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RESEARCH

Barriers to accessing formal cancer care from the perspective of informal caregivers: a qualitative study

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Abstract

Background Cancer is a significant public health concern in Chile, with breast and lung cancers being among the most common and deadly types. Informal caregivers provide essential healthcare procedures and physical, emotional, and financial support to cancer patients, taking on significant responsibilities they must balance with their lives. Many of these responsibilities are directly related to healthcare and patient care processes, so the healthcare system is critical to the caregiver's experience. This study aims to identify health system barriers in the healthcare of lung and breast cancer patients through the voice of informal caregivers in Chile.

Methods An exploratory qualitative case study design was used, following the COREQ criteria. Twenty informal caregivers of adult breast and lung cancer patients were recruited from different regions of Chile through snowball sampling and online outreach. Semi-structured interviews were conducted between March and June 2023. Data were analyzed using deductive thematic analysis guided by Tanahashi's effective coverage framework, which focuses on four dimensions of healthcare access: availability, accessibility, acceptability, and contact. Atlas.ti software was used for coding and thematic organization.

Results Caregivers reported significant barriers across the four dimensions: (i) availability, lack of medical equipment and home care resources, especially in public hospitals; (ii) accessibility, long wait times, fragmented care across institutions, and high out-of-pocket costs, particularly for those outside the public health insurance (FONASA) coverage; (iii) acceptability, inadequate communication from healthcare providers, with limited information on diagnosis and prognosis; (iv) contact, poor continuity of care, with a lack of coordination between healthcare providers, leading to feelings of isolation and frustration among caregivers.

Conclusions The study reveals critical gaps in Chile's healthcare system. Caregivers play an essential role in patient care but receive insufficient support from the healthcare system. Addressing the identified barriers, including improving communication, coordination, and support for caregivers, is crucial for achieving better healthcare outcomes and reducing disparities in cancer care. These findings have significant implications for policymakers, highlighting the need for reforms to support caregivers and enhance the cancer care continuum in Chile.

Keywords Cancer · Caregivers · Health system

Abbreviations

GES	Explicit Health Guarantees plan
NCP	National Cancer Plan
CL	Cancer Law

Introduction

Cancer was the leading cause of death in the world in 2020 [1]. In the Region of the Americas, the Pan American Health Organization predicts 6.7 million cancer cases by 2025 [2]. Also, cancer is one of the non-communicable diseases included in Sustainable Development Goal 3,

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health, and well-being [3]. In Chile, according to data from the Global Cancer Observatory (GLOBOCAN) in 2022, 59.876 new cases were identified, and 31.440 people died [4], with breast cancer in women and lung cancer in men having the highest age-adjusted mortality rate, 13.6 per 100,000 women and 25.9 per 100.000 men respectively [5]. Due to the significant impact of these cancers on national mortality, they are legally guaranteed maximum waiting times for care and a defined set of benefits that encompass suspicion, diagnosis, treatment, and follow-up.

In addition, Chile has a higher mortality rate than the average rate for OECD and Latin American and Caribbean (LAC) countries. In 2017, the mortality rate in Chile was 130.5, compared to the OECD average of 124.6 and LAC's 120 [6]. In Chile, the National Health Strategy for the country until 2030 includes cancer as one of its impact areas, with the aim of reducing premature mortality from cancer in the general population [7].

This scenario presents a significant challenge for the Chilean health system, which is segmented into two main sectors: public and private, both overseen by the Ministry of Health [8]. Most of the population is covered by the public system with the public health insurance FONASA (77.4%), another part of the population is part of the private system (16.9%) affiliated with various health insurances known as ISAPREs, and a smaller part of the population has its health coverage through the armed forces health insurance (5.7%) [9]. This segmentation exacerbates disparities in access to cancer diagnosis and treatment, disproportionately affecting those in lower socioeconomic groups and rural areas [10, 11], reinforcing the structural problems in Latin America.

To address the epidemiological challenge of cancer, Chile has implemented several initiatives, including the Explicit Health Guarantees Plan (GES) [12], the National Cancer Plan (NCP) [13, 14], and the National Cancer Law (CL) [15]. Both the public and private health sectors should adhere to the approaches and guidelines outlined in these programs and laws.

The GES is a health program framed by Law No. 19.966 that establishes a regime of Health Guarantees; it includes 81 pathologies with guarantees of access, opportunity, financial protection and quality, of which 18 are cancers, including breast and lung cancer since 2005 and 2019 respectively [12]. These guarantees apply to all individuals affiliated with the Chilean health system, whether through FONASA or ISAPREs, ensuring that all beneficiaries, regardless of their health insurance provider, have access to these benefits [12]. For both breast and lung cancer, the GES program covers suspicion, diagnosis, treatment, and follow-up. Specifically, for breast cancer, it includes medications, supplies, assistive devices, surgery, and exams, while for lung cancer, it covers medications, supplies, surgery, and exams [12].

The NCP was initially developed for 2018–2028 [13] and has been updated for 2022–2027 [14]. Both versions emphasize the comprehensive care model as fundamental for cancer patient care [13, 14], addressing physical and mental aspects of the person and their illness, recognizing individuals as social beings who belong to diverse families and communities.

The CL, which came into effect in 2020, plays a pivotal role in establishing the regulatory framework for cancer policy in Chile. It guides the planning, development, and implementation of cancer-related policies and the creation of programs to enhance our understanding of the causes and incidence of this disease [15]. Like the NCP, the CL also highlights the importance of comprehensive treatment and civil society participation, including caregivers, as one of its guiding principles.

Despite these efforts, structural barriers persist in ensuring timely and comprehensive cancer care in Chile. Social science research has highlighted significant challenges in cancer treatment, including fragmented healthcare systems, unequal access to palliative care, and geographic mobility due to limited oncological services outside major urban centers [16].

The lack of integration between primary and specialized care, financial constraints, and disparities between public and private sectors have been identified as critical barriers to achieving equitable cancer care in Latin America [17]. Furthermore, palliative care services are often underdeveloped and not fully integrated into standard cancer treatment pathways, leaving many patients and their caregivers without essential support during the advanced stages of the disease [18]. Geographic mobility is another key aspect influencing cancer care access. In many Latin American countries, patients and caregivers must travel long distances to receive specialized treatment, often relocating temporarily or permanently to access tertiary care centers [19]. Understanding cancer care's broader social and structural determinants is essential for enhancing healthcare services. A comprehensive understanding of these processes requires the involvement of multiple stakeholders, including those directly engaged in patient support. Informal or secondary caregivers, often overlooked, provide invaluable insights into the healthcare system's functionality, uncovering critical gaps in care and highlighting areas for improvement. Informal caregivers in cancer are typically family members or close friends who provide short- or long-term care support to patients without financial compensation [20, 21].

A critical yet often overlooked aspect of cancer care is the power dynamics between the biomedical system and informal caregivers. The biomedical model predominantly prioritizes clinical expertise and formal healthcare structures, often marginalizing the role of informal caregivers, despite their essential contributions to patient well-being

[22]. Informal caregiving, largely carried out by family members or close acquaintances, is frequently undervalued within healthcare institutions, leading to a lack of adequate support, training, and formal recognition of their contributions [23]. This devaluation is rooted in a hierarchical healthcare structure, where professional medical authority dictates patient-care decisions, leaving caregivers in a peripheral role with limited agency and resources [20]. The consequence of this marginalization is twofold: caregivers experience high emotional, physical, and financial burdens, and patients may receive fragmented care due to the lack of integration between informal and formal healthcare providers [24] .

Addressing these disparities requires a paradigm shift that acknowledges the interdependence between professional medical care and informal caregiving, ensuring caregivers are included in decision-making processes and supported through structured healthcare interventions [25]

Caregivers are an informal extension of care outside the healthcare system [24]. The care provided by these informal carers is often physical, emotional, social, or financial [21]. Tasks may include accompanying patients throughout their therapeutic journey and disease progression, supporting treatments and managing adverse effects, assisting with treatment decision-making, providing transportation to medical appointments, helping with nutrition, and aiding in mitigating the disease's impact on the patient's quality of life [21, 25]. Although many of these actions are directly related to the disease process and increase in late-stage or advanced cancers [21, 26, 27], informal caregivers are neither recognized nor actively involved as collaborative partners within the healthcare system [23]. In the Chilean context, the NCP recognizes the essential role of supporting cancer patients and their informal caregivers within its comprehensive care framework. It emphasizes the need to integrate and strengthen the role of informal caregivers within the healthcare system, ensuring they have access to adequate resources, information, and designated spaces to effectively carry out their caregiving responsibilities [13, 14]. Furthermore, the CL adopts a holistic approach that prioritizes patient care and the well-being of their support network, ensuring that caregivers receive the necessary tools and support to fulfill their role effectively [15].

The involvement of informal caregivers in the healthcare processes of a patient with cancer provides a unique opportunity to understand the functioning of the health system and the delivery of health services from a new perspective. Their experiences and narratives can reveal both the strengths and weaknesses of the patient's clinical journey, offering important messages for healthcare organizations [28]. Allen et al. emphasize the need to involve caregivers in coordinated discharge planning and decision-making, which improves the quality of care transitions [29], and Lilleheie et al. highlight the importance of their involvement in care coordination and the need to improve communication between interprofessional care teams and caregivers [30].

To understand and address the functioning of the health system, the Tanahashi framework provides a valuable model [31]. Developed to assess the effective coverage of healthcare services, this model evaluates critical dimensions of healthcare access: (i) availability, (ii) accessibility, (iii) acceptability, and (iv) contact. Availability refers to the disponibility of program or care center services, human resources, equipment, supplies, infrastructure, and information. Accessibility evaluates physical access, administrative and organizational access, and financial access to costs related to care. Acceptability considers people's perception of the benefits, and the final dimension assesses contact with the service, which relates to the continuity and adaptation of care to the patient [31, 32]. Examining access barriers to effective health coverage is possible through the study of therapeutic trajectories.

The concept of therapeutic trajectory does not have a single definition in the health sciences literature; however, it is commonly used to describe the path a person follows in search of solutions to their health problems, encompassing clinical care, treatment, and rehabilitation [33, 34]. This concept includes not only the experiences of individuals as they navigate the healthcare system, recognizing their needs and preferences, but also the organizational and administrative processes required for healthcare delivery [33–35]. Understanding therapeutic trajectories from the perspective and experience of caregivers through the Tanahashi model can help understand barriers to accessing cancer care.

Applying this model and considering the caregiver's experiences allows us to identify gaps in cancer healthcare delivery and contributes to improving healthcare performance and achieving health equity through the caregivers' experiences [36], by improving the experience of cancer patients and caregivers. This study aims to identify health system barriers in the healthcare of lung and breast cancer patients through the voice of informal caregivers in Chile.

Methods

Study design

An exploratory qualitative study with a case study design was conducted [37] that allows for understanding a little-known phenomenon. Case studies usually include diverse sources of information to provide a detailed description of the case [38]. For this research, the case study was defined as the experiences of secondary or informal caregivers of breast and lung cancer patients with the Chilean health care system. The methodology followed the COREQ qualitative study criteria [39].

Study participants

The sample was defined at the beginning of the research considering the diversity of study participant profiles [38] following some of the Cochrane PROGRESS guidelines [40] of place of residence, sex, educational level, and occupation. The number of participants was defined considering theoretical criteria and feasibility of recruitment [37]. The sampling units were secondary caregivers of patients with breast or lung cancer treated in the Chilean health system (public or private). The sampling was considered to include diverse participants, considering the relationship with the patient, sex, region of residence, health insurance, and age.

Sample size was defined as having a minimum of 20 participants, which was achieved while conducting the study. The inclusion criteria were (i) age over 18 years old, (ii) being or having been a caregiver or significant other of a patient with breast or lung cancer, and (iii) have access to internet or telephone for participate in the interview. The exclusion criterion was reporting a physical or mental condition limiting the person's ability to participate voluntarily in the study.

Recruitment of participants

Recruitment of participants took place between March and June 2023. To facilitate the participation of people from different regions of the country, the study was conducted online. The strategies used for recruitment were dissemination in social networks through cancer patient organizations and snowball technique [41]. Potential participants provided contact information (telephone or e-mail) and were then contacted by the study's principal investigator, who sent to them an information sheet describing the study and inviting them to participate. Once the participant agreed to be part of the study, the process of obtaining informed consent and agreeing the date and time of the interview began. Twenty participants were invited, and none of them refused to participate. The characteristics of the participants are available in Table 1.

Data collection process

Semi-structured individual interviews were conducted online via Zoom, Meet, or video call via WhatsApp, according to the participants' preferences. The interviews were conducted by CC and FV, researchers with experience in interviewing and qualitative research, between March and June 2023. The research team created the interview script according to the study objectives and literature. The main dimensions addressed by the interview guide were the general experience as a caregiver, experience of accompaniment, perceived barriers in the patient's health care, facilitators in health care, quality of care, and general evaluation of the experience. The approximate duration of the interviews was 45 min.

Table 1 Characteristics of the participants

Code	Sex	Age	Educational level	Occupation	Region of residence
M_BC_35_son	Male	35	University	Academic	Metropolitan region
F_LC_67_doughter	Female	67	University	Housewife	Metropolitan region
M_LC_47_son	Male	47	University	Biochemical	Metropolitan region
F_BC_34_dougther	Female	34	University	Nurse	Metropolitan region
M_BC_30_son	Male	30	University	Medical technologist	Metropolitan region
F_LC_39_dougther	Female	39	University	Engineer	Metropolitan region
F_LC_ > 60_wife	Female	> 60	University	Retired	VI region
F_BC_ > 60_dougther	Female	> 60	Secondary	Housewife	IX region
F_LC_29_doughter	Female	29	University	Lawyer	Metropolitan region
M_BC_49_brother	Male	49	University	Auditor accountant	Metropolitan region
M_LC_37_son	Male	37	University	Physician	Metropolitan region
F_BC_53_doughter	Female	53	University	Physiotherapist	Metropolitan region
F_BC_27_doughter	Female	27	University	Psychologist	Metropolitan region
F_LC_47_nephew	Female	47	Technic	Medical representative	Metropolitan region
F_BC_51_friend	Female	51	University	Midwife	IX region
F_LC_47_dougther	Female	47	Secondary	Housewife	XII region
M_BC_58_husband	Male	58	University	Engineer	Metropolitan region
F_LC_68_wife	Female	68	Technic	Nursing assistant	Metropolitan region
F_BC_67_mother	Female	67	University	Engineer	Metropolitan region
F_LC_54_doughter	Female	54	University	Psychologist	V region

Data analysis

The interviews were audio-recorded for later transcription and stored securely on a personal computer. At the end of the 20 interviews initially planned, the team analyzed the saturation of the information, and it was agreed to have reached it in the main dimensions of the study. Therefore, there was no need to add participants. For data analysis, the interviews were anonymized with an alphanumeric code and transcribed in full in the original language into a Word document by CC and FV. Later, each transcript was checked for accuracy against the original audio by BC an AO.

Deductive thematic analysis was performed, a qualitative method that allows for identifying thematic patterns from the data collected [37]. The coding process was carried out using ATLAS.ti software version 24. To organize the information on caregivers' perceptions of the health system, the Tanahashi effective coverage model was used [31, 32].

Qualitative methodological rigor

This research used triangulation and review guides to ensure methodological rigor [37]. In triangulation, the analysis was contrasted between researchers [37]. Our multidisciplinary research team contributed to a critical approach to the research problem and to reduce bias in interpretation [37]. Regular team meetings were held to ensure sensitivity to the context studied. There was also triangulation among informants including a diverse range of participants, considering participants from different regions, ages, health systems, and genders [37]. The COREQ criteria [39] were used for the stringency criteria of review guidelines [37].

Ethical considerations

The study followed the rules and regulations for research involving human subjects, including the Declaration of Helsinki and CIOMS guidelines. The Scientific Ethics Committee from Facultad de Medicina Clínica Alemana, Universidad del Desarrollo, gave ethical approval (2021–67). All participants completed a digital informed consent form, and all sensitive data were anonymized.

Results

The results are presented according to the four dimensions of the Tanahashi model: (i) availability, (ii) accessibility, (iii) acceptability, and (iv) contact. In each dimension, barriers were identified from the experiences reported by caregivers. The main barriers for each dimension are summarized in Table 2. In addition, the final part of the findings includes a list of recommendations for improving health system performance that emerge from the caregivers' experiences. More quotes are available in supplementary material.

Availability

Barriers related to (a) medical devices, (b) home care, (c) emergency services, and (d) information were identified.

Medical devices

Medical device performance barriers occur when technical failures require repair. In facilities with only one device, these unexpected failures have a negative impact on the user experience. This problem is more prevalent in public health network facilities and affects patients covered by FONASA. Equipment failures mobilize caregivers to seek alternatives in the private healthcare sector, often resulting in increased caregiver burden and out-of-pocket expenses. Patients and caregivers who cannot afford private care have to wait for equipment to be repaired or for referral to another health facility, possibly outside their area.

> Look, we had to go out and look for, for example, in the specific case of when the scanner was ruined, we had to go out and look quickly for a place where we could do it so that we could have, in a short period, the diagnosis through the scanner. M_LC_47_son

Home care

It was recognized that the health system provides supplies for home care; however, barriers exist due to the lack of adequate training for caregivers in administering and using these supplies and medications. Caregivers often assume roles that require them to navigate complex healthcare systems, advocate for consistent and quality care, and manage end-of-life preparations, often without adequate formal support. This situation forces caregivers into a position of taking charge, which can be overwhelming and lead to significant stress and burnout. Carers are an effective extension of the health system, yet they do not receive the support they need. As the patient's disease progresses, these caregiving responsibilities increase in frequency and complexity. Consequently, caregivers of patients in terminal stages or with advanced cancers must perform more complex tasks, leading to an intensified feeling of abandonment by the health system. This is clearly reflected in the following quote:

> They gave us morphine so that we could administer it ourselves and other things like patches and many other things, but it was complicated; I mean, it was very difficult to administer those things because she moved

Table 2 Main barriers of the health system in healthcare for breast and lung cancer according to the Tanahashi model

Main barrier availability dimension:
• Equipment with failures
• Lack of training for the caregiver to administer medications or perform more complex healthcare
• Access to home oxygen devices dependent on self-management
• Emergency services without oncologists or health professionals with experience and training in oncology
• Lack of clear and timely information for patients and caregivers from health teams
Main barrier access dimension:
• Fragmentation and segmentation of the health system
• Pharmacy closing hours before the end of medical care
• Fixed closing hours of palliative care offices that do not allow access to consultations or unforeseen benefits
• Lack of coordination, communication and access to information between the public and private systems for people with mixed trajectories
• High costs of private physician appointments for FONASA patients seeking second opinions and access to faster tests
• High costs to access treatments not part of FONASA and ISAPRES coverage
Main barrier acceptability dimension:
• Unclear delivery of information related to patient prognosis
• Lack of empathetic communication from physicians to patients and caregivers
• Lack of information explaining the decision of the oncology committee to patients and caregivers
• Lack of humanization and contextualized attention to the situation of the terminal cancer patient, mainly in the emergency room
• Lack of information provided to patients and caregivers about clinical decisions
• Lack of care with a multimorbidity approach
• Very short care times between physician and patient
• Lack of instances of access to information for the patient and caregiver outside the care box with the physician
• Lack of integration in the information provided by the different health professionals providing care to the patient
Main barrier contact dimension:
• Barrier contact dimension
• Lack of connection between primary, secondary and tertiary levels of care
• Lack of communication between health institutions that sell/purchase health services to be received by the patient
• The delivery of unclear information by healthcare providers has led to significant patient misunderstandings
• Patients face challenges in obtaining imaging exams necessary for ongoing review during treatment and follow-up phases

> all the time, so it was not easy to do it, I was not in a condition to face that situation. M_BC_35_son

Emergency services

Emergency care often prioritizes immediate life-threatening conditions, leading to delays or inadequate pain control for cancer patients, as reflected in the following testimony:

> After the radiation, my mother went through cycles of radiotherapy; at night, she was in immense pain, so to take her to the emergency room, it was almost impossible to think that they were going to attend to her or give her priority, so it was difficult. M_LC_47_son

Regarding emergency services, it is recognized that such services exist in the country; however, there is a lack of health professionals with experience and training in oncology. The lack of specialized oncology professionals hinders the care of cancer patients, as their needs are not fully understood, and care is not prioritized appropriately. This issue is not solely due to a lack of knowledge about oncological diseases but also reflects the broader disarticulation of medical specialties and the absence of a comprehensive, patient-centered approach. The fragmentation of healthcare services, particularly in emergency settings, highlights the compartmentalization of medical expertise, where disciplines operate in isolation rather than as part of an integrated system. Consequently, cancer patients in need of urgent care may be assessed primarily based on acute symptom, without considering their broader disease trajectory and palliative needs.

Information

Caregivers perceive that physicians often withhold information. This situation is attributed to sociocultural prejudices about the patients' ability to understand or due to the physicians' unwillingness to communicate. To address this gap, the presence of caregivers during patient care is crucial, as they are the ones who ask specific questions about the patient's health condition and care.

> I noticed that they were a bit reluctant to give information, and I saw it as a super determinant as, like, people from the field without understanding much. Hey, why am I going to give them more detail about

> something they are not going to have any idea about it. M_BC_30_son

Another barrier is the lack of information about the benefits that the patient can receive related to the GES, even when the patient or his/her caregiver explicitly requests it. This lack of information mainly impacts patients in the private system since they must pay 20% of the benefits they receive through GES. In the case of benefits that indicate that they are not part of the GES, they must pay out of their own pockets the amounts corresponding to the coverage of their respective ISAPRES, generating a risk of significant financial toxicity.

> I asked the ISAPRE to send me a little table of all the benefits included in the basket of GES, and I could not get them to send me that. Moreover, that was really annoying because the truth is that you do not know where to buy the voucher. In fact, once, they (parents) were really worried about buying a voucher, and I told them that if this is done online, I did get it online. However, it was a bit complicated. So, not giving you a basket with the procedures, with the values, what you have to pay, what the GES covers, and what it doesn't cover is kind of complicated. F_BC_53_doughter.

Accessibility

The results of this dimension are presented in the following order: (a) physical accessibility, (b) organizational/administrative accessibility, and (c) financial accessibility.

Physical accessibility

The main barrier impairing the user experience is the segmentation of the health system and its institutions. The experiences of carers of patients with breast or lung cancer show how this fragmentation and segmentation affect patient trajectories and hamper care processes, as patients are constantly moving from one institution to another. This extends therapeutic trajectories and affects continuity of care.

> Life is not made easier for the cancer patient. On the contrary, it has many obstacles, and you have to go to one place, from one hospital, you have to go to another and from another, they send you to another. It is a very complicated process, it is not organised. M_LC_47_son

Organizational/administrative accessibility

This area of analysis presented the most significant barriers within the accessibility dimension, which strongly impacts the healthcare experience. One notable barrier concerns pharmacy and palliative care in the public healthcare network.

The barriers to pharmacy care identified are mainly related to opening hours and waiting times. Pharmacy opening hours are until 17:00 h, and patients attending consultations that end after this time are unable to access prescribed medicines or supplies. This situation overburdens caregivers, who must return to the health center the next day to pick up the medicines to avoid delaying the patient's treatment. In addition, long waiting times for medication collection have been reported, with carers often spending an entire day at the pharmacy waiting for their turn to access the treatments prescribed in the patient's medical order. This situation further increases the burden on caregivers and their support network, as they must manage personal resources to ensure timely access to the patient's medications. Pharmacy opening hours are also recognized as a barrier to palliative care. This limitation hinders access to palliative care for patients in pain who need a rapid response from the system, making it impossible to obtain necessary medication outside of the established schedule.

> One of my sisters had to go to the hospital to pick up medication, she had to be there at sevenin the morning so that the medicines would be delivered at two o'clock in the afternoon. We had to wait all those hours there. F_LC_39_dougther

Another aspect related to organizational/administrative accessibility barriers is the care modality. People with public health insurance, FONASA, can receive care throughout the public network; however, those with more financial resources can access healthcare from private providers by making a co-payment. For the purposes of this research, we will refer as mixed trajectories in these cases. This mixed trajectory benefits those who can access it, as they obtain faster responses or second medical opinions; however, it also presents a significant barrier due to the lack of coordination, communication, and information access between the public and private institutions. Patients and their caregivers must personally request and transfer information from one institution to another. Access to this information in the public system is often being slow due to bureaucratic processes.

Financial accessibility

A major financial barrier is the high cost of health services in the private system. Even when FONASA patients could access these services, they are unable to do so due to limited financial resources. Another situation was related to the doctor's refusal to give medical orders for specific tests requested by patients and carers for their peace of mind and well-being. This situation leads patients to seek alternatives in the private system, where they can find answers to their questions and obtain orders for specific tests. These tests, as well as the annual check-up, are carried out in private health facilities and are paid for out of pocket.

A final point on financial accessibility arises from the experiences of caregivers who need access to treatments not covered by FONASA or ISAPRES. While overall access to cancer treatments is generally recognized, specific treatments not included in health insurance coverage (FONASA or ISAPRES) must be financed by patients and their families, leading to financial debts.

> My mother, in the last year of treatment, left us with a debt of 750 million. F_LC_29_doughter

> In the most expensive month, I spent a million pesos a month on outpatient medications that were not covered by insurance, Ges, or anything else. M_LC_37_son

Acceptability

The results of this dimension were categorized into three areas: (a) communication, (b) clinical patient care, and (c) palliative care.

Communication

Communication is pivotal in shaping caregivers' perceptions of the healthcare system. One significant barrier identified is the lack of clarity regarding the patient's prognosis and evolution, which creates false expectations and adversely affects acceptability and trust in the healthcare system. Another communication barrier is the way some physicians interact with patients or caregivers. Specifically, in the context of lung cancer, the use of harsh language and blaming the patient for smoking has been identified. This approach has a negative impact on carers' perceptions of healthcare, highlighting a loss of empathy and a lack of concern for patient care. This type of situation was mainly observed in the public healthcare system. In contrast, the private healthcare system is characterized by effective communication and respectful treatment of patients.

Continuing with communication barriers, there is a significant need for providing more information to patients and caregivers regarding the oncology committee's resolutions. The oncology committee, a medical team that analyzes patient cases and determines treatments, currently excludes patients and caregivers from participation. Consequently, the information provided is limited to the therapeutic decision without an explanation of the rationale. Caregivers believe that the information about the committee's decisions should be more detailed, as the current communication generates doubts that cannot be directly addressed with the committee. This lack of detailed information leads to feelings of depersonalized and dehumanized care, resulting in a loss of confidence in the healthcare system. Additionally, when the committee's decisions are not adequately communicated or explained by the healthcare system, patients interpret the information based on their own experiences and knowledge. For example, they may incorrectly associate palliative care with hopelessness, which adversely affects their perception of the disease, prognosis, and adherence to treatment. This misinterpretation not only impacts the patient's mental health and well-being but also places a significant burden on caregivers. They are compelled to address the deficiencies in the information provided by the healthcare system and work to rectify the resulting misconceptions.

Another communication issue that fosters doubt and mistrust is the lack of information about the medical team's decisions and the absence of referrals to specialists for patient comorbidities or cancer complications. Additionally, when patients and caregivers receive diverse opinions from different health professionals, it can become a barrier. This diversity often leads to conflicting information, causing confusion and highlighting a lack of integration within the healthcare team.

> Communication with the patient, the oncologist tells you one thing, another thing told you the palliative physician, another thing the psychologist, another thing the physiotherapist. Then, I do not know what to think; there are many sources of information that are not integrated, that's bad. M_BC_35_son

Clinical patient care

Barriers associated with depersonalized care were identified, particularly among patients in the terminal stage of cancer. Some caregivers perceived that physicians did not adequately consider the patient's oncologic and terminal condition when providing healthcare, especially during emergency care. This often resulted in experiences of dehumanized and unempathetic care. Another barrier negatively impacting patients' clinical care is the limited time they have with their physicians, which hampers effective information delivery. Another barrier identified is the lack of other places where patients and carers can get additional information, support or guidance, leaving them in a state of uncertainty. This results in a distant relationship with the healthcare system.

> A problem that I saw in the whole process…I imagine it was also due to the somewhat hierarchical organization and the status divisions in the health systems. The physician has a very predominant role. However,

> it is a preponderant role that is exclusively medical, as well as that of the oncologist. That makes the relationship with the physician good but distant; there is not much communication, and they do not explain so many things.M_BC_35_son

Palliative care

Caregivers' experiences provide the best evaluation for the palliative care services, particularly those delivered at home. Positive experiences include timely information delivery, training for patient care, access to various health professionals, continuity of home visits, and the availability of urgent contact options when needed.

> We were referred to the palliative care area in the public hospital, and I took my hat off to the unit; they were very good. Here they gave us, uh, medical advice because they had to explain to us the whole procedure we had to do with my mom, and we also had psychological help and, in addition, a medical team came to visit her once a week, but if my mom got complicated, they came more often.F_LC_39_dougther

Contact

The results of this dimension were categorized under the concept of "Continuity of Clinical Patient Care," which refers to the seamless and coordinated delivery of healthcare services to a patient over time.

Inadequate communication negatively impacts several aspects of patient care. Specifically, the lack of communication creates a significant disconnection between different levels of healthcare (primary, secondary, and tertiary) and among the care services provided by the same health institution. This disconnection leads to a loss of continuity in care, which patients and caregivers must address to improve their overall care experience. It is important to note that the lack of communication between healthcare institutions, especially in the context of service outsourcing, significantly impacts the patient and caregiver experience. This is primarily due to inadequate information exchange between the involved institutions. Such instances create substantial barriers for elderly patients, resulting in a loss of independence and worsening of their advanced conditions.

> Sometimes it is not all about money, sometimes it is purely about management, and it is the issue of relating, of talking, eh, to do things for the patient, because sometimes they are very factionalized in the secondary, primary and tertiary care that they do not talk, the registration systems doesn't talk, and a patient who goes to a derived health institution has to tell the whole story. F_BC_34_dougther.

Another issue related to continuity of clinical care is the difficulty in accessing the tests needed for early detection of complications such as metastases or cancer recurrence, especially during treatment and beyond. In addition, there is a need for more education on lifestyle changes that can improve patients' condition, quality of life, and overall well-being.

Criticisms and recommendations for the health system from the caregivers' voice and experiences

Based on the results presented and the direct experiences of caregivers, several recommendations for improving healthcare for patients with breast and lung cancer in Chile have emerged. These are summarized in the Table 3. Corresponding quotes are provided in the supplementary material.

Discussion

This study offers a novel perspective on the experiences of informal caregivers of breast and lung cancer patients in Chile, utilizing Tanahashi's effective coverage model for analysis [31, 32]. By exploring caregivers' experiences, this research aims to contribute to improving the healthcare process and achieving health equity [36].

The results of this study support the existing literature on the role of caregivers as an extension of health systems [24]. The lack of training and education of cancer patient's caregivers identified in this study is a relevant problem in the Chilean context that increases the burden on caregivers,

Table 3 Recommendations for improve the health system performance from the caregivers' voice and experiences

Recommendations	• Enhancing cancer education and navigation strategies in the health care system, for patient and family • Financial, employment and health system support for caregivers • 24-h palliative care • Improving cancer healthcare in regions • Comprehensive care • Include oncology specialists or health professionals trained in oncology in emergency care services • Connect the different health services of the public system efficiently • Connect public and private health institutions to facilitate access to patient information

in accordance with previous studies [23, 26]. This research underscores the universality of caregiver struggles, while also highlighting the unique systemic barriers within the Chilean health system.

In Chile, critical barriers identified include inadequate information, deficient oncological emergency services, fragmented and segmented health system navigation, restricted hours of operation, lack of coordination between public and private institutions, out-of-pocket expenses for expedited second opinions or tests, confusing and unempathetic communication, and insufficient patient follow-up. These barriers are exacerbated in Chile by a fragmented healthcare system and socio-economic disparities [8]

As well as the information recognized in the international literature, misinformation emerged as an important barrier [27]. In Chile, this is of particular concern given the existence of the Patient Rights and Duties Law in Chile since 2012 [12], which requires patients to be informed about their health status and related processes in a timely and understandable manner. The results of the study suggest potential violations of this right and highlight systemic problems in the provision of information.

Another relevant aspect was related to the home care that caregivers must perform. The lack of structured support in oncological home care significantly exacerbates the burden on caregivers and contributes to feelings of abandonment by the health system. This issue is multifaceted, involving both the emotional and logistical challenges faced by caregivers. Some home care actions developed by caregivers were feeding, hygiene, transportation, administration of cancer treatment, or palliative care. Although these care are part of the NCP, CL, and the Palliative Care Law [42], the caregivers often perform these tasks. Our findings reveal significant gaps between these legal frameworks and the lived experiences of informal caregivers who assume critical roles in patients' care. Moreover, the dual burden of providing clinical care and managing personal emotional distress is a significant challenge for family-based caregivers. The lack of support for these caregivers in their clinical roles, such as medication administration and management, can further increase their stress and feelings of inadequacy. [43].

The fragmentation of healthcare systems plays a critical role in exacerbating caregiver burden. Caregivers often encounter systemic issues such as difficulties navigating care across multiple providers and institutions, administrative burdens, and financial challenges. These systemic issues can lead to a loss of trust in the healthcare system and feelings of abandonment [44].

The findings of this study reinforce the notion that informal caregivers play a critical yet undervalued role within the healthcare system. Despite their essential contributions to the care of cancer patients, they remain marginalized within biomedical structures, often lacking formal recognition, adequate training, and institutional support [22]. This study highlights how caregivers navigate complex medical responsibilities with limited guidance, reflecting the power dynamics inherent in the biomedical model, where professional medical authority dominates decision-making while sidelining caregivers as mere auxiliaries [23]. The lack of integration between informal and formal caregiving not only increases caregiver burden but also leads to fragmented care for patients, reinforcing systemic inequities [20].

Despite the existence of legal guarantees, caregivers in our study frequently reported challenges in accessing palliative care resources, particularly in the home setting. Many were expected to manage complex medical tasks, such as administering morphine and handling pain management techniques, without adequate training or guidance. This lack of structured support exacerbates their burden and contributes to feelings of abandonment by the health system.

Barriers related to the functioning of the health system reflect critical structural aspects that need to be addressed to meet the objectives of the NCP and achieve equity in health. Individual economic status plays a crucial role in the healthcare options available to patients in Chile. Access to second opinions, faster diagnostic tests, and comprehensive care not covered by the guaranteed universal health coverage (GES) are often privileges reserved for those with higher incomes, who will be more likely to use financial resources for their healthcare with a lower risk of developing financial toxicity, understood as the monetary burden of paying for cancer care and the negative impact it has on the financial security of patients [45, 46]. This disparity underscores the ongoing challenge of achieving equity and providing comprehensive care for all patients and their support networks.

This study presents both strengths and limitations. Its methodological strength lies in the novel approach of incorporating informal caregivers' perspectives to understand the healthcare system's functionality for breast and lung cancer. Also, the qualitative methodology used here is valuable for revealing caregivers' experiences and contributing to knowledge from key actors' voices. Additionally, Tanahashi's model effectively organized and understood the data, highlighting barriers that must be addressed to ensure effective coverage for breast and lung cancer in Chile.

Limitations include recruitment challenges and the qualitative nature of the study, which does not aim for generalizability or representation of all experiences, particularly those from minority groups. An important limitation is that this study focused on formal care provided by the health system, without exploring informal care. While formal care is structured and institutionalized, informal care emerges within social networks and family settings [22], often without recognition or support from the health system. Although this research did not explore informal care, it is important to recognize its existence and importance, especially in countries with fragmented health systems where the role of informal caregivers is even more pronounced, shaping patient trajectories in ways that formal healthcare structures do not fully acknowledge [47]. Despite these limitations, the findings reveal critical points in cancer care that must be addressed and resolved promptly to improve patient care, health system performance, and equity.

Future research should integrate a broader perspective on informal care and the formal-informal care continuum, recognizing the interdependence of these care modalities. Also, it should explore caregivers of underrepresented groups, examine experiences with other cancers, consider territorial and social determinants of health to further enrich understanding, and improve cancer care. It is also important to move forward in creating formal support and guidance programs for cancer caregivers, considering the caregiver's knowledge, time availability, values, and preferences [20]. Strategies that use technologies and territorial, cultural, and gender approaches can be useful in these scenarios [48].

In conclusion, this study underscores the unique experiences and insights of cancer caregivers, which are not just essential, but pivotal for understanding and improving healthcare in cancer. Their perspectives should not just be considered, but actively sought out and integrated into social participation efforts within the NCP and CL frameworks. This is crucial for developing policies and programs that can effectively address Chile's cancer care challenges. Additionally, addressing the barriers identified in this study requires a systemic approach that goes beyond policy implementation to ensure practical, patient- and caregiver-centered solutions. Strengthening interdisciplinary coordination, enhancing oncological and palliative training for healthcare professionals, and improving communication strategies within the healthcare system are crucial steps in bridging existing gaps. Moreover, it is imperative to integrate caregivers into formal support structures, recognizing their role not only as an extension of healthcare services but as key actors in shaping a more responsive and equitable cancer care system.

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Data Availability The datasets analyzed during the current study are not publicly available due the information could compromise privacy of the participant but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate The study was approved by the Comité Ético Científico de la Facultad de Medicina Clínica Alemana Universidad del Desarrollo (number 2021–67). Informed consent was obtained from all participants.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

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