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“She looked like an Alien”: Experience and definitions children attach to a parental cancer diagnosis

ABSTRACT

Purpose: This paper explores Malay children’s information needs from their experience with parental cancer using information behaviour techniques to elicit sensitive information that provided an indication of what children were thinking.

Design/methodology/approach: Data collection adapted the Participatory Action Research method and used participatory-based techniques that included drawings, essays, and interviews. Data explication used an Interpretative Phenomenological Analysis approach. Social Constructionism, Learning theory and Cognitive Theory were used to analyse the data. Thirty-two participants took part, ten mothers with breast cancer at different stages of their cancer journey, and twenty-two children between 6-18 years old.

Findings: There are shortcomings in the provision of cancer information for Malay children. Unlike verbose and difficult to digest medical definitions and descriptions about cancer and its treatment, Malay children defined cancer as having components made from their experiences and observations about how cancer affected their parent. The findings explain the relationship between children participants’ reaction to a health situation and the subsequent processes they undergo to resolve their state of information need.

Originality/value: It highlights the importance of determining information needs and the combined methods used to gain and interpret the experience children face with a parental cancer diagnosis. 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 authors 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.

1. INTRODUCTION

“(giggles) Her hair got less and less, until it was gone! Ahyo! That was scary, like alien! I was afraid. Mama did not look like herself and I was scared. 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. I was worried that she would be bald forever. That would have been bad. It is like . . . umm . . . a girl must have hair. If a girl does not have hair . . . you are not a girl anymore?”, F6(C1)

Advances in medicine have contributed to the management and treatment of cancer as a long-term chronic illness (Miller et al., 2016; Ljungman et al., 2014). Longevity and the increased number of new cancer cases from among younger adults (Omar and Ibrahim, 2011, p.31) continue to necessitate more economical cancer management (National Cancer Institute, 2009, p.1). A parallel increase developed in the prevalence for home-based care, which in turn, also increased the number of dependent children experiencing parental cancer (Barnes et al., 2000, p.480; 2002, p. 209; Kornreich et. al., 2008, p.64).

This is illustrated by a comparative study of the number of new cancer cases from among families in United States of America, United Kingdom and Malaysia. A combination of data extrapolated from cancer statistics (American Cancer Society, 2016; Macmillan Cancer Support, 2017; Abdul et al.,

2012) of 21–55 year old adults whom were considered in prime childbearing and parenting years and, fertility rates from the World Bank suggested that approximately 3,182, 177 American children, 673,474 British children and 246,087 Malaysian children were possibly exposed to the vagaries of cancer while their parents convalesced at home. Even though Malaysia recorded lower number of children, the ratio was higher at 2.5 children per household (*Banci Penduduk dan Perumahan Malaysia, Jabatan Perangkaan, 2013*).

Visser et al. (2004), Visser et al. (2007), Osborne (2007) and Edwards et al. (2008) reported that parental cancer had a range of consequences from the aspect of children's functioning and psychosocial difficulties. Anxiety, fear and uncertainty were common emotional distresses (Kornreich et al., 2008; Fourie, 2008; Buchwald, 2007; Watson, 2006). However, unlike these studies on latent, cognitive and behavioural development, this paper focuses on meanings and experiential sense-making children develop arising from exposure to parent's cancer journey and information provisions, and the lack of. This is because while the concern to provide caregivers and people impacted by a health situation require special information needs and attention has been long advocated (Granet, 2003; Dervin, 2001; Kubler-Ross, 1969), the domain is still in its infancy (Alzougool et al., 2013; Glassman, 2012; Fletcher et al., 2012). Information provisions for children were mostly developed either from views of parents as proxies or without empirical proof of children's actual needs and experiences.

Greig et al. (2013) also believed that children were a product of, and were influenced by their ethnicity, level of education, social class, upbringing and other influencing elements. An exploration of these influences may provide nuanced insight towards information seeking behaviours of children who were exposed to their parent's recovery and had a role in caregiving. Of particular interest was the increasingly evident role Malay children had as caregivers. Specifically, very little research has been conducted with Malay 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.

This paper began by quoting a child's fear about her mother's hair loss from chemotherapy. Such reactions call for an understanding of what children experience, understand and attribute to cancer. Continued evidence of emotional distress, children's functioning and psychosocial difficulties suggest that children's experience, meanings and sense-making about parental cancer were little understood and, that there were problems and shortcomings in information provisions and the development of interventions. This paper therefore aims to explore Malay children's information needs and views about parental cancer and their experience; specifically, children's meaning and definition of cancer, suggesting a better understanding for information needs resulting from experiences and reactions that surround exposure to parental cancer and providing care.

Section 2 provides the theoretical background, discusses the research design and, details the methods and approach used to collect and analyse the data. Section 3 informs on the research design and section 4 describes the used Interpretative Phenomenological Analysis approach. Section 5 presents findings and provides details of the most salient constructs from participants' responses. Results of the said findings are discussed in section 6. The paper concludes by highlighting that children made sense of cancer through their experience, observations and beliefs and how these findings impact on information provision and the wider academic knowledge.

2. Theoretical Background

This research was interdisciplinary in nature because it focused on various topics related to

1
2
3 information science (health informatics), cancer (patient’s information needs), children (experience
4 of young carers) and psychology (psychological consequences to cancer). The scope of review
5 strategy and search terms is illustrated in Figure 1.
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11 Figure 1- Scope of review and search terms used in this study
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17 Health professionals have begun to recognize cancer as a phenomenon experienced by the entire
18 family (Kristjanson and Ashcroft, 1994, p.1). According to the National Cancer Institute (2012c, para.
19 3) most discussions about cancer focused on new treatments and their impact on cancer patients
20 resulting in the needs of family members “often gotten lost in the shuffle”. According to the National
21 Cancer Institute (2012c, para. 4) while family members provide majority of care, “most are often
22 unprepared and undervalued”. The 2011 National Cancer Policy acknowledged the role of families in
23 providing care and thus advocated for clinicians to communicate cancer concerns better
24 (Department of Health, 2011, p. 48).
25

26
27 Cancer in the family presents challenges to children (National Cancer Institute (NCI), 2012a;
28 breastcancer.org, 2012; Davey et al., 2005, p. 247) with reports indicating these challenges are often
29 unnoticed (Kornreich et al.; 2008, p. 65), had few effective coping strategies to deal with illness-
30 related issues (Kilicarslan-Totuner and Akgun-Citak, 2012, pp. 176-183) and that provisions have not
31 met information needs (Adams, 2013; breastcancer.org, 2012; Brewer and Sparks, 2011; Kennedy
32 and Williams, 2009). These studies and observations suggest there were nuances of concern,
33 questions about children’s information sharing culture and, myriad differences in children’s
34 experiences. When cancer is diagnosed in a parent, this may also have consequences for their
35 children (Greig et al., 2007, p.6; Huizinga et. al., 2003, p. 195; Northouse et. al., 2012, p. 237).
36 However, there has been limited documentation of children’s adjustment to a cancer diagnosis
37 in the family (Christ and Christ, 2006, p. 1999; Davey et. al., 2005, p. 247; Finch and Gibson, 2009, p.
38 214; Kornreich et al, 2008, p. 65; Lewis and Hammond, 1996, p. 456). Children of cancer patients may
39 go through a distressing time (Visser et al, 2004, p. 67) and the burden of palliative care is substantial
40 (Northouse et. al., 2012, p. 237; Becker, 2007, p. 24: Department of Health, 1995, p.3).
41 Somasonduram (personal communication, 29 November 2011) observed similarly for Malaysian
42 families.
43
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45
46
47 Given et al. (2001, p. 214) reported the growing prevalence of home-based care of cancer patients
48 increased the role of families. This was similarly reported by Donovan et al. (2011, p.339) and Cooley
49 (2010, p.24). People with cancer spent more time recuperating at home (NHS Executive, 2011,
50 p.62). According to National Cancer Institute (2009b, para. 1), “cancer patients often felt more
51 comfortable and secure being cared for at home; they did not want to be separated from family,
52 friends, and familiar surroundings”. This suggests that while the survival rates for cancer patients
53 improve, the duration of caring and the number of patients and their families requiring
54 information, advice and support grows (Chiu and Wistow, 2002, p.52 and p. 56; Cooley (2010, pp.
55 24-25); Donovan et al., 2011, p. 339). The literature suggests an evident need to address the myriad
56 issues surrounding the communication and information about the cancer journey to family members.
57 This was compounded when cancer is increasingly diagnosed from among people who are more
58 likely to have young children and adolescents living with them and, technology advancements lead to
59
60

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".

The next section details the methods used to explore Malay children's information needs from their experience with parental cancer using information behaviour techniques to elicit sensitive information that can provide an indication of what children were thinking.

3. RESEARCH DESIGN

The research was conducted among Malay families where participants aged between six and 18 categorised as "children", which could be argued heterogeneous in nature, but a geographically constrained sample. Selection of participants met criteria obtained from an 'Inquiry to Participate' form, InqFE-v.04, distributed to patients at the National Cancer Society Malaysia (NCSM) and Tung Shen Hospital's Cancer Centre with approval from their administrators. Other participation criteria were for children who were already informed about a parent's cancer (Question 6), cancer patients being a parent to children aged between 5 years old and 18 years old (Question 5), cancer patients (stages I - III) (Question 3) and, willingness and consent to participate from both cancer patients (Question 8) and their children (Question 9). Thirty-two people participated: 10 female breast cancer patients (three participants at Stage I, five participants at Stage II and two participants at Stage III), 4 male children and 18 female children. Participants were coded by family number (Fn), identified by parent (P) or child (C) and, numbered by order of birth with the youngest labelled as "1". Participants' demography is provided in Appendix 1.

This study did not explore a specific age range like Kornreich et al.'s (2008) study, but clustered the children and their experience about parental cancer and as a caregiver. Cognitive development and psychosocial difficulties (Osborn, 2007; Visser et al., 2007; Edwards et al., 2008) were not analysed as the focus was for content evidencing children's conceptualisation of cancer irrespective of any specific age. Moreover, an age specific analysis of the type of children's responses may be inconclusive from only 22 children because children participants had different carer roles, interests and skill sets. Those who wrote were from a variety of age range and stated their preferences because either they thought they could not draw or their parents told them that drawing, in general, was a waste of time and hence did not draw responses. So, for these participants, to specifically indicate that age was a predictor for drawing as a preferred format of response could not be made. To argue or assume that younger children or a specific age range preferred to draw can also be false and/or problematic because some parents preferred to draw their responses.

Pursuant to the aim of this paper, it was identified that children participants still lived at home and were dependent on parents. The proximity and dependency exposed children participants to their parent's cancer journey from experience of parental diagnosis, surgery, treatment and its side effects. Seven children participants revealed in discussions that they were the main caregiver. 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. English was not the first language of the Malay. Eight parent participants and all children participants reported that they had some difficulty in the use and comprehension of English language. Participants reported that in their experience most cancer-related information was written in English however, low English literacy made understanding information and contextualising for children's understanding difficult. English literacy had implications to participants' comprehension of cancer.

An adapted Participatory Action Research (PAR) (Kemmis and McTaggart, 1988; Hughes and Seymour-Rolls, 2000) methodology was used to obtain data that "draws on a narrative" (Ribbens McCarthy,

2007) and “lived experiences” (Bauman et al., 2006) of participants. When exploring how children derived meaning from their cancer experiences, **Social Constructionism** provided a theoretical approach because it provided a means to understand how children’s knowledge and reality was constructed through interactions with others (Andrews, 2012) which resulted in “joint meanings” and “joint actions” (Greig et al., 2013). This theory helped to track how children’s knowledge, including misconceptions and beliefs, developed through interactions and observations about their parent’s cancer journey. **Learning theory** helped to identify and explain children’s behavioral changes and, that children learned through observing, modelling and cognitively processing the behaviour of others (Greig et al., 2013; Sherlin et. al., 2011; Bandura, 1993). Specifically, Mineka and Zinbarg (2006, p. 11) “Vicarious conditioning” reported how a child’s observations may be sufficient to develop their similar reaction towards a similar situation. **Cognitive Theory** explained that children had comparatively different capacities and capabilities of learning and processing thoughts, behaviours and relationships and that these were influenced and nurtured by environmental conditions, social relationships and cultural conventions (Greig et al., 2013). According to McLeod (2007), social interaction and the community influenced children’s cognition, psychological function, cultural development and “making meaning”. Papert (1999) believed that children are “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. Data explication used an **Interpretative Phenomenological Analysis** approach which is detailed in the Data explication section. **Information science theories** (information seeking triggers, pathways, behaviours and processes) provided insights into why Malay children sought information. Learning theories provided insights of how learning took place and how Malay children made sense of their experience. Taken together, these theoretical approaches helped in the exploration to better understand what were Malay children’s understanding of their parents’ cancer; its causes, effects, implications and consequences.

The Malaysian Medical Council’s Code of Professional Conduct (1986) and Dissemination of Information by the Medical Profession (2006) were used as a guideline. Ethical considerations 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: a ‘Participant Consent Form’ and a ‘Statement of Confidentiality’ for adult and children participants. Both cancer patients and their children signed their consent on two copies of the consent form after they responded with an understanding of the research, the documents’ content and their participatory role. Of the two copies, one was for participants’ keeping and one kept for the record. The forms and the consent process was developed based on recommendations and sample forms from Lancaster University, Stanford University and adapted from Bailey’s (1996, p. 11) recommended items. As advocated by Heath et al. (2010), Flewitt et al. (2009) and Goodwin (2001), the anonymity of participants were protected transcribed data by codes.

3.1. DATA COLLECTION

Providing children with a voice (Greig et al., 2013; 2007; Kornreich, 2008) by encouraging children’s responses independently and without the overriding influence of their parent, and children’s inclusion in research concerning them (Roberts, 2008, p. 261) necessitated multiple data collection methods. There was a specific parent focus group and children focus group because it was considered appropriate for activity planning, useful in gathering opinions and, discreet observations could be made about responses. This also helped to identify foreshadowed problems (Scheidlinger, 2004) in communicating critical illness to children. The parents group and children’s group were separated so that the other will not unduly influence the others responses. The groups had separate activities to find out their information needs and behaviours. Data was elicited through participative engagement that investigated different nuances of what participants understood and experienced

about cancer. Alongside the collection of the child data, parent data was also collected for cross reference purposes to understand parental perception about their children's experience and how if at all did that align with the child data.

Information behaviour techniques were used to elicit sensitive information that provided an indication of what children were thinking. Multiple data collection methods were from structured and semi structured questions in phenomenological interviews, narratives through drawings or written responses and, answers from a questionnaire. In this way, more detailed data was obtained and the scope of data was not constrained by preconceived assumptions or dimensions about unmet information needs and information seeking behaviour. The multiple data sources also helped triangulate for validation. Data collection continued until the topic was exhausted or when participants did not contribute more information.

Participants' responses were recorded in verbal and written narratives, drawings and a questionnaire. The first activity asked 'What is cancer?' as 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. The objective was to capture a respondent's general understanding of cancer and what was 'readily' known. For example, a child first drew circles and then slashed long lines across the said circles. She explained her drawing as a depiction of cells that were damaged. Follow up discussions elicited an understanding that she equated cancer to something that caused cellular damage. Nuances of meanings from this response was explicated and coded thematically.

The second activity asked 'What does cancer mean to you?' which sought to report on the individual's experienced impact and/or effect of cancer. Answers opened a discourse in which gaps about cancer-related information were identified. For example, a child answered that he had to do more housework. Further discussions elicited the need for information provision about the consequences of cancer including the parent's inability to carry out their normal housework and what were age-appropriate tasks. Nuances of meanings from this response was explicated and coded thematically as "Effects of bodily aches and pains". This code was then categorised as a "Understanding cancer by secondary side effects". This category subsequently became a cluster for the "Understanding cancer from state of parent being sick" theme.

The third activity asked 'What do you think cancer means to your children/parent?' which was adapted to reflect the type of respondent and their perception about cancer's impact to others. This activity also helped to identify knowledge gaps where information needs could be better understood. For example, a few children narrated, wrote and/or drew attributing cancer to mother losing hair. Some felt that "*She (mother) looked like an Alien*". Follow up discussions elicited causation, myths and beliefs about side effects, somatisation and empathy. Possible solutions were offered by participants, such as providing information to children about why chemotherapy caused hair loss, hair loss as not contagious and the ways in which the child could help the parent appear or feel less "Alien". Nuances of meanings from this response was explicated and coded thematically as "Effects of hair loss". This code was then categorised as "Understanding cancer by secondary side effects". This category subsequently became a cluster for the "Understanding cancer from state of parent being sick" theme.

Selected samples to evidence themes and show coding are presented in the findings section. All responses had a four-step data explication, analysis and coding process which is discussed in the next section.

4. DATA EXPLICATION

1
2
3 Data explication used an Interpretative Phenomenological Analysis (Smith and Osborn, 2007).
4 Explication was guided by “memoing” (Glaser, 2004) about participants’ responses, followed by
5 contextual interpretation and meaning using phenomenology approaches and bracketing (Tuffard
6 and Newman, 2010). Preliminary analysis included the identification of participants, repeated words
7 and clustering of responses to organise data and for cohesiveness which were then coded by key
8 words and contextual meaning as clarified by participants. In depth exploration and study (Smith and
9 Osborne, 2007) was aided by illustrated or written depictions of meanings as explained by
10 participants (Greig et al., 2013; Ewald et al., 2011; Ewald, 1985; Osborne, 2006a; 2006b; Skovdal and
11 Ogutu, 2009). Bahasa Malaysia verbatim narrative transcripts were translated into English and then
12 validated for meanings by asking for participants’ clarification and cross referencing with the Oxford
13 Bahasa Malaysia-English dictionary because in a few instances a Bahasa Malaysia word could have
14 different English meanings. For example, “*sakit*” could mean “in pain”, “sickness”, “illness” or
15 “disease”.
16
17
18 Responses underwent data explication steps as described by Hycner (1999) and Groenewald (2004)
19 which included line-by-line coding and specific identification markers to relate and categorise data.
20 This was supported by memmoed observations (Glasner, 2004) and discussions with others to clarify
21 experiences and problems (Rolls and Relf, 2006) associated with a cancer diagnosis and, as a
22 feedback mechanism. The resulting data underwent an Interpretative Phenomenological Analysis
23 (IPA) (Smith and Osborn, 2007; Smith et al., 2009) where data was i) analysed for frequency of a
24 term, meaning, emotion, reaction or event, ii) rigorously examined and categorized into lists of
25 related meanings and events and, iii) developed into clusters of themes. A thematic analysis was
26 then guided by Biggerstaff and Thompson (2008) and Tuffard and Newman (2010).
27
28
29 The most salient constructs from participants’ responses were identified and shaped into themes
30 that were not redundant but still managed to be meaningful. The results were then scrutinized
31 against lists of related meanings (Biggerstaff and Thompson, 2008; Hycner, 1999) developed in the
32 preliminary analysis. The themes were then analysed for patterns and relationships. To validate
33 themes and coding, confirmation was sought from participants to determine if the essence of
34 experiences were accurately understood by way of context and language. The data explication,
35 analysis and coding process is shown in Table 1 and the findings from data explication and thematic
36 analysis are discussed in the next section.
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39
40

Table 1. 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 (Glasner, 2004) 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 (Glasner, 2004) observations were included in transcripts to describe participants’ behaviours in-situ to aid in analysis and researcher’s recall.
3.	DATA EXPLICITATION PROCESS	Guided by 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. Supported by memos (Glasner, 2004) and discussions with others to clarify experiences and problems (Rolls and Relf, 2006, p. 287).
4.	DATA PROCESSING AND ANALYSIS	An Interpretative Phenomenological Analysis (IPA) guided by Smith and Osborn (2007) and Smith et al. (2009). 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.

5. FINDINGS

This paper focused on data explication from exploring participants' experiences that resulted in nuances of definition and meaning of cancer which were previously not reported. Responses provided rich data about the meanings children attributed to cancer, their experiences and unmet information needs. 100 participant contact hours resulted in 96 drawings and essays which were accompanied by self-narratives. This paper is part of a much wider study, which yielded, amongst other things, 95 word-based codes developed from the process of explication, analysis (Coffey and Atkinson, 1996; Hycner, 1999) and bracketing (Tuffard and Newman, 2010) 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. The two perspectives were then combined and explicated from a thematic analysis approach. As informed by Biggerstaff and Thompson (2008), Groenewald (2004) and Attride-Sterling (2001, p. 388), the most salient constructs in the discussions and the 95 word-based codes were then analysed by identifying and shaping data into thematic networks of lowest-order premises (basic themes), then grouping and organising them into categories (organising theme) that summarised more abstract principles. Data explication resulted in six organising themes that were developed from common attributes or elements. These six organising themes were then regrouped to encapsulate principal ideas or metaphors as a whole (global theme) where it was found that children conceptualised cancer as either one or a combination of the following global themes by: 1) understanding cancer from a medical inference, 2) understanding cancer from the state of their parent being sick and, 3) understanding cancer from causes. The three global themes were then regrouped to encapsulate "Nuances of meanings attached to cancer and children's experience". An overview of the resultant thematic network is illustrated in Figure 3.

Figure 3 - Nuances of meanings attached to cancer and children's experience

A description and selected examples evidencing these organising themes are provided.

1) Understanding cancer from "Medical Inferences"

This organizing theme was developed from clustering participants' use of cancer-related medical terms like surgery and chemotherapy and/or explanations including descriptions of illness, cellular damage and other medically descriptive words or drawings. A few participants, especially older carer children understood cancer as "An illness...", "A disease..." or "A sickness...". Cancer seemed to emerge as a term with medical connotations with either a description of the development of cancer, the treatment process or a medical situation. This was identified as a) Cancer is "a type of possibly deadly illness, sickness or disease" and b) Cancer "Requires hospitalisation, special medication and long treatment process". Examples are provided in Figure 4.

Global Theme				
UNDERSTANDING CANCER FROM MEDICAL INFERENCE				
Organising Theme				
a. "A type of possibly deadly illness, sickness or disease"				
Basic Themes	Cancer is dangerous and can be deadly	Cancer damaged cells	Cancer developed from uncontrolled cell growth or mutation	Cancer can spread and damage other cells (metastases)
Codes	F1(C3): "It is a type of dangerous disease . For example, (it effects the) breast, brain and such like"	F2(C3): "(explained drawn circles as) damaged cells "	F5(C2): "Cancer is a sickness. Overgrown tissue that's turn to be lump and accessive in a person body. This accessive lump will become cancerous and dangerous to the person..."	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
Responses				
Organising Theme				
b. "Requires hospitalization, special medication and long treatment process"				
Basic Themes	Surgery, mastectomy or lumpectomy and/or invasive action to save life	Cancer treatment involved chemotherapy, radiotherapy and immunotherapy	Required specialist doctors, complex equipment and special ward	Required vigilant care and frequent medical check-up
Codes	F1(C1): "... surgery ..."	F5(C1): "... have radiotherapy ... have chemotherapy ..."	F3(C1): " Special ward "	F6(C1): "...mama always goes to this hospital "

Figure 4- Thematic structure and examples for “Understanding cancer from medical inference”

Thematic structure from Figure 4:

a) Cancer is “a type of possibly deadly illness, sickness or disease”

It was found that contrary to parents’ perception, children participants understood the seriousness of cancer and the possibility of mortality. Children participants described through 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. Children participants perceived cancer was deadly from their belief that cancer can damage other internal organs. These children seemed to understand that the development of cancer began at the cellular level and this 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. Several children also cited the importance of treatment. This indicated some sensitivity to the parent’s situation and children’s effort in obtaining information about cancer.

Some children participants appropriated their parents’ explanation as their own. This reinforces the finding that parental knowledge influenced their children’s assimilation of information and that children’s environment shapes their learning (Wilson, 2012; Sherlin et. al., 2011):

[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** ...

[F5(C3)]:

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

b) Cancer “Requires hospitalisation, special medication and long treatment process”

Parents required many trips to the hospital to check if they were healthy enough to undergo chemotherapy and to assess their progress. Several children participants almost always accompanied their mother for her check-ups. This resulted in descriptions of their parent undergoing surgery, a biopsy, a mastectomy or lumpectomy. 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**.

INTERVIEWE Could you tell me why you drew this hospital?

R:

F6(C1): Umm ... *mama* always goes to this **hospital**.

INTERVIEWE Why do you think so?

R:

F6(C1): Umm ... because she is always **sick**. **Every time** she has to go to the **hospital**.

INTERVIEWE How often do you mean by every time?

R:

F6(C1): Umm ... **very often**. Like ... **all the time**.

INTERVIEWE Why do you think she has to go all the time?

R:

F6(C1): She is **sick**, she goes to the **hospital** lah.

INTERVIEWE Why is she sick?

R:

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**.

Associations of a hospital stay, requiring surgery and the use of special medication were observations of children who accompanied their parent during medical check-ups or throughout the duration of a hospital stay. This finding supports reports by the American Cancer Society (2012c, para. 2), Christ and Christ (2010), Kornreich et al. (2008) and the National Cancer Institute (2012b) where parents could not keep their cancer diagnosis a secret.

2) Understanding cancer from "State of Parent Being Sick"

This organizing theme was developed from clustering participants' descriptions, observations and/or experience that used descriptive words or drawings related to symptoms of a person defined as being sick or ill. Children participants reported side effects of medication and treatments as one of the defining hallmarks of cancer. Most children participants could clearly recall and describe vividly how sick their parent was. This finding supports reports by National Cancer Institute (2012a, 2012b, 2003e, p. 17), Finch and Gibson (2009) and Sweeney (2004, p.21) where children participants were aware that their parent was ill from mannerisms and visual cues.

Children described this as a person 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 being sick was caused directly by cancer and treatments. This is further discussed from the theme of a) Physical side effects, b) Understanding Cancer by secondary side effects, and c) Understanding Cancer by Non-Physical Side Effects. The structure of this theme and selected examples are provided in Figure 5.

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Global Theme	UNDERSTANDING CANCER FROM STATE OF PARENT BEING SICK				
Organising Theme	a) Physical side effects of cancer and cancer treatment				
Basic Themes	Mastectomy caused pain	Chemotherapy caused nausea, vomiting and hair loss	Parent's bodily aches and pains	Rest as a precursor to getting better	Tamoxifen caused early menopause
Codes	F2(C1): "I drew mother in pain ... cancer hurts emak ... and she feels pain there (chest area)."	F4(C1): "Mother frequently vomited ... It was the cancer ... It was the medicines ... aaa ... the chemo. "	F5(C2): "... all the wires ... like a telephone line entering her 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. "	F4(C1): " Cancer hurts the whole body and it makes the person with cancer feel unwell and need plenty of rest. "	F3(C4): "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."
Responses					
Organising Theme	b) Understanding cancer by secondary side effects				
Basic Themes	Effects of frequent vomiting	Effects of bodily aches and pains	Children's sympathetic somatization to side-effects	Effects of hair loss	Effects of early menopause
Codes	F10(C1): "Ummy got so thin ...She just vomited all her fat out. She's crying because that's what happens	F3(C2): "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): " Cancer is scary because you have to go for an operation ... staying in the hospital alone, injection , feel in great pain ...	F10(C1): " Cancer is scary because ... bald ... not scary, scary, but funny scary ... like an alien (shudders). ... She did not have her 'Rapunzel' hair anymore. She became bald like	F3(C4): "When my period (menses) comes, I do not want to tell my mother because I am afraid that she might feel upset because

Figure 5: Thematic structure and examples for “Understanding cancer from state of parent being sick

c) Understanding Cancer by Non-Physical Side Effects

Participants’ understanding of cancer were also coded from their words of “prayer”, “faith”, “good deeds”, “willpower”, “Thanks to God” and “negative emotion”. These codes were then structured as having two themes: i) spiritual state and ii) emotional state. Approximately 21% of participants included those words in their understanding of cancer. Selected examples are provided in Figure 6.

Children participants realised and acknowledged that their parent was in some sort of distress. This upheld reports by Becker and Becker (2008, p. 15), Kornreich et al. (2008, pp. 64-65) and Forrest et al. (2006, p. 998). These 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. In an effort to make sense of their situation, these children participants attributed cancer as causing the emotional upheaval in their parents.

However, these children could not make precise inferences nor correct causation, and so, made up their own reasons. 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. Some of these reasons, as in the case of children participants from Family One, were very different from their parent’s real concerns. Similar to findings by Finch and Gibson (2009) and Sweeney (2004, p.21), it was found that these behavioural cues contributed to children’s’ misunderstanding about cancer, cancer treatment and, parents’ experiences and expectations about children’s’ behaviours.

3) Understanding Cancer from “Causes”

This organizing theme was developed from clustering participants’ descriptions, observations and/or experience that mentioned or drew participants’ beliefs about what caused parental cancer the cause of cancer. As indicated in Figure 3, a few participants equated cancer as a sickness, an illness or disease caused by either one of two themes: a) medically proven cause and, b) perceived cause. This was developed from participant’s responses that cancer was caused by either one or a combination of codes: “history”, “knowledge”, “smoking”, “pollution”, “exercise”, “stress”, “food”, “alien” and “God’s test”. Selected examples are provided in Figure 6.

Global Theme	UNDERSTANDING CANCER FROM CAUSES			
Organising Theme	a) Medically proven causes			
Basic Theme	History and genetic predisposition		Unhealthy habits	
Responses and Codes	<p>F5(C3): “Our cousin told us what to expect, still, it is nothing like the experience yourself.”</p> <p>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”</p>		<p>F2(C4): “I read and remembered that cancer is caused by smoking, high stress and not eating a good balanced diet with fruits and vegetables. I asked the doctor and he said that could be the cause, so I believe it. It must be the eating of those unhealthy foods.”</p>	
Organising Theme	b) Perceived causes			
Basic Theme	Polluted environment	Lifestyle	Attack	Test from God

Responses and Codes	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 "	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."	F9(C1): " Cancer is a type of sickness ... caused by something attacked a weak person's body..."	F2(C4): "You are tested ... Are you prepared to die? Have you done enough to get to heaven? Cancer lets you have that time to really, really be more religious before your time is up.
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Figure 6 - Thematic structure and examples for "Understanding cancer from causes"

a) "Understanding cancer from medically proven cause"

Cancer was attributed to 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 evident in the case of Family Five where the parent had shared her knowledge of cancer being a family history with her children. Selected examples are provided in Figure 6.

b) "Understanding cancer from perceived cause"

Cancer was attributed to "polluted environment", "lifestyle", "attack" and "test from God". Most children, irrespective of the extent and depth of their knowledge, attributed pollutants and a sedentary and unhealthy lifestyle as probable causes of cancer. Children and parents had either read or heard from people around them. An example is provided in Figure 6.

These findings indicated that children articulated their understanding through anecdotal narratives and drawings. The meaning of cancer was described and explained as having components made from children's experiences, observations and beliefs. Children participants' observations (whether children 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).

6. DISCUSSION

The findings showed that unlike medical definitions, children understood cancer in different ways. Cancer information sourced through the Internet and oncology brochures provided medical definitions that were verbose, used complex language structures and were written in a language that most Malay children were not fluent in. Comparatively, children participants meaning of cancer was described and explained as having components made from their experiences, observations and beliefs.

Participants defined cancer from an experience perspective, based on how cancer affected children on a personal level and their observations about their mother. Age as a variable to children's responses was not a focus of the study. However, responses indicated that older children carers had more information and explained cancer using a medical inference. These children's role as a

caregiver provided different depth of understanding about cancer and can be attributed to the extent and scope of their information needs and information seeking behaviour. Cancer terminologies and information provisions for children's use should reflect an experience perspective and judicious use of age-appropriate medical terms and definitions. Kornreich et al. (2008) for example, advocated for informative communication to be cognizant of children's possible reactions and to reduce long term consequences.

A few parent and children participants understood cancer as a type of possibly deadly illness, sickness or disease. Some of these children did not differentiate the terms and used them interchangeably, which may be attributed to their limited vocabulary or a shallower understanding of nuances of illness and experience of being sick. The use of medical terms could either be simplified into age-appropriate language or be more descriptive to facilitate understanding. Baker (2006) for example, advocated for the development of easier to understand health-related information because reading fluency influenced health outcomes. Moreover, Gupta et al. (2016) reported the advocacy for a separate definition and information provision for cancer because the knowledge and skills required for health management by non-medical persons "were sufficiently complex to warrant a separate conceptualization". These advocacies were even more relevant to help children understand their experience and carer tasks. Cognizant of children's literacy ability may help mitigate children's negative reactions and the carer problems children face.

Cancer was associated with hospitalisation, special medication and a long treatment process. Children feared this and were concerned about their mother being away. Prior discussion with children may help them prepare for exposure to hospital based activities. Information about coping mechanisms, treatment modalities, relevant hospital services, activities and health providers may be of help to mitigate children's fears and anxiety. Most children participants recognised that their parent was sick from descriptions of physical and non-physical side effects of cancer and cancer treatments. Parents' bodily aches and pain, emotional state, hair loss, frequent vomiting, rest requirements and advent of an early menopause were recurring observational themes. Children participants reported being fearful, upset, tired and experiencing sympathetic somatisation. Children needed help to come to terms with their new environment and to understand their parental health situation. Older children specifically needed information to prepare for carer tasks. Buchwald et al. (2011, p.233) for example, reported that being informed and being prepared helped children to better manage their situation.

A few participants formed causal reasons for parental cancer, either medically proven or not. Causation seemed rather limited and was dependent on participants' existing prior knowledge and/or beliefs which included cancer as a "Test from God". Where evident of children participants' misunderstanding about cancer, a lack of information, low literacy 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). Responses suggested that there were gaps in information provisions and that children had unmet needs to facilitate experiential understanding about cancer and caregiving. Information provision could better reflect these needs in a manner that was simplified while not detracting from medical and scientific evidence to ensure that myths and misinformation does not further exacerbate misunderstandings about cancer, its causes, treatment modalities and prevention strategies which can be detrimental to children's wellbeing and health practices.

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. The change in parental behaviours and norms influenced children participants' formation of beliefs about cancer,

its causes and effects. It was not surprising that understanding was influenced by combining observations of parents while undergoing cancer treatments and, contextualising experience and available information into what made the most sense. This is evidence that children developed their “own explanatory principle” (Papert, 1999, para. 3) when they lacked sufficient information or the skills to process information. Responses suggested that learning was an active process to make sense of cancer and experiences. This supports the principles inherent in Learning Theories where learning is a response to a stimulus (Sherlin et. al., 2011, p. 293) and, 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).

7. CONCLUSION

This study suggests that children made sense of cancer through their experience, observations and beliefs. Children participants’ contextual understanding and concept of cancer suggested that their information needs were varied and that children had more nuances of concern than previously documented. The comparison between available information about cancer highlights the disparity between medical and children’s perspectives. The meanings these children attached to cancer and their experiences had not been identified in earlier research. Information seeking behaviours, information pathways and information processing and assimilation fail to reflect the different nuances of non-western, non-English speaking people. The finding reinforces advocacies by Saracevic (1997, p. 6) to develop more “effective and efficient interface between people and literature”. Information provisions and intervention should utilize the language and articulated meanings that children attach to a parent’s cancer. Similar advocacies were made by Kalbach (2000, para. 47), Johnstone et al. (2004, para. 38), Brashers et al. (2002, p. 263) and Dervin and Nilan (1986, p. 16). Health campaigns and its advocacy by many organisations also have come to realize that human-centric information is an integral communication process to create greater relevancy, understanding and adherence to health advice.

From an Information Science perspective, the available information about cancer had failed to deliver solutions to Malay children caregivers. Children’s perception and reaction to cancer has implications in the context and content of information, its design, accessibility and relevancy. In this, older research by Dervin and Nilan (1986) still holds true because information about cancer maintained the philosophy that “... information is seen as the objective ...”, and that the said information provision was from an “engineering perspective rather than the needs of users”. This failure contradicted more current wisdoms by Wilson (2012), Brewer and Sparks (2011) and Kennedy and Williams (2009).

Findings showed how Social Constructionism Theory explained children participants’ knowledge and reality of their parental cancer was constructed and understood through everyday interactions with their family members and their social environment. 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. Learning Theories helped to identify actions and narratives of children participants as their learning through observing, modelling and cognitively processing the behaviour of others through “vicarious conditioning” (Mineka and Zinbarg (2006, p. 11). This was evidenced by children participants’ somatization experience, the development of caregiving skill sets and children’s reactions to the side effects of cancer. Most notably the abnormalcy attributed to mother’s hair loss as being less feminine, less attractive and alien. This could be attributed to the influence of cultural imperatives and community views about gender norms.

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3 In conclusion, the findings from this study accorded with Barnes et. al.'s (2000, p. 481), Skovdal and
4 Ogutu (2009, para. 5-6), Becker (2007, pp. 3-11) and Scott et. al. (2003b, pp. 1-2) and report that
5 children have more potential to understand complex concepts of illness than was previously
6 appreciated or anticipated. All children participants in this research knew that their parent had
7 cancer and even though parents feared full disclosure, the children were pivotal in home care and
8 noticed symptoms of their parent being unwell. This experience reinforces findings by the American
9 Cancer Society (2012a, 2012b), Weaver et al. (2010), Skovdal and Ogutu (2009), Aldridge (2005) and
10 Scott et al. (2003b). Children's assimilation of information resulted in more nuances of emotive and
11 physical descriptions that were influenced by their experiences, observations and beliefs, including
12 misinformation and myths. This contradicted medical definition which presents a mismatch between
13 terms, understanding cancer, caregiving, information needs and, preventive strategies. These
14 phenomena reinforces Kirkby and Whelan (1996, p. 77) recommendations that the adoption of a
15 family systems perspective in future research will further the understanding of how children and
16 their families cope with medical procedures.
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Figure 1- Scope of review and search terms used in this study

Table 1. 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 (Glasner, 2004) 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 (Glasner, 2004) observations were included in transcripts to describe participants' behaviours in-situ to aid in analysis and researcher's recall.
3.	DATA EXPLICITATION PROCESS	Guided by 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. Supported by memos (Glasner, 2004) and discussions with others to clarify experiences and problems (Rolls and Relf, 2006, p. 287).
4.	DATA PROCESSING AND ANALYSIS	An Interpretative Phenomenological Analysis (IPA) guided by Smith and Osborn (2007) and Smith et al. (2009). 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.

Table 1- Steps in data explication, analysis and coding

NUANCES OF MEANINGS ATTACHED TO CANCER AND CHILDREN'S EXPERIENCE				
Global Theme	1. UNDERSTANDING CANCER FROM MEDICAL INFERENCE			
Organising Theme	A. "A type of possibly deadly illness, sickness or disease"			
Basic Theme	Cancer is dangerous and can be deadly	Cancer damaged cells	Cancer developed from uncontrolled cell growth or mutation	Cancer can spread and damage other cells (mestastes)
Organising Theme	B. "Requires hospitalization, special medication and long treatment process"			
Basic Theme	Surgery, mastectomy or lumpectomy and/or invasive action to save life	Cancer treatment involved chemotherapy, radiotherapy and immunotherapy	Required specialist doctors, complex equipment and special ward	Required vigilant care and frequent medical check-up
Global Theme	2. UNDERSTANDING CANCER FROM THE STATE OF PARENT BEING SICK			
Organising Theme	A. Physical side effects of cancer and cancer treatment			
Basic Theme	Mastectomy caused pain	Chemotherapy caused nausea, vomiting and hair loss	Parent's bodily aches and pains	Rest as a precursor to getting better
Organising Theme	B. Understanding cancer by secondary side effects			
Basic Theme	Effects of frequent vomiting	Effects of bodily aches and pains	Children's sympathetic somatization to side-effects	Effects of early menopause
Organising Theme	C. Understanding cancer by non-physical side effects of cancer and cancer treatment			
Basic Theme	Spiritual state		Emotional state	
Global Theme	3. UNDERSTANDING CANCER FROM CAUSES			
Organising Theme	A. Medically proven causes			
Basic Theme	History and genetic predisposition		Unhealthy habits	
Organising Theme	B. Perceived causes

Figure 2 - Nuances of meanings attached to cancer and children's experience

Global Theme	UNDERSTANDING CANCER FROM MEDICAL INFERENCE			
Organising Theme	a. "A type of possibly deadly illness, sickness or disease"			
Basic Themes	Cancer is dangerous and can be deadly	Cancer damaged cells	Cancer developed from uncontrolled cell growth or mutation	Cancer can spread and damage other cells (mestastes)
Codes	F1(C3): "It is a type of dangerous disease . For example, (it effects the) breast, brain and such like"	F2(C3): "(explained drawn circles as) damaged cells "	F5(C2): "Cancer is a sickness. Overgrown tissue that's turn to be lump and accessive in a person body. This accessive lump will become cancerous and dangerous to the person..."	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
Responses
Organising Theme	b. "Requires hospitalization, special medication and long treatment process"			
Basic Themes	Surgery, mastectomy or lumpectomy and/or invasive action to save life	Cancer treatment involved chemotherapy, radiotherapy and immunotherapy	Required specialist doctors, complex equipment and special ward	Required vigilant care and frequent medical check-up
Codes	F1(C1): "... surgery ..."	F5(C1): "... have radiotherapy ... have chemotherapy ..."	F3(C1): " Special ward "	F6(C1): "...mama always goes to this hospital "
Responses

Figure 3- Thematic structure and examples for "Understanding cancer from medical inference"

Global Theme	UNDERSTANDING CANCER FROM STATE OF PARENT BEING SICK					
Organising Theme	a) Physical side effects of cancer and cancer treatment					
Basic Theme	Mastectomy caused pain	Chemotherapy caused nausea, vomiting and hair loss	Parent's bodily aches and pains	Rest as a precursor to getting better	Tamoxifen caused early menopause	
Codes	F2(C1): "I drew mother in pain ... cancer hurts emak ... and she feels pain there (chest area)."	F4(C1): "Mother frequently vomited ... It was the cancer ... It was the medicines ... aaa ... the chemo. "	F5(C2): "... all the wires ... like a telephone line entering her 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. "	F4(C1): " Cancer hurts the whole body and it makes the person with cancer feel unwell and need plenty of rest."	F3(C4): "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."	
Responses						
Organising Theme	b) Understanding cancer by secondary side effects					
Basic Themes	Effects of frequent vomiting	Effects of bodily aches and pains	Children's sympathetic somatization to side-effects	Effects of hair loss	Effects of early menopause	
Codes	F10(C1): "Ummi got so thin ... She just vomited all her fat out. She's crying because that's what happens when you vomit too hard."	F3(C2): "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): " Cancer is scary because you have to go for an operation ... staying in the hospital alone, injection, feel in great pain ... I fear having to	F10(C1): " Cancer is scary because ... bald ... not scary, scary, but funny scary ... like an alien (shudders). ... She did not have her	F3(C4): "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	

Responses		<p>go for an operation. Very frightening ... because it will be painful</p> <p>'Rapunzel' hair anymore. She became bald like some ogre."</p> <p>have her period (menses) anymore (at 43 years old)"</p>
Organising Theme	c) Understanding cancer by non-physical side effects of cancer and cancer treatment	
Basic Theme	Spiritual state	Emotional state
Codes	<p>[F5(C2)]: "Thanks to God, I was there for her radiotherapy. Thanks to God, she had recovered and doing good till now ... 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."</p>	<p>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."</p>

Figure 4: Thematic structure and examples for "Understanding cancer from state of parent being sick

Global Theme	UNDERSTANDING CANCER FROM CAUSES			
Organising Theme	a) Medically proven causes			
Basic Theme	History and genetic predisposition		Unhealthy habits	
Responses and Codes	<p>F5(C3): “Our cousin told us what to expect, still, it is nothing like the experience yourself.”</p> <p>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”</p>		<p>F2(C4): “I read and remembered that cancer is caused by smoking, high stress and not eating a good balanced diet with fruits and vegetables. I asked the doctor and he said that could be the cause, so I believe it. It must be the eating of those unhealthy foods.”</p>	
Organising Theme	b) Perceived causes			
Basic Theme	Polluted environment	Lifestyle	Attack	Test from God
Responses and Codes	<p>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”</p>	<p>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.”</p>	<p>F9(C1): “Cancer is a type of sickness ... caused by something attacked a weak person’s body...”</p>	<p>F2(C4): “You are tested ... Are you prepared to die? Have you done enough to get to heaven? Cancer lets you have that time to really, really be more religious before your time is up.</p>

Figure 5 - Thematic structure and examples for "Understanding cancer from causes"