# Experiences of cognitively impaired elderly patients with a Brazilian oncology service

An analysis through the lenses of inclusive design.

König-Klever E., Federal University of Health Sciences of Porto Alegre, Brazil,

ORCID 0000-0003-4065-3770, konigemanuele@gmail.com

Bohn P.R., Federal University of Health Sciences of Porto Alegre, Brazil,

ORCID 0000-0001-5244-3776, patriciabohn07@gmail.com

Tonetto L.M., Federal University of Health Sciences of Porto Alegre, Brazil,

ORCID 0000-0002-4403-2085, ltonetto@gmail.com

Libânio C.S., Federal University of Health Sciences of Porto Alegre, Brazil,

ORCID 0000-0002-4591-117X, claudiasl@ufcspa.edu.br

Received: 2024-02-12 | Accepted: 2025-01-29 | Publication: 2025-05-11

Abstract: Cancer and ageing are factors that increase the risk of developing cognitive impairments. Given this context, there is a complexity of access to healthcare by cognitively impaired elderly patients in oncological contexts. The aim of this study is to analyse the experiences of cognitively impaired elderly cancer patients with a Brazilian oncology outpatient service from the perspective of inclusive design to outline takeaway messages for the design of inclusive health services for these patients. Non-participant observations of the service and interviews with patients and their caregivers were carried out to understand to what extent the service provides proper care to cognitively impaired elderly patients. Thematic analysis of the data was carried out and categories were generated through an inductive approach. Results show that the service is adequate in terms of inclusion overall, but there are opportunities for improvement. Critical points related to the built environment, informational and communication design, trust in the healthcare team, and empathy were identified as opportunities for service improvement to better include and assist such user groups. Takeaway messages for the design of inclusive health services for cognitively impaired elderly patients were highlighted in this study.

Keywords: Inclusive Design, Oncology, Elderly, Cognitive Impairment.

### 1. Introduction

Cancer is pointed out as a risk factor for disabilities due to the disease itself and the treatment (Hewitt, Rowland & Yancik, 2003). Cognitive acuity is one of the factors that may be largely affected in cancer patients, leading to cognitive impairment (ACS, 2020). Cancer-related cognitive impairment might be caused by the disease's effects, previous conditions unrelated to cancer, or the effects of cancer treatments (Pendergrass, Targum & Harrison, 2017). In that regard, cognitive decline can be more aggravating for groups of people who may already have cognitive limitations prior to cancer, such as the elderly (Crimmins et al., 2011).

Regarding access to health, this can be a complex process for people with disabilities, especially cognitively impaired ones, who need inclusive support to understand health information (WHO, 2020). When interacting with health services, a user needs to comprehend, think, act, access, and receive care (Clarkson et al., 2007). So, users with cognitive impairment and high anxiety and

stress levels caused by age and cancer may find it difficult to access and receive care. This becomes even more complicated when three characteristics already complex to services come together: cancer, ageing, and cognitive impairments. In this context, multiple vulnerabilities are noted since the elderly are more susceptible to cognitive impairments and cancer. In addition, pre-existing cognitive impairment increases the risks associated with chemotherapy, making the elderly even more vulnerable in oncological circumstances (Magnuson, Mohile & Janelsins, 2016).

In addition, studies have shown a lack of adequate health services to meet the needs of elderly patients (Smith & Carragher, 2019; Rudnicka et al., 2020; Moghadasi et al., 2022). Regarding the limitations experienced by the elderly, there are several barriers that make difficult for them to access to healthcare, such as the lack of affordable physical spaces, long waiting lines, excessive information, communication failure for those who have visual and hearing losses, etc. (Araujo de Carvalho et al., 2017). The study by Webber, Bowers, and Bigby (2010) adds foundations to this discussion, emphasising cognitive impairment as another point of complexity in caring for the elderly. Their study identified that health services have difficulty assisting these patients due to professionals' lack of perception and knowledge about the particularities of elderly people with cognitive impairment, and failures in communication with these patients.

This panorama is critical from the perspective of inclusive design (ID), which seeks to include all people when designing services (Goodman-Deane, 2014), especially concerning the needs and capabilities of older and disabled people (Persad, Langdon & Clarkson, 2010 So, the design of health services must develop an inclusive mindset, meeting all existing needs and following the principles of inclusive design (König, Bohn & Libânio, 2022). These principles are highlighted by the London Commission on Architecture and the Built Environment (CABE): putting people at the centre of the design process, recognizing diversity and difference, offering options when a single solution is not able to encompass them all, providing flexibility of use, and designing products, services, processes, technologies, built environments and other solutions that are convenient and enjoyable for everyone, all of which make them easier to use (CABE, 2006).

Therefore, this study aims to analyse the experiences of cognitively impaired elderly cancer patients with a Brazilian oncology outpatient service from the perspective of ID and to outline takeaway messages for the design of inclusive health services for these patients.

# 2. Background

#### 2.1. Brazilian health context

In Brazil, health is provided by both the public and private sectors. Currently, 78% of the Brazilian population does not have private health insurance and is entirely dependent on the public system, which was designed to be universal to guarantee the right to health for the entire population (OECD, 2021). The public system - Unified Health System (SUS) - seeks to ensure universal, equitable, and integral access for all people in Brazilian territory (Brazil, 1988; Brazil, 1990). The private initiative is a complement to the public system in health provision (OECD, 2020). Regardless of the Brazilian federal constitution ensuring that health is everyone's right and duty of the State and that SUS should provide health for all, the population faces inequalities in healthcare (Garnelo et al., 2020). For this reason, people with more favoured socioeconomic conditions have higher access to health services than those from lower socio-economic backgrounds (OECD, 2021).

Concerning the elderly, the change in the profile and the global demographic dynamics has shown an ageing population trend (Almeida et al., 2020), which has also been reflected in the Brazilian context (Veras & Parahyba, 2007; OECD, 2021). The country has more than 30 million older people aged 60 years and older, representing 13% of the country's population (PAHO, 2022). By 2050, it is expected an increase of approximately 21.5% for the population aged 65 years and over and 6.5% for those aged 80 years and over (OECD, 2019). This perspective requires attention from the Brazilian health system as a whole. Given this, the country has Ordinance No. 2,528, which approves and regulates the National Health Policy for the Elderly. This policy aims to recover, maintain, and promote the autonomy and independence of elderly individuals, directing collective and individual health measures for this purpose. Moreover, it establishes regulations for accessibility, humanised care, inclusion, and equity for the elderly in all contexts, including health services (Brazil, 2006).

However, there are many challenges involved in the healthcare of the elderly since ageing leads to the loss of several capabilities, which compromise their execution of activities of daily living (Belasco & Okuno, 2019). Furthermore, population ageing generates a more significant burden of diseases in the population, more disabilities, and increased use of health services (Brito et al., 2013). That way, considering the coexistence of the Brazilian public and private systems, it is crucial to articulate the levels of care from the perspective of comprehensive care for the elderly in both of them (Almeida et al., 2020).

## 2.2. Cancer, ageing, and cognitive impairment

Cancer causes a series of damages, with cognitive impairments standing out among them. Due to cancer and related treatments, many patients have impaired brain functioning concerning communicating, thinking, learning, solving problems, and remembering (ACS, 2020). Many possible factors contribute to the symptoms of memory problems in cancer survivors, such as (i) the stress of receiving the diagnosis, causing anxiety, and depression, contributing to thinking and memory problems, (ii) chemicals that affect memory are produced by certain types of cancer, and (iii) cancers that begin or spread to the brain can cause changes in cognition (MFMER, 2023). Many patients with or without central nervous system tumours develop cognitive problems during their illness that can result in decreased functional independence (Schagen & Wefel, 2013).

Decreased mental sharpness is common during and after treatment for cancers. This condition is known as chemo brain (ACS, 2020; MFMER, 2023). Chemo brain or chemo fog consists of cancer-related cognitive impairment or cognitive dysfunction, presenting symptoms as unusual disorganisation, confusion, difficulty concentrating, finding the right word, learning new skills, and multitasking, a feeling of mental fogginess, short attention span, short-term memory problems, taking longer than usual to complete routine tasks, trouble with verbal memory, such as remembering a conversation, and trouble with visual memory, such as recalling an image or list of words (MFMER, 2023).

Another factor that increases the chances of developing cognitive impairments is ageing, since cognitive functions develop in childhood, peak at some point in adult life, and decline in old age (Tucker-Drob, 2019). More than that, ageing also represents an increase in chronic diseases in the population (Barreto, Carreira & Marcon, 2015). In Brazil, according to data from the National Cancer Institute (INCA), overall cancer mortality in 2020 was significantly higher in groups aged 60 years or older, regardless of gender (INCA, 2020). In this context, elderly people with cancer

are at particular risk of presenting cognitive impairments during treatment (Magnuson, Mohile & Janelsins, 2016).

#### 3. Method

This research is of an applied nature (Zanella, 2013) and has an exploratory objective (Markoni & Lakatos, 2010), utilizing a qualitative approach (Hutton, 1990) and employing the case study method as a technical procedure (Zanella, 2013). The case study was carried out in a private outpatient oncological service of a Brazilian hospital that nowadays assists 86 cancer patients. We conducted non-participant observations of the service for eight days, and in depth-interviews with six patients. Two male and four female patients (mean age 69 years old) and three caregivers were interviewed to understand to what extent the service provides proper care to cognitively impaired elderly patients. For this, the ID principles (CABE, 2006) were considered in the interview script. Two researchers conducted the observations and interviews and refrained from intervening in the normal functioning of the service to map the journey of the cognitively impaired elderly patients in the most reliable way possible.

For the selection of participants, those who were 60 years of age or older and had cognitive impairments were included. The cognitive decline was confirmed by the patients and/or caregivers in the interviews.

Concerning 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 anonymized personal, professional, and institutional data.

For data analysis, we conducted a thematic analysis using an inductive approach (Braun & Clarke, 2014) . The process began with the transcription of the interviews and field diaries. Next, initial codes were generated, followed by the identification of themes and the establishment of relationships among the interviews. Finally, categories were generated and named: built environment; informational and communication design; trust in the healthcare team; and empathy. The inclusive design principles guided the analysis. To ensure the anonymity of respondents, patients will be identified as P1, P2, P3, P4, P5, and P6; and caregivers as C1, C2, and C3. Table 1 presents detailed information about study participants.

Table 1. Information about study participants

Patients	-	-	
Participants	Age	Type of cancer	Cognitive aspects
P1	67	Skin cancer	Forgetfulness intensified after the start of chemotherapy
P2	63	Ovarian, fallopian tube, and peritoneal cancer	Forgetfulness and memory loss intensified after the start of chemotherapy
P3	67	Bowel cancer	Forgetfulness, memory loss, emotional fragility, and anxiety intensified after the start of chemotherapy
P4	83	Pancreatic cancer	Forgetfulness and memory loss intensified after the start of chemotherapy
P5	60	Lung cancer and central nervous system metastasis	Cancer has touched on motor coordination, causing tingling and confusion
P6	75	Pelvic cancer	Forgetfulness intensified after the start of chemotherapy

Caregivers				
Participants	Relationship with patients			
C1	Family member of P3			
C2	Family member of P5			
C3	Friend of P4			

#### 4. Results

The results of this study are presented through four categories of analyses identified as critical points for inclusion in healthcare services: built environment; informational and communication design; trust in the healthcare team; and empathy. Each category highlights (i) how these themes emerge in the service, (ii) areas of adequacy, and (iii) opportunities for improvement based on the experiences of cognitively impaired elderly cancer patients.

#### 4.1. Built Environment

Two interviewees highlighted the importance of the built environment in the context of cognitive impairments. P2 reported that she always gets lost on her way to the service. She indicated that signage could be improved, as she experiences disorientation every time, regardless of whether she enters from the parking lot or the main entrance.

C1 reported difficulties in finding parking and expressed concern about leaving P3 at the entrance to navigate the service alone. Besides cognitive impairments, P3 also has physical and sensory impairments. Additionally, during the interview with P3 and C1, we observed that the patient is extremely emotionally vulnerable due to the challenging phase of her treatment and her inability to maintain the active lifestyle she had before the disease. The combined mental and physical confusion experienced by P3 raises concerns for the caregiver about whether the structure is sufficiently prepared to accommodate her needs.

The other interviewees did not report issues related to the built environment, aligning with our observations that the parking lot includes indicative signs and even a location map. However, we also noted a high volume of information available, as the facility houses multiple clinics and laboratories for various specialties. This abundance of options, including numerous elevators, stairs, and parking floors, can exacerbate navigation difficulties for users who are fragile, anxious, or cognitively impaired.

This category underscores the critical role of thoughtful design in reducing disorientation and emotional stress for cognitively impaired users. They require clear and accessible navigation through healthcare facilities to be able to navigate them.

## 4.2. Informational and Communication Design

This category is related to the built environment, as it forms part of the physical environment. Although we observed that the institution provides signs and maps indicating where each service is located, P3 identified problems with the signage. Referring back to the previous discussion, the way this information is presented—using large amounts of text, varied colours, and arrows among other competing details—may confuse patients with cognitive impairments.

Beyond signage, informational and communication design encompasses all forms of communication between the service and the patient. During the interview with P6, she expressed confusion about her treatment, as she believed that she was supposed to receive an additional chemotherapy drug that day based on her recollections of previous sessions. Although the nurses

reviewed the protocols and explained that her recollection was not accurate, she remained dissatisfied and contacted a relative to express her concerns. This situation highlights that the communication approach failed to ensure clarity and left the patient feeling suspicious and confused.

C1 also reported uncertainties regarding the treatment of P3. Neither the patient nor her caregiver had a deep understanding of the disease itself. Although they followed the care protocols, such as cleaning the colostomy bag, they lacked a comprehensive understanding of the type of cancer being treated.

These examples illustrate the importance of clear, patient-centred communication. There is a need for strategies to foster trust, reduce confusion, and enable cognitively impaired patients and their caregivers to engage meaningfully with their treatment plans.

#### 4.3. Trust in the Healthcare Team

Trust in the healthcare team was another critical point for the inclusion of patients. The example of P6, mentioned earlier, also illustrates a lack of confidence. While the patient reported and demonstrated a good relationship with the team, she became suspicious when the team corrected her misunderstanding (correctly, as she was confused).

P5 also expressed distrust regarding his treatment protocol. He reported that, even after agreeing to the treatment, he did not feel entirely secure due to the differing opinions he had encountered about his case. This patient, who has developed severe cognitive impairment (corroborated by C2), does not acknowledge his condition and often uses humour and sarcasm as coping mechanisms to shield himself from the painful reality of his situation. His distrust seems to stem from a state of denial, which was not reflected in his caregiver's perspective.

Lack of trust was observed and reported in only these two cases. The other interviewees, by contrast, indicated high levels of confidence in the healthcare team and expressed full trust in the competence of the doctors and nurses. These patients were also well-informed about their own cases. Establishing a trusting relationship is therefore essential for professionals, as it enables patients to better understand their diagnoses and treatment processes, fostering greater engagement and contributing to their overall well-being

Building trust with cognitively impaired patients is a vital component of inclusive healthcare. Trust not only ensures adherence to treatment but also promotes emotional security and a sense of partnership between patients and healthcare providers.

# 4.4. Empathy

Empathy was a category identified in all interviews and supported by non-participant observations. This was a critical point for the inclusion of patients, as it placed the person at the centre of the process, while recognizing their individual particularities, demonstrating an appreciation for diversity, and attending to the limitations each patient may present. Empathy proved to be a positive feature of the service and could serve as a model for other contexts. We observed that the service strives to follow the principles of humanized care outlined by Brazilian regulations for elderly healthcare (Brazil, 2006).

P4 shared that, since she is unfamiliar with medical terms and the healthcare environment, a doctor drew a diagram to explain her condition and treatment protocol. She found this approach extremely helpful, as it allowed her to understand her situation. By prioritizing the patient's

unique needs and considering her cognitive impairment, the professional moved beyond treating her as a passive observer, placing her at the centre of the care process.

During P4's interview, we also observed another instance that highlighted the empathy of the service team. The patient uses a cold cap during chemotherapy to prevent hair loss, and the cap requires a wet scalp for better adhesion. At the end of the session, one of the nurses removed P4's cap and brought a hairbrush to comb her hair, ensuring she could leave with her hair neat. This small but thoughtful act clearly pleased the patient, demonstrating the importance of putting oneself in the patient's shoes and addressing their specific needs with care.

P1 also emphasized that the professionals at the service prioritize patient well-being. He noted that having a private television in each chemotherapy room—a feature of the service—added a personal and human touch, allowing him to stay entertained during his sessions.

Empathy not only enhances patient satisfaction but also strengthens the inclusive nature of healthcare services, making them more responsive to individual needs and reinforcing a sense of dignity and humanity in care. These findings, categorized into four critical themes, reveal the current state of inclusion within the healthcare service while also providing a foundation for a deeper exploration of their implications, which will be addressed in the following discussion.

## 5. Discussion

The findings emphasize critical areas for improving inclusivity in oncology services for cognitively impaired elderly patients. By applying ID principles, the study offers actionable insights for designing healthcare services that better accommodate this population.

One critical insight from the study is the importance of designing physical spaces that minimize confusion for cognitively impaired patients. Features such as clear, visually accessible signage and navigation aids play a crucial role in reducing stress and enhancing patients' ability to navigate the service independently. This aligns with research on environmental design for cognitive decline, which shows that factors such as colour adequacy, the presence of mirrors, noise levels, and the placement of furniture can significantly influence patients' ability to move through a space without experiencing mental confusion (Bakker, 2019). Quirke et al. affirm that well-designed environments can offer features to help patients to be independent and to minimise their physical, sensory, or cognitive impairments. Incorporating ID principles, such as flexibility and user-centred approaches, can address these challenges effectively (CABE, 2006).

In addition to the built environment, **effective communication strategies** are integral to creating inclusive healthcare experiences. The study highlights the need for healthcare professionals to tailor their communication styles to the cognitive and emotional capacities of patients. Using simple language, repeating information, and employing visual aids can help bridge communication gaps. For example, while the institution provides signs and maps, the arrangement of this information—dense text, multiple colours, and arrows amidst other details—can overwhelm cognitively impaired patients. Differentiated communication strategies, such as speaking slowly, maintaining eye contact, solving patients' and caregivers' doubts, and repeating information when needed, are essential for fostering trust and engagement (Jootun & McGhee, 2011). Borson et al. (2023) add that clear and effective information, taking into account evidence, could be a good strategy to enhance trust between patients and healthcare professionals.

Building **trust** emerges as another pivotal factor in ensuring the inclusion of cognitively impaired patients in oncological care. In the oncological context, where patients often experience

# © Journal of Accessibility and Design for All (JACCES), Volume 15, Issue 1, 2025, ISSN: 2013-7087 DOI: https://doi.org/10.17411/jacces.v15i1.522

heightened emotional and cognitive vulnerability, trust becomes even more critical. Consistent, clear communication and a personalized approach to care can foster trust, ensuring patients feel supported and engaged. This finding aligns with previous research showing that cognitively impaired elderly patients are more likely to experience confusion and suspicion about their treatments, leading to potential disengagement and fear (Portacolone et al., 2020). The authors emphasise that "trust in their providers may help them accept needed treatment and social supports; the sense that their provider has them in mind may help reduce their anxiety by making them feel cared for" (Portacolone, 2020). A lack of trust may prevent these patients from fully benefiting from the care provided, underscoring the importance of creating supportive healthcare environments that prioritize emotional security.

Empathy, identified as a strength of the service, further highlights the value of humanized care in enhancing patient satisfaction and outcomes. Acts of empathy, such as simplifying explanations or addressing patients' unique needs, demonstrate the importance of recognizing and valuing individual differences. For instance, small gestures like brushing a patient's hair after a procedure or drawing diagrams to explain treatment plans exemplify the power of empathy to create positive healthcare experiences. Previous studies have linked empathy to better outcomes in cancer treatments, as it improves patient satisfaction and overall well-being (Lelorain et al., 2012). Robieux et al. (2018) add that physicians highlight the beneficial effects of clinical empathy on patients outcomes and well-being as well as on their own professional practices. In the context of elderly patients with cancer and cognitive impairments, empathy becomes even more vital.

We would like to discuss **takeaway messages** from the analysed case study, which can serve as examples for similar service projects. Health services must be prepared to accommodate the diversity of patients. ID emphasizes the importance of developing effective solutions that serve as many people as possible. However, we also acknowledge the complexity of addressing the vast range of existing needs. Consequently, adopting different strategies for different groups of people is a crucial and effective approach to fostering inclusion (Clarkson et al., 2007).

In considering such a specific group of users as cognitively impaired elderly patients in an oncology service, several priorities emerge to ensure that health service design projects are inclusive and responsive to the complexities of care for these patients. Table 2 illustrates the connections between inclusive design principles (CABE, 2006), the themes identified in this study, and takeaway messages for the design of inclusive health services.

One key priority is putting people at the centre of the process, which involves developing a deep understanding of patients' needs, even when these are unconventional, unclear, or frequently changing. Cognitive decline presents unique challenges, such as memory and attention issues, difficulties in executive functions, and spatial disorientation. These factors require designers to exert extra effort to create healthcare services that are tailored to the specific needs of patients experiencing cognitive decline.

Recognizing diversity and difference is another essential priority. This entails understanding that individuals have different choices, feelings, perceptions, and sensations, even if they belong to the same demographic group. Healthcare services must take into account the unique preferences, emotions, and experiences of each individual.

Inclusion also depends on offering options when a single solution does not fit all. Providing a range of strategies to accommodate varying patient needs is critical. For example, requiring a caretaker's presence during consultations, using a slow and deliberate communication style, providing printed materials with information, repeating key details across multiple consultations,

and incorporating engaging tools like videos to explain diseases and treatments can be highly effective. Additionally, limiting medical jargon and ensuring that patients clearly understand their treatment journeys are important steps in fostering inclusivity.

Flexibility of use is another key consideration. Making healthcare services easier to understand and use involves presenting information clearly and accessibly. Special attention should be paid to factors such as font style, colour schemes, and the volume of information presented to avoid cognitive overload. This applies to both the design of physical environments and communication materials.

Table 2. Lessons learned for the design of inclusive health services for cognitively impaired elderly patients

ID principles (CABE, 2006)	Connections with the themes identified in the study	Takeaway messages
Putting people at the centre of the design process	Empathy	The healthcare team should strive to gain a comprehensive understanding of their patients to empathise with them, comprehend their difficulties, and provide compassionate care. It is essential to show positivity and attentiveness through gestures of affection and small actions that can significantly impact care delivery.
Recognizing diversity and difference	Empathy Informational and communication design	Among a group of elderly patients with cognitive impairments, there can be significant differences in their conditions, such as variations in memory issues (causing difficulty in retaining information about the treatment) and executive functions (preventing them to function independently). As a result, providing tailored care that meets each patient's specific needs is essential.
Offering options when a single solution is not able to encompass them all	Informational and communication design	Not all patients can easily comprehend diagnostic and treatment information; some commonly require additional support and to understand the information accurately. Consequently, healthcare professionals must tailor their communication strategies based on the cognitive abilities of each patient.
Providing flexibility of use	Built environment  Informational and communication design	The built environments of healthcare facilities, including signage, space, and furniture layout, must be designed with clear understanding as the main goal to ensure that cognitively impaired individuals are not confused.  Several other critical factors to consider include inadequate natural lighting, excessive space fragmentation, and poor ambience characterised by unsuitable visuals and sound/noise levels.
Designing convenient and enjoyable solutions for everyone	Built environment Trust in the healthcare team	All the factors mentioned above should contribute to a better patient experience. Thus, this takeaway message represents a conclusion to the study and a summary of our results. The study shows the importance of an easy-to-understand built environment, organised service structures, prepared staff, and a patient journey that goes beyond meeting the patients' formal requirements. It is crucial for patients to feel comfortable and included in the healthcare environment to trust the healthcare team and be motivated to follow through with their treatment.

Finally, designing solutions that are convenient and enjoyable for everyone extends beyond creating accessible physical spaces to include an organized service structure, well-prepared staff, thoughtful processes, and a coherent patient journey. By delivering not only functional requirements but also addressing emotional and experiential needs, services can provide a more meaningful and satisfying experience for all users.

Table 2 provides a detailed synthesis of the connections between inclusive design principles, the themes identified in the study, and specific takeaway messages for designing inclusive health services for cognitively impaired elderly patients. These priorities serve as a foundation for fostering inclusion and enhancing well-being through thoughtful and responsive design.

By integrating these insights, healthcare services can better support cognitively impaired elderly patients, fostering inclusion and well-being through thoughtful design that prioritizes diversity, flexibility, and empathy.

### 6. Conclusions

This study aimed to analyse the experiences of cognitively impaired elderly cancer patients with a Brazilian oncology outpatient service from the perspective of Inclusive Design (ID) and to outline takeaway messages for designing inclusive health services for this population. A case study was conducted in a private outpatient oncological service of a Brazilian hospital, employing non-participant observations and interviews with patients and caregivers.

The analysis revealed four key themes critical for fostering inclusion in the service: built environment, informational and communication design, trust in the healthcare team, and empathy. These themes provided the basis for identifying lessons learned and actionable insights for designing inclusive health services for cognitively impaired elderly patients. Each principle of Inclusive Design was linked to these themes, emphasizing the need for services to place patients at the centre, deeply understand their needs, recognize their differences, create tailored strategies to address these dissimilarities, facilitate accessibility and service provision, and ensure the service is designed in an organized, easy-to-use manner.

While the study provides valuable insights, its main limitation was the lack of access to the specific types and degrees of cognitive impairment among the patients. Future research could address this limitation by exploring how different types of cognitive impairment influence patients' interactions with healthcare services. Furthermore, comparative studies between countries with different levels of development could provide a broader understanding of how varying healthcare infrastructures, cultural contexts, and socioeconomic factors impact the inclusion of vulnerable patient populations in oncological care.

Expanding this work to include other patient demographics or contexts could also strengthen its applicability in inclusive healthcare. For instance, exploring the application of ID principles in public healthcare settings or with other vulnerable populations may provide additional insights into how to make healthcare services more equitable and accessible across different systems. Ultimately, this study reinforces the importance of designing healthcare services that not only meet functional requirements but also prioritize empathy, trust, and a deep understanding of patients' diverse and evolving needs.

# 7. Acknowledgments

We would like to thank the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) - Programa de Desenvolvimento da Pós-Graduação (PDPG-FAP) for the financial support.

# 8. Bibliography

- ACS. (2020). Changes in Memory, Thinking, and Focus (Chemo Brain). American Cancer Society. <a href="https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/">https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/</a> changes-in-mood-or-thinking/chemo-brain.html.
- Almeida, A.P.S.C., Nunes, B.P., Duro, S.M.S., Lima, R.C.D., & Facchini, L.A. (2020). Lack of access and the trajectory of healthcare use by elderly Brazilians. *Ciência & Saúde Coletiva*, 25(6), 2213-2226. https://doi.org/10.1590/1413-81232020256.27792018.
- Araujo de Carvalho, I., Epping-Jordan, J., Pot, A. M., Kelley, E., Toro, N., Thiyagarajan, J. A., & Beard, J. R. (2017). Organizing integrated health-care services to meet older people's needs. *Bulletin of the World Health Organization*, 95(11), 756–763. <a href="https://pmc.ncbi.nlm.nih.gov/articles/PMC5677611">https://pmc.ncbi.nlm.nih.gov/articles/PMC5677611</a>.
- Bakker, R. (2019). Environmental Design for Cognitive Decline. In Ravdin, L. D., & Katzen, H. L (Eds.). Handbook on the Neuropsychology of Aging and Dementia. (pp. 389–400). Springer. https://doi.org/10.1007/978-3-319-93497-6\_25.
- Barreto, M.S., Carreira, L., & Marcon, S.S. (2015). Envelhecimento populacional e doenças crônicas: Reflexões sobre os desafios para o Sistema de Saúde Pública. *Revista Kairós Gerontologia*, 18(1), 325-339. <a href="https://revistas.pucsp.br/kairos/article/download/26092/18731">https://revistas.pucsp.br/kairos/article/download/26092/18731</a>.
- Belasco, A.G.S., & Okuno, M.F.P. (2019). Reality and challenges of ageing. Revista Brasileira de Enfermagem, 72(Suppl 2), 1-2. <a href="http://dx.doi.org/10.1590/0034-7167.2019-72suppl201">http://dx.doi.org/10.1590/0034-7167.2019-72suppl201</a>.
- Borson, S., Small, G.W., O'Brien, Q., Morrello A. & Boustani, Ml. (2023). Understanding barriers to and facilitators of clinician-patient conversations about brain health and cognitive concerns in primary care: a systematic review and practical considerations for the clinician. BMC Prim. Care 24, 233. <a href="https://doi.org/10.1186/s12875-023-02185-4">https://doi.org/10.1186/s12875-023-02185-4</a>.
- Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*, 9, 26152. http://dx.doi.org/10.3402/qhw.v9.26152.
- Brazil. Constituição da República Federativa do Brasil de 1988. (1988). <a href="http://www.planalto.gov.br/ccivil-03/constituicao/constituicao.htm">http://www.planalto.gov.br/ccivil-03/constituicao/constituicao.htm</a>.
- Brazil. Lei nº 8.080, de 19 de setembro de 1990. (1990). <a href="http://www.planalto.gov.br/ccivil\_03/">http://www.planalto.gov.br/ccivil\_03/</a> <a href="leis/l8080.htm">leis/l8080.htm</a>.
- Brazil. Portaria nº 2.528, de 19 de outubro de 2006. (2006). <a href="http://bvsms.saude.gov.br/bvs/saudelegis/gm/2006/prt2528\_19\_10\_2006.html">http://bvsms.saude.gov.br/bvs/saudelegis/gm/2006/prt2528\_19\_10\_2006.html</a>.
- Brito, M.C.C., Freitas, C.A.S.L., Mesquita, K.O., & Lima, G.K. (2013). Envelhecimento populacional e os desafios para a saúde pública: análise da produção científica. *Revista Kairós Gerontologia*, 16(3), 161-178. <a href="https://revistas.pucsp.br/index.php/kairos/article/view/18552">https://revistas.pucsp.br/index.php/kairos/article/view/18552</a>.

- Commission for Architecture and the Built Environment (CABE). (2006). *The principles of inclusive design: (they include you)*. CABE. <a href="https://www.designcouncil.org.uk/fileadmin/uploads/dc/Documents/the-principles-of-inclusive-design.pdf">https://www.designcouncil.org.uk/fileadmin/uploads/dc/Documents/the-principles-of-inclusive-design.pdf</a>.
- Clarkson, P.J., Coleman, R., Hosking, I., & Waller, S. (2007). *Inclusive design toolkit*. Cambridge: University Of Cambridge. <a href="http://www.inclusivedesigntoolkit.com">http://www.inclusivedesigntoolkit.com</a>.
- Crimmins, E.M., Kim, J.K., Langa, K.M., & Weir, D.R. (2011). Assessment of cognition using surveys and neuropsychological assessment: the health and retirement study and the aging, demographics, and memory study. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66B(S1), i162–i171. <a href="https://doi.org/10.1093/geronb/gbr048">https://doi.org/10.1093/geronb/gbr048</a>.
- Garnelo, L., Parente, R. C. P., Puchiarelli, M. L. R., Correia, P. C., Torres, M. V., & Herkrath, F. J. (2020). Barriers to access and organization of primary health care services for rural riverside populations in the Amazon. *International Journal for Equity in Health*, 19(1). <a href="http://doi.org/10.1186/s12939-020-01171-x">http://doi.org/10.1186/s12939-020-01171-x</a>.
- Goodman-Deane, J., Ward, J., Hosking, I., & Clarkson, P. J. (2014). A comparison of methods currently used in inclusive design. *Applied Ergonomics*, 45(4), 886–894. <a href="https://doi.org/10.1016/j.apergo.2013.11.005">https://doi.org/10.1016/j.apergo.2013.11.005</a>.
- Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer Survivors in the United States: Age, Health, and Disability. The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences, 58(1), M82–M91. <a href="https://doi.org/10.1093/gerona/58.1.M82">https://doi.org/10.1093/gerona/58.1.M82</a>.
- Hutton, P. F. (1990). Survey research for managers: How to use surveys in management decision-making (2nd ed.). Macmillan Press Ltd. <a href="https://doi.org/10.1007/978-1-349-20698-8">https://doi.org/10.1007/978-1-349-20698-8</a>.
- Instituto Nacional de Câncer (INCA). (2020). Taxas de mortalidade por câncer, brutas e ajustadas por idade pelas populações mundial e brasileira, por 100.000, segundo sexo, faixa etaria, localidade e por período selecionado. <a href="https://www.inca.gov.br/MortalidadeWeb/pages/Modelo03/consultar.xhtml;jsessionid=2B1D6709F52093C9EF4DBCD9465764FF#panelResultado">https://www.inca.gov.br/MortalidadeWeb/pages/Modelo03/consultar.xhtml;jsessionid=2B1D6709F52093C9EF4DBCD9465764FF#panelResultado</a>.
- Jootun, D., McGhee, G. (2011). Effective communication with people who have dementia. *Nursing Standard*, 25(25), 40-46. <a href="https://doi.org/10.7748/ns2011.02.25.25.40.c8347">https://doi.org/10.7748/ns2011.02.25.25.40.c8347</a>.
- König, E., Bohn, P.R., & Libânio, C.S. (2022). Informational barriers and recommendations for patient inclusion in a Brazilian outpatient oncological service. *Brazilian Journal of Information Design*, 19(3), 1-13. <a href="https://infodesign.org.br/infodesign/article/view/1010/589">https://infodesign.org.br/infodesign/article/view/1010/589</a>.
- Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2012). A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology*, 21, 1255-1264. <a href="https://doi.org/https://doi.org/10.1002/pon.2115">https://doi.org/https://doi.org/10.1002/pon.2115</a>.
- Magnuson, A., Mohile, S., & Janelsins, M. (2016). Cognition and Cognitive Impairment in Older Adults with Cancer. Current Geriatrics Reports, 5(3), 213–219. <a href="https://doi.org/10.1007/s13670-016-0182-9">https://doi.org/10.1007/s13670-016-0182-9</a>.
- Marconi, M. de A., & Lakatos, E. M. (2010). Técnicas de pesquisa. Atlas. ISBN: 9788522451524. https://biblioteca.itl.org.br/cgi-bin/koha/opac-detail.pl?biblionumber=815.

- Mayo Foundation for Medical Education and Research (MFMER). (2023). Chemo brain. <a href="https://www.mayoclinic.org/diseases-conditions/chemo-brain/symptoms-causes/syc-20351060">https://www.mayoclinic.org/diseases-conditions/chemo-brain/symptoms-causes/syc-20351060</a>.
- Moghadasi, A. M., Sum, S., & Matlabi, H. (2022). Why do older people not use the public health services of the integrated aging program? A multidimensional approach in a qualitative study. *BMC Health Services Research*, 22(1288), 1-12. <a href="https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-022-08689-6">https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-022-08689-6</a>.
- Organization for Economic Co-operation and Development (OECD). (2021). *OECD Reviews of Health Systems: Brazil 2021*. OECD Publishing. <a href="https://doi.org/10.1787/146d0dea-en">https://doi.org/10.1787/146d0dea-en</a>.
- Organization for Economic Co-operation and Development OECD, (2019). *Health at a Glance 2019: OECD Indicators*. OECD Publishing. <a href="https://doi.org/10.1787/4dd50c09-en">https://doi.org/10.1787/4dd50c09-en</a>.
- Pan American Health Organization (PAHO). (2022). *Taking the pulse of the health system's response to the needs of older persons*. PAHO. <a href="https://iris.paho.org/handle/10665.2/56876">https://iris.paho.org/handle/10665.2/56876</a>.
- Pendergrass, C., Targum, S. D., & Harrison, J. E. (2017). Cognitive Impairment Associated with Cancer: A Brief Review. *Innovations in Clinical Neuroscience*, 15(1-2), 36-44. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5819720.
- Persad, U., Langdon, P., & Clarkson, P.J. (2010). Supporting Inclusive Evaluation with User Capability Data. In 3rd International Conference on Applied Human Factors and Ergonomics. Miami, USA. https://doi.org/10.1201/EBK1439835012-59.
- Portacolone, E., Covinsky, K. E., Johnson, J. K., & Halpern, J. (2020). Expectations and Concerns of Older Adults With Cognitive Impairment About Their Relationship With Medical Providers: A Call for Therapeutic Alliances. HHS Public Access, 30(10), 1584-1595. https://doi.org/10.1177/1049732320925796.
- Quirke, M., Bennett, K., Chau, H.-W., Preece, T., & Jamei, E. (2023). Environmental Design for People Living with Dementia. Encyclopedia, 3(3), 1038-1057. <a href="https://doi.org/10.3390/encyclopedia3030076">https://doi.org/10.3390/encyclopedia3030076</a>.
- Robieux, L., Karsenti, L., Pocard, M., Flahault, C. (2018). Let's talk about empathy! Patient Education and Counseling. 101(1), 59-66. <a href="https://doi.org/10.1016/j.pec.2017.06.024">https://doi.org/10.1016/j.pec.2017.06.024</a>.
- Rudnicka, E., Napierała, P., Podfigurna, A., Męczekalski, B., Smolarczyk, R., & Grymowicz, M. (2020). The World Health Organization (WHO) approach to healthy ageing. *Maturitas*, 139, 6–11. <a href="https://doi.org/10.1016/j.maturitas.2020.05.018">https://doi.org/10.1016/j.maturitas.2020.05.018</a>.
- Schagen, S. B., & Wefel, J. S. (2013). Chemotherapy-related changes in cognitive functioning. *European Journal of Cancer Supplements*, 11(2), 225–232. <a href="https://doi.org/10.1016/j.ejcsup.2013.07.007">https://doi.org/10.1016/j.ejcsup.2013.07.007</a>.
- Smith, S., Carragher, L. (2019). 'Just lie there and die': barriers to access and use of general practitioner out-of-hours services for older people in rural Ireland. *Rural and Remote Health*, 19(3). https://doi.org/10.22605/rrh5088.
- Tucker-Drob, E. M. (2019). Cognitive Aging and Dementia: A Life-Span Perspective. *Annual Review of Developmental Psychology*, 1(1). <a href="https://doi.org/10.1146/annurev-devpsych-121318-085204">https://doi.org/10.1146/annurev-devpsych-121318-085204</a>.

- Veras, R., & Parahyba, M. I. (2007). O anacronismo dos modelos assistenciais para os idosos na área da saúde: desafios para o setor privado. *Cadernos de Saúde Pública*, 23(10), 2479–2489. https://doi.org/10.1590/s0102-311x2007001000022.
- Webber, R., Bowers, B., & Bigby, C. (2010). Hospital experiences of older people with intellectual disability: Responses of group home staff and family members. *Journal of Intellectual & Developmental Disability*, 35(3), 155–164. <a href="https://doi.org/10.3109/13668250.2010.491071">https://doi.org/10.3109/13668250.2010.491071</a>.
- World Health Organization (WHO). (2020). Disability-Inclusive Health Services Toolkit. WHO. https://iris.who.int/bitstream/handle/10665/336857/9789290618928-eng.pdf.
- Zanella, L. C. H. (2013). Metodologia de pesquisa (2nd ed.) <a href="http://arquivos.eadadm.ufsc.br/EaDADM/PP1">http://arquivos.eadadm.ufsc.br/EaDADM/PP1</a> 2007 1/Modulo 1/Metologia da pesquisa/Material didatico/Metodologia\_da\_Pesquisa.pdf.

#### How to cite this article

König-Klever E., Bohn P.R., Tonetto L.M., Libânio C.S. (2025). Experiences of cognitively impaired elderly patients with a Brazilian oncology service. An analysis through the lenses of inclusive design. Journal of Accessibility and Design for All, 15(1), 73–86. https://doi.org/10.17411/jacces.v15i1.522







© Journal of Accessibility and Design for All (JACCES), ISSN 2013-7087, is published by the <u>Universitat Politècnica de Catalunya, Barcelona Tech</u>, with the sponsorship of <u>ONCE Foundation for Cooperation and Social Inclusion of People with Disabilities</u>. This issue is free of charge and is available in electronic format.



This work is licensed under an Attribution-Non-Commercial 4.0 International Creative Commons License. Readers are allowed to read, download, copy, redistribute, print, search, or link to the full texts of the articles or use them for any other lawful purpose, giving appropriate credit. It must not be used for commercial purposes. To see the complete license contents, please visit <a href="http://creativecommons.org/licenses/by-nc/4.0/">http://creativecommons.org/licenses/by-nc/4.0/</a>.



JACCES is committed to providing accessible publications to all, regardless of technology or ability. The present document grants vital accessibility since it applies to <a href="https://www.wc.ac.2.2">wc.ac.2.2</a> and <a href="https://www.mc.ac.2.2">PDF/UA</a> recommendations. The evaluation tool used has been Adobe Acrobat® Accessibility Checker. If you encounter problems accessing the content of this document, you can contact us at <a href="mailto:jacces@catac.upc.edu">jacces@catac.upc.edu</a>.

