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Abstract: The patient experience in hospitals regarding treatments of breast cancer can impact their personal strengths to gain motivation to overcome cancer. The goal of this project was to assess the user experience with breast pathology in terms of healthcare and motivation. To evaluate the patient experience, several interviews were conducted with patients with breast pathology during their journey at the institute. This analysis is associated with the ambition not only to better understand the users but also to improve their provision of healthcare. As a result, interviews with health professionals and user family members were also carried out. The interviews were carried out in a semi-structured manner, allowing the parties involved to freely identify what they believe are the major constraints and strengths. The results show that internal process optimisation, professional training, infrastructures improvement, information sessions and co-creation sessions can improve quality of service in healthcare management.

Keywords: healthcare management; patient centricity; breast pathology; decision making; breast cancer; motivation; quality of service.

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1 Introduction

The health sector is constantly changing and modifying its organisational structure in order to provide a better quality in terms of organisational capabilities. The healthcare sector, currently, is facing a dynamically changing environment (Dias et al., 2021; Nair et al., 2018). The user needs and expectations quickly shift, and it's crucial to know and evaluate the user satisfaction by measuring the quality of the healthcare provided, during a treatment, in healthcare organisations (Sacristán et al., 2016). It rewards care providers for raising care standards and for demonstrating evidence-based service goals. The development of new healthcare management models where patients become clients and the enormous expansion of information technology are additional factors that contribute to accelerate this change (Sacristán et al., 2016). The new healthcare models typically evaluate provider performance by examining key activities that lead to improved patient outcomes and patient satisfaction based in the concept of patient centrality (Porter, 2010). The patient/individual centred care is expected to consider patient's desires, expectations, values, family and social circumstances, beliefs, lifestyles and future ambitions. Integrating this into the patient care provides a more collaborative, respectful, personalised and holistic approach to medical practice across the ecosystem, thus it can be a crucial measure to increase patient health response. Thus, patient-centric drug development is now becoming the model that the industry is following (Sharma, 2015).

Patient centricity aims to fulfil the gaps in traditional medical practice that are driving these changes, namely: health decisions are generally taken by health professionals, while patients are mostly passive participants as they are not actively involved in the decision-making; the cost of treatment has been going up without an equivalent improvement in value delivered; patients are being subject to unnecessary tests and treatments; and dangerously enough, patients sometimes receive incorrect treatment. Besides the healthcare treatments, the patients are demanding that drug development becomes more patient centric which will create more patient-centric relationship (Yeoman et al., 2017). These operational approaches also impact the effectiveness and sustainability of patient-centric practices (Stergiopoulos et al., 2020).

Among the several different types of cancer, breast cancer has the highest incidence and mortality rates among cancers in women worldwide (Lian et al., 2020). The aim of this project was to identify the main trends that have been observed in the management of cancer healthcare, in the Portuguese Institute of Oncology (IPO), and the specific needs of the institute based in its connection with the decision making concept and patient centricity methodology and workflow. The main goals of the project were to assess the satisfaction of the users with breast pathology as well as that of their family members, to identify potential improvement points for the institution through the analysis of the information gathered during the interviews with users, family members and health professionals, and to investigate how and when patients want to be involved in the design and conduct of patient preference studies. Roles, levels and requirements for patient involvement, as well as communication of results to patients, were discussed with patient representatives. These healthcare quality measurements have been studied by Nyhof et al. (2020).

This study leads to the development of two main research questions:

- i Is patient centricity evaluated in the way that corresponds to the patient needs?
- ii Is the patient centricity methodology applied as a service or solution around the patient?

2 Literature review

The Patient Centricity and Decision-Making processes in the healthcare industry have been studied by several authors (Gray et al., 2019; Fisher et al., 2018; Blumenthal-Barby et al., 2020). These two concepts are connected in order to provide a better medical response for the patient based in their values, preferences and incorporation into clinical decisions (Jordão et al., 2020).

2.1 Patient centricity

The concept of Patient Centricity is a dynamic process through which the patient regulates the flow of information to and from him or her via multiple pathways to exercise choices consistent with his or her preferences, values, and beliefs (Robbins et al., 2013). Currently, there is a change in the traditional methods in the healthcare sector in order to understand the patient centricity, thus the current sector needs to evaluate how the opinion of the patient has been changing the methodological approach in the

healthcare industry. A patient centricity methodology is an very effective approach to create a strong partnership with practitioners and patients, and with families to improve the quality and satisfaction of services. To support the methodology it is very relevant to give education and to understand the patient's needs to guarantee that all health systems work in an holistic way (Duque et al., 2020).

Although the concept of Patient Centricity is widely used and applied, there are some authors which mention that although it has an intuitive appeal, it is based on jargon and ethical imperatives rather than empirical data (Howley et al., 2016; Miller et al., 2002; Ivsen, 2014). Patient-centricity requires operational parameters to be utilised in clinical research, and ultimately this will have implications for healthcare costs (Robbins et al., 2013). According to Sacristán et al. (2016) and Mühlbacher (2015), the patient centricity methodology has been replacing the traditional methods in order to provide better healthcare treatments. To understand patient centricity, the industry needs to evaluate the impact of this methodology in the patient overview.

2.2 Decision making in the healthcare sector

The links between medical and healthcare decision making have several kinds of variables which are related to specific decisions including environmental, social, physical, organisational, social, professional criteria (Mardani et al., 2019) and are also related with soft skills, such as emotional intelligence, people management and service orientation. There are several studies which explain the way that decisions are affected based in the previous criteria.

Based for example on the work of Fisher et al. (2018), the preference and readiness of patients to participate in shared decision making (SDM) is influenced by several interacting factors, including the patient's understanding of the decision, their emotional state, the strength of their relationship with the doctor, and the nature of the decision itself. However, it has been perceived in this same study that uncertainty often inherent in information can lead to misconceptions and poorly formed opinions that impair patients' understanding. In combination with cognitive biases, these factors can even result in decisions that are incongruent with patients' preferences. In the same study, it is clear that there are circumstances in which the basic elements needed for the MDG are not present in certain contexts, which leads to doctors often failing to achieve the goal of a patient-centred decision.

Blumenthal-Barby et al. (2020), in this context, concluded in their study that there are also time-related barriers that must be addressed to increase and maintain outreach, although outreach can vary between sites, ongoing work to assess additional barriers and facilitators experienced by high and low-performing clinical sites, which in this case requires future work that can synthesise best practices for implementation and development of a long-term sustainability plan for each site.

The importance of decision making over healthcare might not be focused as lots of the related decisions are complicated and include doubts as well as extracting the shareholders' favourites and standards. Various approaches were offered to enhance the quality of decision-making processes in healthcare. The patient centricity approach has initiated a change in healthcare decision-making paradigms (Mühlbacher, 2015). The concept of decision making, applied to the healthcare industry, occurs within the context of wider social networks and commonly extends beyond the patient and the healthcare provider relationship (Gray et al., 2019). This relation began, in the first stage, with the

patient and the provider. Currently, it has been extrapolated into a new stage because the illness affects also the family of the patient and makes them also to get involved and to make decisions (Northouse, 2012). In case of the patient cannot make a decision due to the illness, the family may act in the role of decision makers in shared decision-making (Washington et al., 2016; Lin et al., 2017).

3 Methodology

The adopted methodology aims to identify the level of patient satisfaction and the decision-making process from third parties enrolled and which one has more weight to this process. This project considers the satisfaction of patients with breast pathology through interviews, assesses the satisfaction of family members of patients and health professionals through interviews, with a view to identifying common points and to identify potential points of improvement for the institution through the analysis of information collected in interviews with users, families and health professionals.

The information gathering was conducted through semi-structured interviews allowing the parties involved to freely identify what they believe are the major constraints and strengths they face (or have encountered) at the institute. The goals of the user interviews were the possibility for each user to report their journey within the institute, identification of the means through which the user was sent to the institution, identification of the positive aspects and the ones that need improving and to globally assess the institute and hospital services.

The respondents were 103 women with breast pathology (Group 1), 20 user family members (Group 2) and 23 health professionals (Group 3).

3.1 Data sample

The data used in this study has been divided in three different groups: patients, family members of the patients and health professionals. The criteria for identifying the users and characterising the personas, in the case of the sample for the patients, was the age of the women, as it was found that the expectations and needs of the users change significantly according to this criterion. Personas consist of a fictional characterisation of a typical user, which enables the development of solutions, based on their real characteristics of their users. The patient's identification was anonymised in order to be compliant with the General Data Protection Regulation (GDPR). The sample was the following one:

Patient 1: Represents women up to 45 years of age.

Patient 2: Represents women between 46 and 65 years old.

Patient 3: Represents women with 66 or more years.

These patients are representative of the distribution (%) presented in the Table 1.

Regarding the family members interviewed, the sample selected was only based in the criterion that the respondent was accompanying a breast pathology patient on the day of the interview. The goals of these interviews were to describe the journey of the family members that follow up the patient with breast pathology, recognition of strengths and points of improvement from the perspective of family members and identification of

aspects that are determinant for themselves in the relationship they have with their relatives, as well as some of their major concerns.

The sample characterisation was the following one:

- 7 Husbands
- 7 Sons/Daughters
- 3 Brothers/Sisters
- 2 Parents (Mother, father or both)
- 1 Daughter-in-law.

The information gathered was grouped in three categories: processes, relationship with professionals and infrastructures and materials resources.

The last group of interview people was the Health Professionals. The Health Professionals play an essential role in the therapeutic journey of patients with breast pathology in the institute. For this reason, interviews were carried out with professionals from different categories that intervene, at some point, in the day of patients with breast pathology, being this the selection criterion. The goals of these interviews were to explain the choice of that institute for developing the professional activity, gain a perception of the culture and evolution of the institute, make a global approach to the institute and understand the satisfaction with the hospital services used.

Sample characterisation:

- 7 Doctors
- 7 Nurses
- 3 Senior Health Technicians and Senior Technicians and Therapeutics
- 6 Other Senior Technicians, Technical Assistants and Direction Secretaries.

3.2 Data characterisation

The data has been characterised based in the age, service distribution, profile distribution and profile of service distribution.

It's important to mention that almost 60% of the people interviewed have been at IPO for less than 1 year. It is also important to consult users who have made their journey at IPOL more than 3 years ago, 26% must use the procedures for another pathology. Almost 20% of the interviewed users were undergoing treatments at the Oncology Day Hospital, which was the most represented service.

The threshold age from the interviewed people is described in Table 1.

To obtain the information, testimonies were collected from different hospital services that constitute their journey at the institute which is made by nine different stages and which one of them has to be made in order to complete the treatment for the breast cancer. The services are:

- 1 Patient reception hall
- 2 Multidisciplinary Breast Clinic (MBC)
- 3 Radiology Service (RS)

- 4 Ambulatory Surgery Unit (ASU)
- 5 General surgery service (GSS)
- 6 Oncology Day Hospital (OCH)
- 7 Radiotherapy service (RS)
- 8 Physical Medicine and Rehabilitation service (PMRS)
- 9 Medical Oncology (MO).

The service distribution is based in the different stages mentioned previously and had the following distribution (Table 2).

Table 1 Sample age distribution

<i>Op</i>	<i>Distribution (%)</i>
15–30	2
31–45	17
46–60	32
61–75	32
76–90	17

Source: Authors

Table 2 Data service distribution

<i>Service</i>	<i>Distribution (%)</i>
MBC	15
RS	17
ASU	5
GSS	15
OCH	19
RS	7
PMRS	11
MO	11

Source: Authors

The profile distribution had the following characterisation (Table 3):

Table 3 Data profile distribution

<i>Age</i>	<i>Distribution (%)</i>
<45	17
45–65	38
>65	45

Source: Authors

The last table, with the characterisation of the data, was related with the service profile of service distribution and it's also linked with the distribution of the Table 3 in terms of age. This information is described in Table 4.

Table 4 Service profile of service distribution

<i>Service</i>	<i>Distribution (<45) (%)</i>	<i>Distribution (45–65) (%)</i>	<i>Distribution (>65) (%)</i>
MBC	13	27	60
RS	29	29	42
ASU	60	0	40
GSS	20	53	27
OCH	6	47	47
RS	17	33	50
PMRS	18	55	27
MO	8	33	59

Source: Authors

4 Data analysis

From the interviews of group 1 (patients), it was possible to identify strengths and weaknesses in these different services as mentioned in Table 5.

Table 5 Strengths mentioned in each service

	<i>Institute</i>	<i>MBC</i>	<i>RS</i>	<i>ASU</i>	<i>GSS</i>	<i>ODH</i>	<i>SRT</i>	<i>PMRS</i>	<i>MO</i>
Relationship between patients and professionals and between relatives and professionals	x	x	x	x	x	x	x	x	x
Relationship between teams	x								
Prior notice of treatments		x			x		x		
Competence of the professionals	x	x		x		x			

Source: Authors

In Table 6 is mentioned the most needed improvement points about the service.

Table 6 Improvement points mentioned in each service

	<i>Institute</i>	<i>MBC</i>	<i>RS</i>	<i>ASU</i>	<i>GSS</i>	<i>ODH</i>	<i>SRT</i>	<i>PMRS</i>	<i>MO</i>
Long waiting times	x	x	x		x	x	x	x	x
Infrastructures with poor conditions	x	x		x	x	x	x	x	x
Inadequate communication		x	x		x			x	x
Phone contact difficulties	x	x							
Appointments without exam results		x	x						x

Table 6 Improvement points mentioned in each service (continued)

	<i>Institute</i>	<i>MBC</i>	<i>RS</i>	<i>ASU</i>	<i>GSS</i>	<i>ODH</i>	<i>SRT</i>	<i>PMRS</i>	<i>MO</i>
Lack of human resources	x	x			x	x		x	
Decentralised Hospital Services	x								
Lack of installed capacity	x	x	x	x		x		x	x
Parking constraints	x								
Faulty communication between teams	x					x			
Work overload	x	x			x				
Little recognition of professionals	x								

Source: Authors

It was also possible to understand the relationship between the three different groups from the data (patients, relatives and health professionals) in Tables 7 and 8.

Table 7 % of patients that mentioned each relationship strength

	<i>Patients</i>	<i>Relatives</i>	<i>Professionals</i>
Relationship between patients and professionals and between relatives and professionals	68%	40%	13%
Relationship between teams	–	–	48%
Prior notice of treatments	11%	–	–
Competence of the professionals	44%	50%	13%

Source: Authors

Table 8 % of patients that mentioned each improvement point

	<i>Patients</i>	<i>Relatives</i>	<i>Doctors</i>
Long waiting times	73%	15%	9%
Infrastructures with poor conditions	39%	10%	35%
Inadequate communication	27%	15%	–
Phone contact difficulties	19%	–	17%
Appointments without exam results	17%	–	22%
Lack of human resources	17%	–	100%
Decentralised Hospital Services	16%	10%	–
Lack of installed capacity	16%	10%	57%
Parking constraints	15%	25%	13%
Faulty communication between teams	–	15%	–
Work overload	–	–	48%
Little recognition of professionals	–	–	35%

Source: Authors

5 Results

The results obtained with this project led to five generic recommendations, which have been extracted from the questionnaires. Namely, the internal processes optimisation, training the professionals, infrastructures improvement, information sessions and co-creation sessions (da Costa et al., 2020).

In terms of internal processes optimisation, it's mentioned that is needed to map and optimise internal processes, increasing their efficiency to achieve

- i waiting times reduction
- ii ensure that there are no evaluation appointments before the patient has done the medical exams
- iii facilitate phone contact.

For the topic training of the professionals, it will be of benefit if the hospitals train the professionals in emotional intelligence and good practices of communication with patients, guaranteeing the best treatment for them. This training will help to achieve to

- i better inform and clarify the patients
- ii ensure that the communication used is appropriate to the context
- iii improve internal communication among the institute teams.

The results also point the level of infrastructures improvement, namely the infrastructures conditions, especially, waiting rooms, hospitalisation areas and parking spots. This would allow to offer better treatment conditions and improve the parking system by, for example, increasing the number of parking spots. For instance, patients mentioned decentralised hospital difficult access. Additionally, in the Oncology Day-Hospital 16% of the patients consider that the waiting room is noisy and does not have enough chairs. Patients also mentioned constraints with the parking lot. They believe parking is expensive and that there is lack of parking spots.

The results provided also mention the information sessions and co-creation session. For instance, the information sessions are essential to conduct group sessions with family members (especially husbands), to clarify about the pathology and the treatment process. This improvement would allow a better follow-up from the relatives to the patient during the treatment process.

The results obtained allow understanding the importance of patient engagement, participation and co creation to develop a patient centricity effective practice. To double check the understanding or meaning that comes from the inputs, a second sample can be used to iterate or go deep in the analysis. The co-creation session can be profitable to hold sessions with professionals of the institute that are able to stimulate the generation of ideas and solutions that can be implemented. This would create a bigger engagement from the professionals and recognise their value and ideas, encourage creativity and innovation in the institute and generate solutions adapted to the real needs of the institute.

Regarding the group 1 (patients) data analysis (Table 7), the major strength is the great relationship established with the professionals, with 70% of the patients pointing it out. It's also important to mention that more than 10% of the patients stated receiving prior notice of the treatments.

The long waiting times in some stages of the journey, especially in the multidisciplinary breast clinic, general surgery and oncology day-hospital were considered as the main critical point representing 73% of the sample, followed by infrastructures that present inadequate conditions with 39% of the patients interviewed (Table 8). Poor communication between patients and doctors was also mentioned, representing 27% of the patients interviewed. Subsequently, 19% mentioned having difficulties when establishing phone contact with the institution, especially at weekends. The increasing number of patients in the institute is also bringing some issues, namely the medical appointments being scheduled before the patients have their medical exams result.

From group 2 (family members), it's important to mention the relatives' trust in the competence of the professionals and in the good relationship established between them. However, they believe that parking and communication issues are factors that need to be improved.

The relatives also point some strengths and improvements. They believe that their presence is essential to the support the patients need. On the other hand, 25% of the relatives interviewed feel fear and uncertainty regarding the course of the disease. In this group, 100% of the interviewees state that there's a lack of human resources, a lack of installed capacity is also mentioned as an improvement needed by 57% of the respondents, that 48% of the professionals interviewed believe that the spaces, like waiting rooms, are too small and there's also a perception of work overload, being mentioned by 48% of the professionals interviewed.

In group 3 (health professionals), 48% of the professionals point out that the relationship between them is one of the institute strengths. Additionally, more than 10% of the professionals believe that the relationship with the patients is also one of the institute strengths. In this group, the poor conditions of the infrastructures are also one of the improvements needed, according to 35% of the professionals, and 35% of the respondents also point out the lack of professional recognition.

The present research therefore responds to the two hypotheses initially described in the introduction of this research, namely through five generic recommendations, which have been extracted from the questionnaires. Namely, the internal processes optimisation, training the professionals, infrastructures improvement, information sessions and co-creation sessions, as well as continuing the work developed by Gray et al. (2019), Fisher et al. (2018) and Blumenthal-Barby et al. (2020), not only bridging a research gap in these studies, but also proving that shared decision making (SDM) is influenced by several interaction factors, as mentioned by Fisher et al. (2019), but also in identifying real practices for implementing and developing a long-term sustainability plan of SDM (Pereira et al., 2021).

6 Conclusions

6.1 Theoretical implications

Patient centricity is becoming a central aspect of therapeutic growth and value-based management of healthcare. Health outcomes depend on patient involvement and there is a strong need to consider the needs of patients and their interaction during the care sessions between their family and medical professionals, namely in terms of discovery, study,

growth, delivery and access to medicines in order to achieve better results. In recent years, various campaigns involving regulatory agencies, patient advocacy organisations, healthcare providers and payers have begun.

The conclusions obtained with this paper are summarised in several different assumptions, namely the strengths pointed out by the patients, improvement points pointed out by the patients, strengths and improvements pointed out by relatives of the patients, strengths and improvements pointed out by relatives. This will lead to an adoption of a more perceived methodology in order to support properly the patients, relatives and the health professionals. There are many opportunities for patients to participate more actively in the entire research process.

Patient involvement in patient preference studies could increase question comprehension by study participants and ensure correct interpretation of results by previous studies related with Patient Centricity. Patients want to be involved as advisors or collaborators in terms of medical care and considering their personal situation at the hospital as well as establishing agreements on roles and time involvement it will increase the role of patient centricity.

In terms of the research questions, it's clear that the patient is not evaluated in a way that corresponds to the patient needs since most of the replies point out the lack of human resources and capacity from the hospitals. Regarding the second research question, patient centricity methodology is applied as a solution in order to provide an approach that drives personalised interactions among the different people interviewed.

In summary, we co-created important principles for patient engagement and a definition of patient centricity as the basis for decision-making, and provides organisations with the potential to integrate and use these aspects as a focal point for patient participation in the decision-making process.

6.2 Limitation of the study

Although interviews by nature provide subjective evidence that may not be generalisable to other populations, our study design safeguarded the inclusion of diverse types of patients from the same disease and from different ages. A limitation of this study is the small sample of relatives and health professionals included. Our overall pool of candidates was already limited to start with as we focused on experienced patient representatives. Therefore, we should be cautious when extrapolating conclusions.

6.3 Future research

This study, based in the concept of patient centricity and decision-making, provides insights on how to, according to patients, family members and health professionals adopted this methodology and aims for identify better outcomes. Further studies could be set up to explore perspectives of other relatives or even from other medical centers which aim to be part of this project and can provide a different output in terms of geographical dispersion. Another important factor should be the type of specialised healthcare professionals and researchers conducting patient preference studies, to understand how they want to involve patients and third parties to provide additional insights on topics for which the responses have been observed among patients (e.g., the involvement of patients in sample data, data collection and questionnaires). Furthermore, a deep analysis of the results in a larger patient sample, from different medical centers, could improve the

generalisability of these results to a bigger population and investigate heterogeneity in responses.

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