Humanities & Social Sciences Communications

ARTICLE

https://doi.org/10.1057/s41599-024-04259-9

Perceived barriers to reaching equity in effective access to diagnosis and treatment for women with breast cancer in Chile

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Globally, it has been reported inequities in breast cancer effective access to health care. The objective of this study was to explore perceived inequities in access to effective diagnosis and treatment in women with breast cancer according to Tanahashi model and social determinants of health model. An exploratory case study, under a qualitative paradigm, was conducted. Theoretical sampling guided the selection of diverse participant profiles, comprising breast cancer patients, healthcare professionals and a civil society leader. The strategies for the recruitment process included social networks, civil society organizations, health professionals, and the snowball technique. Online semi-structured interviews were conducted. Interviews were transcribed, anonymized, and coded using ATLAS.Ti for deductive thematic analysis. Barriers to effective healthcare access were identified in all components of Tanahashi model. Accessibility and acceptability were the components with most perceived barriers. From the determinants of health model, a woman from the public health system, with low income, under 30 or over 40, and residing in a different region from the metropolitan region faces more barriers to access to an effective healthcare. The main barriers were for the high centralisation of healthcare in Chile, not integrated health system network, misinformation to the patient, and non-humanized healthcare. The results of this study offer a comprehensive exploration of perceived barriers to effective breast cancer diagnosis and treatment in Chile, using a qualitative approach incorporating diverse perspectives. Findings underscore significant systemic challenges across Tanahashi's model components, impacting the overall care experience. The study reveals structural inequities hindering healthcare access, reflecting global patterns in fragmented health systems.

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Background

Breast cancer (BC) is a global health concern and the most prevalent cancer among women worldwide(Siegel Mph et al. 2023). Higher mortality rates have been observed in poor and rural patients (Kenzik et al. 2020), along with an increased risk of late-stage diagnoses in individuals residing in high-poverty (Williams and Thompson, 2016) and lacking health insurance coverage (Obeng-Gyasi et al. 2022). Qualitative studies have also unveiled different experiences among BC patients, influenced by sociodemographic factors and religious identities (Leão et al. 2022; Moodley et al. 2018; Obeng-Gyasi et al. 2022; Wen et al. 2014). In all, opportunities for effective diagnosis and treatment of BC are associated with several social determinants of health (SDH). SDH are the conditions surrounding individuals' birth, growth, work, living, and ageing, including a range of forces and systems that shape the circumstances of daily life (Organización Panamericana de La Salud OPS/OMS, 2009). Social inequities in health have been defined as avoidable and unfair differences between groups due to their relative social class (Organización Panamericana de La Salud, 2023; Torres-Román et al. 2023).

In Chile, BC is the second most common cancer in the country (International Agency for Research on Cancer, 2020) with a mortality rate of 10.2 per 100,000 inhabitants (Frenz et al. 2014). Despite the statistics, women are an underrepresented group in decision-making and in the oncology workforce and senior management (Ginsburg et al. 2023). This situation makes invisible the experiences and realities of women with cancer, and the burden of BC remains unequal across less-represented social groups (Barrios, 2022). Chilean studies have suggested that age (Acevedo et al. 2015; Madariaga et al. 2024), area of residence (Cabieses et al. 2022; Durán and Monsalves, 2020; Herrera Riquelme et al. 2015; Madariaga et al. 2024), type of healthcare insurance and educational level (Cabieses et al. 2022; Herrera Riquelme et al. 2015; Madariaga et al. 2024) are significant determinants of social inequities in access to diagnosis and treatment of BC. To face this problem, BC is part of the Explicit Guarantees in Health Law (GES) that establishes guarantees of opportunity, quality, and financial protection for health problems with high health impacts, including BC (Infante and Paraje, 2010). These guarantees are rights to effective access to healthcare for patients from public and private systems. Public insurance is provided by the National Health Fund (FONASA), and private insurance is managed by social security institutions (ISAPRES) (Mondschein et al. 2020). Optional complementary health insurance can be added out of pocket, with a range of financial coverage and costs. Public healthcare is organized based on the level of complexity, with the primary level representing the lowest degree of complexity. Healthcare centres interact with one another through mechanisms of referral and counter-referral (González et al, 2019). The service provider network (public and private) is not adequately integrated and often generates barriers for patients, including cancer patients (Frenz et al. 2014). Fragmented health systems, such as those in Chile and Argentina, present significant inequities exacerbated by centralization and unequal resource distribution, where wealthier populations access better services, leaving poorer groups with limited or fragmented care options (Ruano et al. 2021; Siqueira et al. 2021). Studies from countries with more integrated healthcare systems, such as Canada and Denmark, demonstrate the potential benefits of streamlined care networks and patient-centric policies, which significantly reduce barriers to timely cancer diagnosis and treatment (Rudkjøbing et al. 2012; Stone et al. 2018). In the Chilean context, despite notwithstanding legislation such as the National Cancer Plan (NCP) (Ministerio de Salud, 2018) and the National Cancer Law (NCL) (Ministerio de Salud, 2020), and healthcare advancements in BC, evidence indicates that social inequity persists (Barrios, 2022; Herrera Riquelme et al. 2015).

One model to analyze equity in access to health care is the one proposed by Tanahashi in 1978 (Adauy et al. 2013; Tanahashi, 1978). This model allows analysis of equity in access to health care by identifying specific groups with unmet needs, barriers, and facilitators in achieving effective coverage of specific diseases (Adauy et al. 2013). Tanahashi's model considers five components to achieve effective coverage: Availability, Accessibility, Acceptability, Contact, and Effective Coverage (Adauy et al. 2013; Tanahashi, 1978). Components are described in Table 1.

Unlike other models that focus solely on individual patient factors or healthcare outcomes, the Tanahashi model provides a framework for evaluating both systemic and personal barriers, making it ideal for this context. While other models such as Aday and Andersen's Behavioral Model of Health Services Use (Aday and Andersen, 1974) or Levesque's model of access to healthcare (Cu et al. 2021) offer valuable insights into healthcare access, they focus primarily on the interaction between patient behaviours and health service utilization. The Tanahashi model, by contrast, is uniquely structured to assess healthcare system capacity and performance across different components, including the physical and organizational availability of services. This is particularly

Table 1 Definitions of the 5 main components of the Tanahashi model to achieve equity in effective access to care (11).

Component	Definition
Availability	Understood as availability of programme or care centre services, human resources, equipment, supplies, infrastructure and information; that is, the number or density of health centres and personnel (age, sex, expressions used, language) or the availability of technology, which can become barriers or facilitators.
Accessibility	Associated with physical accessibility such as distance, connectivity, and existence and transportation time; organizational/administrative, related to administrative requirements for health care and the modality to obtain hours and schedules of health care; and financial, related to the cost of transportation, out-of-pocket expenses and loss of earnings at work. Even if all the necessary resources are available, the service must be located within a reasonable distance from the people who should benefit from it.
Acceptability of services	Depends on the perception of benefits, influenced by social, cultural and religious factors, beliefs, norms and values, treatment and privacy. Once the service is accessible, it must still be acceptable to the population. Otherwise, people will not come for it and may seek alternative care. If the potential user accepts the service, this is one more step in providing health services.
Contact with the service	The continuity of care given by adapting health services to the patient and quality of care. It is the contact between the service provider and the user.
Global perceptions of effective Coverage	People who receive effective care. Contact between the service provider and the user does not always guarantee successful intervention related to the user's health problem or an effective service.

Table 2 Inclusion criteria for patients, health professionals and civil society representatives.

Inclusion criteria		
Patients	**Health professionals**	**Civil society leader**
(i) Age over 18 years old. (ii) History of breast cancer diagnosis. (iii) Having been treated for breast cancer in Chilean health system (private or public). (iv) Access to internet or telephone for participate in the interview.	(i) Working in the Chilean health system (public or private). (ii) Being physician specialist in breast cancer. (iii) Access to internet or telephone for participate in the interview.	(iv) Age over 18 years old. (ii) Have an active role in civil society organizations related with breast cancer. (iii) Access to internet or telephone for participate in the interview.

relevant in the context of breast cancer care in Chile, where systemic issues like centralization of services and lack of infrastructure play a significant role in access disparities.

This study employed the Tanahashi model and the SDH framework to explore perceived inequities and barriers in access to effective diagnosis and treatment in BC patients. The unique contribution of this study lies in its application of the Tanahashi model of care alongside the SDH framework to explore the barriers faced by breast cancer patients in Chile. While previous research has highlighted inequalities in access to cancer care, few studies have provided such an in-depth qualitative exploration, incorporating both systemic and personal perspectives.

A significant knowledge gap exists regarding BC patients' perceived barriers in diagnosis and treatment across varied socioeconomic contexts. Understanding these perceptions is crucial to addressing healthcare inequities (Adauy et al. 2013; Leão et al. 2022). Its findings can enhance the analysis of Chile's health system, spotlight areas for enhancement, and inform future clinical strategies.

Methods

'Methods' section is structured following the consolidated criteria for reporting qualitative studies (COREQ) (Tong et al. 2007) (Supplementary File 1).

Study design. Exploratory case study design conducted under a qualitative paradigm (Vásquez Navarrete et al. 2011) to understand a little-known phenomenon. Case studies involve various sources of information to provide a detailed description of the case (Creswell, 2014). For this research, the case study was defined as the perceived barriers to reaching equity in effective access to diagnosis and treatment for BC in Chile, following the components of the Tanahashi model.

Participant selection and recruitment. The study employed a theoretical sampling strategy, which is often used in qualitative research to ensure that participants with diverse and relevant experiences are selected to address the research question comprehensively (Vásquez Navarrete et al. 2011). This strategy aimed to capture a diversity of experiences regarding access to breast cancer care, including variations based on age, region of residence, and type of health insurance. By focusing on these factors, the study sought to explore the intersection of sociodemographic and healthcare system-related barriers.

The sampling units were three: (i) women with BC (patients), (ii) health professionals (HP) who diagnose and treat BC patients, and (iii) one civil society leader (CSL) linked to BC. The inclusion of breast cancer patients ensured that the study captured firsthand experiences of navigating the healthcare system. Healthcare professionals provided insights into the systemic and operational aspects of cancer care delivery, while the civil society leader contributed perspectives on advocacy and broader social influences on healthcare access.

Sampling was purposive to achieve diversity of experiences and discourses. The goal of this sampling strategy was to capture a diverse range of experiences to fully explore equity in access to breast cancer care, and not only identify the common barriers faced by patients but also the unique challenges experienced by those in more vulnerable or underserved groups. This diversity in experiences was crucial for applying the Tanahashi model and social determinants of health framework to understand inequities in effective healthcare access.

Considering these dimensions, a theoretical minimum of 20 patients, 5 healthcare professionals and 1 civil society leader was defined which was reached during the study. The inclusion criteria for each group of participants are in Table 2. The exclusion criteria for all participants were reporting a physical or mental condition limiting the person's ability to participate voluntarily in the study. The sample size remained flexible throughout the study, and recruitment continued until data saturation was achieved. In this context, saturation occurs when no new themes or insights emerge from additional data collection, indicating that the sample size is sufficient to capture the relevant experiences of the participants. As data collection progressed, the research team continually assessed whether additional participants were needed to capture new insights or themes, which ultimately led to the decision to conclude with 26 participants. While the sample size may appear small relative to the population of Chile, the aim was not to achieve statistical generalization but rather to explore in-depth, qualitative insights into healthcare access, particularly focusing on underrepresented voices.

Recruitment was carried out between October 2021 and March 2022. It was conducted remotely because of the pandemic context. Recruitment strategies included mailing, flyers, and infographics inviting to participate in this study through contacts from several social networks and civil society organizations related to BC, and the subsequent snowball technique (38). Potential patients participants provided contact information (telephone or email) and were contacted by study coordinator. No one refused to participate. HP and CSL were recruited via email among professional networks of the researchers.

Setting. Participants filled out an online informed consent available on an encrypted platform. Individual semi-structured interviews were conducted online, taking approximately 45 min. They were conducted using Zoom, WhatsApp or Meet depending on the participant's preference. The interview was performed by CC and FV.

Technical challenges were encountered during the interview process. A common issue was unstable internet connections, particularly for participants in rural areas, which sometimes caused delays or interruptions during the interviews. Additionally, some participants were unfamiliar with the online platforms used for the interviews, resulting in initial difficulties with joining the virtual meetings or adjusting audio/video settings. To address these challenges, the research team implemented several solutions. For participants experiencing connectivity issues, the interview was paused and resumed after reconnection or an alternative platform (such as a telephone call) was used to complete the interview. To assist participants unfamiliar with online platforms, the research team provided simple, step-by-step instructions for joining the meetings. Despite the technical challenges encountered, the research team was able to conduct all interviews successfully, ensuring that participants' experiences were captured in full. The solutions implemented helped to mitigate potential disruptions, and the remote nature of the interviews allowed for greater geographic diversity in the participant sample, enhancing the study's findings.

Data collection. The interviewer used a flexible pre-defined script prepared by the research team based on the study's objectives and available literature (Vásquez Navarrete et al. 2011) (Supplementary File 2). Following the SDH approach, sociodemographic data (age, health insurance, region, education) were identified. According to the Tanahashi model, perceived barriers to effective access to diagnosis and treatment of BC (availability, accessibility, acceptability, contact with service, effective coverage) were inquired. Interviews were recorded for transcription and securely stored on a personal computer.

All anonymized interviews were fully transcribed to Word and confirmed by CC and FV. Each interview was assigned a unique code to ensure participant information and confidentiality. Deductive thematic analysis, a qualitative method that allows for identifying thematic patterns from the data collected, was carried out (Vásquez Navarrete et al. 2011).

For the codification process, ATLAS.Ti software was used. Information was organised based on categories according to the Tanahashi model components (availability, accessibility, acceptability, and contact) serving as the initial framework for coding. Each interview transcript was reviewed line-by-line by FV and CC separately, and specific segments of the data were assigned codes corresponding to one or more of the components of the model. This initial round of coding helped to organise the data into broad categories based on the study's theoretical framework. The coding process was iterative and the codes were continually refined and adjusted as new data were reviewed. This iterative approach allowed for the identification of nuanced sub-themes within the broader framework of the Tanahashi model. Throughout this process, the codes were discussed between FV and CC in a consensus-building process, where discrepancies were discussed and resolved.

Each Tanahashi component was also analysed through the lens of SDH by examining perceived differences in effective access based on age, region of residence and the type of health insurance. The research team translated the textual citations from Spanish to English for publication ensuring accurate interpretation.

Scientific rigour. Several measures were employed to ensure the quality and rigour of the data collection process. Triangulation of responses from participants (patients, HP, and one CSL) and reflexivity notes were considered (Creswell, 2014; Cypress, 2017). Triangulation was conducted and integrated with descriptive findings by CC and FV. Triangulation of data was achieved by comparing responses across patients, healthcare professionals, and civil society leaders. This approach helped identify common themes and discrepancies across different perspectives. Researcher reflexivity was a critical component of this study. Both interviewers (CC and FV) engaged in continuous self-reflection throughout the data collection process, documenting personal assumptions, values, and potential biases in reflexivity notes. Reflexivity notes were taken throughout the research project and integrated into findings during qualitative analysis, mostly in incorporating the SDH dimensions into the components of the Tanahashi model.

To minimize interviewer bias, a standardized semi-structured interview guide was used, ensuring that each participant was asked similar questions in a consistent manner. The interviewers (CC and FV) were trained in qualitative interviewing techniques, emphasizing neutrality and avoiding leading questions. Interviews were conducted with open-ended prompts, allowing participants to share their experiences freely without steering from the interviewers. Regular team discussions were conducted to critically assess these reflections and ensure that biases were minimized during the data analysis.

Results

Study participants characterisation. A sociodemographic characterisation of all participants was displayed in Table 3. Patients were from different regions, health systems, ages, and educational levels. HP were physicians from public or private health systems. The CSL was the president of a BC organisation in Chile.

The study identified several key themes related to barriers in accessing breast cancer care, which were categorized according to the components of the Tanahashi model.

Perceived barriers to effective access related to the availability. Participants identified two main categories related to the availability: (i) limited human resources, particularly a shortage of oncologists who mainly operate in private systems, and (ii) geographical barriers. This scarcity contributes to an unstable and inequitable care system.

> *'We are very few oncologists, so if an oncologist leaves a hospital or a private health institution, it destabilises the system everywhere' M1, F_PUBLIC*

In terms of geographical barriers, this is firstly connected to Chile's high centralisation of care in the Metropolitan region (Santiago), which generates significant inequities in the health infrastructure and services available between regions such as the extreme north and south of the country. People from the Metropolitan region and other regional capitals have fewer barriers than those from rural, island or distant territories. The lack of infrastructure in regions and rural areas limits the installation of advanced technologies and treatments. See quote #1 and #2 Table 4.

This is especially severe in the public system due to the reference processes implemented between centres based on the complexity of care. Due to the lack of specialised cancer centres in some regions, patients are referred to other regions, requiring them to change their residence places. There is no consistent communication between the different institutions or support in providing patient information; therefore, patients report feeling lost, confused, or stuck in their navigation. See quote #3 Table 4.

CSL also recognise this referral system as a barrier that causes delays in health care processes, especially at the beginning of the process in patients from the public system. See quote #4 Table 4.

Perceived barriers to effective access related to limited accessibility. The perceived barriers to accessibility were related to (i) age, (ii) type of health insurance, and (iii) lack of information.

Age is a critical barrier to accessing mammography for BC suspicion. In Chile, people under 40 and over 60 are not included in the annual mammography recommendation group, making timely diagnoses difficult in young women. Mammography also presents difficulties in establishing suspicion in women who have

Table 3 Sociodemographic characteristics of participants.

Patients

Identification code	**Health system**	**Gender**	**Age**	**Education**	**Region of residence**
P1_FONASA	Public	Female	41	University	Other región (southern)
P2_FONASA	Public	Female	64	University	Other región (northen)
P3_FONASA	Public	Female	38	Secondary	Other región (southern)
P4_ FONASA	Public	Female	70	Secondary	Metropolitan
P5_ FONASA	Public	Female	42	Secondary	Other región (southern)
P6_ ISAPRE	Private	Female	50	University	Metropolitan
P7_ ISAPRE	Private	Female	61	Secondary	Metropolitan
P8_ ISAPRE	Private	Female	66	University	Metropolitan
P9_ ISAPRE	Private	Female	55	University	Metropolitan
P10_ FONASA	Public	Female	70	Secondary	Other región (northen)
P11_ISAPRE	Private	Female	57	Secondary	Metropolitan
P12_ ISAPRE	Private	Female	57	University	Metropolitan
P13_FONASA	Public	Female	53	University	Metropolitan
P14_FONASA	Public	Female	64	Secondary	Metropolitan
P15_FONASA	Public	Female	44	Secondary	Metropolitan
P16_FONASA	Public	Female	51	Secondary	Other región (southern)
P17_ISAPRE	Private	Female	38	University	Metropolitan
P18_FONASA	Public	Female	46	University	Metropolitan
P19_FONASA	Public	Female	44	University	Other región (northen)
P20_ISAPRE	Private	Female	46	University	Metropolitan
Health professionals					
Identification code	Health system work	Gender	Age	Medical specialty	Region of work
M1_F_PUBLIC	Public	Female	40	Oncologist	Metropolitan
M2_M_PRIVATE	Private	Male	50	Oncologist	Metropolitan
M3_M_PRIVATE	Private	Male	[a]	Oncologist/Radiotherapist	Metropolitan
M4_M_PRIVATE	Private	Male	[a]	Oncologist	Metropolitan
M5_F_PUBLIC	Public	Female	[a]	Oncologist	Other región (northen)
Civil society leader					
Identification code	Work	Gender	Age	Specialty	Region of work
SCL	Patient foundation	Female	68	Chilean breast cancer patient organization	Other región (southern)

[a]Participant does not provide information.

dense breasts, which is often the case of those under 50. In these cases, a breast ultrasound can be used; however, it is not part of the free-of-charge preventive examination and requires a medical order, which makes access more difficult. See quote #5 Table 4.

Health insurance barriers were referred to: (i) bureaucratic complexities in scheduling appointments; (ii) coverage disparities between public and private systems; and (iii) differences in accessibility to multiple services. The appointment process differs significantly across health centres and between public and private sectors, posing challenges for patients unfamiliar with the system's workings.

> *'That's how my odyssey began, because before I had breast cancer, I didn't, I've never gotten sick from anything, I mean, I had no idea about hospitals, I didn't even know about the Regional Hospital…' P16_FONASA*

Patients, HP and CSL also perceived differences in coverage between public and private systems. They reported that ISAPRES refuse to provide coverage for specific procedures like control MRI, ultrasound for suspicion or high-cost drugs. See quote #6 Table 4.

Some of these procedures are not covered by the GES basket. In those cases, one option is to pay out of pocket the amount requested by the private system, lodge a complaint with the Health Superintendent, and await the resolution along with the corresponding reimbursement. The second alternative is to file a complaint, await the Health Superintendent's resolution, and proceed with the payment at the end. The last alternative results in extended therapeutic pathway times. See quote #7 Table 4.

Information barriers were identified for both health systems. These are: (i) treatment for adverse effects, (ii) mental health, and (iii) breast reconstruction surgery.

Patients often face a lack of therapeutic options for managing side effects like nausea, vomiting, pain, hair loss, physical discomfort, dehydration, and anxiety, leading them to rely on personal resources and family support for solutions. See quote #8 and #9 Table 4.

Mental healthcare is considered part of the NCP and NCL, however, patients from FONASA perceive that these actions are deficient. On the other hand, a barrier identified by HP is the difficulty in acceptance of psychological therapy by some patients from both public and private healthcare. See quote #10 and #11 Table 4. Also, patients perceive that they have better access to mental healthcare in the public system compared to the private, which is beneficial for developing coping strategies related to BC. See quote #12 Table 4.

Surgical breast reconstruction is guaranteed by the GES. Perceived barriers identified are related to waiting time and uncertainty of its results. This process is slower in the public system, and sometimes patients pay their surgery out of pocket in the private system to get it sooner. See quote #13 Table 4.

Finally, lack of information is perceived in critical aspects of the therapeutic trajectory like waiting times, health guarantees and coverage, and adverse effects during treatment. This produces unequal experiences that negatively affect those with lower levels of health information, even within the same type of health insurance. See quote #14 Table 4.

Table 4 Representative quotes for each barrier identified according to Tanahashi Model and SDH framework.

Quote number	Quote
# 1	*'Here in Santiago, there are most of the oncology centres; there are most of the radiotherapy centres and most of the specialist doctors' M3_M_PRIVATE*
# 2	*'I am currently living in Coyhaique [extreme south of Chile], but I previously lived in Chile Chico, which is an even more extreme area; a lake borders it, so to be able to get out of there, it has to be by barge, and it is quite complicated to get in and out.' P1_FONASA*
#3	*'Here in Copiapó until that moment, very basic treatments were being done for cancer. Because now they are doing chemo here at the hospital. But only chemo, those patients that require hospitalisation have to go to Antofagasta.' P2_FONASA*
#4	*'The general practitioner is consulted, and when the physician sees something strange, he refers the person to their midwife at CESFAM or to another physician. That is a flow that is made.' CSL*
#5	*'They didn't send me to do the mammography because I was 34 years old and no one in my family had had cancer, so…when the biopsy arrived, the doctor confirmed it. That it was cancer, that the tumour measured 9 cm or something, it was big.' P3_FONASA*
#6	*'There are certain types of medication that are high-cost drugs, which are difficult to get for patients from private system' CSL*
#7	*'Patients who have Isapre [private system], if the treatment is in the baskets defined by the GES, then the treatment will also be very fast. But, if there is a part of the treatment that is not in the GES, these indications go to a committee at Isapre, and Isapre may require a letter from the patient requesting the medication. That can take longer, a week, sometimes it can even take a month.' M2_M_PRIVATE*
#8	*'They have denied me medication for nausea and vomiting. Um… they denied me the morphine patches, because my cancer was not metastatic' P15_FONASA*
#9	*'The last three chemo were horrible, horrible, horrible. My bones hurt, I couldn't walk, terrible. My husband had to bathe me, dress me, help me stand up…all horrible' P3_FONASA*
#10	*'The MINSAL guide, in the section on comprehensive patient support, it has, it's perfect. It includes psychological support, kinesiological support, occupational therapy, um… and it has psychological therapy for the family, group therapy, but in reality, this isn't there, you know?' P15_FONASA*
#11	*'I believe that (psychological care) is available, and they can access it, but there is a personal barrier that makes them feel weak when one proposes that they have a psychologist' M4_M_PRIVATE*
#12	*'I was being treated by a psychologist through video calls… I really needed it because there were days when I felt very down, and I would wonder what to do and not know what would come next… ' P2_FONASA*
#13	*'I had an appointment with the plastic surgeon and with the oncologist, because I didn´t know if the expander was placed correctly. I had super burned skin, eh, the doctor said that the reconstruction was complicated' P18_FONASA*
#14	*'They told me no, that there was no time, that I should call later, that the appointments were made in the first five days, so I had to insist and insist, then no, you have to do it through WhatsApp.' P1_FONASA*
#15	*'(Prophylactic mastectomy) I told the doctor at the… public hospital and she told me that I was crazy. I told her that if I want, it's my body. She says yes, but it's not medically necessary. And that was all. I would have taken out both breasts. It's sad, but, but I want to live now. If they had given me a choice, I would have done it.' P14_FONASA*
#16	*'They have you sitting there for hours and hours, even when it occurs to the doctor who calls you, he arrives when it occurs to him. Midday was passing and the doctor had just appeared and goes 'Oh hello girls, how are you!' Without saying, hey, excuse me, I was in a meeting, I was operating…give you an explanation, tell you.' P10_ FONASA*
#17	*'Here comes the frustration because the billing process takes between 9 and 10 months…after 9 months, they find out that they have to pay 1 million 2, 1 million 3, 3 million… So there is a lot… it is a source of stress for patients.' - M4_M_PRIVATE*
#18	*'I'm grateful because they cured me. It's simply because of that, but the waits; no, they're horrible. It's horrible to have to constantly ask for everything. That's frustrating, having to almost beg for help or for help' P14_FONASA*

Perceived barriers to effective access related to acceptability and contact. Barriers in acceptability are perceived in relation to two main categories: (i) distrust in therapeutic indications, and (ii) limited continuity of care. In terms of distrust to therapeutic medical indications, patients perceive there is a predominance of medical decisions over the patient voice, particularly in the public health system. For example, patients expressed concern and discomfort for not having the capacity to decide and negotiate around their treatment. See quote #15 Table 4.

Limited continuity of care perceived by participants relates to (i) self-navigation around the system, (ii) delayed medical appointments, and (iii) mistreatment during billing processes. Patients oversee their own navigation around the system, without expert advice or accompaniment. This situation is more severe in patients from the public system and in those with poor health information in general and in relation to GES guarantees.

> *'I think there is negligence towards other patients, because if I did not insist on my oncology exams, they would not do anything to me. Because it is one as a patient who has to be insisting.' P3_FONASA*

Delays in scheduled appointments are often experienced in waiting rooms. These delays are not communicated to patients, and neither apologies or explanations are provided to them. See quote #16 Table 4.

Regarding patient billing processes, the private health system does not immediately invoice the patient for hospitalizations. There is an indeterminate period during which the patient is unaware of the amount owed to the ISAPRE, and upon receiving the invoice, the patient realizes they lack the financial capacity to make the payment. See quote #17 Table 4.

Perceived barriers to effective access related to global perceptions of effective coverage. Regarding global perceptions around effective coverage, patients perceive they have received good care when the cancer is under control. In all, participants belief that patients perceived satisfaction is reported to be largely related to health outcomes. See quote #18 Table 4.

Nine areas of recommendation for improvement around global perceptions of participants around effective coverage are displayed in Table 5.

Discussion

This study integrated perceptions from patients, HP and CSL. Qualitative approach has been recognized in the literature as relevant for addressing health inequalities in BC (Gehlert et al.

Table 5 Areas that need improvement to enhance the overall perception of healthcare delivery from the voice of participants (final component of global perception of effective coverage in the Tanahashi model).

Area to improve	Quotes
1) Human relations: Vocation, good treatment, respect, humanization	*'It surprises me here (in the public system) there is not that vocation with patients and even more so with one who has cancer, there has to be delicacy and special treatment, and that does not exist. Not all those who work with the cancer patient have that treatment' P18_M_Spu* *'The team that works with cancer patients must be doubly well chosen. Because of all my visits to the clinic, on several occasions to insert the catheter, then to remove it due to the thrombosis and then to put it back in and what do I know, each time it is a ward, it is a process…I would tell you that 93% I found smiling, problem- solving… friendly people, which generally not everyone always has to be like that' P7_M_SPr* *'Yes, I had to fight for my needs. And for the attention. For better treatment in the hospital, better treatment for one' P10_M_Spu* *'In the hospital there is a lack of humanization, here they don't talk to the patient' M5, public* *'They really, really value that their doctor is empathetic, loving, that he takes the time to explain, to be able to clarify doubts, and that they feel that he is someone who is committed to them and that he is not someone who fights. The patient says that they are there writing the file and that they do not see them, or that they are there writing the paper file, I also think that patients value a lot, the human quality of their treating doctor' M3, private*
2) Communication	*'I think it is communication, it is what is most difficult. Because sometimes institutions can be super agile in terms of opportunity and quality and so on, but communication is so individual and so dependent on the person and the moment the person is at. Because if a day comes with many personal complexities, it affects the ability to communicate, then it is very variable individually and with different patients, as well as within the institution with different professionals. Not everyone has the same capabilities or the same ability, or they are not in the same conditions to be able to communicate well. M4, private*
3) Prioritize care for cancer patients in the public and private system	*'The quality has been generally good, but as I repeat, there is a lack of attention, more attention, more priority to cancer patients' P5_M_Spu* *'Difficulty…look, I would say going to Isapre, to the office to do the paperwork, or a lot of delay. It was a long wait, two, three, four hours of waiting. A couple of times I just said, I'm an oncology patient, can you get me a special number…I don't know' P8_M_SPr*
4) Continuity of health care	*'As I told you, the information, the treatment and the follow-up… see how the family is doing. It is true that they have 15–20 min, but they can make an appointment with your family and say, look, this and that are going to happen to your wife and she needs this and that… As I say, they should do more of that in hospitals, In private clinics, why are we going to say if we know that the treatment is very different. But what it is here in public health, there must be more humanity. There must be more, because the one who comes to the hospital is because he has a serious illness, because he is depressed, he is with… what he has the most is terror because as we are human beings, we all fear death. Even though we are old, we are afraid of dying.' P10_M_Spu* *'But for the public health system, the follow-ups should be done, in our case, by the clinics, not the cancer centres. We have to work on this, so that the monitoring of our patients or of the patients of all the hospitals is followed in their offices. But for that we have to have a more connected network. A unique electronic token. 'That would change the history of medicine in Chile instantly.' M2, private*
5) Oncology training	*'…more knowledge of the area that is not oncological, that is, the… having a more humane treatment, listening to each other' P15_M_SPr* *'When you talk to colleagues, there is a lot of ignorance regarding the specialty. There is a lot of ignorance regarding treatments, how oncology has been advancing. Which is super strange, that undergraduate and graduate schools do not encourage it so much today, because it is an important cause of mortality in our country, it is the first in some regions' M1, public*
6) Family health care	*'Knowledge also at the level of, uh… children, support for the family, cachai? For example, we found ourselves, thanks to the psychologist who is seeing Anto, because she has been the one who has been with a psychologist since the departure of the process' P15_M_SPr* *'As I told you, the information, the treatment and the follow-up… see how the family is doing. It is true that they have 15–20 min, but they can make an appointment with your family and say, look, this and that are going to happen to your wife and she needs this and that… As I say, hospitals should do more of that.' P10_M_Spu*
7) Administrative staff training	*'There is a lot of lack of training in the administrative line, especially when people are like me with breast cancer, that, there are some times that, that are in accordance with the Ges, or, or, that you are against time, You can't be like one, a patient who can wait, I don't know, I say, a gallbladder for seven months, although I know that people with gallbladders suffer a lot. But I am against a time to start treatment' P16_M_Spu*
8) Improve public system times	*'The public system is delayed, it is the reality, although it is true until the GES, clearly, there is the GES and it has its times, but what happens is that the public system still does not understand or the doctors themselves do not understand, that when they tell you that you have cancer, in my case, I have four or five relatives who have died of cancer, so when we found that I also had cancer, it was OMG!.* *No one understands it, that one enters into desperation, that is not understood, so no, the biopsy has to wait, I don't know twenty-something days, 30 days, but in private clinic that doesn't take long. It should*

Table 5 (continued)

Area to improve	Quotes
	be the same as the private system.' P18_M_Spu *'I think we have to improve the times, the access to biopsies of the people who do it, the people who do biopsy or the biopsy machines, they require human resources, people who know how to do that and that is not everywhere, This can produce a waiting list or congestion in some public hospitals.'M2, private* *'To get to the specialist with the result of the biopsy, I believe that in a public hospital, it can easily take 2 or 3 months from when the patient suspects he has cancer until he has the biopsy and reaches the specialist, From the moment the patient notices something to when he arrives with…doctor, I have this biopsy that says cancer. Easy two-three months. And in the private system, I think it is more or less a month' M3, private*
9) Systems to ensure attendance at follow-up controls	*'In the foundation, the controls are super rigorous, one has to go, but it also depends a lot on oneself, because if I don't go, no one called me to tell me, oh, you missed the control, no. Maybe too, that would be a point that… that, I don't know how to say it, that it is difficult to be called po', to remind you, but, but of course, that is, if there is a patient who is absent for a long time, there should still be a rescue of patients, because for some reason he is not going and it is important so that he does not return to… the disease' P19_M_Spu* *'There is no active person who says, damn, Mrs. xxxx it was your turn to check up today and she didn't come, let's call her on the phone, damn… and let's reschedule her time. No, if the patient did not go to the appointment, she will have to worry about requesting a new appointment' M3, private.*

2021; Lau et al. 2022) and this study advances in current knowledge by informing about unequal experiences in BC diagnosis and treatment based on age, region of residence and type of health insurance in a South American industrialized country.

This study explored perceived barriers to accessing effective diagnosis and treatment for BC in Chile, following the Tanahashi model´s components and some SDH. By organizing the findings according to the Tanahashi model, we were able to identify which specific aspects of healthcare access as the availability, accessibility, acceptability, or contact, present the greatest challenges for patients with BC in Chile.

The findings of this study have significant implications for healthcare policy, particularly in addressing significant and structural barriers to reach effective coverage in healthcare and equity in BC in Chile, like many other countries with fragmented health systems in Latin America and beyond (Kaler et al. 2022; Ragas et al. 2014). By identifying challenges related to geographic accessibility, healthcare infrastructure, and financial constraints, this study highlights critical areas where policy reforms are needed to improve equity in healthcare access and outcomes. National statistics on breast cancer inequities mirror the experiences shared by participants in this study (Acevedo et al. 2015; Cabieses et al. 2022; Herrera Riquelme et al. 2015; Madariaga et al. 2024). By triangulating the qualitative themes with existing quantitative data studies (Acevedo et al. 2015; Cabieses et al. 2022; Herrera Riquelme et al. 2015; Madariaga et al. 2024), this study offers a more comprehensive understanding of the barriers to breast cancer care in Chile.

Following Tanahashi´s model, most perceived barriers were around accessibility and acceptability, yet not limited to them (Adauy et al. 2013; Tanahashi, 1978). Barriers were observed in every component of care: availability, accessibility, acceptability and contact with services, hence affecting the global experience of effective coverage during diagnosis and treatment processes in BC patients. From an intersectional lens (Sibeoni et al. 2018; Veenstra, 2013), being from the public health system, having low income, be under 40 or over 60, and residing in a different region from the metropolitan region are relevant dimensions that affect the perception of barriers to effective health care in BC cancer in Chile. Findings suggest the existence of structural inequities that create unequal and persistent barriers to effective access to healthcare, which has been also recognized in other international and national research involving BC (Barrios, 2022; Durán and Monsalves, 2020; Herrera Riquelme et al. 2015). If these barriers are not resolved, the achievement of equity in access to health services in BC proposed by the 2005 health reform will not be achieved (Infante and Paraje, 2010). Also, inequities due to sociodemographic and economic aspects will be perpetuated (Organización Panamericana de La Salud, 2023). One of the most urgent policy implications emerging from this study is the need to decentralize cancer care services. Patients residing outside the metropolitan region face significant geographic and financial barriers to accessing timely care. To address this, policy reforms should focus on increasing the availability of specialized oncology services in rural areas and improving the integration of regional healthcare networks. Additionally, providing financial support to low income patients for transportation and other out-of-pocket expenses could reduce the inequities observed in the public healthcare system.

With GES there has been progress in equity, mainly in availability, however, there is still a need to advance in a process with a broader perspective that puts the patient at the centre and recognizes their preferences and knowledge. Although the GES programme provides important guarantees for breast cancer care, this study reveals gaps in its implementation, particularly in relation to accessibility and acceptability of services. For instance, the lack of coverage for certain diagnostic procedures, such as mammograms for women under 40, disproportionately affects younger patients. Policy reforms should expand GES coverage to include more comprehensive preventive care for younger women and ensure that bureaucratic delays in the public healthcare system are minimized.

The study findings are novel to the country and reveal the importance of qualitative research and participant diversity in promoting health equity in BC. Limitations related to an underrepresentation of some patients with more severe stages of BC, with aboriginal ethnic backgrounds, and identified as sexually diverse in the country, whom may experience unique barriers. Also, an exploratory, inquiring approach of the qualitative method used does not aim for establishing causal relationships, yet it informs about perceived bottlenecks that can be improved to catalyse health systems and global experience of care. Future studies might consider exploring these differences from a structural determinants approach, including gender, sexism and ageism (Ginsburg et al. 2023); from other healthcare professionals, including nurses, social workers, and administrative staff; and also delve into the relationship between clinical factors and healthcare access barriers.

Key recommendations emerge from the results. Firstly, targeted interventions are needed to address structural inequities, particularly in accessibility and acceptability components, as outlined in Tanahashi's model. Some interventions that has proven effective are mobile cancer screening units, telemedicine platforms, and patient navigation programmes (Freeman, 2012; Greenwald et al. 2017; Khanna et al. 2024). Strengthening regional healthcare infrastructure, ensuring prompt communication of healthcare changes to patients, and fostering a patient-centric approach are crucial. Additionally, a comprehensive review of GES implementation is warranted to better align with patient needs and knowledge. These measures are vital to prevent the perpetuation of sociodemographic and economic inequities in BC care and reach equity. In conclusion, this study offers a comprehensive exploration of perceived barriers to effective BC diagnosis and treatment in Chile, using a qualitative approach incorporating diverse perspectives.

Findings underscore significant systemic challenges across Tanahashi's model components, impacting the overall care experience. The study reveals structural inequities hindering healthcare access, reflecting global patterns in fragmented health systems. Insights gained contribute novel evidence to understanding health inequities in BC, emphasizing the value of qualitative research in informing health policy for equitable care access.

Conclusion

Barriers to effective healthcare access for women with breast cancer in Chile were identified in all components of the Tanahashi model. Barriers related to human resources, infrastructure, health coverage according to age, health insurance operation, access to information, continuity of care and mistrust were identified. In Chile, breast cancer patients from the public health system, with low income, under 40 or over 60, and who do not reside in the metropolitan region experience more barriers to accessing effective healthcare. This study demonstrated the utility and necessity of qualitative methods in comprehensive health services research. It underscores the importance of exploring the perspectives of patients and other participants to understand health problems deeply and contribute to the effectiveness of healthcare and equity.

The implication of this study is significant for the field of public health and healthcare policy, particularly in the context of breast cancer care in Chile. The findings suggest that a multifaceted approach is needed to address the barriers to equitable access in diagnosis and treatment.

Data availability

The datasets analyzed during the current study are not publicly available because they contain information that could compromise participant privacy. However, they are available from the corresponding author upon reasonable request.

Received: 28 July 2024; Accepted: 13 December 2024;

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Acknowledgements

The authors express their gratitude to Doctoral Programme of Science and Innovation in Medicine, Universidad del Desarrollo, and Centre for Prevention and Control of Cancer in Chile (CECAN), FONDAP 152220002 ANID Chile. Project funded by the Centro para la Prevención y Control del Cáncer en Chile (CECAN), ANID FONDAP 152220002.

Author contributions

Conceptualization and study design: CC, BC, AO. Data collection and data analysis: CC, FV. Manuscript writing: CC, BC. Review and editing: AO, FV. All authors approved the submitted version.

Competing interests

The authors declare no competing interests.

Ethics approval

This study was performed in line with the principles of the 1964 Declaration of Helsinki. The study was approved by the Comité Ético Científico de la Facultad de Medicina Clínica Alemana Universidad del Desarrollo (number 2021-67) on October 2, 2022.

Informed consent

Informed consent was obtained online from each study participant by researchers CC and FV during the study's implementation period (October 2021 and March 2022). The consent process began with the distribution of an information sheet outlining the purpose of the research, the nature of their participation, the risk-benefit assessment, measures to protect data confidentiality and privacy, and the intended use of the information for research purposes. Participants were then invited to ask any questions or address any concerns they had. Once they fully understood the research and their role in it, they were provided with an online consent form to complete prior to the interview. The consent covered participation, data usage, and permission to publish the results. All participants were thoroughly informed, and their anonymity in the research was guaranteed. This study did not include vulnerable individuals.

Additional information

Supplementary information The online version contains supplementary material available at https://doi.org/10.1057/s41599-024-04259-9

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