*Promoção da Saúde*
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# Organizational structure in caring for women with breast cancer

## *Estrutura organizacional no atendimento à mulher com câncer de mama*

***Luiz Guilherme Lindemann[1*], Larissa Fialho Machado[2], Tuany Nunes Cunha[3], Lílian Moura de Lima Spagnolo[4], Rosani Manfrin Muniz[5]***

[1]Nurse, master in science from the Postgraduate Program in Nursing at the Nursing School of the Federal University of Pelotas (UFPel); [2]Nurse, master's student in science from the Nursing Postgraduate Program at the Nursing School of the Federal University of Pelotas (UFPel); [3]Nurse, doctoral student in science at the Postgraduate Program in Nursing at the Faculty of Nursing of the Federal University of Pelotas (UFPel); [4]Nurse, permanent lecturer at the Postgraduate Program in Nursing at the Faculty of Nursing of the Federal University of Pelotas (UFPel); [5]Nurse, permanent lecturer at the Postgraduate Program in Nursing at the Faculty of Nursing of the Federal University of Pelotas (UFPel).

***Corresponding author**: Luiz Guilherme Lindemann - Email: luguilindemann@hotmail.com

**ABSTRACT**
Objective: to describe the organizational structure belonging to the care flow aimed at caring for women with breast cancer in a medium-sized municipality in Rio Grande do Sul. Method: exploratory qualitative research applied a semi-structured interview with seven professionals from three health services Careful. Results: show that there is no referral and counter-referral system in the municipality, hindering communication between services that are essential for comprehensive care. Conclusion: There is a need to develop information systems to ensure the principles of the health system and primary care guidelines.

**Keywords:** Breast neoplasms. Communication. Health policy. Oncology. Primary health care.

**RESUMO**
Objetivo: descrever a estrutura organizacional pertencente ao fluxo assistencial destinado ao atendimento da mulher com câncer de mama em um município de médio porte do Rio Grande do Sul. Método: a pesquisa qualitativa exploratória aplicou uma entrevista semiestruturada com sete profissionais de três serviços da linha de cuidado. Resultados: mostram não haver um sistema de referência e contrarreferência no município prejudicando a comunicação entre os serviços fundamentais para a integralidade do cuidado. Conclusão: Percebe-se a necessidade do desenvolvimento de sistemas de informação para assegurar os princípios do sistema de saúde e as diretrizes da atenção primária.

**Palavras-chave:** Atenção primária à saúde. Comunicação. Neoplasias de mama. Oncologia. Política de saúde.

## INTRODUCTION

Breast cancer causes physical and psychosocial suffering from the moment the disease is diagnosed. Women have their body image altered and may experience physical symptoms such as fatigue and pain. The adverse effects of systemic therapies have an impact on the various areas of patients' lives, as well as their financial conditions[1].

Female breast cancer is the most common cancer worldwide, with 2.3 million cases in 2020. In Brazil, 73,610 cases are estimated for the three years from 2023 to 2025, corresponding to 66.54 new cases per 100,000 women. Disregarding non-melanoma skin tumors, breast cancer is the most common cancer in all Brazilian regions. In the state of Rio Grande do Sul, 62.67 cases per 100,000 women are estimated for 2023[2]. Studies have confirmed this incidence[3,4].

Given the epidemiological importance of breast cancer in Brazil, Health Care Networks ("RAS, in Portuguese") must meet the health needs of this population[5]. Of note are the Lines of Care (LC), guaranteed by the National Oncology Care Policy (PNAO), which integrates health services for oncological diseases. In this way, care is structured and planned so that there is standardized and regular monitoring, supporting Primary Health Care (PHC) in coordinating care. To maintain a constant flow of information between services and in line with the PNAO proposal, the National Policy for Cancer Prevention and Control organizes the continuous provision of healthcare actions structured in support, logistics, regulation, and governance systems for the healthcare network[6].

Thus, the LCs define organized and safe care flows to guarantee that the user's needs are met in full, which is fundamental for promoting the health of this population. To this end, an itinerary is drawn up for the user to follow within a health network[7]. LCs are organized by passing through all the points of care, as follows: the gateway and coordination of PHC and specialized outpatient and inpatient care. Comprehensive care is offered, including promotion, prevention, diagnosis, treatment, rehabilitation, and palliative care, according to the user's needs. The flow includes diagnostic tests, requested at the PHC, referral for consultation with a specialist in outpatient care, and confirmation of the diagnosis with a breast biopsy. Once confirmed, the Ministry of Health recommends a maximum of sixty days to start treatment[8-10].

However, for this to work properly, PHC and specialist services must be organized in their attributions and linked to the other points in the care network. As a result, the provision of continuous and comprehensive care is guaranteed with PHC as the provider[11]. This link is built through health communication, which is essential for the development of both management and care actions, involving the population, professionals, and health managers. The referral and counter-referral system organizes the sharing of information between different services, developing comprehensive care through organized and articulated interaction, without the fragmentation of care, given the hierarchization of networks, with PHC being the gateway[12]. International studies have found that the lack of information between services hampers the care offered, and there is a need for rapid and precise communication between health professionals at different levels of care, using e-mails or integrated electronic systems[13,14].

The implementation of this system depends on the organization of services and managers. Professionals encounter difficulties in implementing or practicing communication between the different levels of the LC. The shortage of human resources, work overload, lack of dialog between the different areas of activity, lack of information about the patient, lack of knowledge about the flow of LC, lack of planning, consolidation, and the definition of the attributions of the services by the professionals[15,16]. For this reason, questions have been raised about women's access to services, their attributions, and whether communication between services is carried out effectively. This study aims to describe the organizational structure of the flow of care for women with breast cancer in a medium-sized municipality in Rio Grande do Sul.

## METHODOLOGY

This is an exploratory qualitative study. It was carried out in the municipality of Pelotas, located approximately 260 kilometers from the capital of the state of Rio Grande do Sul, Porto Alegre, with a population of 342,405. At the end of 2020, the municipality of Pelotas had 59 Basic Health Unit teams, 25 of which were Family Health Strategy (FHS) teams and 34 traditional Primary Health Care (PHC) teams, totaling 79.64% of the PHC network[17]. In the area of oncology, the municipality has diagnostic and treatment services through the Brazilian Unified Health System (SUS), divided between the School Hospital of the Federal University of Pelotas (HE-UFPel), with radiotherapy and chemotherapy services, and the Radiotherapy and Oncology Center (CERON) of the Santa Casa de Misericórdia de Pelotas.

Data collection took place between October 2020 and April 2021, in the services that make up the line of care for women with breast cancer, which are: the PHC unit, chemotherapy and radiotherapy services at HE-UFPel and the manager of the Municipal Health Department (SMS, in Portuguese), references in cancer care and service management. The inclusion criteria for participants were managers and team coordinators at the selected health services, who agreed to take part in the research by signing two copies of the Informed Consent Form (ICF). The exclusion criteria were managers and coordinators who were away or on vacation during the collection period. This resulted in a total of seven professionals being interviewed.

Data was collected through semi-structured interviews, using digital recording. Initially, contact was made by telephone or e-mail with the research sites and the day and time most suitable for the professionals and the researcher were arranged. Three interviews were conducted in person at a suitable location in October 2020, and four were conducted via videoconference, due to the worsening of the COVID-19 pandemic.

The data collected was transcribed in full and analyzed according to the thematic analysis proposed by Braun and Clarke[18], which is defined as a qualitative analytical method. This analysis has six phases: 1) familiarization of the data, transcription of the data, reading and pointing out ideas; 2) generation of initial codes, coding in organizational structure and communication; 3) search for themes, grouping the codes in relevant themes as used organizational structure belonging to the flow of care for the user with breast cancer; 4) reviewing the themes, reviewing the relationship between the themes and the coded extracts; 5) denominating and naming the themes, a new analysis to refine the themes; and 6) producing the report, producing an opinion with reflections between the examples experienced and the selected extracts.

Based on this analysis, it was categorized into two themes: attributions of services in the care of women with breast cancer and communication between referral and counter-referral health services. The first reports on the attributions of each service from the perspective of the managers who took part in the study, of these services within the LC. The second highlights the two-way transmission of information between the different services that make up a health network.

To discuss the data, the reference of the flow of care for women with breast cancer in the SUS will be used. Ordinance No. 483, of April 1, 2014, stipulates that there must be articulation between health services and actions, ensuring integration and connectivity between the different points of care, with care being user-centered and carried out by multidisciplinary teams, always articulated between health managers[19]. It is important to highlight Law No. 12.732 of November 22, 2012, which regulates that the first treatment of users with proven malignant neoplasms must be provided by the SUS within sixty days of diagnosis. As such, coordination between points in the network is extremely important to meet the recommended timeframe for care[20].

Ethical principles were respected, complying with the guidelines and norms regulating research involving human beings, Resolution No. 466/2012 and No. 510/2016 of the National Health Council, as well as Circular Letter No. 01/2021. It was approved by the Research Ethics Committee (CEP) of the Faculty of Nursing of the Federal University of Pelotas, under opinion number 4.301.262. The signing of the

ICF guarantees anonymity and the participants were identified as Manager (Gest), followed by their place of work and increasing number. The Enhancing the Quality and Transparency Of Health Research (EQUATOR) Network was used to write up the study.

## RESULTS

The seven participants were aged between 33 and 63, six female and one male. Six had a degree in nursing and one in business administration. Two had an academic master's degree in nursing and two specialized in oncology. The length of time the managers have worked in the services varies between two months and 18 years.

### ATTRIBUTIONS OF THE SERVICES IN THE CARE OF WOMEN WITH BREAST CANCER

This first theme categorizes the managers' perceptions of the attributions of each service within the organizational structure in which the user travels. The answers show that the services are structured in line with the Ministry of Health's proposal for the implementation of LC within the RAS for chronic condition care.

Considering that the services are the gateway to the Line of Care, the managers highlight their duties as user reception, health promotion, and prevention activities. They emphasize guidance for users to prevent and promote health during nursing consultations, active search for users in the target age group for mammography screening, and health education in the community.

> We do a lot of work in the waiting room, we do this health education in the office with the women, we talk about it [...] we're always working on health education when information arrives, we do team training on the subject, but especially in pink October we do actions. (Gest 1 - UBS).
>
> We've done a lot of actions, and usually, we end up falling into the routine of using Pink October, the action we do is daily when the doctor is doing the gynecological consultation, even in prenatal care we've focused a lot on this because it talks about diet, it talks about breast cancer prevention [...] we ask the agents to help us with the sweep looking for those women who have never had a mammogram and who are at that age. (Gest 2 - UBS).
>
> We do awareness-raising work with women, we also use the nursing students, right, we do wait room work, we talk to the general population, and of course, the focus is on women. (Gest 3 - UBS).

From the participants' accounts, the SMS's role as a governance service stands out. These include the coordination of health programs in PHC; administration and management of care for users with breast cancer by regulating appointments and exams, and contracting the services needed to meet user demand.

> Overseeing many processes about the programs that need to be carried out at the top, is our biggest challenge here, as coordinators and nurses of the actions to be carried out, I think it's these issues, as well as our being involved in management issues a lot of the time because the professionals need proper guidance, as well as care and administrative issues, everything that can be truly aligned with the flow. (Gest 1 - SMS).
>
> We regulate all appointments and exams. We regulate all consultations, there

> is no other sector in the municipality that does this, that regulates consultations, exams, or hospitalizations. (Gest 2 - SMS).

In conclusion, this category highlights the discourse of high-complexity care professionals, in which they recognize their role in welcoming and accompanying the user during treatment, monitoring, and providing the necessary care for her health condition.

> The attributions of our service are to welcome this patient [...] we only take this patient here when she has already been diagnosed, this patient comes to us with the diagnosis of breast cancer from oncology, we take her for treatment. (Gest 2 - HE).
>
> We end up treating this patient [...] we demarcate the area that's going to be treated, it's the planning part, which demarcates the whole area that's going to be treated and the area that's going to be protected, the areas that don't need radiation [...] we do the nursing consultation, we do all the daily monitoring of side effects, so we monitor everything during the treatment. (Gest 1 - HE).

## COMMUNICATION BETWEEN REFERRAL AND COUNTER-REFERRAL HEALTH SERVICES

Communication plays a fundamental role in the promotion, prevention, and rehabilitation of diseases, so there is a need to provoke intense exchanges of information and knowledge. Therefore, the transmission of information must be bidirectional between the different services that make up the health network, with professionals reporting referral and counter-referral communication.

> These referrals are made via the system, via AGHOS, which is our system that is made by the city council together with the providers. (Gest 2 - SMS).
>
> We used to make a referral and counter-referral document on paper and the patient would be referred directly to the service to make an appointment with the specialized service, but nowadays it doesn't work like that, today it's through a system, which we call AGHOS [...]. When he (the doctor) examines the patient and the tests, he makes the referral. (Gest 1 - UBS).
>
> We refer them to women's health, and that's where they go [...] the doctor goes into the AGHOS system, goes into the system and makes the referral. (Gest 3 - UBS).
>
> The oncology referrals go straight to the receptionists here at the radiotherapy, the doctors access them through the system. (Manager 2 - HE).

The professionals also highlight the use of forms and physical documents for referrals, in addition to the electronic system.

> We have our proper form from the Ministry of Health which includes all this identification and, above all, the justification for the mammography request. Once this request has been made, it's done physically in a document, which follows a flow for regulation, and after that, it also must be put into the municipality's information system, which is AGHOS. (Gest 1 - SMS).
>
> The services seek to obtain information about users in different ways, as the managers explained. This way, one the users have

been referred, they can expedite referrals efficiently.

We have to get in touch by phone with the exams regulation [...] We also go through another channel, which is the women's health service, which is run by the SMS, this service serves as a support for the basic network [...] we get in touch with the service, pass on the woman's name, they listen to our demand, assess the seriousness of our demand and they get in touch with the exams regulation sector to somehow organize that emergency. (Gest 1 - UBS).

What we do sometimes is call the head of women's health, it's not even supposed to be like this, but you start to see that the referral is taking too long, this woman isn't being called, so we call, try to talk to the head of women's health here at the SMS [...] to try to speed up this process, so that this woman gets to where she needs to be as soon as possible. (Gest 2 - UBS).

Communication is done directly, often by telephone, but lately, we've been trying to get support from all sides, so we've seen the need, in addition to communication by telephone, to seek written communication, so we exchange e-mails [...] sometimes we communicate by memos, by letters, because we need to have a basis for any response situation, not just the user's health issue. ( Gest 2 - SMS).

When there's a very urgent case and there's a social worker at UBS, she contacts us by phone and asks for a quick assessment. (Gest 1 - SMS).

The interviewees report weaknesses in this search for information, and access to services and users' medical histories is difficult.

> AGHOS is a system linked to the municipality's SMS. HE doesn't have access in this way, it has access to other systems, not AGHOS. (Gest 1 - SMS).
>
> AGHOS shows where the patient went until she got there, but the providers have their own medical records systems, which they have access to, but the other places don't. (Manager 2 - SMS).
>
> We have a system that we use to make progress [...] which is being organized so that we can use it on an outpatient basis, but that's internal to the hospital, right, for the time being, it's only for inpatients, other services don't have access, only us. (Manager 2 - HE).

Integrity and resolution are weakened by this lack of information about the users in the network. The professionals point out that the fragmentation in the flow of information is due to the lack of a counter-referral structure in the municipality.

> The counter-referral doesn't work in practice, we can't get a response from the professional who made the referral [...] the ideal would be for us to make a counter-referral to the responsible sector, but there isn't one, so everything ends up being very informal. (Gest 1 - HE).
>
> The counter-referral is another very fragile issue, in general, there is no

> counter-referral [...] This issue is fragmented, this is an obstacle, they are obstacles, they are barriers in the system, at least that's my point of view. (Manager 1 - SMS).
>
> There's a failure of clinical counter-referral from the hospital, they don't send anything to us [...] it's a failure of communication because this interferes a lot with the patient's treatment. (Manager 3 - UBS).
>
> We don't make any counter-referrals here in the service (Gest 2 - HE).
>
> Very rarely do we have counter-referrals, like some gynecologists in the city, for some gynecological problems with cervical cancer, but the breast cancer function is much more difficult. (Gest 2 - UBS).

In their speeches, the services show an increased effort to make some kind of counter-referral. In cases considered serious, such as injuries resulting from treatment or physical and social vulnerability, managers step up their efforts to monitor patients' conditions.

> If any injuries need to be monitored, then we make a counter-referral to the BHU closest to the patient. We always rely on the support of our social worker, who contacts the BHU social worker via telephone. (Gest 2 - HE).
>
> Today, the radio-oncologists provide a discharge report, but it's a very specific procedure on their part [...] They describe a lot of things so that the clinical oncologist can better understand how the process went [...]. Ideally, we should make a counter-referral to the responsible sector [...] we make this general form for them to send back to the referring doctor. (Gest 1 - HE).

## DISCUSSION

PHC is the gateway to the SUS for users, and its care is less complex. Its objectives include universal access, coordination, expanding care to other points of care, programming health promotion and disease prevention actions[21]. To guarantee the attributions and form a link with the points of care, the services must organize themselves into LC, thus committing themselves to continuous and comprehensive care for the user[11].

The interviewees say that PHC fulfills its role of initially welcoming the user into the LC. They reported on consultations with the general practitioner and the request for tests. They also talked about health promotion activities, in which they highlighted some weaknesses, which are only concentrated in October. This disagrees with what is recommended by the Ministry of Health, in which activities should be continuous in the team's work process.

Pink October is a worldwide event for breast cancer prevention and diagnosis, promoting awareness and access to services. However, instead of trying to compensate for early investigation strategies in this seasonal model, it would benefit users to strengthen the strategies provided in the guidelines. However, awareness-raising strategies, a priority referral protocol for cases with suspicious signs and symptoms, and diagnostic confirmation in a single service depend on the effective organization of the health system [22].

The findings show that the SMS governance system plays its role together with PHC, through the administrative and organizational coordination of the RAS. Its attributions enable flows to be streamlined and the levels of the SUS to be integrated[23]. In addition to management, the Municipal Health Secretariats (SMS, in Portuguese) have a strategic vision for negotiations to make health care feasible, developing the LC for the early detection of breast cancer. The work of the SMS is essential for understanding the regulatory intervention of health demands involving multiple actors. It is

fundamental for regulating the services needed to access points of care such as medium and high complexity services[24].

Monitoring users with chronic diseases or conditions is reported by the interviewees as being the responsibility of the services, from drawing up the individual therapeutic plan to treating the diseases and the resulting complications. PHC should keep up the monitoring by encouraging matrix support and establishing a permanent interrelationship between general practitioners from PHC and specialists from the other services in the line of care in the work process[25]. This specialized care for the LC users is extremely important for PHC to complement diagnostic investigation, treatment, and care. In this way, technology compatible with the user's health needs is concentrated, favoring referrals to other services[10].

According to the interviewees, there is no counter-referral system in the municipality surveyed, which hinders communication between services. The PHC is the coordinator of care, so it must be aware of the patient's entire LC pathway. Thus, access to information on procedures and the health situation should be facilitated by contact between specialized outpatient and inpatient care and PHC. Communication difficulties once the user returns to the PHC network reveal discontinuity of care and poor case resolution[12].

Effective communication between the services that make up the LC, at different points in the network, enables the doctrinal principles of the SUS to be put into practice. As a result, users will receive care based on their health history and past treatments. For this to happen, there needs to be a well-structured referral and counter-referral system in health, where the different services of the LC have access to information about the individual's state of health, illness, and treatment[19,26].

The use of information and communication technologies in healthcare is evolving, seeking improvements and creating strategies in Brazilian healthcare institutions. These information systems are essential for speeding up the referral and counter-referral system[27]. Electronic records enable better decision-making and the adoption of best practices, whether in care or bureaucracy, improving efficiency compared to physical documents. Paper forms lead to loss of information, delays, and poor communication. Thus, the inclusion of digital media enhances access to information and interaction between services and production[7].

One study, reports that organizational communication is seen in an integrated and informal way, requiring standardization. Professionals report valuing personal and informal conversations, either orally or via messaging apps[28]. This shows the disarticulation of communication between services and the disorientation of the user in the flow of the system. The lack of communication between services is shown by the lack of organization among professionals and in the system[29]. The managers interviewed resort to informality to maintain equity in the SUS, reducing the barriers to regulated communication. However, this information is not standardized, depending on each professional and service.

Given this, the implementation of the LC becomes a challenge for health professionals and teams. The lack of information causes difficulties in the continuity of care and user assistance[12]. Health planning depends on reliable and valid information about the user's health situation, showing that the search for efficiency is important for improving and expanding health services[30]. The lack of counter-referral interferes with the comprehensiveness and effectiveness of users' health demands[29].

Counter-referral is essential for the best approach and handling of cases within the LC, and when a user's needs are met, they are referred to another service for continuity of care. Thus, as the user is cared for by the services, data on treatments and procedures is not lost in the network, providing integrality and equity[29]. Another study shows that communication between managers and professionals, seeking to find solutions through the referral and counter-referral system, promotes comprehensive care[31].

Since the municipality does not have a referral and counter-referral system, the coordination of care in PHC must develop elements of vertical and horizontal integration

between services and health professionals. Mechanisms can be used to plan care, define flows, exchange information on users, and monitor therapeutic plans and health needs to provide continuous care[9]. In addition, for PHC to act as an organizer and coordinator of LC, multidisciplinary teams must be guaranteed, the scope of practice of other professionals must be increased, and coordination must be strengthened by ensuring better therapy and infrastructure. This will only be possible if managers recognize the real needs of the population and seek greater investment in health[16,32].

These findings help health professionals to reflect on whether their practice is integrating health quickly and accurately. In this way, it contributes to urging managers and the health system to promote a referral system that guarantees the promotion of the population's health.

## CONCLUSION

Therefore, the study achieved its objective by describing the organizational structure of the care flow for women with breast cancer in a medium-sized municipality in Rio Grande do Sul. Despite the limited access to the study participants due to the COVID-19 pandemic, this study contributes to health service managers and professionals reflecting on their practices and seeking investment to guarantee comprehensive and resolutive care for users with breast cancer. It shows that PHC is fundamental for getting users into the health system, programming health promotion, and disease prevention actions. It should be emphasized that activities to monitor the public at risk should be encouraged and committed throughout the year, not just during Pink October.

The SMS's governance system is essential in the regulatory intervention of health demands, to guarantee the best development of the care service. Thus, there is a need to develop a well-structured health reference and counter-reference system in the municipality to ensure comprehensive care and communication between the services that make up the LC. Although there is a formal information system, counter-referral does not take place, leading professionals to resort to informal methods such as telephone and e-mails to try to promote continuity of care for women affected by breast cancer. We, therefore, conclude that it is necessary to develop counter-referral information systems to ensure the principles of the SUS and the guidelines of primary care.

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