User Experience of Brazilian Public Healthcare System: A case study on the accessibility of the information provided.

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**Abstract:**

This paper describes a preliminary study into user experience of Brazilian Public Healthcare System - Sistema Unico de Saúde (SUS). It focuses on the accessibility of the information at three stages: information delivered by the doctor to the patient; the information available for the patient outside the clinic; and the type and amount of information the patient has to handle with meanwhile being diagnosed. This was based on a two-month ethnographic study of a patient diagnosed with liver cancer. The study takes into account the patient’s condition, his age, and his partner’s age, aiming to highlight challenges and gaps in the process, especially those extra demanding for elderly people. The results indicate that mapping the user experience and the key stages throughout the process are useful to outline and understand accessibility issues. The findings highlight opportunities in the process to design better interactions and ways to deliver information, considering elderly users needs.

Keywords: SUS, service design, patient journey, inclusive design, patient experience

1. Introduction

In the world, almost two-thirds of the people aged over 60 live in developing countries. Latin America is experiencing this demographic shift, with some countries, like Brazil, Argentina, Uruguay and Chile having more than 10% of the population aged 60 and older (IMF, 2018). The number of older persons in Latin America will nearly triple to 196 million by 2050 (United Nations, 2014).

The challenges of ageing societies in developing countries are particularly new and of great concern as they reflect on how to implement sustainable infrastructures, including those for public healthcare service. The growing number of elderly people directly affects healthcare systems and costs. People aged over 60 are the most affected by health problems compared to any other age group. And thus, preparing healthcare infrastructures in order to be sustainable, safe and inclusive means to consider elderly people needs, especially those related to accessibility to healthcare services.

1.1 Brazilian Context

The Brazilian public healthcare service (SUS) was designed to cover primary and clinical care in all regions of the country, similarly to the British National Health Service (NHS). Although the history of SUS is recent, being institutionalised in 1990 (Kleinert & Horton, 2011 – p.4), it serves around 162 million people of 209 million of Brazilians, disregard of their age and income (O Globo, 2018). Among the challenges faced by SUS, a significant one is that Brazil has experienced a huge demographic shift in the last decades, the older adult population has doubled in the last 40 years and life expectancy has increased 40% during the same period (Paim, Travassos, Almeida, Bahia & Macinkoand, 2011).

The increase of older adult population and their life expectancy has significantly affected healthcare service in Brazil. According to last census, in Brazil there are more than 23 million people aged 60 and over (IBGE, 2011), from which 70% (16million) are dependent of public healthcare - SUS (Ministerio da Saúde, 2014). Additionally, the elderly population in Brazil is expected to be the sixth largest in the world by 2025 (Ramos, 2016). As a result, the services provided by the healthcare system must consider the great proportion of users that are older and possibly have special needs.

1.2 Special Needs Among Elderly People

Worldwide, within the ageing process, especially for people aged 60 and beyond, there is a steady increase in the chances of all measures of sensory, intellectual and physical function decline away from optimum. For example, age affects several visual abilities, four of them are listed below:

1. Visual acuity: the ability of eye's pupil to change size to adapt to ambient light diminishes, decreasing the capacity to see fine details;

2. Contrast sensitivity: the increased opacity of the lens of the eyes decreases the capability to distinguish between light and dark;

3. Accommodation: loss of elasticity of eye's tissues affects the ability to focus on near and far objects;

4. Colour discrimination: with age the lens of the eyes build an yellow pigmentation which decreases the ability to distinguish between colours;

Similarly, with age some cognitive capability decreases, for example:

1. Reaction time changes and in more complex tasks, older adults react slowly if compared to young people;

2. Short term memory changes with age affecting how elderly people learn and recall, especially unfamiliar procedures and tasks;

3. The difficulty of doing two things at the same time increases with age affecting divided attention.

One way found effective to measure the disability incidence (or loss of capabilities) among the population is by using disability scales that relates to the capability of performing daily 'ordinary' tasks (Martin et al, 1989). Using this disability scales, Keates and Clarkson (2003) presented the incidence of disabilities among age groups – shown on figure 1. The authors based their studies on the research carried out by Grundy et al (1999), introducing the percentage of the population related to the disability severity scores. In this way, they initiate the concept of exclusion that certain tasks and certain interactions can cause. The Inclusive Design Toolkit and the Exclusion Calculator is part of this development (Waller et al., 2010b).

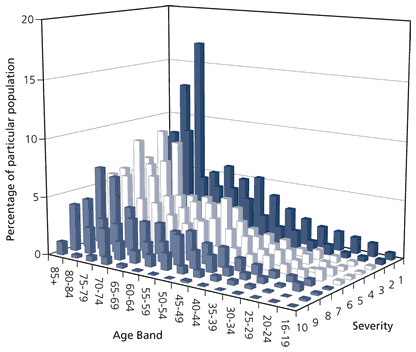


Figure 1. Disability severity group by age band and percentage of the UK adult population (Keates & Clarkson, 2003).

By considering disabilities from an interaction point of view, it is easier to build the connection between the design and the exclusion it can cause (Zitkus et al, 2018). A design difficult to read can exclude a huge percentage of the population. Such consideration enable the design or re-design of accessible, understandable and ease of use spaces, information and products, not only for the older adult, but also for other patients with disabilities whether temporary or not (due to their illness or treatment they are undertaking). In this way, losses of capability, such as locomotion, dexterity, learning, memory, divided attention, visual acuity, contrast sensitivity, colour discrimination and hearing must be considered when designing services, products and physical environments.

In fact, worldwide disability prevalence is higher in elderly people. For instance, in Europe on average, the disability prevalence among people aged 65 and over is four times higher than people aged 15 to 44 and two times higher than people aged 45 to 64 years (Eurostat, 2015). Similarly, in the USA more than 38% of people aged over 65 reported having at least one type of disability, which is the age group with the highest incidence of disability (He and Larsen, 2014). In Brazil, the figures are notable, among the people with any kind of disability 68% are aged above 65 years old, being the visual disabilities the most common disability among the elderly (50%), followed by dexterity problems (38%), hearing loss (26%) and cognitive disability (3%) (IBGE, 2011). Therefore, the services provided in healthcare must consider the needs of elderly people in order to design and develop systems and services that accommodate and include them.

Accessibility issues faced by elderly users of the SUS is a topical issue that has not yet been intensively investigated or monitored (Romero et al, 2018; Baldoni and Pereira, 2011). In fact, a body of research in accessibility issues of healthcare services has not been found. Moreover, only recently, accessibility policies in benefit of people with disability have been of concern to SUS (RCPCD on SUS, 2017). Accessibility issues in this paper, range from physical structures to ways of delivering patient information that are inaccessible for elderly people with reduced physical, sensorial or cognitive capacity - i.e. motion, visual, hearing impairments, memory loss and decrease on learning capability.

2. *Methods: User Experience in Healthcare Design*

Research into healthcare services, processes, and systems has been of enormous value to the society (Lowes & Hulatt, 2005). Healthcare service research conducted within NHS has helped to understand some of the issues and gaps in the system and in some cases has contributed with recommendations on re-design of building, services or products to propose a safer and more inclusive environment (Clarkson et al, 2017; Adams et al, 2013). User experience can play a significant role in understanding and rethinking healthcare service design. Across the world, the healthcare services are widely acknowledged as complex systems, in which the cognitive load of key moments throughout the processes can be very demanding to the users. User experience is defined as "*a person's perceptions and responses that result from the use of a product, system or service*" ( ISO 9241-210). In the design disciplines, User experience design refers to design process that place people (potential users) in its centre (Van der Bijl-Brouwer and Dorst, 2017). In this way, user experience is of particular importance to assess healthcare processes and the key moments of user interaction, helping to rethink the design of services (Trebble *et al*., 2010; Ben-Tovim *et al*., 2008).

The design of services is understood by the information available and the user capabilities to process this information; the way the information is displayed and the users' needs; the context in which the information is delivered with the user's motivations, feelings and values related to that context (Barnard *et al*., 2013). It is important to emphasise that the primary user of healthcare services is the patient, who can be already affected by the medical condition and suffering with some losses of cognitive, sensorial or physical capabilities. In addition, in some occasions, the primary user (patient) or secondary user (patient's relatives and carers) will have to deal with unfamiliar information, such as medical terminology, procedures and treatments, implying in extra complicated and distressing situations. Hence, user experience design helps to understand users’ attitudes, perceptions and expectations in order to design compatible, safe and reliable service attributes.

In the recent years, the number of research into design as a strategic tool for enterprise innovation and transformation has increased significantly. One of the highlighted front areas where design has the potential to innovate and transform is the healthcare sector (Libânio and Franzato, 2018; Tsekleves and Cooper, 2017). Nevertheless, in Brazil, the potential of applying design in the healthcare sector has not being widely disseminated (Freire, 2016). Libânio and Franzato (2018) state that the complexity of the Brazilian healthcare system is a result of high service provider's coverage, involving unpredictability, plurality, dynamics and uncertainties in its ecosystem. Therefore, this article concentrates in a single case study that highlights accessibility issues of the service provided by a University Hospital that belongs to SUS and the challenges faced by a patient that may be recurrent in several healthcare services across the country.

According to Trebble et al (2010) “Process mapping allows us to ‘see’ and understand the patient’s experience by separating the management of a specific condition or treatment into a series of consecutive events or steps. The sequence of these steps between two points can be viewed as a patient pathway”. Figure 2 represents the patient pathway of this study, from the first contact with GP through a series of 17 steps until start treatment.

2.1 An Ethnographic Study

This paper draws on an ethnographic study conducted during two months within a patient diagnosed with liver cancer and his family, as well as their interactions with the University Hospital that is part of the Brazilian public healthcare system - SUS. It is based on what was reported back to the researcher by the patient, his wife and his daughter. As the study is based on the patient's report, the researcher did not involve doctors or any member of the University Hospital as part of the research. Nevertheless, observations of the building environment and the facilities used were carried out to understand patient’s pathway.

The study concentrates on the views of the patient on the healthcare process, consisting of **everyday** observations and unstructured interviews during two months. Long conversations followed every step taken in the patient journey. They happened in the same day it occurred. Then, in the next day, some of the topics that emerged during the conversation were clarified and explained in more details. This paper is a summary of some key steps the patient went through, considering how the circumstances, environment and the way the information is delivered affected its accessibility.

The study was conducted in the province of Sao Paulo where a University Hospital is available for the use of the general public of 68 cities in its region. Patients in the catchment area are first assigned to their General Practice - Unidade Básica de Saúde (UBS) - which in turn refers to the University Hospital for the necessary specialised care (see figure 2).

This study focused on the accessibility of the information at three stages: information delivered by the doctor to the patient; the information available for patient outside the clinic (i.e. online information); and the type and amount of information the patient has to handle with meanwhile being diagnosed.

3. Mapping Patient Experience

The patient experience in this study started on the first clinical appointment held at the University Hospital. It followed the patient pathway from his first appointment, through the series of consecutive events. The study considers the patient's routine and the challenges encountered in the process. The focus of the study is on the accessibility of the information received through medical appointments (the type and amount of data gathered in this appointments are also discussed) and, the information available outside the clinic.

Accessibility is discussed in terms of physical, sensorial and cognitive capability in order to understand the abilities that might decrease with age, whether slightly or severely. In general, it takes into account any restriction or lack of ability to perform an activity in the manner or within the range considered normal. This approach helps to classify the design problems encountered in the service provided by correlating design and older users capability (Zitkus *et al*., 2018; Lim and Sato, 2006).

3.1 A Common Pathway of SUS Patient

Patients are referred to their General Practice - Unidade Básica de Saúde (UBS) according to the catchment area of where they live. They are assessed by the GP and if the illness is not recognised and a treatment is not assigned, the patient is requested to do some health screening tests and make another GP appointment, which will determine the treatment, will ask for more tests / scans or will refer to a specialist in the University Hospital. The flow-chart below shows the patient journey from UBS to Tests / Scans, Clinics, Tests / Scans and Treatment.



Figure 2. SUS Patients journey - common pathway to diagnose and treatment of Cancer.

The numbers in the Figure 2 are the sequence of steps from UBS interaction (1), blood tests (2), UBS appointment (3), scan ultrasound (4), another UBS appointment (5) and then referred to University Hospital. The transition from UBS to clinic can be a problem with unpleasant delays of several weeks or months. The figure 3 shows the common steps taken by patients with cancer and how the waiting times can be dealt differently according to urgency or the GP direct contact. Differently, in the case of waiting time for scans, the urgency of the patient condition do not interfere in the appointment, patients have to wait until the next available time, which can take an unexpectedly long time (few to several months). However, there is an internal (informal) procedure of doctors contacting the Lab Manager to discuss the urgency of the case and ask for an earlier appointment.



Figure 3. SUS Patients journey - common steps from UBS to treatment.

4. *The Journey of a Patient with Liver Cancer*

Doctor specialist appointments take place from 1pm to 5pm in this University Hospital, and patients are asked to attend to the reception from 12:30 onwards to check-in. The access to the clinic - ambulatory care facility - is through stairs or a steep access ramp, which sometimes require wheelchair assistance to help the patients on the way to the reception. In the reception the volume of patient is very high and during the check-in every patient is informed that they will see the doctor in order of arrival. However, there is not a reference regarding how many patients have checked in ( (i.e. a sequence number and a screen showing next patient number) or the estimated time to be seen by the doctor. Although they are sat together in the reception area, they will see different specialists from different areas, which makes difficult to predict how long they will have to wait to see the doctor, as a consequence of which all patients have to wait in the reception area from the time of arrival onwards, sometimes for more than four hours.

When the time to see the doctor comes, the reception calls for the name of the patient. Often the calls are not audible due to the surrounded noise. The waiting room is an open space, it is not a closed room. The fact that the patient struggles to hear the name being called affects the reception flow as often patients double check whether they were called or not. Hearing impaired people would have to refer for special assistance (whether assistance is available on demand is not known).

When patients are called they are told the room number to attend. They walk through a corridor that takes to several rooms where the doctors are. The way the doctors interact with patients vary enormously from one doctor to another, information delivery by the doctor to the patient is greatly affected by the way the doctor interact with the patient. Doctors that avoid eye contact, look at the computer screen while talking and restrict the sessions with patients as brief as possible (generally a session do not last more than 20 minutes), tend to be the ones that delivery the patient information without any awareness of patient health literacy and understanding of what is going to happen next. These consultants use terminology that are unfamiliar for patients and family members. They do not check if they communicated correctly and thus if the patient, family members or carers are understanding the instructions being given.

Typically at the end of each doctor specialist appointment in the clinic (University Hospital) the patient had instructions related to prescriptions; screening tests (blood, urine, etc.); other tests and scans (varying from computed tomography, biopsy, endoscopy, etc.); and next appointments. Usually the instructions would not be reviewed with the patient, who would leave the doctor's room with several piece of papers referring to several procedures. Figure 4 shows the type and amount of information sheets for prescriptions, appointments and tests provided to the patient. The following section will discuss step by step what was the outcome of every appointment and how this interfere on the way information is handled.

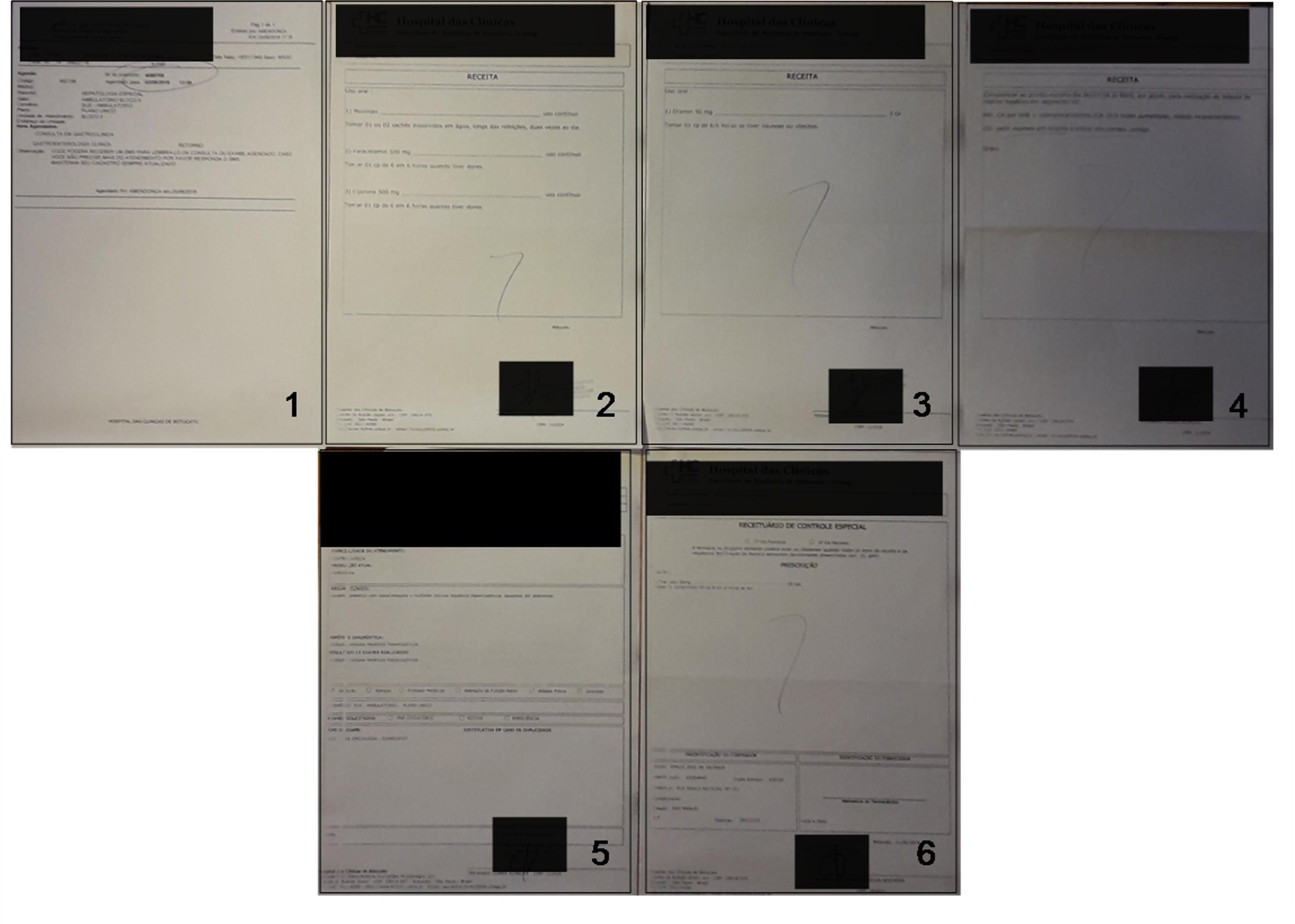


Figure 4. SUS Patients journey - common steps from UBS to treatment.

4.1 From First Clinical Assessment to First Computed Tomography

In this paper, the patient journey started with the appointment with a doctor specialist - hepatologist in the university hospital - and followed the first five key steps taken by him (number 1 to 5 in the figure 5). Figure 5 displays the part of figure 2 that is analysed in this paper. The patient was suffering with an abdominal pain that was getting worse every week. He could not be diagnosed in the first and second instance in the UBS. The patient (a 69 years old men) attended the appointment with his wife (a 68 years old woman). They checked in at the reception around 12:30pm and waited in the waiting area for almost two hours until being called by the doctor.

They brought with them the ultrasound result and several blood tests - the ultrasound test was carried out in a private lab to avoid waiting several weeks to get an appointment with a public lab. The doctor examined the patient and read the test result. He asked few questions related to symptoms; health, eating, drinking habits; medications being taken; and previous conditions that affected the liver like Hepatitis. While the patient answered the questions, the doctor typed in the computer. At the end, the doctor told the patient that a scan (Computed Tomography - CT) would be necessary to understand better the type and size of the tumour. The doctor had a voucher of a private laboratory and gave to the patient to enable the scan to occur in few days, instead of asking him to make an appointment in the university hospital. Also, the doctor gave a letter to present to the ambulatory return appointments to book the next one. The letter explained the urgency and that the doctor would see the patient as soon as the patient had the results of the scan.

The patient and his wife left the room without a diagnosis but confident that they knew the next steps - scan (2 in the figure 5) and next appointment (3). They head to the hospital outpatient department to make an appointment. The next available date (for this urgent case) after the scan would be in one week. The CT was conducted in a private Laboratory two days after the initial appointment. Although private Laboratories have a good demand in this city, they are capable to schedule scans within one week. The price for CT varies around half of the minimum monthly wage in Brazil (minimum monthly wage in 2018 was R$954 - around £194).



Figure 5. The Journey of the Patient with Liver Cancer: 12 steps until treatment.

4.2 From Being Diagnosed to the First Biopsy

In the following appointment (3) the same procedure was taken, reporting at the reception at 12:30 pm and waiting the call for almost two hours. This time the patient was accompanied by his wife and their daughter to see the same doctor - hepatologist. There were several medical students during this consultation; they took notes while one of them examined the patient and the doctor guided what to look for when examining the abdomen. The patient answered few questions and explained about the intensity of the pain that increased since last visit, resulting in a lack of sleep in the nights before the appointment. After explaining that the pain and lack of sleep are common symptoms the patient was diagnosed with liver cancer. The doctor explained that they would act with urgency. However, in order to prescribe the right treatment more blood tests and a biopsy would have to be conducted. Also, to alleviate the pain, the doctor prescribed pain killers every 4 hours.

The doctor did not check whether the patient or his family members had understood what they would do next and where they should go to book the tests and biopsy. The doctor handed in the printed prescription, the letters for appointment, blood tests and biopsy. He avoided answering the questions raised by the patient's daughter regarding how severe was the condition, how long it would take to start treatment, etc. He did not refer to any alternative source of information (for example SUS online resources or other) where the patient and family members could understand the stages of cancer, the severity, the treatment options, etc.

The patient, his wife and daughter left the room with a diagnosis but without understanding how severe it was and the certainty of treatment. The information about next steps were given altogether; the patient knew he was diagnosed with cancer, but could not tell what would be the next steps. His wife could tell that the next steps were the biopsy, and more health screening but could not tell where to make the appointments, she found difficult to understand the sheets she had in hands at the end of the appointment.

The information sheets to present for next appointments, next blood tests, the biopsy and for the prescriptions were printed and given altogether. They are very similar (like the ones on figure 4) same colour, small text size, with similar header and footer, and written in very technical / medical terms. Their daughter was able to tell the next steps but was not sure where to go to make the appointments. She went to the hospital outpatient department to make an appointment for the biopsy and blood tests. The attendant scheduled the blood tests, but could not confirm the date of the biopsy - due the urgency, they would call the patient to confirm the next availability.

The feelings among the patient, his wife and daughter was a mixture of sadness and uncertainty as they reported. Sadness due to the diagnosis. Uncertainty as the treatment depended on a procedure - biopsy - that they were not able to tell when it would happen; also uncertainty about the severity of the condition.

Four days after the second appointment they received a call from the hospital to confirm that the biopsy would take place on Monday in the following week. The biopsy (4) was conducted in the university hospital with entry in the morning and discharge before lunch. The patient was fine but complaining about the abdominal pain that increased after the biopsy. The pain killers every 4 hours are not helping and the patient did not sleep more than two hours per night since being diagnosed. Following the biopsy their daughter scheduled the next appointment with the hepatologist.

4.3 From Third Clinical Assessment to Second Computed Tomography

The third appointment (5 in the figure 5) followed the same procedure, though this time the patient reported at the reception later, just after 1pm, they had to wait the call for almost four hours. This time he went with his daughter only as his wife was stressed with the uncertainty and delay for treatment. The doctor had only one chair in the consultation room and the patient's daughter had to stand during the consultation. He avoided eye contact while explaining the patient's condition. This time the doctor explained that the tumour was in advanced stages and that a curative treatment would not be possible, but one to prolong his life instead. The patient's daughter (who had searched about several possibilities on internet) wanted to know other options, whether a surgery or organ transplant would be an option. He answered that both were not possible anymore due to the stage of the cancer. The doctor did not explain the differences among cancer stages and cancer types, neither he referred to any source of information; leaflet, brochure, website or any other resource.

The patient explained about the intensity of the pain that increased since last time, lack of sleep and other issues. He did not ask for more details about his condition. The doctor prescribed other pain relief, sleep pills and constipation medicines, while explaining that he would start a palliative treatment in ten days, after other specific blood tests. The doctor did not give details about the treatment and how it would affect the tumour. He mentioned though, that it should help to alleviate the abdominal pain. In addition, he requested another scan and an endoscopy.

The information about next steps, next scans, tests, appointments, and prescriptions were given altogether. Again they were very similar (like the ones on figure 4) same colour, small text size, with similar header and footer, and written in very technical / medical terms. However, this time they were many more (12 in total - 7 were prescriptions, the others were hard to understand where). The patient refused to look at them, and asked the doctor to hand to his daughter.

The patient left the room without a clear understanding of anything. As reported later, he understood that it would be treated and that the tumour was a little one. His daughter understood the severity of the diagnosis by associating what the doctor said with the information she found on internet (she stated that all information she got was from websites written in English). Also, she mentioned that only by what the doctor described she would have a vague understanding about of the case. Moreover, still she could not identify the treatment the doctor was proposing.

The patient could not tell when, where and what would be the next steps. His daughter was able to tell the next steps but again, she was not sure of where to go to make the appointments. She went to the ambulatory return appointments, where she was informed that she should go to the hospital outpatient department to make an patient entry request (to start treatment), to inquiry regarding the next appointments for the CT scan, for the endoscopy and for the next blood tests. However, it was late and the departments were closing, she had to return on the next day.

On the next day, she returned to the hospital outpatient department to make an patient entry request (to start treatment), where she was informed to go to hospital admissions. In the admissions the information was another: a letter should be provided with date and time, which should be presented on the day of hospital entry.

In the hospital outpatient department she was able to enquire about CT, endoscopy and make the appointment for next blood test. Blood test was scheduled in two days, but unfortunately the next available time for CT scan would be in three months and two weeks; and endoscopy in five months and 1 week. She was told though, that she could try directly in the reception of Endoscopy Department and Scan Department. In the first, she was asked to leave her phone number in order to be contact as soon as any appointment was cancelled. In the second, she was explained that she should ask the hepatologist to call the CT department manager to discuss the urgency in order to find an extra slot. In all the three cases (admission, CT and endoscopy) the information provided was not accurate and the user journey was very unpleasant. If the patient and his wife could not count with their daughter and if they were the only people able to follow the process, the journey could cause an immense distress to the couple.

5. The Accessibility of the Information Provided

The accessibility of the information provided to the patient is vital. It is decisive on the continuity of the healthcare process, which includes the next steps to be taken, like tests, scans, appointments, returns and treatments. The previous pages described a case where a patient diagnosed with cancer and his family members had to process and manage a great amount of unfamiliar information. The patient condition, provided verbally by the doctor specialist and then printed on similar pages, in small letters and delivered altogether, making difficult to distinguish them.

The doctor played a huge role in this case. The way he communicated with the patient and his family partially contributed to the confusion caused every time they left the consultation room. On the one hand, doctors are able to access the health literacy of the patient, family member(s) or carer(s). They are the individuals that can check whether they communicated right and whether the patient are confident about the next steps to be taken. On the other hand, doctors have to be able to attend a high number of patients in the ambulatory care facility. Short consultation sessions may be justified as the specialist in this clinic are highly qualified, short in numbers, receiving patients from many districts in the Sao Paulo province, and consequently in high demand. The short sessions unable healthcare consultants to give detailed information for every patient.

Nevertheless, the lack of supportive information does not help patients and carer to improve their health literacy. Another source of information was never mentioned to support patient and family to become familiarised with liver cancer; types and stages of cancer; medical terms; treatments; common procedures, etc. The doctor never referred to any extra, trustable and accessible information to help patient and carer to become better informed about procedures and cancer condition (types, severity, symptoms as the illness progress, etc.). The SUS do not have a website with this type of information ease to find in the same way that NHS does. The daughter was able to read in English and to become more familiar with her father's condition. However, a second language is not a reality for the great majority - 95% - of the Brazilians (Folha de Sao Paulo, 2017), who are possibly the users of SUS.

Outside the consultation room some of the problems related to accessibility are listed below:

1. after checking in at the reception, audio call is the only source of information in the waiting area. Patients have to recognise when they are called. The call exclude hearing impaired people, including those with loss of hearing abilities, like some elderly people;
2. the printed information delivered by the doctor do not have any indication of where to go to schedule appointments, scans, biopsy, blood tests, etc; neither the outside area have any indication of general appointments, nor the receptionists are able to help in this matter.
3. finding the places where to schedule the next steps were hard to recognise and to find due to lack of clear indication (signs around the hospital).

5.1 The Design of Healthcare Interaction Points

When designing healthcare interaction points the end users needs (patients and carers' needs) should be considered. As previously mentioned, people aged over 60 are the most affected by health problems compared to any other age group. In the case described here, the patient and his wife were aged 69 and 68 respectively, with visual, hearing and cognitive abilities affected by the ageing process. Both had to wear spectacles to read small texts or in the case of the patient's wife, to recognise large text in a long distance (like large text information across the street). Both had hearing capabilities reduced along the recent years. Both are unfamiliar with medical procedures, medical terminologies and cancer terminology, which affects the ability to learn and recall. The study presented here illustrates just a tiny portion of the problems that could be considered to improve the accessibility of the information delivered to patient, specially the elderly.

6. Research Limitations and Future Research

The present study analysed a specific case and although it reflects on how information is delivered to patient, it has neither investigated the extent to which it reflects the whole system, nor if the experience reported is recurrent in other cases. Past studies related to patient experiences in the Brazilian Public Healthcare were specific cases of particular clinics or practices, however, the extent to which they reflect the general practice, procedures, services and environment standardised by public healthcare systems is not clear (Castiglione, Lovasi & Carvalho, 2018; Freire, 2016). Future research will explore more user cases, as well as will investigate the types of environments, services, protocols and patient record that are standardised by SUS, allowing generalisation of the research findings throughout other SUS clinics. This would highlight accessibility issues to improve a large extent of the SUS practice.

This study slightly mentioned how information affects the users (patient and family members) emotionally. The emotional load however, was not discussed among the factors that may affect how the information is perceived. Having to coordinate what to do next, at the same time you were told that the doctor will do whatever is possible to prolong your life and that treatment to cure the cancer is not an option any more due to the size of the tumour is a huge emotional load, that cannot be ignored. Next studies could consider the cognitive effects of this type of circumstances.

7. Conclusions

The danger of inaccessible information is that patients can possibly **not** take the next step due to difficulties to understand what the next step is, where to go and how it can help them. This paper described the users experiences of one University Hospital that belongs to SUS by mapping the patient journey and his interactions (as well as his family members interactions). Along the study it became clear the difficulty encountered by the users to understand unfamiliar information and to recognise the requests and how to procedure for appointments, tests, scans, biopsy and hospital admission. Although the paper is based on one single ethnographic study, which cannot be generalised, it highlights several issues that elderly people can face. The ability to distinguish where to go and what to do next at the end of patient consultation became a challenge facing all users, but specially facing the patient and his wife - an elderly couple. Therefore three areas where patient experience can improve immensely in the case analysed are: 1) doctors' communication practice; 2) printed information delivered to patient; 3) supportive source of information (i.e. website).

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