploit technology and advocate for better cooperation and coordination of between information service providers).

In Chiu & Wistow's (2002) needs assessment project for improving access to cancer information for Doncaster residents, they reported five key findings: 1) Many patients and their carers were unable to access information throughout their care and that information should take into account patients' vulnerability and diverse social backgrounds, 2) The psycho-social needs of carers have not been addressed, 3) There are gaps between primary, secondary and continuity of care, 4) Cancer is still considered a taboo in the public's consciousness, and 5) Community Health Educators have the potential to facilitate information to patients and carers.

In articles by Mills and Sullivan (1999), Mossman et. al. (1999) and Stewart (1995), while information reassures cancer patients by providing them with realistic expectations and empowers them to enquire further which in turn prevents unnecessary distress, not many studies look into the effects of communication of information to patient health outcomes (Kerr et. al., 2003). According to Mossman et. al. (1999), most research was interested in the psychological sequalae which were limited to a measurement of anxiety and depression (Kerr et. al., 2003). Another issue is that while younger patients have been found to have greater information needs, hardly any research exists to understand what they are and the relationship between age, communication and quality of life has yet to be undertaken (Mills and Sullivan, 1999 and Kerr et. al. 2003).

While information has been perceived and proven to alliviate concerns, issues and problems, many cancer patients still rely on non medical persons to provide them with answers. Baker and Pettigrew (1999) poses the question that if information service practitioners and researchers believe that people who are better informed are also better able to reduce their personal uncertainties about their health care, why do people seem not to want it and why do they prefer to obtain it from non-institutional or non-professional sources?

Besides that, the 2000 National Cancer Plan of Doncaster NHS, United Kingdom, had recognised the importance of information in cancer prevention, detection and treatment (Chiu and Winstow, 2002). The 'Calman-Hine Report' (1995) also advocates for equity access to . . . education, information, communication . . . for patients and carers. Additionally the report outlined the need for access to fast, reliable and appropriate information and sensitive, appropriate information about their conditions and their 'cancer journeys' to help them make decisions about their treatment and care (Chiu & Wistow, 2002). The report provided seven principles to govern the provision of cancer care, notably;

> 1) Patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards.
>
> 2) The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communication between professionals and patients is especially important.

It is believed that this study will help to clarify some of the issues mentioned above by develop a demographically sensitive information solution or solutions. In any case, Baker and Pettigrew (1999) believes that knowing a layperson's preference for information may help not only in tailoring information, but also in the amount of information and specific needs of the people or individual needing the information. This then highlights the necessity of incorporating multiculturism into research involving cancer survivors as well as the importance of developing relevancy of cancer issues and delivering information that are culturally sensitive that would make cancer-related information more readily acceptable.

3. Important Stakeholders

The results of this project may provide valuable information to the following stakeholders:

- Cancer patients who are parents
- Children of cancer patients
- Hospitals and organizations offering cancer diagnosis, treatment and support services
- Doctors, nurses and other healthcare professional
- General Public

Cancer Control Agenda

It is hoped that from this research an information solution to communicating about cancer to patients, their children, other family members and friends may be extracted. The strategies, tools and methods co-developed between the researcher and the patients and their children should be able to counter and help in managing the problems and issues arising from a cancer diagnosis of a parent. The solution or solutions will then have an adjunct role in helping cancer centric organizations and hospitals as well as cancer patients further the goal of a cancer control agenda of strength through education and support.

In addition, central to the implementation of the solution or solutions, cancer patients and their healthcare professionals will have a concrete guide in communication skills and coping with the disease.

4. Research Aims and Objectives

It is with the above context as background that this research aims to investigate the information needs of children with a parent that has been diagnosed with cancer. The proposed research holds the following objectives:

- To investigate information best practices and methods as employed by several reputable cancer centres and support mechanisms in United Kingdom, Scotland, United States of America, Australia, Japan, India and Malaysia in addressing information needs of individuals diagnosed with cancer, from a cultural and socio-economic cross sectional perspective specifically into the area of informing children of a parent's cancer diagnosis.
- To understand the children of cancer patients' information-seeking behaviour and information needs in Malaysia from socio-economically deprived environments leading to the identification and an understanding of a set of core and generic information that details the information context, type, scope, platform and method of dissemination that is sensitive to their demographic circumstances.
- To develop a test for information solutions that would lead into a national cancer agenda in Malaysia, in particular the information strategies that have the potential to help children to become informed via appropriate channels.

5. Methodology

Both qualitative (i.e. interview) and quantitative (i.e. survey) methods will be used. To achieve this end, the following strategies will be utilized:

a) **Literature Review** – this involves progressive readings of past and current work into information seeking behavior, information needs and interventions for children exposed to a critical illness situation. Methodological issues from these researches shall be reviewed to identify areas in which this current study may be beneficial as a means to promote further understanding of the phenomenon of information seeking behavior and identifying information needs. This would ultimately lead towards to formulation of a specifically tailored information solution strategy.

b) Recruit Participants

500 people who are undergoing treatment will be contacted through cancer support groups in hospitals and cancer organizations. This will be done by using the support groups' mailing list and by attending sessions to derive groups of 30 children and 30 adults. Should funding be allocated, a call for participants will also be made through publicity and advertising in the local cancer organization's newsletter and website as well as invitation to participate letters to cancer patients in hospitals and clinics.

c) Field observation – Participants will be selected based on common criteria. An invitation to participate will be sent to the selected participants. Copies of participant interview sheet, participant consent form for themselves and their child, and guarantee of anonymity will be forwarded to them. A field work schedule will be developed to assist in organizing PAR sessions.

Five three-hour PAR sessions and activities will be held at NCSM to identify:

(i) key information needs;
(ii) opportunities/situations that may provide the need for information;
(iii) information seeking behavior and source and format preference;
(iv) barriers/problems to information seeking, information processing and information recall, and
(v) participants' ideas of information solutions that meet their needs.

The main researcher will conduct all interviews and PAR activities. Permission to record the sessions will be requested/obtained after volunteers are made aware of the purpose of the sessions (Covering Letter, Participant Information Sheet, and Participant Consent Form).

Other key points that will be considered

- **Selecting the survey sample**
  In general, participants will be any cancer patient treated by the cancer centric organization.

- **Encouraging a high response rate**
  Cancer Patients:
  It is hoped that Head of Directorates will encourage hospital staff members to respond voluntarily to this research by allowing their individual patients to respond to the survey. The individual doctors will then be contacted to release the patients for the fieldwork research. Patients may be rewarded for their participation.

  Children:
  It is hoped that cancer patients will encourage their children to participate as a method to help both the parent and the chil/children to cope with the diagnosis. Children may be rewarded for their participation.

- **Time frame of the project**
  The survey will be disseminated and collected within a two-week period. The culling and selection process is estimated to take 2 weeks. Setting up of fieldwork to take one week. The sessions will be weekly 3-hour sessions over a period of five weeks. After tabulation and data entry (estimated one month), an information solution or information solutions will be developed. This may take two

months after which the solution(s) will be piloted with the PAR participants and compared against survey respondents who were not selected to participate in the fieldwork research.

- **Ethics**
  The researcher was referred to Kementerian Kesihatan's 'Buku Nilai dan Etika' (KKM Code and Ethics) published by INTAN. Kementerian Kesihatan was contacted for approval. KKM Code and Ethics Guideline was available at http://mmc.gov.my/v1/index.php? option= com_ content&task =view&id=41&Itemid=70. The research methodology was approved by the research supervisor from Loughborough University. Patient participation approval was received from the National Cancer Society of Malaysia.

6. The Researcher Involved

Suzanie Adina binti Dato' Dr. Mat Saat Mohd. Baki

Suzanie graduated from the University of Missouri-Columbia, USA in 1998 with an upper second class honours degree in Interdisciplinary Studies: Art, Marketing and Journalism with an emphasis in Computer Animation and Advertising. While studying, she has worked in several capacities, one of which as a student researcher with the Centre of Advanced Social Research at the university and was employed in two internship programmes with Walt Disney World Resorts Inc.

After graduation, she accepted an executive position at Multimedia Development Corporation (MDC), the organization that spearheads Malaysia's Multimedia Super Corridor initiative. Among her tasks included (i) Internal and external corporate affairs, marketing and media support; (ii) Secretariat for the 3rd and 4th MSC-IAP Summit involving international participants from the Information Technology industry, Institutes of Higher Learning, and Government Infrastructure; (iii) Events and overseas support to USA and Germany's CeBit; and (iv) the developed of print collateral, corporate video and corporate premiums to promote the Multimedia Super Corridor and its various flagship applications. She has also represented Malaysia in assignments addressing members of the US Congress and United Nations. While in Germany, she was headhunted by Malaysia Venture Capital Management Berhad (MAVCAP) and promoted to PR and Communication Manager.

At MAVCAP, she developed the inaugural marketing campaign, public relations budget, print and electronic collateral, corporate video and corporate premiums. She also oversaw the project management of overseas' missions to Korea and Saudi Arabia, signing ceremonies, entrepreneurial development programmes and internal events. Besides that, in order to promote entrepreneurism, she was a Ghost writer and speech writer on a wide range of subjects such as Venture Capital, Biotechnology, and Entrepreneurial Development. Along that capacity, she developed a network of local and foreign media and wrote press releases, conducted interviews and press conferences. She left MAVCAP to follow her husband to England where he conducted research for his PhD in Competitive Intelligence.

After six months in England, she came back with an offer from Flare Studios Sdn. Bhd. Where she proceeded to translate and adapt a feature length animation of an English version of an Arabic production of 'Muhammad: The Last Prophet' into Bahasa Malaysia. The movie's premier was graced by the Sultan and Sultanah of Trengganu and its charity premier was attended by several orphanages in Negeri Sembilan. After that, Suzanie decided to do public service work by applying to National Cancer Society of Malaysia (NCSM).

While educating schoolchildren and members of the public on cancer prevention and risk factors, she spearheaded several cancer awareness and education campaigns. The more notable campaigns were the month long 'Celebrate Life' campaign which included a week-long cancer expo in Bangsar Shopping Centre, Yellow Ballon Race launched by Her Majesty the Raja Permaisuri Agong, and the 'Celebrate Life' wristband campaign that was launched by Betty Banafe, Radhi Khalid, Zainal Abidin, M. Nasir, Natasha Hudson and several other local celebrities. She was recently awarded the NST-PwC 2004 'Team Humanitarian Award' as bestowed by the Deputy Prime Minister. It was while providing services to cancer patients and furthering the aims of cancer awareness and education, she observed the need for further research into communicating and informing cancer patients, their family members and the public about the cancer impact and experience. Her PhD proposal was accepted by Loughborough University in 2004 under the aegis of the Research School of Informatics.

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APPENDIX 5

Sessions Guideline Script

SESSION GUIDELINE: 230 minutes inclusive of two 15-minute breaks.

No.	Activity	Description	Researcher Script	Time
1	**SESSION ONE** Objective: Introduce participants to the research, research objectives and activities, PAR and establish ground rules. PAR Stage: Reflection	i) Introduction to researcher, research objectives & summarize activities	Good Morning (insert generic address). Thank you for being involved today. My name is Suzanie Adina Mat Saat, Suzie for short. I am a Phd student from Loughborough University and my research is 'Investigating the information needs of children of a parent with cancer'. I am doing this research because I want to show that children of cancer patients in Malaysia have little or no knowledge about i) their parent's cancer and, ii) cancer as a disease. I want to do this so that children are better prepared to deal with their parent's situation and to be prepared to some of the changes brought by the diagnosis. I want children to become better prepared so that they are better able to i) cope with their parent's experience and possible side effects and, ii) manage their life. With these objectives in mind, I want to find out the type of information, scope, looks, accessibility and language of information that children need as well if there is a preference of text or pictorial information. At the end of today's session I hope to record your experiences and opinions so that a solution or some solutions may be developed. With your cooperation, the feedback that I receive will then be used to provide children in a similar situation with the information they need to come to terms with their parent's cancer diagnosis. We will work together to identify specific information needs and come up with a solution to the problems we have identified. This type of research is called a Participatory Action Research. Together we will find out what type of information is needed, organize those needs into themes and priorities, try to develop possible solutions, work on the solution together	5 min

			and then test if the solution works. I need your help by participating in several individual and group activities. Each activity will be between 25 minutes to 60 minutes long. We will be using art block paper, mahjong paper, colorful sticky notes, coloring pencils, markers and some forms. There will be a short 15-minute break after each session where drinks and food is provided.	
		ii) Obtain consent for participation **TOOLS:** PIS Consent Form Statement of Confidentiality	Ladies and children, in order to start the whole series of activities, Loughborough University and National Cancer Society will now require you to sign three forms. The first is the 'Participant Information Sheet', the second a 'Participation Consent' form and the third a 'Statement of Confidentiality' form. The 'Participant Information Sheet' provides more detail about what I had informed you earlier. Your signature is required so that the university is made aware that you were informed about this research and the activities involved. The consent form is to obtain your agreement as an individual as well as a parent for you and your children to participate. The confidentiality form is to protect you from any misuse or disclosure of any of your information to any person or project outside of this research. I will first distribute the 'Participant Information Sheet'. After signing this, I will then distribute the 'Participation Consent' form. This followed lastly by the 'Statement of Confidentiality' form. Thank you for your cooperation.	10 min
		iii) Organise participants into two sets: one parent set and one children set **TOOLS:** **M&M** **Coin**	We will now form two groups. May I please have the 'Parent' group to be seated on my left and the 'Children' group on my right. You will remain in your groups and you will be identified in the research only based on your identification tag. I will give a random identification to you. For the 'Parent' group, I will flip a coin. I will ask one of you to choose 'heads' or 'tails'. Whoever's choice	5 min

			faces up, will be identified as M1. (Researcher to take note of ID tag) For the 'Children' group, I will ask each child to pick out one M&M chocolate. Your identification tag will be the same as the color of the chocolate you pull out, provided that no other child has the same color. (Researcher to take note of ID tag.) You may now eat your M&M chocolate.	
2	**SESSION TWO** **PART A** Objective: To gain an understanding of participants perspective on cancer by finding out what participants think about i) cancer in general and ii) what they think about what cancer means to the other group. This exercise is to find out what the information gaps are. PAR Stage: Plan	**PART A** **TOOLS:** **Art Block & drawing materials** **Audio/video recorder** i) Instruct children to illustrate what a) they think cancer is, b) what cancer means to them and, c) what cancer means to their parents. ii) Instruct parents to illustrate what a) they think cancer is, b) what cancer means to them and, c) what cancer means to their children. iii) Have a show-and-tell session so both groups can compare	Please allow me to introduce you to our second session. This session is divided into two parts. The first part is for us to gain an understanding of your perspective on cancer. The second part is to find out how you found out about information. Lets participate in the first part of this session. This exercise is just to gain an understanding of what you think about cancer. There is no wrong or right answer. I would like to have everyone get three pieces of art block. Please write the question number and your ID tag on the back of the paper. I will ask you three questions. Please answer each question as a drawing or as a written answer in one art block each. Please draw or write the first few things that pop up in your head. You may use any of the drawing/writing materials in front of you. You will have only 5 minutes to answer each question. Question 1: What is cancer? Please draw or write what you think cancer is. ***After 5 minutes*** – Please put your answer on the table; face down and on your left. Question 2: What does cancer mean to you? For the parent group, please draw or write your cancer experience. For the children group, please draw or write what your parents' cancer means to you. ***After 5 minutes*** – Please put your answer on the table; face down and on top of the first art block. Don't forget to write the question number and your ID tag.	50 min

			Now, question 3: For the parent group, what do you think cancer means to your children? For the children group, what do you think cancer means to your parent; i.e mother who was diagnosed? ***After 5 minutes*** – Please put your answer on the table; face down and on top of the second art block. Don’t forget to write the question number and your ID tag. We will now have a short show-and-tell. We are doing this so that all of us get an idea of what we and others think cancer means. I would like for the children to take turns and to please show the room what you answered for the first question. After that, I would like the parents to do the same. (Give each participant 2 minutes to explain and thank each one of them. Researcher is to record explanations.) Lets put up these art blocks against the wall. We will reuse them later. Now, let us consider the second question. May I please have the children show-and-tell what they think cancer means to them? I would want the parent group to pay attention to these answers. (Give each participant 2 minutes to explain and thank each one of them. Researcher is to record explanations.) Thank you children. I would now like to have the parent group to share with the children group their answer for question 3. (Give each participant 2 minutes to explain and thank each one of them. Researcher is to record explanations.) Lets put up these art blocks against the wall. We will reuse them later. Now, let us consider the third question. May I please have the children show-and-tell what they think cancer means to their parent? I would want the parent group to pay attention to these answers. (Give each participant 2 minutes to explain and thank each one of them. Researcher is to record explanations.) Thank you children. I would now like to have the parent group to share with the children group their answer for question 2. (Give each participant 2 minutes to explain and thank each one of them.	

			Researcher is to record explanations.) Lets put up these art blocks against the wall. We will reuse them later. We have part two to continue which takes 10 minutes to complete. After that, we will take a 15-minute break.	

No.	Activity	Description	Researcher Script	Time
3	**PART B** Objective: To find out how children find information about their parent's cancer so that I can have an understanding of what information children need, how they get said information and, if said information met their needs. PAR Stage: Plan	**PART B** Ask children: i) who told them about their parent's cancer? ii) What information were they given? iii) Was that information enough? iv) What information did they want? v) Where did they go to find the information ? vi) Did they find the information sought? vii) Did the information they find satisfied their needs? viii) How did the information look like? ix) What more would they like to know? **TOOLS:** **Questionaire** **Sticky notes**	We will now continue our second session with an activity to identify what information children need, how they get said information and, if said information met their needs. Could I please have each child pick out one M&M chocolate that is the same color as the one they picked out earlier? Thank you. First, lets have you fill in this questionnaire. Lets identify who told you about your parent's cancer. Who was the first person that told you about your parent's diagnosis? Who else informed you about this? How were you told and how did you feel about it? What did this person said? What did you feel about the information? Was the information enough for you to understand what is going to happen to i) your parent and, ii) to you? (Rate 'not enough at all', 'not enough', 'just about enough', 'enough', 'more than enough') What other information did you need in order to understand what is going to happen to i) your parent and, ii) to you? (Please rate in order of importance) Where did you go to find this information? Did the information you found meet your needs? (Rate 'did not meet my needs at all', 'did not meet some of my needs', 'just about met my needs', 'met all my needs', 'more than met my needs') How did the information look like? What more would you have liked to know? Parent questionnaire similar but from parent angle.	10 min

			Lets have a 15-minute break. Please be back in the room at XX:XXam	
No.	**Activity**	**Description**	**Researcher Script**	**Time**
4	**SESSION THREE** Objective: To find out what are the information themes/issues/concerns of children so that I and participants can understand what the information problems are and to prioritize information needs. PAR STAGE: Action and Observe	i) Identify and organize issues in Session One and Session Two so that themed issues/concerns can be developed. ii) Participants to work out details of issues. **TOOLS:** **Mahjong paper** **Drawing materials** **Sticky notes**	(Researcher to organize answers in questionnaire by priority and list them accordingly) Thank you for staying on. The third session is an exercise for us to identify information gaps that could help us identify information themes or concerns. In the first session, we drew or wrote our perceptions of cancer. Lets reuse that and think about where the differences in perspective are. From here we can identify broad areas that most of you are concerned about. We will also match these concerns with the information you provided in the questionnaire. (Researcher to call out themes like side effects of treatment, continuation of care, what happens next, etc. as well as get sticky note inputs to put up) Now lets see a vote of hands of what we can agree to be an important concern. Everyone is allowed to vote for the three most important concerns to themselves. Please write on a sticky note your vote from most important to least important concern. The three concerns that gets the highest votes will be concern that we will try to solve. (ESTIMATED 30 minutes) All right. Lets identify all the elements related to these three concerns. Could I please have the parent group to work on one concern while the children group to work on two concerns? The children can be split up into two smaller groups. I will assign numbers 1 and 2 for each child to say. Children who recited number 1 will form sub group 1 and likewise for sub group 2. We will use Mahjong paper to write out the details of our issue. You will be given 15 minutes to write this and 2	60 min

			minutes to explain, after which all participants may add their comments to each issue. Lets have a 15-minute break. While at break please think up ideas in which to solve the issues we just discussed. I have some sample solutions or information provisions on this desk for you to look through. You may borrow ideas from these samples or combine these ideas or come up with new methods in providing a solution.	
No.	**Activity**	**Description**	**Researcher Script**	**Time**
5	**SESSION FOUR** Objective: To find out solutions proposed by participants and their assessment of viability so that I and participants can work together in developing solutions to agreed-upon problems. PAR STAGE: Reflection	i) Instruct participants to brainstorm for ideas or strategies to resolve issues in Session Three. ii) Open discussion on merits and demerits for each issue **TOOLS:** **Mahjong paper** **Drawing materials** **Sticky notes**	Earlier we had identified our problems, issues and concerns. Now, lets try to work on solution(s). I would like for you to stay in your sub groups and try to figure out how we could help other people with the information problem you just highlighted. You can be as creative as possible. I would like for you to write down a list of possible ways of how to satisfy the information need(s) you had identified by: i) What type of information should be given ii) How should the information be given, by whom, where and when iii) How should the information look like? Please sketch your idea(s) You will be given 30 minutes to discuss, write or draw your ideas. Your group will then be given 5 minutes to inform the room about your wonderful idea. After this, everyone will get a chance to comment. (Researcher to record activities)	50 min
No.	**Activity**	**Description**	**Researcher Script**	**Time**
	SESSION FIVE Objective: To try and reconcile information problems to its corresponding suggestion solution(s) so that I can get a better idea of prioritized problems and	i) Instruct participants to rate presented problems and possible solution(s) by priority ii) Solicit other solution(s) options from participants	We are almost at the end of today's activities. I would now like to open the floor to comments on which one issue and solution could be developed first. I will require the person giving the comment to state reasons why he or she chooses the issue and solution.	25 min

	solution(s). PAR STAGE: Plan	iii) Inform participants of further activities by researcher	After this we will have a vote and the issue and solution that gets the most vote will be the combination that I will work on. The vote is a ‘closed’ vote. You choose which issue is the most important and which solution(s) the most attractive. I would like to invite a representative from the children group to have their say first. Each person will be given 2 minutes to speak. Thank you for your views. I would now like to call for a ‘closed’ vote. Write down on a sticky note the issue that you feel is the most important and the solution that you think could work the best with children. Put your vote into this voting box. I will give you 5 minutes to do this. Please remain in the room until everyone has put in their votes. Thank you for your votes and your cooperation. Later, I will look at the votes and see which issue/solution had the most votes. Next I will develop and fine-tune the solution. I forecast that this might take me 2 months, after which I will try to arrange for a last meeting for you to feedback if the solution meets the information need. I sincerely appreciate your input and hope that this can form a viable platform that could help other children and parents in a similar situation as yours.	

APPENDIX 6

Sample Responses

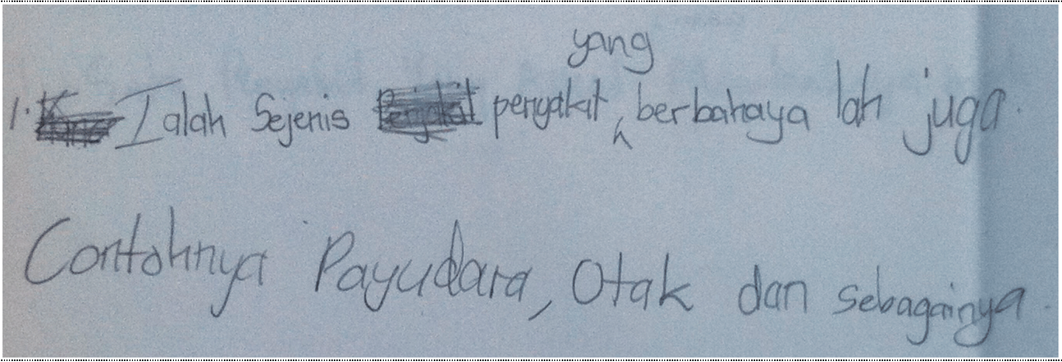
(Sample transcription of audio record and photograph of illustrations/written responses from Family 1)

NOTE:

Samples of participants' responses for the research questions **'What is cancer?'** This was a request for both children and parent to answer their i) understood definition and/or ii) observed experience of the symptoms or treatment of cancer and/or iii) what cancer can do to either a person or self. It was hoped that this question would be able to capture a respondent's general understanding of cancer that would hopefully lead to an understanding of what cancer information is 'readily' known.

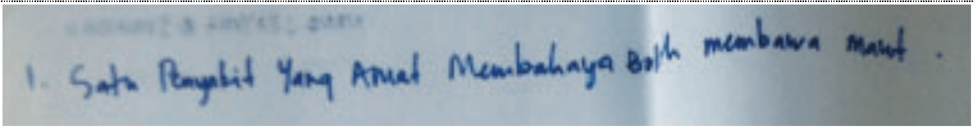
SAMPLE RESPONSES (transcription of audio record and photograph of illustrations/written responses)

SESSION TWO, PART A: "What does cancer mean to you?"

SPEAKER	CONVERSATION
SUZIE	Kakak Shahira. Ok. Uh … I would like kakak Shahirah to tell everybody here, about that first picture. Ok? Um . . . (looking for drawing as a reference). The drawing session has finished. Here, everyone will talk about what they drew or wrote. Ok? Ok. How about this? We will have kakak share her explanation about her drawing first.
	 1. Ialah Sejenis ~~Pengakit~~ penyakit yang berbahaya lah juga. Contohnya Payudara, Otak dan sebagainya.
SHAHIRA [F1(C3)]	(nervous laughter)
SUZIE	Ok, the first question was, 'What does the word cancer mean?'
SHAHIRA [F1(C3)]	(nervous laughter) What 'cancer' means?
SHAHIR [F1(C1)]	Kakak you are just the same like me. You said I could not answer, but look at you …
SHAHIRA [F1(C3)]	(nervous laughter)
KAK JUN [F1(P)]	Aaaah …
SHAHIRA [F1(C3)]	(sheepish smile) Aaah, it's just a picture?
SUZIE	Why don't you try to explain to us what you drew and why so that all of us can understand it better? Ok. The first picture had the question; what does cancer mean, right? Ok, just tell everyone here what you think cancer means.
SHAHIRA [F1(C3)]	Uh… I don't know (nervous laughter). Aaaa ... think that cancer is a dangerous disease
SUZIE	Ok, some more?
SHAHIRA [F1(C3)]	That's it lah. A dangerous disease … if you get it somewhere in your body ... like the brain ... (umm)
SUZIE	How do you mean dangerous?
SHAHIRA [F1(C3)]	Dangerous because it makes people feel in pain like you can die from it ... and you can die from having it.
SUZIE	Do you want to add anything else?
SHAHIRA [F1(C3)]	(shakes head 'no')
SUZIE	Ah ... what about you? (to [F1(C2)]) What do you think 'cancer' means? It's alright, it's for cutting. For everyone to know. Ok whats the first thing? Ah … what about you? What did you write for your first question?

	
SHAHIDA [F1(C2)]	Cancer is ... a dangerous disease
SUZIE	Could you tell us some more; how and why you think it is dangerous?
SHAHIDA [F1(C2)]	I don’t know. Mama said it was dangerous.
SUZIE	What did you draw?
SHAHIDA [F1(C2)]	A picture is just a picture. What can I say more about it?
KAK JUN [F1(P)]	Why don’t you try Kak Ida to tell us a bit about what you drew?
SHAHIDA [F1(C2)]	Aaa ... a picture of “Love”
SUZIE	Ah. Love? (Pause) Tell us a bit about the picture that you drew.
SHAHIDA [F1(C2)]	Love for mama.
SUZIE	What do you mean by that?
SHAHIDA [F1(C2)]	Ida loves mama lah. Mama is sick or healthy, I love mama the same.
SUZIE	Is there anything else you want to tell us about your ‘Love’ drawing?
SHAHIDA [F1(C2)]	Umm … I think Mama loves us, even when she is sick … even when she is scolding us … that is to show she loves us. (pause) I think Mama also needs to know lah, that I love her also lah. (giggles)
SUZIE	Is that what you mean by this drawing?
SHAHIDA [F1(C2)]	(Nods head “yes’)
SUZIE	Is there anything else you want to tell add?
SHAHIDA [F1(C2)]	(shakes head ‘no’)
SUZIE	Ah . . . how about you? (to [F1(C1)]) What do you think ‘cancer’ means?
SHAHIR [F1(C1)]	Ummm . . . (reluctant and shy to share)

	
SHAHIRA [F1(P3)]	Eh, his picture . . . (referring to [F1(C1)]'s self portrait)
KAK JUN [F1(P)]	Aa, his picture.
SUZIE	Ok what can you tell us about this picture.
SHAHIDA [F1(C2)]	Will you look at that . . .
SHAHIRA [F1(C3)]	Ha . . . hurry up . . .
SHAHIR [F1(C1)]	*(shyly responding)* . . . A sickness . . .
SUZIE	Ya?
SHAHIR [F1(C1)]	I don't know …
SUZIE	(Showing [F1(C1)]'s drawing) Is this a picture of you?
SHAHIR [F1(C1)]	*Ya…*
KAK JUN [F1(P)]	Ah, what are you doing in the photo?
SHAHIDA [F1(C2)]	Ha, what is it . . ?
SUZIE	May I see it for a bit?
SHAHIDA [F1(C2)]	Just say whatever . . .
SUZIE	What are you doing here? *(Referring to action in drawing)*
SHAHIRA [F1(C3)]	Ha, be quick!
SHAHIR [F1(C1)]	A drawing of Shahir.
KAK JUN	Ah. What are you doing in that picture?
SHAHIR [F1(C1)]	Nothing. Its just me. Mama has cancer, but I still want mama.
KAK JUN [F1(P)]	Yes, Shahir is my child, of course I love you . . .
SUZIE	(Looking at the time and after a short silence to allow CP1 to elaborate, but CP1 does not elaborate)
KAK JUN [F1(P)]	Its just his picture. He wants his mother to love him is all . . . (laughter) Its just his picture . . .
SHAHIR [F1(C1)]	(nervous laughter and nods head in agreement)
SUZIE	Ok, we can accept that. I can write that explanation for Shahir. The second question, opps, Kak Jun's turn, what do you think the word 'cancer' means? *(takes out to show what Kak Jun wrote as her answer for the first question*) Aa, this is it . . . *(giving back the paper to kak Jun to refer to)* Ok . . .

	 1. Satu Penyakit Yang Amat Membahaya Bolh membawa maut .
KAK JUN [F1(P)]	I think, *(reading what was written)* it is a dangerous disease that can cause death. These kids don't understand. This thing *(referring to cancer)* is not fun and games. When the pain comes, God only knows. I am sitting alone thinking about death *(sobs).* These kids don't understand . . .
SUZIE	This is why we are doing this research today, Kak Jun. Lets get our children and everyone involved to understand what you and other people inflicted by cancer to understand what actually goes on, ya?
KAK JUN F1(P)]	*(Nods head)*
SUZIE	Ok. Could you please elaborate?
KAK JUN [F1(P)]	I wrote, a disease that can kill
SUZIE	Is this something you feel and believe?
KAK JUN [F1(P)]	Ya. I know that there is a cure for cancer. It's just that I have to endure and be patient. I do feel emotional stress because there is a lot on my mind. I am worried about the children. I have to do a lot of preparation, pray.
SUZIE	Ya?
KAK JUN [F1(P)]	(Nods in agreement) Yes, life and death is in God's hand. But we must still try to get better. So to me, cancer is a test. (Pause) A very difficult test (Pause)

APPENDIX 7

15-question questionnaire
Parent version (English and Bahasa Malaysia)
Child version (English and Bahasa Malaysia)

NOTE:

The importance of this questionnaire was to understand children's experience in obtaining information. This questionnaire asked participants to identify:

- Who informed children about their parent's diagnosis
- How were children informed and what they felt about it
- Sufficiency of information about treatment process and cancer's impact to parent and self
- Sources of information
- Types of information required
- The information's format and in what way could it be improved?

The questionnaire also sought strategies for resolving perceived information problem(s).

15-question questionnaire

Parent version (English)

‘INVESTIGATING THE INFORMATION NEEDS OF CHILDREN OF A PARENT WITH CANCER’ INFORMATION SOURCE QUESTIONAIRE

Please answer all of the questions. All information will be held with the strictest confidence. No identifying names or other personal particulars other than research results will be published towards the completion of the researcher’s PhD report.

1. Please write your name and all of your contact details below.

Full Name:	
Mailing Address:	
Phone Number:	E-mail address:

2. Who was the first person to tell your child(ren) you about your diagnosis?

☐ Me
☐ A neighbor or family friend
☐ I don’t remember
☐ My husband/wife
☐ The doctor taking care of me
☐ Another family member
☐ The nurse taking care of me

3. Who else informed you about your child(ren) about your diagnosis? If nobody else, skip this question and continue to question number 3.

☐ Me
☐ A neighbor or family friend
☐ I don’t remember
☐ My husband/wife
☐ The doctor taking care of me
☐ Another family member
☐ The nurse taking care of me

4. How were your child(ren) told about it?

____

____

____

5. How did you feel about the way they were informed?

☐ The information was too rushed
☐ The information was too short
☐ The information was too confusing
☐ I had to ask again
☐ I did not understand the information
☐ I don’t remember/ know

I felt that:

____

____

6. What did you feel about the information?

☐ The information was too rushed
☐ The information was too confusing
☐ I did not understand the information
☐ My child(ren) were not told enough
☐ My child(ren) had to ask again
☐ I don't remember

I felt that:

7. Was the information enough for your child(ren) to understand what was going to happen to you?

☐ More than enough
☐ Enough
☐ Just about enough
☐ Not enough
☐ Not enough at all

If you felt the information was not enough, what more do you think they would have liked to know?

8. If your children needed more information, what kind of information did they want?

☐ Cancer in general
☐ A specific cancer
☐ Types of treatment
☐ What will happen to me
☐ Surviving cancer
☐ Possible side effect of treatment(s)
☐ How my children could help
☐ What will happen to my children
☐ Food and diet
☐ Other information:

9. What do you think is the three most important information to have?

1.

2.

3.

10. If your children needed more information, where would they get it from? (Tick all that you did to get more information)

☐ Me
☐ My husband/wife
☐ Another family member
☐ A neighbor or family friend
☐ The doctor taking care of me
☐ The nurse taking care of me
☐ The library
☐ The internet
☐ I don't remember/know
☐ Other sources:

11. Do you think the information they found meet their needs?

☐ More than met all of their needs
☐ Met all of their needs
☐ Just about met their needs
☐ Did not meet some of their needs
☐ Did not meet any of their needs

12. How did the information look like?

13. In what way could the information be better? (Tick all that apply)

☐ Information in Bahasa Malaysia

☐ More information provided

☐ More pictures

☐ Information that is better organized

☐ Easier to get

☐ Information that is easier to understand

I think the information should be:

14. In informing your children about your diagnosis, what more would you have liked to know?

15. What would you like to suggest be done about the information problem?

15-question questionnaire

Parent version (Bahasa Malaysia)

‘INVESTIGATING THE INFORMATION NEEDS OF CHILDREN OF A PARENT WITH CANCER’ INFORMATION SOURCE QUESTIONAIRE: PARENT

Sila jawab semua soalan. Semua Maklumat dijamin sulit dan rahsia. Tiada sebarang pengenalan nama mauhupun maklumat peribadi selain daripada untuk keperluan kajian akan diberi kepada mana-mana pihak ketiga.

1. Sila tuliskan nama penuh dan alamat surat menyurat yang lengkap di bawah.

Nama Penuh:	
Alamat surat menyurat:	
Nombor Telepon:	Alamat e-mail:

2. Siapakah orang pertama yang memaklumkan/memberitahu anak-anak anda mengenai diagnosis anda?

☐ Saya
☐ Jiran atau rakan keluarga
☐ Saya tak ingat
☐ Suami/isteri
☐ Doktor yang merawat saya
☐ Ahli keluarga yang lain
☐ Jururawat yang merawat saya

3. Ada sesiapa lain yang memaklumkan/memberitahu anak-anak anda mengenai diagnosis anda? Sekiranay tiada, sila kesoalan yang berikutnya.

☐ Saya
☐ Jiran atau rakan keluarga
☐ Saya tak ingat
☐ Suami/isteri
☐ Doktor yang merawat saya
☐ Ahli keluarga yang lain
☐ Jururawat yang merawat saya

4. Bagaimanakah anak-anak anda diberitahu mengenai keadaan anda?

____

____

____

5. Apakah perassan anda dengan cara anak-anak anda diberitahu?

☐ Maklumat yang diberi terlalu cepat untuk mereka fahami
☐ Maklumat yang diberi terlalu ringkas dan tidak mencukupi
☐ Maklumat yang diberi terlalu mengelirukan bagi mereka
☐ Mereka tanya lagi dan maklumat perlu diulang
☐ Mereka langsung tidak faham maklumat yang diberikan
☐ Saya tidak ingat

Saya merasakan bahawa maklumat itu adalah patut:

____

____

6. Apakah perassan anda dengan maklumat itu sendiri?

☐ Maklumat yang diberi terlalu cepat untuk mereka fahami
☐ Maklumat yang diberi terlalu mengelirukan bagi mereka
☐ Mereka langsung tidak faham maklumat yang diberikan
☐ Maklumat yang diberi terlalu ringkas dan tidak mencukupi
☐ Mereka tanya lagi dan maklumat perlu diulang
☐ Saya tidak ingat

Saya merasakan bahawa maklumat itu adalah patut:

7. Pada pandangan anda, adakah maklumat itu mencukupi supaya anak-anak anda boleh/mampu memahami apa yang bakal berlaku terhadap anda?

☐ Lebih daripada mencukupi
☐ Mencukupi
☐ Cukup-cukup sahaja
☐ Tidak mencukupi
☐ Tidak mencukupi langsung

Sekiranya anda rasa maklumat itu tidak mencukupi, apakah maklumat lain yang anda ingin ketahui?

8. Sekiranya anak-anak anda memerlukan maklumat yang lebih/lain, apakah maklumat tersebut? (Tick semua yang berkenaan)

☐ Perihal kanser pada umumnya
☐ Sejenis kanser yang khusus
☐ Jenis-jenis dan cara-cara rawatan
☐ Apakah yang akan berlaku kepada saya
☐ Cara-cara mengatasi kanser
☐ Kesan-kesan sampingan rawatan kanser
☐ Bagaimanakah anak saya boleh membantu saya
☐ Apakah yang akan berlaku kepada anak saya sendiri
☐ Pemakanan dan diet saya yang baru
☐ Maklumat lain:

9. Apakah tiga maklumat yang anda rasa paling penting untuk diketahui mengenai kanser anda?

1.

2.

3.

10. Sekiranya anak-anak anda memerlukan maklumat yang lebih/lain, dari manakah mereka boleh memperolehinya? (Tik semua yang berkenaan)

☐ Saya
☐ Suami/isteri
☐ Ahli keluarga yang lain
☐ Jiran atau rakan keluarga
☐ Doktor yang merawat saya
☐ Jururawat yang merawat saya
☐ Perpustakaan
☐ Internet
☐ Saya tak tahu
☐ Punca maklumat yang lain:

11. Adakah anda rasa maklumat itu memenuhi kehendak/keperluan maklumat mereka?

☐ Lebih daripada mencukupi
☐ Mencukupi
☐ Cukup-cukup sahaja
☐ Tidak mencukupi
☐ Tidak mencukupi langsung

12. Bagaimanakah rupa maklumat itu?

13. Bagaimanakah maklumat itu boleh diperbaiki? (Tick semua yang berkenaan)

☐ Maklumat didalam Bahasa Malaysia
☐ Lebih maklumat untuk didapati
☐ Lebih banyak gambar
☐ Maklumat yang lebih terurus
☐ Lebih mudah untuk didapati
☐ Maklumat yang lebih senang difahami

Saya rasa maklumat seperti ini harus:

14. Untuk memberitahu anak-anak anda mengenai diagnosis anda, maklumat apakah yang anda ingin ketahui?

15. Apakah yang anda ingin cadangkan menegani masaalah maklumat?

15-question questionnaire

Child version (English)

'INVESTIGATING THE INFORMATION NEEDS OF CHILDREN OF A PARENT WITH CANCER' INFORMATION SOURCE QUESTIONAIRE: PARENT

Please answer all of the questions. All information will be held with the strictest confidence. No identifying names or other personal particulars other than research results will be published towards the completion of the researcher's PhD report.

1. Please write your name and all of your contact details below.

Full Name:	
Mailing Address:	
Phone Number:	E-mail address:

2. Who was the first person that told you about your parent's diagnosis?

☐ The parent with cancer
☐ A neighbor or family friend
☐ I noticed my parent was not well
☐ The parent without cancer
☐ The doctor taking care of my parent
☐ I noticed that something was different at home
☐ Another family member
☐ The nurse taking care of my parent
☐ I don't remember

3. Who else informed you about your parents' diagnosis? If nobody else, skip this question and continue to question number 3.

☐ The parent with cancer
☐ A neighbor or family friend
☐ I noticed my parent was not well
☐ The parent without cancer
☐ The doctor taking care of my parent
☐ I noticed that something was different at home
☐ Another family member
☐ The nurse taking care of my parent
☐ I don't remember

4. How were you told about it?

____

____

____

5. How did you feel about the way you were informed?

☐ The information was too rushed
☐ The information was too short
☐ The information was too confusing
☐ I had to ask again
☐ I did not understand the information
☐ I don't remember

I felt that:

____

____

6. What did you feel about the information?

☐ The information was too rushed
☐ The information was too confusing
☐ I did not understand the information
☐ I was not told enough
☐ I had to ask again
☐ I don't remember

I felt that:

7. Was the information enough for you to understand what was going to happen to your parent?

☐ More than enough
☐ Enough
☐ Just about enough
☐ Not enough
☐ Not enough at all

If you felt the information was not enough, what more would you like to have known?

8. Was the information enough for you to understand what was going to happen to you?

☐ More than enough
☐ Enough
☐ Just about enough
☐ Not enough
☐ Not enough at all

If you felt the information was not enough, what more would you like to have known?

9. If you needed more information, what kind of information did you want?

☐ Cancer in general
☐ A specific cancer
☐ Types of treatment
☐ What will happen to my parent
☐ Surviving cancer
☐ Possible side effect of treatment(s)
☐ How I can help
☐ What will happen to me
☐ Food and diet
☐ Other information:

What do you think is the three most important information to have?

1.

2.

3.

10. If you needed more information, where did you get it from? (Tick all that you did to get more information)

☐ The parent with cancer
☐ The parent without cancer
☐ Another family member
☐ A neighbor or family friend
☐ The doctor taking care of my parent
☐ The nurse taking care of my parent
☐ The library
☐ The internet
☐ I don't remember
☐ Other sources:

11. Did the information you found meet your needs?

☐ More than met all of my needs

☐ Met all of my needs

☐ Just about met my needs

☐ Did not meet some of my needs

☐ Did not meet any of my needs

12. How did the information look like?

____

____

13. In what way could the information be better? (Tick all that apply)

☐ Information in Bahasa Malaysia

☐ More pictures

☐ Easier to get

☐ More information provided

☐ Information that is better organized

☐ Information that is easier to understand

I think the information should be:

____

____

14. What more would you have liked to know?

____

____

15. What would you like to suggest be done about the information problem?

____

____

____

15-question questionnaire

Child version (Bahasa Malaysia)

‘INVESTIGATING THE INFORMATION NEEDS OF CHILDREN OF A PARENT WITH CANCER’
INFORMATION SOURCE QUESTIONAIRE: PARENT

Sila jawab semua soalan. Semua Maklumat dijamin sulit dan rahsia. Tiada sebarang pengenalan nama mauhupun maklumat peribadi selain daripada untuk keperluan kajian akan diberi kepada mana-mana pihak ketiga.

1. Sila tuliskan nama penuh dan alamat surat menyurat yang lengkap di bawah.

Nama Penuh:	
Alamat surat menyurat:	
Nombor Telepon:	Alamat e-mail:

2. Siapakah orang pertama yang memaklumkan anda mengenai dianosis ibu/bapa anda?

☐ Ibu/bapa yang menghidap kanser
☐ Jiran atau rakan keluarga
☐ Saya sendiri perasan ibu/bapa saya nampak kurang sihat
☐ Ibu/bapa yang tidak menghidap kanser
☐ Doktor yang merawat ibu/bapa saya
☐ Saya perasan ada sesuatu yang tidak kena/luar biasa dirumah
☐ Ahli keluarga yang lain
☐ Jururawat yang menjaga ibu/bapa saya
☐ Saya tidak ingat

3. Siapa lagi yang memberitahu anda mengenai diagnosis ibu/bapa anda? Sekiranya tiada sesiapa yang lain, sila ke soalan yang berikutnya.

☐ Ibu/bapa yang menghidap kanser
☐ Jiran atau rakan keluarga
☐ Saya sendiri perasan ibu/bapa saya nampak kurang sihat
☐ Ibu/bapa yang tidak menghidap kanser
☐ Doktor yang merawat ibu/bapa saya
☐ Saya perasan ada sesuatu yang tidak kena/luar biasa dirumah
☐ Ahli keluarga yang lain
☐ Jururawat yang menjaga ibu/bapa saya
☐ Saya tidak ingat

4. Bagaimanakah anda diberitahu ibu/bapa anda menghidap kanser?

____

____

____

5. Apakah perasaan anda dengan cara anda diberitahu meneganai kanser ibu/bapa anda?

☐ Maklumat yang diberi terlalu cepat untuk saya fahami
☐ Maklumat yang diberi terlalu mengelirukan
☐ Saya langsung tidak faham maklumat yang diberikan

☐ Maklumat yang diberi terlalu ringkas dan tidak mencukupi
☐ Saya kena tanya lagi dan perlu diulang
☐ Saya tidak ingat

Saya merasakan bahawa maklumat itu adalah patut:

6. Adakah maklumat yang diberikan mencukupi untuk anda memahami apa yang bakal berlaku kepada ibu/bapa anda?

☐ Lebih daripada mencukupi
☐ Mencukupi
☐ Cukup-cukup sahaja
☐ Tidak mencukupi
☐ Tidak mencukupi langsung

Sekiranya anda rasa maklumat itu tidak mencukupi, apakah maklumat lain yang anda ingin ketahui?

7. Adakah maklumat yang diberikan mencukupi untuk anda memahami apa yang bakal berlaku kepada diri anda?

☐ Lebih daripada mencukupi
☐ Mencukupi
☐ Cukup-cukup sahaja
☐ Tidak mencukupi
☐ Tidak mencukupi langsung

Sekiranya anda rasa maklumat itu tidak mencukupi, apakah maklumat lain yang anda ingin ketahui?

8. Sekiranya anda memerlukan maklumat lain, maklumat apakah yang ingin anda ketahui? (Tick semua yang berkenaan)

☐ Perihal kanser pada umumnya
☐ Sejenis kanser yang khusus
☐ Jenis-jenis dan cara-cara rawatan

☐ Apakah yang akan berlaku kepada ibu/bapa saya
☐ Cara-cara mengatasi kanser
☐ Kesan-kesan sampigan rawatan kanser

☐ Bagaimanakah saya boleh membatu ibu/bapa saya
☐ Apakah yang akan berlaku kepada saya
☐ Pemakanan dan diet ibu/bapa saya yang baru
☐ Maklumat lain:

9. Apakah tiga maklumat yang anda rasa paling penting untuk mengetahui mengenai kanser ibu/bapa anda?

1.

2.

3.

10. Sekiranya anda perlukan lebih maklumat, dimanakah anda akan/boleh mendapatkannya? (Tick semua yang berkenaan)

☐ Ibu/bapa yang menghidap kanser
☐ Ibu/bapa yang tidak menghidap kanser
☐ Ahli keluarga yang lain

☐ Jiran atau rakan keluarga
☐ Doktor yang merawat ibu/bapa saya
☐ Jururawat yang menjaga ibu/bapa saya

☐ Perpustakaan
☐ Internet
☐ Saya tak tahu

☐ Punca maklumat yang lain:

11. Adakah maklumat itu menepati kehendak anda?

☐ Lebih daripada mencukupi
☐ Mencukupi
☐ Cukup-cukup sahaja
☐ Tidak mencukupi
☐ Tidak mencukupi langsung

12. Bagaimanakah rupa maklumat yang anda jumpa itu?

13. Bagaimanakah maklumat itu boleh diperbaiki? (Tick semua yang berkenaan)

☐ Maklumat didalam Bahasa Malaysia
☐ Lebih banyak gambar
☐ Lebih mudah untuk didapati
☐ Lebih maklumat untuk didapati
☐ Maklumat yang lebih terurus
☐ Maklumat yang lebih senang difahami

Saya rasa maklumat seperti ini harus:

14. Apa lagi maklumat yang anda ingin ketahui?

15. Apakah yang anda ingin cadangkan menegani masaalah maklumat?

Appendix 8

Sample of the data explication process (observation and memoing) and the data processing and analysis

NOTE:

A sample of preliminary observations and memoing, the data explication process is appended. This is followed by a sample overview of selected findings for development of themes and codes.

SAMPLE OF PRELIMINARY OBSERVATIONS AND MEMOING TO:
1) Find out children's own definition of the word 'cancer'.
2) Find out information gaps for the word 'cancer'

FAMILY 1

ID: [F1(C1)]

Definition of 'Cancer': Cancer is a disease.

OBS. NOTES	DREW	WROTE	SELF EXPLANATION	INFERENCES
• Hesitant to draw and write. • Looks over other's work for inspiration. • Seeks mother's guidance and approval. • Last to start and finish. **"Nak lukis apa lah? Ummph!"** (What should I draw?) - *indicating frustration and attempting to erase drawing*		'Kancer ialah peyakit." *(Cancer is a disease)*	"Penyakit lah" *(a disease)* "Mama ada kanser tapi Shahir nak mama jugak. *(Eventhough mama has cancer, Shahir still wants mama)* Participant drew a self-portrait. Participant explained that he thinks 1. Cancer is a disease 2. Even though his mother was diagnosed, he wanted her to (show) that she loved him.	1. Identified that cancer is a disease. 2. Questions the importance/value of a child when a parent is chronically ill; who is going to take care of the child **ADDITIONAL QUESTION(S)** 1. Definition of cancer 2. Definition of disease 3. Child's position in parent's world **EMERGING ISSUE(S)** 1. Don't know the medical definition of cancer. 2. Parent's cancer impact on children. 3. Concern with show of 'Love' from parent to child.

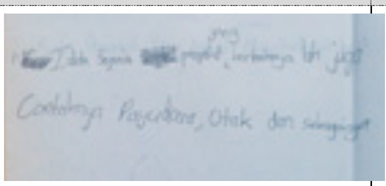
ID: [F1(C2)]

Definition of 'Cancer': Cancer is a dangerous disease, but does not know why it is so.

OBS. NOTES	DREW	WROTE	SELF EXPLANATION	INFERENCES
• Starts drawing immediately her first thoughts. • Adds colors and details after initial drawing. • Laughs throughout session, seems to like drawing and making fun of the quality and content of sibling's drawings.			"Kanser tu . . . penyakit bahaya." *(Cancer is a dangerous disease)* "Tak tau. Mama kata kanser tu bahaya je." *(I don't know why. Mama just said that cancer was dangerous)* "Gambar tu, gambar lah" *(The picture is just a picture)* "Love, sayang mama" *(love mama)* "Ida sayang mama lah. Mama ada sakit ke, sihat ke. Sayang sama ajalah." *(Ida loves Mama. It does not matter if Mama is sick or ill. I love the same)* Participant explained that she knows cancer is something experienced by her mother and so she drew that she loved her mother even with the diagnosis.	1. Identified that cancer is something to fear. 2. Cancer is a dangerous disease. 3. Does not know why it is dangerous. 4. Love of child to parent still exists in the face of illness. **ADDITIONAL QUESTION(S)** 1. Definition of cancer 2. Definition of disease 3. How to show concern/care/ love **EMERGING ISSUE(S)** 1. Don't know the medical definition of cancer 2. Parent's cancer impact on children. 3. Show of 'Love' from child to parent.

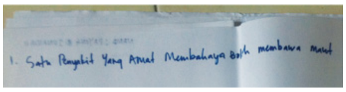
ID: [F1(C3)]

Definition of 'Cancer': Cancer is scary because it causes a lot of pain.

OBS. NOTES	DREW	WROTE	SELF EXPLANATION	INFERENCES
• Takes awhile to think about the question before drawing. • Adds colors and details.		Ialah sejenis penyakit yang berbahayalah juga. Contohnya payudara, otak dan sebagainya. *(It is a type of disease that is quite dangerous, for example breast, brain and etc.)*	"Saya rasa kanser tu penyakit bahaya" *(I feel that cancer is a dangerous disease)* "Itu lah. Satu penyakit yang bahaya . . . kalau kena di tempat-tempat di dalam badan . . . otak ke." *(That's it. It's a dangerous disease . . . if it is inside the body . . . the brain)* "Bahaya sebab dia buat orang rasa sakit macam nak mati . . . dan boleh bawa mati." *(Dangerous because it makes people feel painful as if one is dying from the pain . . . and it can lead to death)* Participant explained that she thinks cancer is a dangerous disease.	1. Cancer is a dangerous disease as location of occurrence and how cancer affects those areas. **ADDITIONAL QUESTION(S)** 1. Definition of cancer 2. How cancer impacts affected area **EMERGING ISSUE(S)** 1. Don't know the medical definition of cancer. 2. Perceives cancer as a dangerous disease because it could involve elements inside the body 3. Perceives cancer causes very painful pains that could lead to death.

ID: [F1(P)]

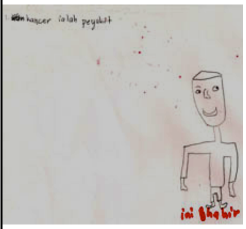
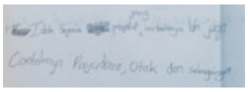
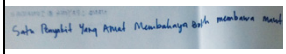
Definition of 'Cancer': Cancer is a dangerous disease because it can result in death.

OBS. NOTES	DREW	WROTE	SELF EXPLANATION	INFERENCES
• Takes awhile to think about the question before drawing. Adds colors and details.	 1. Satu Penyakit Yang Amat Membahaya Boleh membawa maut	Satu penyakit yang amat membahaya boleh membawa maut. *(A disease that is very dangerous and can kill.)*	*Reading from what she wrote:* "Satu penyakit yang amat membahaya boleh membawa maut". Benda ni (referring to cancer) bukan main-main. Bila datang sakit, tuhan saja tau. Kita ni duduk fikir seorang-seorang pasal mati (sobs).Budak-budak ni, tak paham . . " *(It is a very dangerous disease as it can cause death. This thing (referring to cancer) is not a game. When the pain comes, only God knows how painful it is. I constantly think about death and dying. (sobs) My children don't understand. . .)* Participant explained that she thinks cancer is a very dangerous disease and she knows one can die from it.	1. Cancer is a dangerous disease because it can result in death. 2. The pain and fear of death can not be shared with children as they would not understand (the depth and scope). **ADDITIONAL QUESTION(S)** 1. Definition of cancer 2. How cancer effects and affects a person **EMERGING ISSUE(S)** 1. Keeping issues related to cancer, notably, death, to self rather than something to inform others and sharing problems. 2. How to tell children how cancer physically effects self.

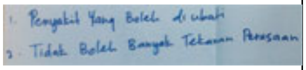
SAMPLE OF DATA EXPLICATION PROCESS:

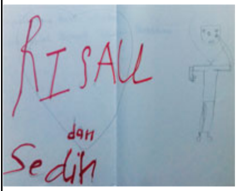
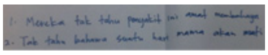
Sample of selected findings for development of themes and codes

FAMILY 1   Number of children in family: 3   Number of children who participated: 3

INQUIRY	C1	C2	C3	P
A. Characteristics of participants:				
1. Age at parental diagnosis	6	9	11	39
2. Gender	M	F	F	F
3. Education level	Kindergarten	Primary 2	Primary 4	SPM
B. Knowledge base - Definition and conceptualisation of cancer				
1. Definition	 "Cancer is a disease"	 "Cancer is a dangerous disease" "I don't know why (cancer is a dangerous disease). Mama just said that cancer was dangerous." "I love Mama. It does not matter if Mama is sick or ill. I love the same."	Contohnya Payudara, Otak dan sebagainya "It is a type of disease that is quite dangerous, for example breast, brain and etc." "I feel that cancer is a dangerous disease." "That's it. It's a dangerous disease . . . if it is inside the body . . . the brain." "Dangerous because it makes people feel painful as if one is dying from the pain . . . and it can lead to death"	Satu Penyakit Yang Amat Membahaya Boleh membawa Maut "A disease that is very dangerous and can kill." "It is a very dangerous disease as it can cause death. This thing (referring to cancer) is not a game. When the pain comes, only God knows how painful it is. I constantly think about death and dying. (sobs) My children don't understand. . ."
2. Conceptualisation	- Cancer is a disease - Even though mama has cancer, I still want mama (to look after me and my needs)	- Identified that cancer is something to fear. - Cancer is a dangerous disease. - Does not know why it is dangerous.	- Identified that cancer is a dangerous because it can lead to death. - Cancer is a painful disease.	- Identified that cancer is a dangerous because it can lead to death. - Cancer is a painful disease.
3. Inference	a) Identified that cancer is a disease. b) Questions the importance/value of a child when a parent is chronically ill; who is going to take care of the child.	a) Identified that cancer is a disease. b) Explained that she knows cancer is something experienced by her mother and she drew that she loved her mother even with the diagnosis.	a) Identified that cancer is a dangerous disease as in location of occurrence and how cancer affects those areas. b) Having cancer is painful. c) Cancer can lead to death.	a) Identified that cancer is a dangerous disease because it can kill b) Having cancer is painful. c) The pain and fear of death can not be shared with children as they would not understand (the depth and scope).
4. Emerging issue(s)	4. Don't know the medical definition of cancer 5. Definition of 'disease', 'illness' and 'sick' used interchangeably 6. Parent's cancer impact on children. 7. Concern with show of 'Love' from parent to child e) Child's position in parent's world	a) Don't know the medical definition of cancer b) Definition of 'disease', 'illness' and ' 'sick' used interchangeably c) Why is cancer dangerous? d) Parent's cancer impact on children. e) How a child may show 'love' and 'concern' to parent	a) Perceived cancer as a dangerous disease because it could involve elements inside the body b) Perceived cancer causes very painful pains (as if one is dying) that could lead to death	a) Perceived that children were unaware, were unconcerned with and did not understand what she was experiencing b) Keeping issues related to cancer, notably, death, to self rather than something to inform others and sharing problems c) How to tell children how cancer physically effects self
5.	Does not know	Not sure	Being tired all the time	a) Experienced abnormal and

Symptoms of cancer			from stress	constant fatigue b) Attended an NCSM talk and read the available brochure on symptoms of cancer c) Conducted self test and discovered a suspicious lump on breast
6. How is cancer diagnosed	Does not know	Does not know	See the doctor at the clinic	Doctor’s consultation, Mammogram and biopsy
7. Causes of cancer	1. Not eating vegetables 2. Too much stress	1. Not eating vegetables 2. Too much stress	1. Too much stress 2. Being around people who smoke	1. Too much stress 2. Being around people who smoke 3. Not eating vegetables 4. Eating too much meat
8. How to treat cancer	Go to hospital	Cancer medicine	1. Remove the part that is damaged or rotten from cancer 2. Get treated with chemotherapy and radiotherapy 3. Get injects or swallow medicines 4. Have to rest a lot 5. Cannot be stressed 6. Have to eat proper food	1. Surgery to remove the cancer and damaged area 2. Go for chemotherapy and radiotherapy 3. Being disciplined with medication 4. Special diet 5. Cannot be stressed 6. A lot of bed rest 7. Prayer 8. Need the support of family and friends
9. Side effects of treatment	- Nausea - “Uweek” (Vomiting) - Headache - Body aches and pains - Loss of appetite - Hair loss - To weak to do housework	- Nausea - Vomiting - Headache - Body aches and pains - Loss of appetite - Hair loss - To weak to do housework - Feeling sick - Easy to anger	- Nausea - Vomiting - Headache - Body aches and pains - Loss of appetite - Hair loss - Feeling sick - Easy to anger - Always tired - Feel weak - Mood swings (crying) - Thirsty - Complaining of being hot and cold	- Nausea - Vomiting - Headache - Body aches and pains - Loss of appetite - Hair loss - Feeling sick - Feel weak - Thirsty - Symptoms of early menopause
9. Cancer screening	Does not know	Does not know	Go to any clinic	Go to NCSM or government hospital with a cancer unit
10. Cancer Prevention	- Eat a lot of vegetables	- Eat a lot of vegetables - Eat fruits - No stress - Be more patient	- Eat a lot of vegetables - Eat fruits - No stress - Not being around smokers - Eat less fried chicken and satay	- Eat a lot of vegetables - Eat fruits - No stress - Not being around smokers and pollution - Eat less fried foods - Eat less meat, especially chicken and satay because of injected hormones into the meat - Exercise three times a week - Pray that you do not get it
11. Where to get more information about cancer	i. Mother ii. Father iii. Sibling iv. Doctor	i. Mother ii. Father iii. Sibling iv. Doctor v. Internet	i. Mother ii. Father iii. Doctor iv. Internet v. Library vi. NCSM	i. Doctor ii. Nurse iii. Cancer friends iv. NCSM v. Newspapers

			vii. Newspapers	vi. Books
12. How to get help in dealing or coping with cancer	i. Mother ii. Father iii. Sibling iv. Doctor v. NCSM	i. Mother ii. Father iii. Sibling iv. Doctor v. NCSM vi. Friends from mother's support group	i. Mother ii. Father iii. Doctor iv. NCSM v. Friends from mother's support group	i. Support group ii. Doctor iii. Nurse iv. NCSM v. Children vi. Husband vii. Other family member viii. Neighbours
a. Information source(s)	i. Mother ii. Father iii. Sibling iv. Doctor	i. Mother ii. Father iii. Sibling iv. Doctor vii. NCSM v. Friends from mother's support group	i. Mother ii. Doctor iii. NCSM iv. Friends from mother's support group ix. Other family member	i. Support group ii. Doctor iii. Nurse iv. NCSM v. Other family member
b. Knowledge of organisations	NCSM	NCSM	NCSM, General Hospital Kuala Lumpur	NCSM, Universiti Kebangsaan Malaysia, General Hospital Kuala Lumpur, MAKNA
C. Outcomes of Children's involvement				
1. Role in parent's care	None	Secondary	Primary	Patient
2. Impact of cancer				
i. Personal Narrative	 "(Involves) surgery" "see the surgeon"	 "(someone with cancer) is in pain" "Painful because there is something growing inside the body, and that person will feel pain." "Something that should not be there. It is rotting and damaged, like mama said" "(The pain is caused) that's because when it (cancer) is growing it pushes other things aside and it uses blood and meat to change to rot. It makes the place painful." "Umm, very painful." "Doctor operates. Painful" "Painful because need to heal from the operation" "(The drawing has a girl crying) Crying because in pain."	  "Afraid" "I am afraid of cancer because it causes a lot of pain." "Afraid of feeling pain." "Afraid and in pain when the doctor injects cancer medicine or pain killers before surgery." "The person feels terrible pain at the place where there is cancer. So, when he sees the doctor in the hospital, the doctor says that the place that hurts needs to be operated on and taken out so that the place is not painful anymore." "Umm . . . when the doctor	 1. Penyakit Yang Boleh di ubati 2. Tidak Boleh Banyak Tekanan Perasaan 1. A disease that can be cured, 2. Can not have too much emotional pressure. "I know that there is a cure for cancer. Its just that you have to be patient and strong. I do feel emotional pressure because there is a lot that I am thinking about. I am worried about my children. I have to prepare for a lot of things, pray." "life and death is in the hands of God. But we try to be come better. To me, cancer is a test. A very heavy test."

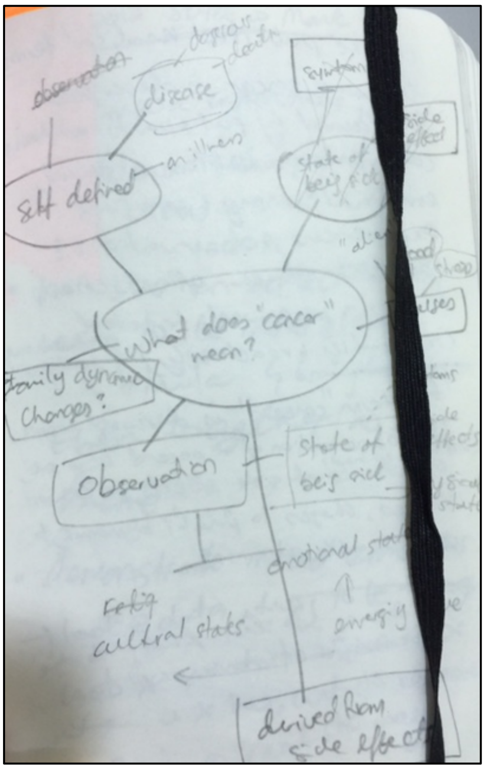
			operates, the person feels pain, but the doctor injects a painkiller, so it does not hurt that bad anymore. After the operation, the person needs to rest a lot. Well, he was operated on and he is hurt and in pain right?”	
ii. Inference to experience	1. Cancer needs to be removed by a surgeon in a hospital 2. Agreed with explanation provided by C2(P) that someone with cancer has to undergo an operation to remove the cancer. Cancer means surgery.	1. Cancer is something fearful and scary. 2. Cancer is a growth inside the body that is painful and needs to be removed by a specialist doctor. 3. Cancer causes pain. 4. Cancer treatment is painful too. 5. Doctors play a role in helping cancer patients get better.	1. Cancer is a growth inside the body that causes pain. 2. Cancer needs to be removed by a surgeon in a hospital. 3. Removing cancer is a painful process. 4. Cancer is feared because it causes a lot of pain. 5. After surgery, a person is still in lots of pain from the wound and needs a lot of rest.	Participant explained that she thinks cancer is a very dangerous disease and one can die from it. Cancer is a dangerous disease with a possibility of death
iii. Emerging issue(s) to experience	1. Fear of cancer due to fear of surgery 2. Cancer and its treatment causes pain	1. Fear of cancer due to fear of surgery 2. Fear of pain caused by the cancer growth and its treatment 3. Reactions to pain	1. Fear of cancer due to fear of surgery 2. Fear of pain caused by the cancer growth and its treatment 3. Reactions to pain	1. How to tell children what is cancer 2. How to tell children how cancer physically effects parent
iv. Perception of another’s experience	 “In pain and worried” “Mama says that she is in pain. She can’t do work. She needs to rest and lay down.” “Mama says she’s worried.” “I don’t know why she is worried.”	 “Stinging pain and afraid.” “Stinging pain because of the cancer, mama said the pain stings (like scrapping skin)” ‘Stinging pain at the place of surgery. On her chest. She says it is very painful. She has to bend over because if the skin comes into contact with cloth, she will be in pain.” ‘I think (mother is) afraid to see the doctor again.” “Afraid if there is anything else in the body and have to inject medicine.” ‘I love Mama’	 “Worried and sad” “I don’t know (why mother is worried and sad). Her face looks worried.” “Because her face looks worried” “She is sad. I see her cry and ask why.” “She says she’s worried. But sometimes, she says ’nothing’ (no reason)” “Sometimes she does not have the ‘mood’. She does not want to go out or talk. I don’t know. She just doesn’t have the ‘mood’.” On crying: “Not all the time. But, I have heard and seen. I don’t know why.”	 1. Mereka tak tahu penyakit ini amat membahaya 2. Tak tahu bahawa suatu hari mama akan mati “They don’t know that this disease is very dangerous.” “They don’t know that one day I will die (from cancer).” “I think that my children don’t know that cancer is a very dangerous disease. They don’t know that one day I will die”
v. Assumption s of participants to perceived experience of others’	**On worrying:** Noticed mother’s complaint and that mother looked worried but did not know the cause. **On being in pain:** Knows that mother was in pain post surgery and had side effects to cancer treatment. Does not understand her definition	**On being in pain:** Observed mother being in pain as indicated by mother’s complaints, tears, facial expression and body language. **On mother’s fear:** Assumes mother is afraid to see the doctor for her check-ups because she has to receive injections.	**On crying:** Observed mother crying but does not know why. **On worrying:** Noticed mother’s complaint and that mother looked worried but did not know the cause.	1. Children are unaware that cancer can kill

	and expression of "being in pain". Assumes 'being in pain" means that she cannot do work and she needs to rest.			
vi. Emerging issue(s) to perceived experience of others'.	1. Parent's information-shielding behaviour. 2. Children making assumptions from parent's non verbal cues 3. The physical impact of cancer to a patient – inability to do normal daily chores 4. The physical impact of cancer to family dynamics - importance/value of a child when a parent is chronically ill	1. The impact of cancer physically to a patient – post surgery pain 2. Fear of a doctor's appointment for check-ups. 3. Fear of injections. 4. Fear of pain following a surgery 5. Ability to show of concern and love to parent	1. Cancer's emotional impact to a patient 2. Cancer's emotional impact to child as care giver: fear of hospital, pain, injections, cancer and mother's health 3. Role in caregiving 4. Ability to provide care	1. How to inform children about cancer prevention 2. How to communicate and inform children about experience

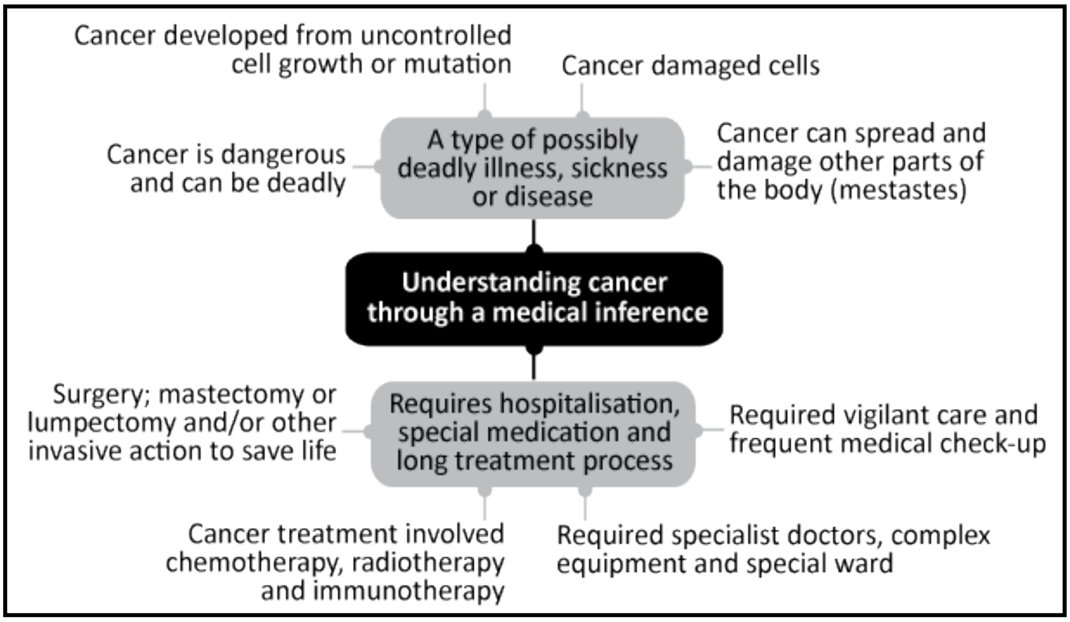
DATA PROCESSING AND ANALYSIS SAMPLE

In accordance with Interpretative Phenomenological Analysis (IPA) (Smith and Osborn, 2007; Smith et al, 2009) principles, data was i) Analysed for frequency of a term, meaning, emotion, reaction or event, ii) Rigorously examined and categorized into lists of related meanings and events and, iii) Developed into clusters of themes. Resulting data was scrutinized against lists of related meanings developed in the first process of data explication (Hycner, 1999, p. 153; Biggerstaff and Thompson, 2008, pp. 179-182). Findings were validated with participants' confirmation to determine if the essence of experiences were accurately understood by way of context and language.

Sample of memmoed notes about children participants' meaning of cancer



Sample of Thematic Network Diagram To Understand "Cancer" As A Medical Inference



APPENDIX 9

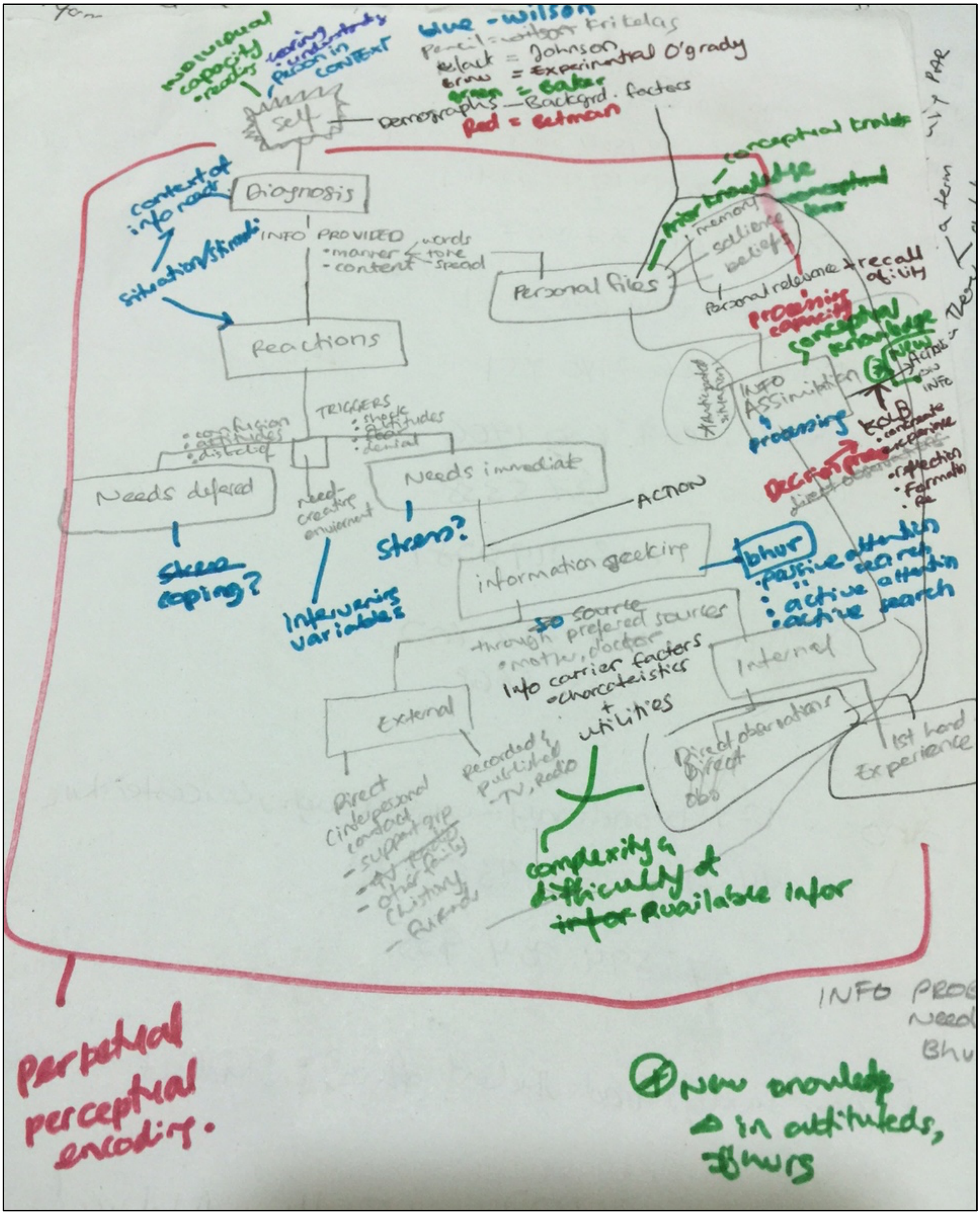
Researcher's original "Children's Reactive Information Seeking Behaviour – An Integrated Model"

NOTE:

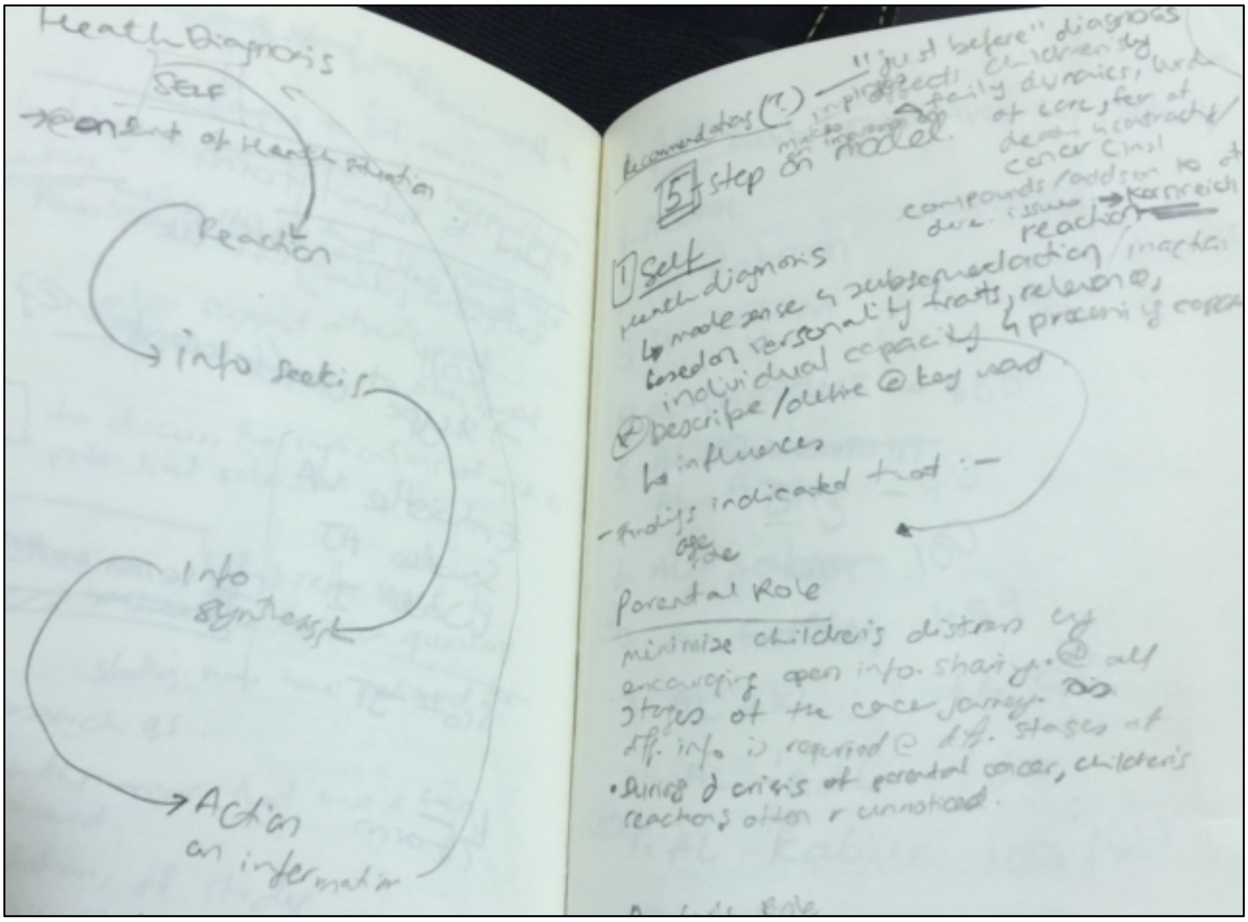
The "Children's Reactive Information Seeking Behaviour – An Integrated Model" (Model) was an original contribution of this research. The Model described children participants' information processing flow when experiencing an unfamiliar health event or situation. This included children participants as the "user" (termed as "self" in the Model), the health situation, the children participants' reactions, information seeking, information synthesis and, action on information that subsequently forms a feedback loop.

The Model was developed from observations and findings from the research. Some components were informed and built upon earlier findings by Finch and Gibson (2009), Wilson (1999), Dervin (2003), Krikelas (1983), Johnson (1997), Baker (1995) and Bettman et al. (1991). Other supporting components were influenced by Gallistel (2008), Kellman and Garrigan, (2009), Prince et al. (2005), Wilson and Walsh (1996), Belkin (1980), Ford (1980) and, Schutz (1967).

Original hand-drawn concept for “Children’s Reactive Information Seeking Behaviour – An Integrated Model” to link research observations and findings.



Original hand-drawn concept for organising components of "Children's Reactive Information Seeking Behaviour – An Integrated Model" as a cyclical and non liner process.



Recommendations (?) — "just before" diagnosis
impinges/affects children by family dynamics, burden of care, fear of death & contracting cancer (inst)
make an impression on model.

5 step on model.

compounds/adds on to other issues → reaction

1 Self
health diagnosis
↳ made sense ↳ subsequent action / inaction
based on personality traits, religion, ↳ processing capacity
individual capacity

2 describe/outline @ key word
↳ influences

- findings indicated that :-
age
role

Parental Role

minimize children's distress by encouraging open info. sharing @ all stages of the cancer journey. as diff. info is required @ diff. stages of

- during a crisis of parental cancer, children's reactions often r unnoticed.

Finalised concept for “Children’s Reactive Information Seeking Behaviour – An Integrated Model” describing children participants’ information processing flow when experiencing an unfamiliar health event or situation. This included children participants as the “user” (termed as “self” in the Model), the health situation, the children participants’ reactions, information seeking, information synthesis and, action on information that subsequently forms a feedback loop.