







ORIGINAL ARTICLE

CANCER PATIENT CARE FROM THE PERSPECTIVE OF PRIMARY HEALTH CARE NURSES

HIGHLIGHTS

1. Nurses are responsible for caring for cancer patients in PHC.
2. It entails services improving their care for cancer patients.
3. Nurses must take the lead in improving their care of cancer patients.
4. Organizational structure/protocols are priorities for PHC nursing.

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ABSTRACT

Objective: To describe nurses' perceptions of cancer patient care in Primary Health Care. **Method:** A qualitative study was conducted in 26 Family Health Centers in a municipality in western Santa Catarina - Brazil, between September and October 2022. A total of 33 nurses took part and completed an online questionnaire. The text was interpreted based on the conceptual precepts of organizational culture from Chiavenatto's administrative theory. The frequency of responses analyzed objective questions; the Collective Subject Discourse was used for the essay questions. **Results:** Nurses perceive themselves as unprepared and identify a lack of protocols and organizational flows. **Final considerations:** In primary Health Care, there is a belief consolidated in everyday work and becomes part of the organizational culture of health services, that cancer patients should go on to specialist care. There is a lack of knowledge of health policies, which implicates professionals in caring for cancer patients.

KEYWORDS: Nursing Care; Medical Oncology; Primary Care Nursing; Palliative Care; Qualitative Research.

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INTRODUCTION

The National Cancer Prevention and Control Policy (Ordinance No. 874 of May 16, 2013) guarantees health care for cancer patients, which states that care must be comprehensive, regionalized, and decentralized¹. Based on the hierarchization of care, it is the duty of the state and municipalities to organize this care, defining flows in the public system, with access being based on the Primary Health Care Network².

In order to guarantee the quality of services in follow-up care, Ordinance SAES/MS No. 1399, of December 17, 2019³, redefines criteria for the qualification of health establishments in high complexity oncology. Furthermore, since cancer is a potentially fatal chronic disease, it has specific protection guaranteed by the National Policy for the Prevention and Control of Cancer in the Health Care Network for People with Chronic Diseases in the SUS, of 2017⁴, as well as the guarantee of palliative care described in Resolution No. 41 of 2018 of the Ministry of Health⁵.

Thus, within the scope of Primary Health Care (PHC), Ordinance No. 825 of 2016, which redefined Home Care in the Unified Health System (SUS), structures multi-professional teams to work in Basic Health Units (BHU), making these teams responsible for the first care of any and all users who access the service⁶.

In this scenario, the nurse is a key player, generally because he or she plays the role of manager, becoming the articulator of care, and also acts in direct assistance to the cancer patient in the reception, in the nursing consultation, and the continuity of care in all phases of treatment. Therefore, nurses have the chance to strengthen the bond with the patients in their territory, which makes them a reference for treatment support⁷.

In view of the above, a contradiction can be seen: although health legislation establishes that PHC is a constituent sphere of care for cancer patients, the fact is that health professionals see care for them as the responsibility of tertiary care. When these patients come to the PHC, they make professionals feel insecure, believing that this is not the ideal place for them to receive care. This "*modus operandis*" of the professionals at the SUS's front door is sustained by the specificities of the disease and its treatments and the complexity of the care⁸.

A study of 10 nurses in PHC in northeastern Brazil revealed gaps in their knowledge of protocols and programs that guide cancer care and other difficulties experienced in clinical practice⁸⁻⁹. Another study¹⁰ showed that superficial knowledge of palliative care, attributed to weaknesses in academic training and a lack of training, is a barrier to be overcome in PHC.

The authors, therefore, report on the positive experience of the remote outpatient clinic, which aims to integrate the outpatient clinic of the Hospital do Câncer IV of the José Alencar Gomes da Silva National Cancer Institute (INCA) and PHC in the city of Rio de Janeiro, demonstrating that it is possible to provide care in PHC. Professionals evaluated this initiative as a strategy that ensures quality care¹⁰. In view of the above, this study aims to describe nurses' perceptions of cancer patient care in Primary Health Care.

METHOD

The text was interpreted based on the conceptual precepts of organizational culture, present in Chiavenatto's management theory¹¹, for which professionals in a given institution share values and expectations that display their habits and beliefs and characterize their attitudes in the institution's internal and external environment.

The research sites were the Family Health Centers (FHCs) of a municipality west of Santa Catarina, which has a basic network with 62 nurses distributed among 26 FHCs. A total of 33 nurses working in the FHC took part in this study, with the exception of those on leave or on sick leave during the data collection period.

Data collection took place online between September and October 2022, and an individual invitation was sent by email, containing a Google Forms link with an Informed Consent Form (ICF) and a form with semi-structured questions related to cancer patient care in PHC.

With the approach described, 12 of the 62 professionals took part. Therefore, it was decided to restructure the data collection proposal to facilitate access and broaden participation. Thus, the same invitation was forwarded individually via 1 DOC (official internal communication channel of the municipality), respecting all ethical aspects, which allowed 21 more nurses to take part, totaling 33 participants.

When the questionnaire was sent out, a deadline of 15 days was set for a reply. It was structured based on questions that allowed the researchers to obtain answers in order to meet the study's objective. Therefore, we asked about more general aspects, i.e., how nurses care for cancer patients in PHC and how they feel about it. We also asked about more specific aspects: whether nurses consult cancer patients in PHC and whether they consider it relevant to have instruments to guide the nurse's consultation with these patients. The estimated response time was 30 minutes.

The objective questions were analyzed based on the frequency of responses, which allowed the research team to group them by the recurrence of their content. For the dissertative answers, the Collective Subject Discourse (CSD) technique was used, which in the first person singular expresses a set of similar or complementary individual statements¹². The authors of this methodology propose four methodological figures for making the CSD: key expressions (KEs), central ideas (CIs), anchoring (ACs), and the CSD.

The KEs are fragments of speech that reveal themselves as essential content to what is being discussed. The CIs are linguistic expressions that correspond to a homogeneous and as precise as possible synthesis of the KEs, giving rise to the CSD. In CA, the researcher captures the expression of a theory, ideology, or belief adopted by the participant, which is embedded in the discourse as if it were a statement. Therefore, the CSD is a non-mathematical aggregation or sum of isolated excerpts from statements to form a coherent discursive whole, in which each of the parts is recognized as a constituent of this whole. It is a summary discourse, written in the first person singular and comprised of a collage of KEs with the same CI or AC¹².

To structure the CSD, we follow a classic schematization with a beginning, middle, and end, from general to particular. The parts of the speech, the paragraphs, are linked using connectives that provide cohesion, eliminating particular data such as gender, age, particular events, specific illnesses, and repetitions of ideas. After each DCS, the central idea was discussed using bibliographies to support the topic¹².

The study was submitted to and approved by the Human Research Ethics Committee (CEPSH) of the Federal University of the Southern Frontier (UFFS), under opinion no. 5.633.551. The rights of the participants were preserved throughout the study, and all these stages complied with the standards established by Resolution 466/2012 and Resolution 550/2016 of the National Health Council.

RESULTS

The sociodemographic profile, frequency analysis, and DCS will be presented. Figure 1 shows the profile of the participants based on age, gender, continuing education, and professional experience.

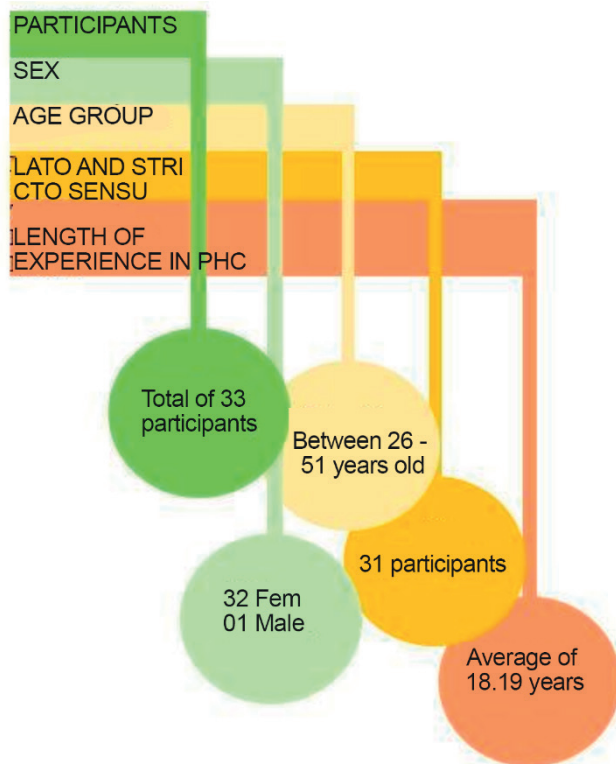


Figure 1 - Characterization of the participants. Chapecó, SC, Brazil, 2023

Source: Authors (2023).

With regard to how nursing care for cancer patients is developed within the scope of PHC, 16 of the participants answered that there is no defined organization in the unit where they work and said that care is taken to the specialized oncology service, six cited the use of a structured flow of care in the unit, and five used some kind of protocol.

DCS 1 and 2 refer to CIs related to the previous question:

Patients' demands are met during their treatment, without a specific flow of care. The initial diagnosis usually takes place in Primary Care [AB] and is then referred to high complexity [oncology] via regulation. (CSD1)

Lack of workflow and protocols that standardize nursing care. After the result of the mammogram [MMG] or cytopathology [CP], or any other suggestive test, the result of the test is evaluated and the flow to the specialist is carried out according to the municipal protocol. (CSD2)

As for the continuity of care for cancer patients through PHC, 28 said that it occurs simultaneously in PHC and specialized services, four cited exclusive care in specialized services, and one indicated exclusive care in PHC.

Next, the CIs:

Patients are usually followed up in the hospital's oncology department. The Basic Health Unit [BHU] generally provides assistance by helping with orientation, scheduling exams and consultations, requesting transport, making dressings, home care and monitoring other health demands, in other words, it fits into the flow of care for other patients at the AB, they are assisted according to the needs of their health condition, and their demands are prioritized. (CSD4)

We receive patients on a spontaneous basis, with various complaints and care needs, in the follow-up, cure or terminal phase, with palliative care. He is welcomed by the team and referred to the nurse for assessment. The professional carries out the nursing consultation and prescribes the guidelines and/or treatments pertinent to the patient's needs. (CSD5)

Participants answer how they evaluate health care for cancer patients in the context of PHC. Of these, 15 believe that the care is partially resolute; seven point to non-resolute care because it is not structured; five perceive resolute care; and another six perceive non-resolute care, even if it is partially structured.

As for preparation for care, 21 feel partially prepared; six do not feel prepared in general, that is, regardless of whether it is specialized care or not; four do not feel prepared because it is a specialty; and two say they are prepared to care for cancer patients in PHC.

The CI below describes professional preparation:

Professional unpreparedness and one-sidedness due to being more focused on a biomedical model, limited knowledge about the disease, treatment, and care, i.e., little experience, not knowing how to deal with acronyms and treatment cycles, and the complexity of some cases. There needs to be more preparation and more training for the FHSC teams. (CSD6)

The sequence of CIs reveals the difficulties encountered by the service in caring for cancer patients in PHC:

Reference and Counter-reference, i.e., difficulty accessing information on cancer treatment in the Oncology Service, lack of training and updates in oncology, difficulty in the transversality of care. It would be important for every cancer patient to have a written summary of their treatment, needs, medications, upcoming appointments, and tests. This can contribute to follow-up care at the BHU. (CSD7)

Elderly patients with little education unaccompanied; difficulty in understanding the care process, counter-referral from the specialized service with no or insufficient clinical information, delay in responding to return appointments. (CSD8)

Little psychological support is offered to the family and patient since patients and their families can be psychologically affected, and family members are often poorly oriented and unable to offer emotional support to patients. Listening sessions are interrupted due to other demands, and our time differs from the patient's. (CSD9)

Difficulty for professionals to manage patients' pain and lack of more specific medications for treatment. It is difficult to get to know all the cancer patients attending the FHC in order to plan their care, and there are difficulties with transportation in order to be able to monitor them continuously, as well as difficulties in getting to the FHC. (CSD10)

Finally, the questionnaire asked about the existence of potential in the care of cancer patients. Multiprofessionalism and professional commitment are factors identified as potential and the CIs expose these issues:

Integrated and active multi-professional team. The closeness and bond between the patient and the FHSC team is an excellent care tool that can enhance care by adapting to the patient's real conditions, according to the technologies on offer, and developing targeted

actions to improve quality of life. Use of alternative and complementary practices. (CSD11)

Professional commitment and technical capacity, speedy referrals, a well-established flow in the Regulation System [SISREG] sector, support networks, a humanized welcome, and holistic collective follow-up, for comprehensive and humanized care. I believe that all units have power. (CSD12)

DISCUSSION

Care for cancer patients in PHC was described from the perspective of the work process experienced by nurses. With regard to structuring a care model, this study allows us to conjecture that there is a lack of standardization, which induces the majority of participants to refer these patients to specialized oncology sectors.

Nowadays, the need to standardize care practices for cancer patients¹³ requires a search for alternatives in the absence of specific protocols. A resolute path could be adherence to the Singular Therapeutic Project, in which care is planned by the interdisciplinary team and the patient, considering their real needs¹⁴.

The evidence described in the collective speeches highlighted the professionals' lack of knowledge regarding the content of the National Primary Care Policy (PNAB) and the National Policy for Cancer Prevention and Control in the Health Care Network for people with chronic diseases^{1,4}. This lack of knowledge, as an object of concern, has been the focus of research, as in a study carried out in northeastern Brazil in 2019, in which it was identified that nurses consider it important to carry out actions aimed at caring for cancer patients in PHC; however, they do not do so and still admit the incipience of the Ministry of Health's programs and protocols to guide care for this public⁹.

Another study ratifies the existence of deficient knowledge and adds that professionals recognize the lack of technical capacity in dealing with cancer patients, which results in gaps in assistance, jeopardizing the continuity of care¹⁵. When it comes to continuity of care, the participants in the study value this prerogative, as they believe that their needs should be prioritized in the flow of care.

Therefore, the impact of lack of knowledge of the policies affects the continuity of care for cancer patients as much as it compromises the quality of that care. This finding reflects a problem that goes far beyond cancer patient care. The fact is that there is a detachment between the production of public policies and their implementation, and, in general, it stems from the distance between the technicians who draw up the policy text and the professionals who are responsible for the care structured in the policy. This fact was found in a study in which it was possible to detect the lack of knowledge of professionals in the care network regarding the policy that involves assistance to the riverside population, a situation that makes it difficult for professionals to organize care, as well as to identify the available resources¹⁶.

Sharing comprehensive cancer treatment itineraries results in resolute care, providing patients peace of mind and security while navigating healthcare. Thus, articulation is provided for by the Health Care Network (RAS) and has the potential to avoid overloading specialized care¹⁷. In this case, it is necessary to guarantee this articulation in order to respond effectively to the policies created.

As far as nursing is concerned, the most critical issue involving the role of PHC nurses in caring for cancer patients is the delimitation and understanding of this role. There are doubts among professionals about the scope of their actions; therefore, in addition to protocols that explain how to care for cancer patients in PHC, the role of nurses needs to

be clearly defined, as well as professional training.

The literature shows different perceptions of care for this specialty in PHC, but understanding the flow of care for cancer patients and the SUS care network is crucial for all professionals and the quality of care¹⁸.

At the root of this problem is what has already been pointed out: knowledge and understanding of cancer patient care policies. In this sense, the importance of public health policies in the fight against cancer is highlighted, as well as social rights and fundamental guarantees as the foundation of human dignity and the Democratic Rule of Law¹⁹.

Knowledge about health policies, which define rights and ensure care for cancer patients, must be built up from professional training, and critical thinking must be encouraged to qualify nurses' praxis. To this end, the subject should be part of the undergraduate and postgraduate curricula, since the lack of training for professionals is recognized, reinforcing the importance of including knowledge in the field of oncology in the curricula⁹.

In this training area, it is pertinent to introduce concepts relating to Advanced Practice, i.e., training Advanced Practice Nurses (APNs). Although the debate is still in its infancy in Brazil, it has been widely discussed around the world and its potential for improving the care process in clinical practice has already been demonstrated²⁰.

One study, which aimed to investigate evidence regarding the training of APNs in the care of cancer patients, discusses the relevance of the strategy in the oncology area, arguing that adjustments in training have boosted the results and the relevant repercussions on the rise in deaths caused by cancer, whose statistics and forecasts are alarming, and, ultimately, the reduction of costs²¹.

The training scenario also includes the constant need for professional development, which reinforces the demand for specific training in caring for cancer patients in PHC and their families¹⁸. Permanent health education is considered a strategy that has a resolute and participatory character and can be developed through active methodologies, such as realistic simulations, and result in more effective and efficient communication²².

It is worth noting that ongoing training is the responsibility of the service; however, continuing education is the responsibility of the professional, and even if the education provided by the service is organized in the institution, it must meet the needs reported by the professionals. This debate also includes the involvement of professionals in their own development: they are the protagonists of their own training. This analysis has repercussions on the professional's perception of their ability to care for cancer patients, portraying how they see the effectiveness of this care²³.

In view of this, the literature reinforces the importance of service management fostering the qualification of professionals, either by organizing the processes essential to the production of EPS or by encouraging professionals to produce continuing education, such as specialization courses and participation in events, in order to improve cancer patient care and avoid dissatisfaction and inefficiency bilaterally, in relation to the work process imbricated in this specialty¹⁵.

Next, the participants discuss the difficulties they perceive in the work process involving cancer patients. In this sense, there are divergences that can result in consequences and losses in the treatment of these patients, such as a waiting time for diagnosis and the start of treatment that is not in line with what the policy advocates, implying survival since it reduces the chances of cure and increases the risk of sequelae for these patients^{15,24}.

A study in a municipality in southern Brazil identified flaws in the coordination of care associated with referral and counter-referral and communication between the different points in the network. These flaws could be corrected if telecommunication technologies were available²⁵. In order to minimize these difficulties, we recommend organizing a

counter-referral report to ensure effective intersectoral communication and organizing a counter-referral report developed by the PHC, which is responsible for ordering care, as provided for in Law No. 8,142, which regulates the SUS¹⁵.

In addition, the participants value emotional support or, rather, the lack of it: they perceive that the patient and family lack a look at this health need, which accompanies this health condition from its diagnosis to its outcome. They also add that the structure of the service should analyze the real conditions of the patients when it comes to assimilating care, especially when they are elderly²⁶.

On the other hand, the participants saw potential in caring for cancer patients, teamwork, the creation of stronger bonds, and a humanized care model, which stood out. These findings are similar to those found in another study, which showed that attributes such as the team's bond with the patient/family, welcoming, trust, and empathy are important aspects of humanized care²⁷.

A limitation of this study is the fact that only one instrument was used to collect data so that nurses could express their perceptions. From a scientific point of view, the more instruments you use to collect data, the more exuberant and comprehensive the results will be. It is important to point out that in this area of nursing practice, involving the role of nurses with cancer patients in PHC, more studies should be carried out in order to show the future results of resolute practices at this level of care.

FINAL CONSIDERATIONS

The discourses of the nurses from the Family Health Center analyzed show that in the organizational culture of Primary Health Care, there is a belief that cancer patients are perceived as specialized care, for which they do not feel prepared; thus, in the midst of this feeling, they are unable to assertively capture the role of nurses in the context of cancer patient care in this locus of care. The lack of knowledge of health policies involving this population reinforces the idea that cancer patients should be referred to specialized services, which implies that it is not mandatory for these professionals to prepare themselves to provide this care.

In this way, an action to be taken within the scope of the management of the services of the Unified Health System, with the aim of rescuing this professional role of nursing in PHC, is precisely to promote strategies that encourage this professional to take on this role, with technical and scientific knowledge, as well as the legislation that supports the care of cancer patients; as well as to build a space of trust and support with PHC, in which nurses feel strengthened and aware of how to care for cancer patients. In this case, ultimately, promoting an institutional organizational culture, in which the belief that nurses are suitable for this practice is sustained.

In this sense, the guiding principle is the solution to the problem revealed in this study, which is to activate training processes, whether of a collective nature by involving institutions in this social commitment, or of an individual nature by committing the professional to the search for improvement in order to care for these patients whose specialty is factual, but does not exempt PHC nurses from providing care. Therefore, by unraveling this basic problem, protocols, and organizational structures will be developed, and the systematized care model will finally include this patient population.

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