Informational barriers and recommendations for patient inclusion in a Brazilian outpatient oncological service

Barreiras informacionais e recomendações para a inclusão de pacientes em um serviço oncológico ambulatorial brasileiro

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The paper aims to map informational barriers to promote inclusion and accessibility with safety and autonomy for patients in an outpatient oncological service.
We performed an exploratory study through a case study in a Brazilian outpatient oncological service which included non-participant observation. The results were categorized into failures in the signaling of service facilities, lack of alternative communication resources, and lack of accessible communication considering diverse needs. The main barriers observed in the service were mistaking service entrance, verbal call/ written medical requests, and the absence of architectural elements for accessibility. Recommendations were proposed, seeking to include all the diversity of patients, and enabling them to receive information and make their own decisions in the service independently and safely. All the proposed recommendations sought to look at different needs in order to make the service inclusive.

*inclusão,
acessibilidade, design,
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Este artigo objetiva mapear as barreiras informacionais e propor recomendações para promoção da inclusão e acessibilidade com segurança e autonomia de pacientes em um serviço ambulatorial oncológico. Foi realizado um estudo exploratório por meio de um estudo de caso em um serviço ambulatorial oncológico brasileiro, que incluiu observação não participante. Os resultados foram categorizados em falhas na sinalização das instalações dos serviços, falta de recursos de comunicação alternativa, e falta de comunicação acessível considerando diversas necessidades. As principais barreiras observadas no serviço foram erro de entrada no serviço, chamada verbal/ pedido médico por escrito, e ausência de elementos arquitetônicos para acessibilidade. Foram propostas recomendações, buscando incluir toda a diversidade de pacientes, possibilitando que estes recebam informações e tomem suas próprias decisões no serviço de forma independente e segura. Todas as recomendações propostas buscaram olhar para as diferentes necessidades de maneira a tornar o serviço inclusivo.

1 Introduction

The Unified Health System (sus) – the Brazilian public healthcare system – was designed to cover primary and complex care in all regions of the country (Organic Health Law, 1990). Despite the Brazilian federal constitution ensuring that health is everyone's right and duty of the State, and the fact that sus is an universal system for accessing healthcare, inequalities in health are recurrent in the country (Garnelo et al., 2020). Due to insufficient resources, sus faces problems that limit investments to expand public infrastructure (Paim, 2018). In this context, there is a concern about access for all people to health services, in addition to mechanisms used to allow and facilitate this process.

If we consider the perspective of access for all people, we should think about accessibility and inclusion, encompassing all the existing characteristics and needs. In this regard, Amaral et al. (2012) note there is a lack of knowledge about access in the Brazilian health system, especially concerning those who are in a situation of vulnerability, such as people with disabilities and reduced mobility. For the proposition of this research and following the issues pointed out, it is critical to understand some concepts and aspects related to inclusion, accessibility, and topics related to that, such as barriers to healthcare access.

Regarding inclusion, etymologically, it refers to "the action or state of including or of being included within a group or structure" and "the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalized" (Oxford English Dictionary, 2022). According to this definition, Fisk et al. (2018) propose the concept of service inclusion, which refers to a system able to provide customers with fair access to services, as well as equal opportunities to receive treatment and exit the service. In opposition to this concept, the authors explain that when services fail to include customers (deliberately or unintentionally), service exclusion occurs and people may be left out (Fisk et al., 2018).

Concerning accessibility, its definition is "the quality of being able to be reached or entered", "the quality of being easy to obtain or use'' and "the quality of being easily understood or appreciated" (Oxford English Dictionary, 2022). Considering the health context, accessibility is related to the possibility of accessing healthcare services effectively (Liu, 2018). Amaral et al. (2012) explain that accessibility depends on mobility and physical environment aspects. In Brazil, there is NBR9050:2020 standard, that deals with requirements of accessibility for people. NBR9050:2020 was proposed with the aim of establishing "criteria and technical parameters to be observed when designing, building, and proceeding installation and adjustment of urban buildings to the conditions of accessibility".

Despite that, several barriers undermine fair and equitable access to health services. These barriers are related to some specific

aspects. We highlight architectural/physical aspects (Santos et al., 2020; Geraldo & Andrade, 2022), technological aspects (Carayon, Hundt & Hoonakker, 2019; Geraldo & Andrade, 2022), attitudinal aspects (Hashemi et al., 2022), and informational/communicational aspects (Geraldo & Andrade, 2022). For this research, we will discuss inclusion and accessibility from the perspective of informational/ communicational barriers. Thus, some concepts brought by the literature review performed by Geraldo and Andrade (2022) will be considered, specifying informational barriers as failures in the signaling of service facilities, lack of alternative communication resources, and lack of accessible communication considering diverse needs (encompassing signaling and staff to serve people with disabilities). However, we highlight that, despite our focus being on informational/communicational barriers, the other barriers will also be addressed in our discussion – even if indirectly – since they can provide useful information. For example, architectural projects for blind people seek to provide them with some information (Vermeersch & Heylighen, 2019). So, if these people face barriers regarding architecture, they probably won't be informed about the characteristics of the spaces where they are located. By the same token, that also occurs with other existing barriers.

In this sense, it is relevant to point out that accessibility aims to allow autonomy to a wider range of people, enabling them to enjoy environments more safely (Brazil, 2008). NBR9050:2020 also highlights the importance of promoting environments, information, products, technology and services with safety and autonomy, especially regarding people with disabilities. Then, autonomy and safety are considered important aspects in the context of accessibility and inclusion. In this research, we will consider autonomy as the "belief that individuals can think logically and decide" (Parman et al., 2020, p. 104). The authors explain that this concept is related to individual independence and freedom. However, Hewitt-Taylor (2003) highlights that available information is needed for patients to be independent and to make decisions. Concerning patient safety, it is related to risk prevention and reduction during healthcare provision (World Health Organization [WHO], 2019). Biasibetti et al. (2019) points out that in the context of patient safety, effective communication is essential. Studies by Doak, Doak and Root (1996) suggest relevant aspects of language, illustration and layout in the construction of printed educational materials in health.

If we think about this scenario, where some people might face informational barriers to accessing healthcare services, we must ponder different profiles and multiple vulnerabilities. For this reason, we will consider cancer patients, who need to face, beyond the disease itself, the treatment effects (Hewitt, Rowland & Yancik, 2003), age – with higher probability of having another chronic disease, dementia or reduced mobility (Roh et al., 2014), poverty (Tomatis, 1992), etc. Furthermore, cancer is a risk factor for the development of disabilities

(Hewitt, Rowland & Yancik, 2003). Then, it is critical to reflect on how these people understand and act in a healthcare environment during their journey, based on the available information and communication. Thinking from the perspective of inclusive design – considering all the diverse needs – could be useful for solving existing problems (Keates, Clarkson, 2002). Furthermore, we should think about the autonomy and safety of these people, considering their right to health access. Thus, the paper aims to map informational barriers and propose recommendations to promote inclusion and accessibility with safety and autonomy for patients in an outpatient oncological service.

2 Methodology

We performed an exploratory study, following a qualitative approach, through a case study. We carried out a non-participant observation in an outpatient oncological service of a Brazilian hospital, which assists sus' patients coming from five different regions of the state. The outpatient service includes consultations, medium-complexity exams, surgical treatment, and chemotherapy. A protocol with field diaries was used to guide data collection. The non-participant observation was conducted during outpatient care of patients undergoing cancer treatment, and a total of 12 patients and 7 health workers were observed. Two researchers observed the hospital's external environment, the service entrance doors, the reception rooms, circulation area, and the service rooms, considering the entire scope of the service.

This observation took place for eight days, in different shifts, according to the availability of the service and prior arrangement with the staff. The researchers sought to observe barriers to service users, paying particular attention to informational barriers (which are the focus of the study), as well as to the users' needs and particularities. This way, the observations provided the discussion about points of improvement for the inclusion of users, taking into account the aspects of safety and autonomy. The field diaries guided this process, as they predicted the analysis as follows: identification; what happened; impressions; what needs further clarification; steps taken by the patient; and observed interactions.

For data analysis, thematic analysis was performed (Braun & Clarke, 2014), in which the content generated in the observations was categorized and discussed based on the literature.

Regarding research ethics, the study was approved by the ufcspa's Institutional Review Board (caae 55467222.5.0000.5345). The hospital also provided a term of acceptance to carry out the research. The study has complied with the Data Protection Act, which requires personal, professional and institutional data to be anonymised.

3 Results and Discussion

Based on the proposed objective and the data collected, analyses were developed, classifying them into categories related to informational/ communicational barriers based on the research developed by Geraldo and Andrade (2022). This way, the data collected from the non- participant observation was categorized into: failures in the signaling of service facilities; lack of alternative communication resources, and lack of accessible communication considering diverse needs. Based on the mapping of informational barriers in the outpatient oncological service, we will discuss how much they impact in terms of inclusion, in addition to proposing recommendations. Furthermore, we will discuss promoting inclusion and accessibility with safety and autonomy, considering the aspects observed in the service.

3.1 Failures in the signaling of service facilities

During the observations, it was noted that it is common for patients to go through the wrong entrance doors. Some cancer patients wish to have their consultation at the outpatient clinic enter another service located close to it. The opposite also occurs, where patients who should seek care at other services, mistakenly enter the reception of the oncology service.

Another interesting point is that there are two spaces for carrying out clinical examinations: one on the ground floor and the other one on a different floor in the same building. One of them is intended for oncological referrals from SUS (as well as care through health insurance plans or private individuals). The other is intended for hospitalization, emergency care, and for patients contaminated by COVID-19. As they are spaces that offer practically the same type of service, patients often mistake locations, targeting the wrong service. In addition, during non-business hours, access to both locations is restricted to a single floor, which contributes to misinterpretation.

Given that, it was observed that there were failures in the signaling of service facilities. In other words, even though there are signs that indicate what the service is, it was found that these alone are not enough. This can be understood for several reasons: 1. Patients do not read the signs; 2. The service is not located at the institution's main and best-known gateway; 3. Oncology-related services are very close to other gateways; 4. The oncology service and its treatments are located at different points of the hospital; 5. Signage design problem; 6. Patients access the service from different locations; and 7. Support services adjust to demand, according to the time of day.

However, from the perspective of failing to read the signboard, we can start to think about accessibility and inclusion, based on our perceptions: why do patients fail to read? Is the patient able to read? Does he/she know how to read? Is the font large enough? Can the

patient see? Does the patient face visual impairment? Does the patient have too much information to handle and that is why he/she failed to read them? Is the patient used to the environment? Is it his/her first time coming? Is he/she accompanied? These questions emerged based on our observations, mainly because the people who made a mistake when entering the service were mostly elderly and unaccompanied.

From the perspective of existence of different gateways for accessing the service, we should think about additional strategies, in addition to signage, to help everyone get to their correct destinations. For example, a hospital map – directing people to different destinations and pointing to main gateways and services available in each building – was not located. Furthermore, there are guards at the entrance of each building. However, it was observed that they often fail to guide patients to the correct service. When patients entered the wrong service, the secretaries/receptionists themselves informed them that was not the correct service and, verbally, gave them directions.

About that, it would be useful to include a signage map for information and guidance in all the entrances. Maps could be available throughout the hospital, at all entrances, indoors and outdoors, showing patients where they are and how to get to other environments. Moreover, the placement of support personnel in all environments with uniforms of "how can I help?" would be very useful, since patients could identify in these employees the possibility of obtaining the necessary information to get around the institution.

About the signage design problem, we should also think about strategies in order to improve visualization. In multi-building structures, a wayfinding project can be developed, since patients access the service from different locations. It is possible to work with different elements on the facade of each building or zoning by colors or icons. The identification of colors can facilitate the identification of the place to which the patient needs to go. It is a resource that requires few cognitive skills but it does not include colorblind or blind patients. An alternative to facilitate the patient's locomotion to the service is the establishment of interactive kiosks or totems, in which patients can trace their destinations, as in a GPS device. Patients and family members can print out directions or send them to their smartphones.

3.2 Lack of alternative communication resources

In the internal environments of the oncology service, some critical aspects were observed. These aspects were categorized into lack of alternative communication resources. When patients arrive at the service, they must get paper tickets to wait for a nominal verbal call from receptionists. After the receptionist's call, patients sit down and wait for the doctor/healthcare professional's call (for consultation, exams or chemotherapy). The healthcare professional's call is also nominal and verbal. Sometimes, it was observed that the doctors do

not leave the room to call for the patient. Instead, they call at a higher tone of voice within the room itself and wait for the patient there.

It was also noted that, in the case of oncological outpatient consultations for surgery, patients leave the doctor's room with written requests, for exams, medical procedures or a letter to the doctor responsible for the patient (usually the primary care doctor who referred the patient to the specialist consultation) informing the negative diagnosis of cancer. With this information after consultation, the patient needs to make the necessary appointments, by phone or in person, according to verbal instructions given by the doctors and receptionists at the end of the consultation. If we think from the perspective of fragile patients that face a number of concerns, insecurities, pain and also can face intellectual, cognitive or physical disability, this after-consultation process might be difficult to manage. We observed patients leaving the doctor's room with questions about the next step, even though the doctor has just given them instructions.

Adopting clear communication and easy-to-understand terms is a good starting point for patient safety and effective communication. An alternative is to seek to centralize and organize the information communicated to the patient, through analog or digital mechanisms. For example, a patient booklet can facilitate the service's communication through the presentation of basic and guidance information, as well as organize information and demands to be provided by the patient. This suggestion is in line with the proposal by Hewitt-Taylor (2003) that states available information is needed for patients to be independent and to make decisions. When the information is easy to understand and uses simple language, it provides improvement in knowledge and reader satisfaction, as they help in the clarification of doubts and in the development of reflective skills, providing autonomy and membership.

The adoption of educational booklets in health is an alternative that is easily viable. They can be considered as a means of communication to promote health as they go beyond the simple release of information, allowing, during the educational practice, the sharing of knowledge. Such technology contributes to replacing models anchored in communication practices that are unidirectional and dogmatic by discussion and reflection (Doak, Doal & Root, 1996). Educational booklets reinforce oral information, serving as a guide in case of questions and assisting in everyday decision-making. But, it is important that it is illustrated with well designed figures and texts to make it easier to understand self-care, thus facilitating visual communication and access by subjects with little familiarity with the written language, considering the concept of informational/communicational aspects of Geraldo and Andrade (2022).

During the non-participant observation, it was found that the oncology service establishes contact by telephone or WhatsApp to schedule appointments, exams, and procedures, as well as to remind the patient of appointments scheduled for the week. This initiative seeks to facilitate communication, minimize absences, and pass on

necessary guidelines. This reinforces the points raised by Biasibetti et al. (2019), that point out that in the context of patient safety, effective communication is essential and needs to be reinforced whenever possible.

Another example, to minimize the concerns and insecurities of patients, is to structure guidance support groups, aiming to share experiences, feelings and information about the journey of cancer treatment. The structuring of guidance support groups can make communication accessible considering different needs, aiming to allow autonomy to patients and enabling them to enjoy environments more safely (Brazil, 2008). Similarly, better-informed patients tend to incur fewer adverse events, increasing patient safety (WHO, 2019).

It is important that all areas of a hospital follow the same communication code through a single identity. Communication in external and internal areas, for example, must have the same identity to function in an integrated manner and avoid confusion.

3.3 Lack of accessible communication considering diverse needs

This category of analysis comprises some of each thematic category extracted through the collection of observational data. This is because it consists of a category that encompasses accessible communication to everyone. In the previous categories, we highlighted general situations in which there are barriers if we consider all the existing diversity: need to read signs; lack of information materials; verbal communication, etc. Specifically for this category, we would also like to highlight aspects related to accessibility regarding disabled people and reduced mobility. In other words, during the observations, we noticed a lack of accessible information and communication considering diverse needs – physical, hearing, visual, intellectual, cognitive, mental, sensory, multiple disabilities, and others.

Ramps with slope within the standards were not observed. As much as there are ramps, not all spaces are covered by them. In addition, the physical space of the hospital is full of unevenness, which makes it difficult for people with reduced mobility to move around autonomously and safely. It was also observed that bedridden patients, who are unable to get around, are taken to the service by ambulance, and it is the doctor who is directed to attend to him on a stretcher in the emergency service. In other words, the oncology outpatient consultation service itself is not prepared to receive this patient.

It was also observed that some spaces of the hospital do not have tactile floors, including the oncological service. If some cancer patient faces visual impairment or blindness, he will probably not be able to access the service or even communicate, unless he is accompanied. Likewise, no braille signs or staff prepared to guide these people during their journey were identified. So, in addition to the difficulty encountered by patients who are not blind in finding their way

around, we should think about blind patients. How will this person receive information and communication from the service if it does not have sufficient architectural elements and attitudinal resources? Communication and information for the deaf were also not identified. Verbal calls do not consider deaf patients. Staff available and capable of sign language were not identified either. Concerning the doctors' verbal call, it would be useful for deaf people to adopt screens that indicate the call. Here, when we talk about blind and deaf people, we can also think about the elderly, who perhaps experience vision and hearing loss and probably struggle to navigate the service.

Considering the concept of service inclusion, brought by Fisk et al. (2018), we note that the outpatient oncological service fits, in some aspects, as service exclusion. If we think about all the users' diversity, some profiles could be excluded and unattended in terms of information and access. One of the aspects that NBR9050:2020 defends is the promotion of environments that guarantee the safety and autonomy of users. The standard also highlights that it is necessary to design devices that make use of at least two of the human senses: visual and sound or tactile and visual in order to be able to include and reach a greater number of users. We did not observe this concern in the design of the oncology service studied.

Concerning the proposed strategies to overcome the identified barriers in order to promote inclusion and accessibility with safety and autonomy for patients, we would like to highlight that even more efforts are needed if we want inclusion taking all needs into account. About the maps to guide patients through the service, they are not enough if we talk from the perspective of blind people. If we want service inclusion, we need to think about all possible characteristics. In this sense, we should also propose tactile maps, allowing information to be made available to blind patients, and for them to have the opportunity to decide independently (Parman et al., 2020) and safely (WHO, 2019).

About the support personnel in all environments with uniforms of "how can I help?", it would be better explored if these personnel could guide all patients. For example: how would blind people locate this help?; How would these personnel communicate with deaf people?; How would these personnel deal with people with dementia? We should reflect on all the possibilities and enable them to serve all needs. Another suggestion is for staff who speak other languages to be identified by means of a different badge, considering the perspective of patients who do not speak Portuguese – for example, Haitians living in Brazil. Considering the educational booklets and recommendations related to that, in spite of being resources that require few cognitive skills, they also require a braille version for blind patients, as well as materials adapted for sign language. Another important point highlighted in NBR9050:2020 is the use of pictograms to communicate the use of a certain space, seeking to include people who cannot read or who have low vision. To reach this last public, contrasting colors can also be used, facilitating identification in the signage.

In relation to architectural elements, it is critical to consider implementing accessibility standards in all spaces. The cancer and treatment effects cause a range of mobility problems (Hewitt, Rowland & Yancik, 2003), so the concern with the locomotion of these people must be a priority.

Chart 1 presents the summary of the analysis results, bringing relationships between the themes discussed. We highlight that all the analyzed data from the observations (informational barriers in the service) are related to the category "lack of accessible communication considering diverse needs", because we observed that, regardless of the barrier, failures related to the accessibility of patients considering all needs were perceived. Furthermore, we understand that all the proposed recommendations correspond to the possibility of receiving information with autonomy and safety: if information is passed on in an accessible way to all users, they will be able to make decisions independently and safely, considering everything is designed to serve and include them, according to the standards.

Chart 1 Summary of analysis results.

Barriers	Related to	Recommendations	Inclusion	Literature category	Safety/ Autonomy
Mistaking service entrance	Signaling	Signage maps Wayfinding project Support personnel wearing "How can I help?" signs Zoning by colors or icons Interactive kiosks	Tactile maps Staff trained to deal with diversity Resources for people with disabilities	Failures in the signaling of service facilities Lack of accessible communication considering diverse needs	
Verbal call/ Written medical requests	Communication and personal organization of appointments	Patient booklet Guidance support groups	Screens indicating the call Version to blind and deaf patients	Lack of alternative communication resources Lack of accessible communication considering diverse needs	Possibility of receiving proper information and making their own decisions in the service independently and safely
Absence of architectural elements for accessibility	Mobility	Implementing accessibility standards in all spaces	Making all recommendations inclusive considering all needs (service inclusion)	Lack of accessible communication considering diverse needs	

4 Conclusion

This paper analyzed aspects to map informational barriers and to propose recommendations to promote inclusion and accessibility with safety and autonomy for patients in an outpatient oncological service. A non-participant observation in an outpatient oncological service of a Brazilian hospital was carried out. The main barriers observed in the service were mistaking service entrance, verbal call/written medical requests, and the absence of architectural elements for accessibility. Recommendations were proposed, seeking to include as many as possible the diversity of patients, and enabling patients to receive information and make their own decisions in the service independently and safely.

Given the results and proposed recommendations, we would like to make a reflection on the role of inclusive design in healthcare service design propositions. We sought to bring recommendations that reflect on the different patients' characteristics and how they can benefit and have better healthcare if environments, attitudes, and, above all, information, are designed to include them. It is critical that we also reflect on how possible solutions can still be barriers for people with disabilities. Therefore, all the proposed recommendations sought to look at different needs and, more than that, they were designed to be intuitive, and easy to use, without requiring great physical or even cognitive effort, in addition to ensuring information is quick and easy to perceive, in accordance with the principles of inclusive design. Service design needs to develop an inclusive mentality so that it can generate better quality healthcare for users.

The limitations of the study are context-dependence and the usage of only one data collection technique. For future studies, we recommend that the study be carried out in other institutions and healthcare services, as well as that literature reviews and other data collection techniques be used, such as interviews and surveys, in order to understand the patient perspective.

Acknowledgment

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