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RESEARCH ARTICLE **OPEN ACCESS**

Users' Experience of Being Treated for Malignant Neoplasms in the Brazilian Public Health System: A Phenomenological Approach

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Abstract:

Background: Cancer represents a significant public health concern, accounting for a considerable number of deaths and reducing life expectancy on a global scale. In order to facilitate an early diagnosis, countries have enacted legislation with time goals for access to treatment, advocating for the interval between access to various services.

Objective: To explore the experiences of users of the Brazilian National Health System (SUS) in accessing treatment for malignant neoplasms.

Methods: This is a qualitative study employing Alfred Schütz's phenomenological approach to elucidate the social dimensions of human action. A semi-structured interview was conducted with 26 patients diagnosed with malignant neoplasms within the health microregion of central-western São Paulo state, Brazil.

Results: The experiences were shown to fall into four categories: (A) *Awakening to signs and symptoms associated with cancer,* (B) *Facing difficulties in accessing the Health Care Network quickly for cancer diagnosis and treatment* (C) *Looking for other ways to diagnose and treat cancer.*

Conclusions: The study findings indicated deficiencies in the Brazilian public healthcare system for patients with neoplasms. It was concluded that there is a need to review national health policies and improve the referral and counter-referral system in order to foster faster and more effective care for patients with malignant neoplasms.

Keywords: Neoplasms, Cancer, Effective access to health services, Legislation as a topic, Life-changing events, Qualitative research.

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1. INTRODUCTION

Cancer represents a significant public health concern, accounting for a considerable number of deaths and reducing global life expectancy [1].

The report published by the World Health Organisation (WHO), based on estimates by the Global Cancer Observatory (Globocan), indicated that, in 2020, the number of cancer cases exceeded 19.3 million. It is estimated that by 2040, there will be 30.2 million cases of cancer worldwide [2]. In Brazil, it is estimated that 704,000 new cases of cancer will emerge over the three-year period from 2023 to 2025. The most prevalent form of cancer is non-melanoma skin cancer, with an estimated number of 483,000 cases. This is followed by breast cancer (74,000), prostate cancer (72,000), colon and rectum cancer (46,000) and lung cancer (32,000) [3].

The introduction of novel therapeutic approaches has led to a shift in the epidemiological scenario, offering a more favorable prognosis for individuals utilizing public healthcare services and enhancing their survival prospects. This is not merely a consequence of technological advancements; rather, it is primarily attributable to early identification and prompt initiation of treatment. It is crucial to underscore that prompt diagnosis is the most efficacious strategy for enhancing patient survival, mitigating morbidity, and streamlining treatment. In this context, there are strategies for timely care, including public education and the provision of accessible healthcare services, as well as clinical evaluation and diagnosis, and finally, access to treatment [4]. The data provided by the Pan American Health Organisation (PAHO) indicate that late diagnosis and lack of access to treatment are common occurrences [5].

Furthermore, it is assumed that the majority of SUS users are unaware of their rights as outlined in the National Cancer Control Policy. This lack of awareness is associated with a lack of resources and, consequently, the organisation of care processes in health systems in less developed countries [5, 6]. In order to facilitate the early diagnosis of diseases, the Brazilian government has enacted legislation that aims to reduce the time elapsing between the first emerging symptoms and the start of treatment.

Two pieces of legislation address the issue of early diagnosis: 12,732/12 [7] and 13,896/2019 [8]. The 60-Day Law 12,732/12, enacted in May 2013, guarantees cancer patients the right to begin treatment, whether chemotherapy, radiotherapy, or surgery, within 60 days of receiving the anatomopathological report [7]. Moreover, Law No. 13,896, as of October 2019, has broadened the scope of such rights to encompass the performance of diagnostic tests for malignant neoplasms within a 30-day period [8]. Moreover, these legislative acts facilitate access to SUS, which encompasses not only care provision but also its individualisation within the context of health services. This requires the consideration of particular users' needs at the opportune moment and location in accordance with the regionalised and decentralised healthcare network.

It is estimated that approximately 45% of cancer patients in Brazil present the disease in an advanced stage [7]. In response to this, Law 13.896/2019 was enacted in October 2019 and became effective on 28th April 2020 [8]. This legislation guarantees patients with a cancer diagnosis the right to undergo tests to elucidate the disease within 30 days. In view of the above, the question arises: What is the perception of users diagnosed with malignant neoplasms of access to oncological services, and what is their knowledge of legislation? Therefore, the objective of this study was to understand the experiences of Brazilian National Health System (SUS) users in accessing treatment for malignant neoplasms.

2. MATERIALS AND METHODS

2.1. Ethical Aspects

This study was carried out after approval by a Research Ethics Committee (CAAE 64262217.4. 0000.5411, Report 1.950.283), and Informed Consent was provided by the participants. All the patients invited to participate in the study consented to do so before the interviewer introduced herself and explained the purpose of the interview/study.

Furthermore, in order to preserve their anonymity, after the interview, audio recordings were fully transcribed, the digital files were deleted and identified alphanumerically (U1, U2, ...). The interviews were carried out individually (face-to-face) and in a private room at the oncology service, where only the interviewee and the interviewer were present. One of the researchers (a female nurse), who had been trained to perform the data collection technique, was the interviewer. Furthermore, the nurse made her field notes.

Artificial Intelligence (AI) was used to translate the article from Portuguese into English, firstly by DeepL Translate, followed by checks by Open Writefull.

2.2. Theoretical-methodological Framework and Study Design

This qualitative study was guided by the Consolidated Criteria for Qualitative Research Reports (COREQ) [9]. Alfred Schütz's methodological approach to social phenomenology [10] was used to gain insight into the experiences of patients with malignant cancer who were treated in the oncology department based on the path they travelled in their search for a specialised service. This approach is recommended when there is limited knowledge of the studied phenomenon, and it is necessary to describe it from the subject's point of view. Qualitative studies must be conducted in the individual's environment and in the context in which the phenomenon occurs. Such studies are considered part of the data. Qualitative approaches are inductive, whereby hypotheses and theories emerge from the collection and analysis of data, which the researcher analyses to identify descriptions, patterns, and relationships with the phenomenon [10]. The rationale for selecting Alfred Schütz's social phenomenological approach is that it enables the understanding and description of the experience of people with cancer in their daily lives [11]. Consequently, the use of this methodology is of significant importance, as it allows the description of the disease experience and its therapeutic route to the specialised service.

2.3. Research Setting and Participants

The study was carried out at a university hospital that is a leading cancer treatment centre in the western region of São Paulo state, Brazil. It included a convenience sample of 26 adult patients over 18 years of age (16 female and 10 male) who had been diagnosed with malignant neoplasms and followed up at the outpatient oncology clinic since 2014.

2.4. Data Source

The semi-structured interviews were conducted from August 2017 to February 2018, according to a set of guiding questions: Can you describe in detail your experience of the cancer treatment? Can you describe in detail how you accessed the specialised service? What do you know about your legal rights to cancer treatment? The interviews lasted from 30 to 40 minutes. In addition, field notes were used.

2.5. Data Analysis: Methodological Framework

At the end of the interviews, they were transcribed and analysed according to the methodological framework of phenomenology using the Nvivo-11 software [10]. The participants' experience was interpreted in the context of the theoretical framework proposed by Alfred Schütz [11] and the rights of SUS users with malignant neoplasms [7, 8]. There was no need to repeat interviews. The number of interviews was determined on the basis of theoretical saturation. Upon analysing the 23rd interview, it was observed that the data was repetitive, and no new information was forthcoming. Consequently, the researcher proceeded to analyse three additional interviews, thereby ensuring that the process would be concluded with the analysis of 26 interviews.

2.6. Research Trustworthiness Criteria

The quality criteria established by Lincoln and Guba were employed to ensure the rigor of the investigation [12]. Credibility was achieved through the use of in-depth interviews conducted from the perspective of the study participants. Following transcription, the participants were given the opportunity to confirm the data, after which they validated the experience abstracted by the researchers. The research process was conducted so as to ensure reliability. In order to guarantee the transferability of findings, the setting, participants, and methodology were clearly delineated, as were the results derived from the analysis. Additionally, in order to enhance dependability and confirmability, the researchers conducted independent analyses of the interviews and subsequently agreed upon the final thematic categories.

3. RESULTS

Four thematic categories were identified through data analysis: (A) *Awakening to signs and symptoms associated with cancer,* (B) *Facing difficulties in accessing the Health Care Network quickly for cancer diagnosis and treatment* (C) *Looking for other ways to diagnose and treat cancer* (Chart **1**).

Awakening to signs and symptoms associated with cancer (category A) is related to body alterations, which were considered abnormal. From then on, users sought a solution to return to their normal state. It could be observed that signs and symptoms, which were the trigger to seek help, were given attention to the detriment of prevention. Category (A) brings together the subcategories: *lack of engagement in health promotion and cancer prevention* (A1) and *being assumed to have signs of cancer* (A2). U-05 reported: *"[...] I started feeling pains in my lower abdomen, which came and went. Then I went to the health centre near my house [...]".*

Chart 1. Categories and subcategories of the experience of users of the brazilian unified health system (SUS) in accessing treatment for malignant neoplasms. Botucatu, São Paulo, Brazil, 2019.

Categories	Subcategories
(A) Awakening to signs and symptoms associated with cancer.	(A1) Lack of engagement in health promotion and cancer prevention.
	(A2) Being assumed to have signs of cancer.
(B) Facing difficulties in accessing the Health Care Network quickly for cancer diagnosis and treatment.	(B1) Users finding it difficult to schedule their first appointment in Primary Health Care (PHC).
	(B2) PHC facing a shortage of user referral slots for diagnosis.
	(B3) PHC professionals feeling powerless to comply with the 60-Day Law.
	(B4) Users feeling unassisted with the hypothesis of having cancer.
	(B5) Delay to access expert service
(C) Looking for other ways to diagnose and treat cancer.	(C1) Seeking the Private Health System.
	(C2) Looking for mixed health systems (public-private).
	(C3) Seeking emergency services to overcome difficulties in accessing cancer diagnosis and treatment.

However, the search for a health service does not always produce an effective solution, as the complaint-conduct model can lead to a misdiagnosis. Moreover, this is exactly what happened to some users. In addition, due to the importance placed on symptoms, they sought to address the immediate problem rather than its underlying cause.U-09 said: *"[...] He had diarrhoea, but he thought it would go away, and as it did not, he went to the doctor´s, and the doctor said it was a viral infection [...]".*

On the contrary, there are users who do not recognise signs and symptoms and do not seek a resolution. Consequently, the presence of signs and symptoms does not always facilitate a diagnosis, as fear of the unknown can paralyse them until symptoms become more severe. As one user reported: *"I started to snore and then it took me three months or more to go to the doctor's"* (U-14).

Although signs and symptoms are noticed, the search for care and prevention through periodic examinations is also of paramount importance, and it was mentioned by users as something that belonged to their self-care and prevention routine. As users reported: *"[...] The Pap smear did not show cancer, and I continued to bleed from time to time; it was very little [...]"* (U-23). *"[...] I had mammograms and ultrasounds, and the tests never showed anything. I used to do these tests at the clinic, so nothing ever came up...nothing! [...]"* (U-02).

Another category was related: *Facing difficulties inaccessing the Health Care Network quickly for cancer diagnosis and treatment* (category B) and *in finding a location near a* *primary care unit*. Within the proposed Brazilian public healthcare system (SUS), primary care is recognised as ordering and coordinating care. It is located at a strategic point in the area that it covers, is responsible for the care of an assigned population, and offers preventive and rehabilitative services.

A pertinent issue raised by users was the delay in accessing tests and treatments through primary health care (PHC). The perception of nonresolution and delay was strongly related to PHC. U-02 said: *"[...] In my opinion, the use of the health centre is not a satisfactory solution; I would rather find the financial resources to visit a private clinic [...]"*.

In addition, the quality of the services provided was also mentioned. Access to tests is challenging, even when provided by competent professionals, and there are delays in service delivery. The prompt completion of tests is attributed to chance rather than to the efficacy of the system. According to U-05: *"[...] In my city, it is only by chance that one is able to access the required services. I was lucky to have an ultrasound that week, as the nurses were very competent. However, in the primary care unit, patients are taken care of promptly, but many express dissatisfaction due to long waiting times [...].*

Users have observed that the unit lacks sufficient resolution and that there is no indication as to when the tests will be carried out. However, the infrastructure and resolution of the system are not solely dependent on PHC; rather, they are contingent upon a range of services offered within the system. Consequently, the user's need is contingent upon the delay in PHC. Furthermore, for users, the waiting period represents a significant risk factor, as the condition may worsen while waiting for diagnostic tests. A user reported: *"[...] In my city, the waiting period is particularly long due to the lack of resources and facilities. [...] the time required for blood tests is considerable, typically covering a period of two or three months [...]"* (U-26). Despite the recognition of the delay in accessing tests and specialists, users still make comparisons with other regional realities that are common to them. According to U-12: *"[...] She has been through this entire process; it is due to the long waiting periods at the post office, but even with all this delay, it is still beneficial, it is commendable! "Because my mother in the Northeast has no alternative accommodation [...]"*.

Schütz posits that each individual organises his reality according to his immediate context, comparing time/delay, and thus classifying things according to the individual situation of each being (9). For people diagnosed with cancer, the experience of prolonged waiting periods can potentially exacerbate existing health complications. However, the notion of rapidity and duration depends on the specific circumstances under consideration.

In contrast, there were users who followed up in the public sector, advocating for prevention in PHC and, therefore, had their tests performed in a timely manner and continued their treatment. U-15 reported: *"[...] I initially consulted with a healthcare professional at a local health centre, where I underwent a mammogram on an annual basis. However, after completing the tests for the previous year, the physician observed some unusual findings, which required a repeat of the mammogram. I did not experience any discomfort, as the test was a standard procedure that I had been performing annually [...]*. However, the qualification of the healthcare professionals working in primary care was also brought to the fore. As PHC is designed to rehabilitate users, lack of training hinders the implementation of more complex care. A user U-05 reported that *"[...] A more robust structure is required"*, explaining that the nurse could not perform the dressing procedure and stating that she was unfamiliar with the technique due to the use of a bag. From the moment users start treatment in the tertiary sector, follow-up healthcare is provided only there. Users value specialised care. U-10 said: *"[...] Following my arrival at this facility, I completed all the necessary procedures here, with no further visits to the health centre [...]*. A common perception among users is that PHC does not address complex cases, which can contribute to a lack of return visits and a weak connection with the tertiary sector. It is obvious that the health centre is not a solution provider and that it deals with simple cases. U-09 reported: *"[...] He does not attend the health centre, merely obtaining medication. The health centre does not monitor him due to his cancer diagnosis. If he remains at home and does not visit the health centre, it is unclear what the centre can do. In addition, there is no indication that he should go to the hospital. Consequently, we remain here [...]"*.

Users recognise that PHC is confronted with significant challenges. The lack of resources is not inherent to the problem. Consequently, the oncology sector is also affected, as there are delays in performing surgeries and radiotherapy. Furthermore, there is a shortage of drugs to perform chemotherapy, which puts the user in a peculiar situation. U-04 said *"[...] Therefore, I believe that I waited approximately two or three months to begin chemotherapy due to the overcrowding of the relevant facilities [...]"*.

One of the users reported that due to a lack of medication and the recognition of the need to continue treatment, she took the initiative to address her problem at that time. It is crucial to acknowledge that each user responds in a distinct manner, contingent upon the circumstances in which they reside, manifesting an 'attitude' towards the predicament they are confronted with. According to Schütz, this "attitude" is adopted in response to the necessities of life and the demands of the moment and may prove beneficial or otherwise (9). U-25 reported: *"[...] I contacted the Health Department to express my concerns, submitted an electronic message as a formal report was required, and sent it to the Regional Health Board (DRS). I also sent it to the director of the hospital where I was receiving treatment because I was concerned that my medication could be discontinued. I was particularly distressed by the possibility of being without my medication [...]"*.

Additionally, users reported experiencing physical structure and lack of beds, particularly during the diagnostic process and in the event of surgical cancelations or postponements. As users reported: *"[...] We were forced to remain in the room and in the chairs, awaiting a bed to become available. I was unable to deal with the situation and* *subsequently started crying. The staff then proceeded to obtain a stretcher [...]"* (U-05). *"[...] I was forced to leave the facility for two days due to the lack of beds. I spent the night in my car. I was unable to stay at the facility with pain. The doctor advised me to rest and return the following day until a bed became available [...]"* (U-12).

Looking for other ways to diagnose and treat cancer (category C) is related to the fact that the user commenced his care map on two fronts: through the public service or the private service and completed his journey in the public service. While seeking a diagnosis, patients may choose to consult with private sector specialists, undergo diagnostic tests and biopsies, *etc*.

Upon the user's creation of their care map, they encounter a multitude of professionals who provide care in both the private sector and the referral hospital, which subsequently leads to a route change. In contrast to the proposed care network, after a consultation with a private-sector physician, the user is subsequently directed to continue treatment in the public sector, sometimes in a more streamlined manner. U-01 said: *"[...] The doctor, who is also a professor at the University Hospital, referred me here for treatment after surgery [...]"*.

The intentionality described by Schütz [11] also justifies the search for the private sector and for professionals who have a connection to the University Hospital. The attitude is taken consciously and is also based on the experience of others, which is applicable to the user's reality.

Some interviewees began their experience at SUS. However, in light of the complexity of the system and the advice of certain professionals, they opted to conduct the tests in the private sector, prioritising the time factor. U-19 reported: *"[...] I decided to have the endoscopy performed privately because the waiting time for SUS would have been unacceptably long and I was already experiencing weight loss. "For SUS, I could still wait for an endoscopy, but I was fortunate that my family was able to help. I paid and came here [...]"*.

It is noteworthy that while some users pay for services, others adhere to the itinerary recommended by the healthcare network within the scope of SUS. However, they indicate that they only do this because they lack the financial resources to transition between the various health services. According to U-06: *"That is where it takes a while to do some tests; I have already done it right here at the ER!"* The process was expedited due to the seamless coordination of services and the absence of the need for private testing. The entire experience was conducted within the SUS framework, but the financial constraints of the individual in question prevented him from accessing the necessary resources.

The search for a private service is sometimes motivated by a lack of resolution in PHC. Consequently, the user seeks a second opinion from the private sector. This is also related to the user's trust in the public sector, especially when it is related to primary care. U-13 reported: *"[...] The patient went to consult with a private physician, who came to take an X-ray and later informed the patient that there was a woodworm in her spine, which ate the bones. The physician then provided the patient with a letter to be taken to the city hospital [...]"*.

This oscillation between the public and private sectors also occurs when the public service fails to meet the needs of its users. Consequently, they are compelled to seek care in the private sector and, subsequently, contingent upon future circumstances, may or may not return to the public sector. In the event of an urgent need for treatment, the patient is responsible for creating his own care map and seeking a solution. The establishment of a "mini care network" represents a key aspect of the user's active involvement in his own care. This change in itinerary and searches is indicative of the reasons why the user migrates from one system to another. U-01 said: *"[...] I went to the hospital and was asked to consult with a urologist. I did so independently and was diagnosed with malignant cancer in my right testicle. The doctor recommended immediate surgical removal of one of my testicles [...]"*.

Although the mixed system is a potential avenue of care, many patients use the public system, primarily through emergency services. Given that time is a critical factor in the survival of those affected by this disease, those using public services are looking for a faster and more accessible means of diagnosing the disease. Due to the context in which the user finds themselves and the knowledge they gain through exchanging experiences with others, the emergency room becomes the preferred location for them, as symptoms are already acute and the search for resolution is immediate. According to U-18: *"[...] I was playing with the pain in my eye, then they took me to the emergency room, the doctor said it could be a stroke [...] I couldn't walk anymore, and I had a seizure, then I went back to the emergency room, the other doctor said it was a stroke [...]. I was referred to the referral hospital [...]"*.

In addition to the speed with which the emergency room provides care, users reveal that at the time of their visit, the necessary tests were also performed to finalise the diagnosis, such as ultrasound, tomography, and even biopsy. This action serves to reinforce the user's perception that the emergency room is more effective in its resolution due to the speed with which tests are carried out and a diagnosis is made. U-06 reported: *"[...] In the emergency room, the attending physicians provided comprehensive care, including colonoscopies and a multitude of diagnostic tests [...]"*.

Notwithstanding the user's autonomous decision to seek emergency care, the care network maintains its own configuration, which is communicated to the user. It is well established that to access referral hospitals and specialised services, and initial care must be provided by the PHC, which then refers the patient. However, given the acute nature of the situation, users are forced to seek alternative routes. According to Schütz, the user is inserted into his world of relationships, and other individuals interfere in his decision-making [11]. Such interference occurs because of the 'reasons why,' which causes the user to seek a more immediate solution to his situation. U-05 said: *"[...] I was in a critical condition, and I sought the advice of my neighbours, who advised me to go to the University Hospital. However, upon arrival, the medical professionals* *informed me that I had to first visit the clinic and request a guide to accompany me here [...]"*.

It is noteworthy that the search for emergency care is concentrated in the university hospital or the city's municipal emergency room since this is where the user will be allowed to continue treatment. Although the emergency room is the initial point of contact for many cancer diagnoses, a significant number of cases are closed at this location. Then, referrals are made to other sectors for continuity in the disease staging process and, finally, the start of treatment. U-07 reported: *"[...] He initially presented himself at the city's emergency room, where he was diagnosed with bleeding from the mouth. He was subsequently referred to the University Hospital, where a battery of tests was conducted, leading to the discovery of the disease. He was then referred to the oncology department [...]"* (U-07).

In some instances, the emergency room is not the initial point of contact for users seeking medical care. However, based on the reasons for seeking care, they attempt to identify a strategy that aligns with their worldview and enables them to address the problem in the most expedient manner. According to U-9: *"[...] Subsequently, in my municipality, I did not take any further action; then, I went to the emergency room; I was presented with the colonoscopy paper; then, treatment started [...] and, the tests were conducted here; I went to the emergency room independently [...]"* (U-9).

In addition, users describe their journeys through the public health system as established by the healthcare network. U-10 said: *"[...] He went to the health center, where the doctor ordered an ultrasound examination. On exami-nation, the doctor observed an anomaly in the patient's bladder and, to confirm this, repeated the test. Subsequently, he was referred directly to a urologist and subsequently to an oncologist [...]"*.

Although some users begin their follow-up through the established healthcare network, they subsequently switch from one service to another and seek to acquire equipment within SUS that can accelerate their treatment. U-23 reported: *"[...] I went to the health centre and asked her to refer me to the university hospital. Subsequently, she referred me, but the paper she provided me to make an appointment would take a considerable amount of time and I cannot wait. I took an action that was not in accordance with the established protocol, but it was the only viable option available to me. Subsequently, they indicated that the procedure was not appropriate, but that they would address the matter [...]"*.

In the absence of alternative options, users devise strategies based on their understanding of the world to obtain treatment. Consequently, some users elect to seek emergency care on their own, relocate to a different location to expedite their treatment, or use the services of a family member or acquaintance employed in the healthcare sector. 09 said: *"[...] I am continually preoccupied with the notion that they will not perceive our relocation as a negative occurrence." Provided that we do not relocate from this location, the aforementioned considerations will remain valid. Because this is my hometown. However, the location in question does not offer the same advantages. Furthermore, it is more convenient to reside in this location, as returning to my hometown would require a longer journey [...]"*.

The user's trajectory is shaped by his individual needs and his understanding of the world. He seeks individuals or entities who can help navigate the diagnostic and treatment processes. The search for private physicians is intentional, as they can also facilitate access to the university hospital through fewer bureaucratic referrals. According to U-13: *"[...] The private doctor provided us with a referral letter to present to the hospital in our city, which would facilitate our referral to the university hospital. However, despite presenting this letter, we were still unable to gain admission to the university hospital. We were fortunate to have the help of a family member who was able to facilitate a referral to the university hospital. This person was familiar with the attending physician and was able to request an appointment for my mother. The appointment was scheduled for Monday night at 7 p.m. and upon arrival at the university hospital, my mother was already admitted and had undergone the necessary diagnostic procedures [...]"*.

Care pilgrimage is carried out in various ways, and users face numerous obstacles along the way. They also meet professionals who, according to them, do not provide a definitive diagnosis and increase the length of their journey through the care network. U-20 reported: *"[...] The process was prolonged. The patient waited up to nine months to obtain an appointment. Upon examination by an ENT specialist, the patient was referred to a cardiologist, who ultimately concluded that the patient's symptoms were consistent with gastroenteritis. However, it took a considerable time to determine the diagnosis. We waited approximately a year to undergo a colonoscopy, after which we had to wait another three months before undergoing surgery [...]"*.

Another aspect that is worth noting is the temporal aspect. Although the interval between diagnosis and cancer treatment is of paramount importance, users still perceive a waiting period and a delay. Furthermore, they are aware that the delay in treatment is attributable to the public health service and accept this as a reality of waiting. It is evident that users perceive a correlation between delays in the public health service (SUS) and efficiency in the private sector, which facilitates earlier diagnosis. According to U-01, *"[...] the waiting time to see the specialist was relatively short, approximately 30 days. I believe that if the appointment had been scheduled through the health centre, the waiting time would have been longer [...]"*.

Waiting is mainly due to diagnostic tests, which may be relatively straightforward or more complex. There is a perception of a lengthy waiting period, mainly due to the distress caused by the anticipation of a diagnosis. In addition, there is a comparison of the time between services. In some cases, people elect to use the private service, as the public service lacks a projected timeline for scheduling appointments. U-26 reported: *"It took approximately four to five months to schedule the ultrasound, as the process is somewhat lengthy in that particular setting"*.

It is noteworthy that users perceive a correlation between the time spent at SUS and the time spent in the private system. They frequently mention that early access was facilitated by most of the tests conducted in the private service. The use of a mixed system confers on users the ability to exercise control over their itinerary. Additionally, medical professionals in the private system perpetuate delays at SUS, thus promoting the mixed system as a means of expediting treatment through the public service. *"[...] The doctor said: I can refer you to the university, where you can undergo these tests." However, the estimated waiting time at the university is approximately 30 days, and if the results are available at that time, the process will be expedited"* (U-02).

The participation of health professionals in SUS facilitates the rapid provision of diagnostic tests and specialist consultations. It is crucial to note that these tests were carried out through the primary health care system (PHC), thus exemplifying its crucial role in healthcare provision and ensuring equitable access to it. U-10 said: *"[...]* Ultrasound *was performed at the clinic, and the test took approximately 15 days to complete. This was expedited at the request of the emergency room doctor [...]"*.

One of the users mentioned that due to her regular follow-up appointments, she was able to access the service in a timely manner without having to use the mixed system. She followed the recommended route proposed by the healthcare network, which demonstrated that, for breast cancer, the route is better defined. U-15 reported: *"[...] I am grateful that I did not have to pay anything. I had the biopsy the same day as the mammogram"*. The result of the biopsy was received approximately one month after the procedure. This was a relatively quick turnaround, which was beneficial from a patient's perspective. Following the surgical procedure, the patient started radiotherapy 25 days later.

It is evident that users are aware of the fact that prolonged waiting can have adverse effects on their condition, potentially leading to death. Consequently, the system is inefficient and precarious, causing harm to users and feigning a violation of the proposed universal access law. The health centre is perceived as a place that provides care but does not address underlying problems or facilitate prompt diagnosis. U-05 said: *"If one visits the health centre, [...] individuals are seen, but a significant number of people express dissatisfaction with the lengthy waiting periods [...] there are individuals who have been waiting for more than a year to undergo a colonoscopy. It is, therefore, highly precarious [...]"*.

However, long waiting periods extend beyond primary care. Additionally, users encounter this issue when undergoing highly complex tests, such as a biopsy, which is essential for the diagnosis of cancer and enables the user to enter the oncology service for treatment. However, there is a delay in performing the tests and obtaining the results, which can result in a worse prognosis. According to U-02, *"[...] The biopsy through SUS would take 30 to 40 days, and then one would wait until all tests are completed and the results are available, which takes approximately three months [...]"*.

In addition to the time required for a diagnosis, there are instances when treatment is delayed, whether it be chemotherapy or surgery. This can have a detrimental impact on the patient's condition. In some cases, the interval between the decision to proceed with surgery and the actual surgical procedure exceeds 90 days, a period that exceeds the recommended time limit established in the legislation. U-18 said: *"[...] The chemotherapy treatment was administered for a longer period than the radiation therapy treatment. As chemotherapy is administered orally, it took a considerable period for the medication to arrive. However, when the medication arrived, I had already been hospitalised and had undergone the second surgical procedure [...]"*.

However, some users were able to access services with greater alacrity. Even though some people continue to cite a two-month waiting period to access certain services, the perception of time is inherently subjective and varies from one individual to another. Consequently, some patients were able to access the oncology service in a few days and start treatment after the biopsy result, according to relevant legislation. U-07 reported: *"[...] When they had this test (biopsy), it did not take a month to find out [...] and within a month they started treatment [...]"*.

An alternative way to quickly access treatment was through the emergency service, which was particularly beneficial for users who had more acute symptoms of the disease. According to U-06, *"[...] I came to the emergency room in the neighbouring municipality on Thursday night and was seen by a gastroenterologist at the university hospital the next day. All my tests were successfully completed. Subsequently, he scheduled a colonoscopy for me on Monday"*.

The time required to access treatment varies depending on the route the user has taken. When patients use a mixed service, beginning in the private sector and subsequently transitioning to SUS, the required time is significantly reduced, and oncology treatment is completed in a matter of days. U-03 reported: *"[...] I visited a private physician on one occasion, if memory serves, and was seen again the following day. The next morning, I was already at the outpatient clinic [...]"*.

Considering the long journey and waiting time required to obtain a diagnosis and treatment, respondents were asked about their familiarity with the Sixty-Day Law. Only one individual was aware of the legislation, although, at the time of his illness, he did not consider it a viable option to accelerate care. Therefore. I did not adhere to it. U-01 said: *"[...] I was already aware of the 60-Day Law, but at the time, I did not consider it a viable option to accelerate the pace of care. I reasoned that it would be prudent to act immediately [...]"*

4. DISCUSSION

The responsibility for disease prevention lies with the state, which is mainly carried out by PHC. This must maintain a balance between preventing health problems and treating those who fall ill. The concept of prevention is defined as an action taken to prevent the onset of a disease [13]. The need to transcend simple prevention and to urge health professionals to reflect on the lenses they use to problematise iatrogenesis and medicalisation has been correctly identified [14].

This study indicated that users are not inclined to prevent themselves and thus value the signs and symptoms they present, particularly when they diverge from what is considered normal for them. The definition of symptoms varies depending on how common they are, according to the principles and values of a given society. This means that a sign can be characterised as common to some and interpreted by others as a health problem or suffering. Consequently, people seek help based on symptoms.

In this study, users perceived PHC as a unit for the follow-up of simple cases and thus tended to seek specialised care, forming a bond with it. This highlights the existing challenge of strengthening the primary sector, as the service is not perceived as a solution to problems, and the lack of interaction with the population implies the need to improve it [15]. Furthermore, the individuals' statements indicate that they do not perceive PHC as a place for continuous care.

According to some studies and the National Primary Care Policy, the link is identified as a prerequisite for effective care delivery, often resulting in better adherence to treatment. Primary care is typically the individual's initial point of contact with health services, and, as such, it is inherent to the nature of the service that it will be perceived as good or bad. Consequently, the bond is defined as a positive attitude that encompasses aspects such as care, interaction, coexistence, and zeal [16].

Although primary care is considered the gateway to the system, users frequently access services in the opposite direction, focusing on symptom resolution rather than on prevention.

In this manner, users perceive PHC as a time-consuming service that does not provide a solution to their problems, particularly for people who have acute symptoms. Primary care is responsible for resolving approximately 85% of cases. In addition to prevention, it is also responsible for treatment and rehabilitation [17, 18]. Users are in a state of urgency, which is why PHC is unable to address their complaints when the situation is acute.

Primary care is sometimes perceived to offer few services and is aimed at the low-income population. However, a non-specialised outpatient service is provided, with various activities of low technological density. On the contrary, in other countries, the provision of primary care services is of high quality, with the responsibility of coordinating care provision and organising the system [19, 20]. This responsibility is also included in the National Primary Care Policy guidelines; however, the reality presented by the users is different from what is recommended.

Furthermore, users have pointed out the challenge of accessing specialised tests and consultations through PHC. Although they recognise the local functionality of PHC, they have identified a delay in accessing tests, which they believe contributes to a worse prognosis of the disease. This is due to the fragmentation of the system, which results in care discontinuation and jeopardises the completeness of the care provided.

The absence of diagnostic and therapeutic support has implications for the user, who is dependent on a diagnosis to access treatment. Furthermore, lack of access to this equipment results in care discontinuation, which can have significant implications for patient safety, as it compromises care quality.

This results in the 60-Day Law not being complied with, as there are several gaps that limit user access within the recommended time. PHC cannot provide the necessary resources, and even with the existence of the care network, access to various types of service is restricted, demonstrating a significant discrepancy between the effective implementation of the legislation and its stated objectives.

It can be observed that users are unaware of the legislation in question and that the long period required for a diagnosis, particularly when SUS is the sole source of healthcare provision, is a significant concern. It is accurate to state that the legislation is generally complied with, as it stipulates a period of sixty days from the result of the biopsy. However, the previous pathway is not always clearly understood, which can cause users to access the disease-free service already at a more advanced stage. Furthermore, the data are available only to those patients who ultimately receive treatment. However, a significant number of people die while waiting for diagnostic tests and consultations.

When faced with obstacles in the itinerary proposed by the system, users demonstrate greater autonomy and initiative to navigate alternative services despite professional guidance to adhere to the recommended flow. It is evident that significant theoretical and scientific advances have been made in recent years in the field of therapeutic itinerary and its implications in the context of biological and reductionist approaches to health and disease care [21].

Those who recognise their current situation seek means, whether recommended or not, to access the system. In doing so, they use the mixed health system (public-private). This route, which can be considered a lay action in healthcare, makes the user an active participant in their care process. The following paths are used: private service to speed up diagnosis, acquaintances or relatives who work in health services, political acquaintances, to the use of the emergency room to be seen quickly. The study participants were active in their own care, thus traversing the various existing facilities.

The acute symptom represents a significant threat to the user's condition of normality, outweighing chronic conditions. Furthermore, the population must be educated about the appropriate services to seek for their condition. Despite the existence of networks within the health system, it remains fragmented. Consequently, users perceive the emergency room as a convenient and appropriate service to address their current and long-term needs [22].

The search for emergency services is related to inherent aspects of the organisation of services. For users, the emergency room is perceived as the location with the most advanced technology, the largest resolution capacity, and the most convenient access. The image of the emergency service is considered favourable, with guaranteed care and the possibility of returning [23, 24].

The user's “care map” includes various services and professionals that facilitate their access to the system. Through a trial-and-error process, users identify services and establish their own “mini health systems” within the formalised system [20].

In this new paradigm, users have transitioned from the role of passive recipients of care to active subjects engaged in the process of their own care. They can build their care map based on their knowledge of the world and through established social relationships [22]. Although there is a recommended care network in which the system establishes the user flow, user mobility is still facilitated, as users identify and exploit loopholes to meet their needs, accessing different sectors.

Furthermore, users use private services despite their inability to pay them, which highlights the urgent need to rectify the imbalances observed within the healthcare network [24]. Users' paths are informed by their knowledge of the world and their experience of living with others. Consequently, they are inclined to seek alternative avenues within the health system and are also financially supported to obtain a diagnosis.

In Brazil, a significant proportion of the population that begins their follow-up in the private sector or through health insurance, in the case of an oncological follow-up, subsequently migrates to the public service due to the high cost of treatment, be it surgery, chemotherapy, or radiation therapy, which is not always available through health insurance. The duration of the diagnostic process does not align with the legislative framework, which prioritises early diagnosis and treatment. However, the legislation has not provided for restructuring the health system to ensure compliance. It can be assumed that the legislation is flawed and unknown to the public. Furthermore, even if individuals are aware of the legislation, they may still lack confidence that it will be effectively implemented [24].

On the international stage, there is no established standard for access to treatment. In England, for example, the established time frame for an individual with a serious suspicion of cancer is two weeks between the consultation with the primary care physician and the initial consultation with the specialist. Once a cancer diagnosis is confirmed, treatment must begin within 31 days, with a maximum of 62 days between the referral from the general practitioner and the start of cancer treatment. In Canada, the interval between the initial consultation with a general practitioner and the start of cancer treatment is considerably shorter, with a range of up to 4.2 weeks [25]. In Brazil, it is recommended to seek access within 60 days of the biopsy report [7].

This illustrates the importance of time in the journey of a patient with suspected cancer. Early diagnosis is well established to offer a higher chance of cure and a longer survival time. Although early diagnosis is recommended in Brazil and a legal framework is in place, there are still significant barriers to timely access. Consequently, starting treatment, which should be quick to improve survival rates, is not a reality for most people. Furthermore, the long distances travelled, both for hospitalisation and therapy, present additional challenges for treatment and post-surgical recovery [26, 27].

Legislative advances are often observed not to be aligned with the actual provision of healthcare in the healthcare network. Regardless of government efforts, there will always be gaps in the health system that require further attention. Access to diagnostic resources remains a significant challenge. This reduces the beneficial impact of legislation.

CONCLUSION

In Brazil, the 2012 enacted law recommends that patients with malignant neoplasms have the right to treatment within 60 days of the anatomopathological diagnosis. However, there are still several shortcomings in the efficacy of treatment.

There is a lack of care provision continuity when we observe that, although there is a healthcare network in the region, services are disjoint at different levels of care, which adds to the user's lack of connection with primary care. Consequently, it is imperative to reassess the referral and counter-referral system, strengthening the connection between primary care and other sectors in order to ensure that patients are not neglected and receive continuous care.

Consequently, it became evident that primary care has limited capacity to address the needs of cancer patients and requires a greater capacity to coordinate and manage care provision in a comprehensive manner. This underscores the importance of not only enacting legislation, but also implementing reforms to ensure that services align with the law. One such reform would be to expand the range of services provided in PHC, prioritise early diagnosis, and improve access to specialist networks. These measures would improve the survival chances of patients.

The study, which is qualitative in nature, is subject to certain limitations, including the inability to generalise its findings to the Brazilian context. However, the framework used illuminated the reality of patients in a regional health centre, indicating the need to improve the care network for cancer patients, thus facilitating a more expedient and effective approach.

AUTHORS' CONTRIBUTION

It is hereby acknowledged that all authors have accepted responsibility for the manuscript's content and consented to its submission. They have meticulously reviewed all results and unanimously approved the final version of the manuscript.

LIST OF ABBREVIATIONS

COREQ = Consolidated Criteria for Qualitative Research Reports
Globocan = Global Cancer Observatory
PHC = Primary Health Care
SUS = Brazilian public health system
PAHO = Pan American Health Organisation
AI = Artificial Intelligence

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was evaluated and approved by the Research Ethics Committee of the Botucatu School of Medicine, São Paulo State University (Unesp), Brazil, under CAAE 64262217.4.0000.5411 and Report 1.950.283.

HUMAN AND ANIMAL RIGHTS

All human research procedures followed were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national), and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

Data were collected after the research participants signed the informed consent form.

STANDARDS OF REPORTING

COREQ guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The authors confirm that the data supporting the findings in this study are available in the article.

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CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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