

Care received in Primary Health Care: perspective of patients in palliative oncological care and their families

Assistência recebida na Atenção Básica: perspectiva de pacientes em cuidados paliativos oncológicos e suas famílias
Asistencia recibida en la Atención Primaria: perspectiva de los pacientes en cuidados oncológicos paliativos y sus familias

Juliane Maria Guedes de Carvalho¹

ORCID: 0009-0009-5038-7913

Gabriel Zanin Sanguino¹

ORCID: 0000-0002-3273-5496

Jordhan Abner Teixeira Murilho¹

ORCID: 0009-0005-7855-2459

Lucas Eduardo de Oliveira¹

ORCID: 0009-0009-7391-9062

Mateus Souza da Luz²

ORCID: 0000-0003-2405-0152

Sonia Silva Marcon¹

ORCID: 0000-0002-6607-362X

Mayckel da Silva Barreto¹

ORCID: 0000-0003-2290-8418

Abstract

Objective: to understand how health care is provided in Primary Health Care from the perspective of oncological patients in palliative care and their families. **Methods:** descriptive-exploratory study, with a qualitative approach, carried out with patients diagnosed with cancer in palliative care and their families. Data collection took place between September and November 2023, using open-ended interviews, guided by a semi-structured instrument. The audio recorded was transcribed in full and later analyzed using Content Analysis. **Results:** two thematic categories were identified: "Health care provided by Primary Health Care" and "Satisfaction with care despite obstacles perceived". Health care involved referrals to specialists, support in the initial diagnosis and treatment of the physical consequences of the disease. Despite the obstacles experienced, such as delays and lack of professional training, the participants perceived the care as satisfactory. **Conclusion:** palliative care is not present in the daily routine of Primary Health Care, which to some extent may reflect the need for professional training.

Descriptors: Palliative Care; Hospice Care; Primary Health Care; Unified Health System; Family.

¹State University of Maringá, Maringá, Paraná, Brazil.

²Univel University Center. Cascavel, Paraná, Brazil.

Corresponding author:
Mayckel da Silva Barreto
E-mail: msbarreto@uem.br

Whats is already known on this?

Ideally, Primary Care is responsible for offering continuity of care after the establishment of palliative oncological care. However, it is necessary to implement public policies that ensure the longitudinality of care.

What this study adds?

Primary Care supported the initial diagnosis and treated physical symptoms of cancer. There was a lack of professional training for palliative care. Even so, the participants perceived the care as satisfactory.



How to cite this article: Carvalho JMG, Sanguino GZ, Murilho JAT, Oliveira LE, Luz MS, Marcon SS, Barreto MS. Care received in Primary Health Care: perspective of patients in palliative oncological care and their families. Rev. enferm. UFPI. [internet] 2025 [Cited: ano mês abreviado dia];14: e5336. DOI: 10.26694/reufpi.v13i1.5336

Resumo

Objetivo: compreender como ocorre a assistência à saúde no âmbito da Atenção Básica na perspectiva dos pacientes oncológicos em cuidados paliativos e seus familiares. **Método:** estudo descritivo-exploratório, de abordagem qualitativa, realizado com pacientes diagnosticados com câncer em cuidados paliativos e seus familiares. A coleta de dados ocorreu entre setembro e novembro de 2023, a partir de entrevistas abertas, guiadas por instrumento semiestruturado. O áudio gravado foi transcrito na íntegra e, posteriormente, analisado a partir da Análise de Conteúdo. **Resultados:** foram identificadas duas categorias temáticas: “Cuidados em saúde dispensados pela Atenção Básica” e “Satisfação com o atendimento apesar dos entraves percebidos”. A assistência em saúde envolveu encaminhamentos a especialistas, apoio no diagnóstico inicial e tratamento de consequências físicas da doença. Apesar dos entraves vivenciados, como demora e falta de capacitação profissional, os participantes perceberam a assistência como satisfatória. **Conclusão:** os cuidados paliativos não estão presentes na rotina da Atenção Básica, o que, em certa medida, pode ser reflexo da necessidade de preparo profissional.

Descritores: Cuidados Paliativos; Cuidados Paliativos na Terminalidade da Vida; Atenção Primária à Saúde; Sistema Único de Saúde; Família.

Resumen

Objetivo: entender cómo se presta la atención sanitaria en la Atención Primaria desde la perspectiva de los pacientes oncológicos en cuidados paliativos y sus parientes. **Métodos:** estudio descriptivo-exploratorio, con enfoque cualitativo, realizado con pacientes diagnosticados de cáncer en cuidados paliativos y sus parientes. La recogida de datos tuvo lugar entre septiembre y noviembre de 2023, mediante entrevistas abiertas guiadas por un instrumento semiestructurado. El audio grabado se transcribió íntegramente y, posteriormente, se analizó mediante Análisis de Contenido. **Resultados:** se identificaron dos categorías temáticas: “Atención sanitaria prestada por la Atención Primaria” y “Satisfacción con la atención a pesar de los obstáculos percibidos”. La atención sanitaria implicaba derivaciones a especialistas, apoyo en el diagnóstico inicial y tratamiento de las consecuencias físicas de la enfermedad. A pesar de los obstáculos experimentados, como los retrasos y la falta de formación profesional, los participantes percibieron la atención como satisfactoria. **Conclusión:** los cuidados paliativos no están presentes en la rutina de la Atención Primaria, lo que en cierta medida puede ser un reflejo de la necesidad de formación profesional.

Descriptorios: Cuidados Paliativos; Cuidados Paliativos al Final de la Vida; Atención Primaria de Salud; Sistema Único de Salud; Familia.

INTRODUCTION

Currently, in Brazil, the health care model is organized so that Primary Health Care (PHC) is configured as the coordinator and main gateway for users to the health system. In addition, it is expected to be resolute for 85% of the cases and to develop its activities based on health promotion and protection, disease prevention, diagnosis, treatment and rehabilitation, based on individual and/or community care.⁽¹⁻²⁾

PHC is responsible for users who traditionally seek the Primary Health Care Units (PHCU) and those who are included in the care provided by the Family Health Teams at home. In most cases, the profile of patients is marked by the presence of some chronic non-communicable disease (NCD), such as diabetes mellitus and systemic arterial hypertension. Although cancer is among the NCD, it is noted that patients with this diagnosis often end up not frequently using PHC services, as they more routinely attend emergency rooms, hospitals and oncology outpatient clinics.⁽³⁾

This entire context described is inserted in a country that is experiencing a demographic and epidemiological transition, characterized by the growth of the adult and elderly population and, consequently, by a gradual increase in NCD and their complications and/or sequelae that affect multiple organs and sometimes threaten the continuity of life.⁽⁴⁾ In this scenario, a portion of people with NCD end up not responding to the modifier treatments instituted, thus emerging Palliative Care (PC) as an alternative therapeutic possibility.⁽⁵⁾

PC is understood as a way to care for, with dignity and compassion, those who experience intense suffering due to a serious and life-threatening illness. Its objective is to improve the quality of life of the person, including his/her family, from a multidisciplinary approach, preventing suffering and treating physical, social, psychological and spiritual symptoms. It also aims to envisage death as a natural process, without accelerating or slowing it down.⁽⁶⁾

However, the current situation suggests that universal access to PHC has been threatened and, consequently, the ideal of implementing PC in this context. This demonstrates that such care for oncological patients is not part of the daily routine of PHC and, therefore, is not part of the usual work process of health professionals in these services.⁽⁷⁾ In addition, the reformulation of the National Policy on Primary Health Care – which took place in 2017 – and the subsequent ordinances have threatened the feasibility of implementing PC policies within the scope of PHC. For example, the funding of the teams of the Family Health Support Centers (NASF, as per its Portuguese acronym) was extinguished, associated with the lack

of incentive for the incorporation of PC, given the absence of specific indicators that evaluate performance in this area.⁽⁷⁾

Ideally, PHC is responsible for maintaining the continuity of care after the establishment of PC, and is valued by patients, as it maintains the care of the person preferably at home and surroundings, providing proximity to his/her family and personal life.⁽⁸⁻⁹⁾ On the other hand, it is perceived that the number of professionals working in PHC is small, sufficiently trained to meet the growing demand of patients in PC. Therefore, palliative care is mostly centralized in hospital centers in large cities. It should be added that, although PHC is the gateway to the health system and direct contact with patients, specialized and highly complex services do not communicate with it much.⁽¹⁰⁾

In the meantime, shedding light on the factors that influence the way individuals and their families perceive PC related to the PHC service can be useful to expand knowledge and identify aspects for improvement.⁽¹¹⁾ In addition, the results listed here can encourage the creation of public health policies that link PC and PHC, in order to ensure the continuity and longitudinality of care, respecting the autonomy of the patient and his/her family, in addition to optimizing the existing geographic and cultural proximity and the resources employed by the health service itself.

In view of the above, the present study aimed to understand how health care occurs in the context of Primary Care from the perspective of oncological patients in PC and their families.

METHODS

This research is typified as is descriptive-exploratory, with a qualitative approach, which used the Consolidated Criteria For Reporting Qualitative Research (COREQ) for its description and presentation.

The participants were oncological patients in PC and their families. The recruitment of these participants took place through a partnership with the Women's Network to Fight Cancer in the municipality of Maringá, which serves patients from the 15th Health Region (HR) of the State of Paraná, which is located in the Northwest Macro-region. The main objective of the network is to care for users of the Brazilian Unified Health System (SUS, as per its Portuguese acronym) undergoing treatment for different types of cancer through accommodation in the support house, when undergoing chemotherapy and radiotherapy treatment, with 16 beds available, as well as those registered who, after a proven situation of social vulnerability, receive support. The researchers were provided with a list of people who met the inclusion criteria for the survey. The initial contact with these people occurred through a telephone call, when the objectives of the study were presented and the invitation was made. After acceptance, a face-to-face meeting was scheduled with potential participants on a day, time and place of their preference.

The inclusion criteria for the study were: being over 18 years of age; being in oncological PC or being a family member of a oncological patient who is in PC; reside in a service area in the territory of the 15th HR of the State of Paraná and have a preserved cognitive condition, identified from the application of the Mini Mental State Examination (MMSE). In turn, patients who, as a result of the disease, had difficulty in verbal communication, and family members who were emotionally unstable and/or crying, who were not used, would be excluded. Patients and family members could be interviewed together, depending on their preferences; But not necessarily, the participants were incorporated into the research in dyads.

Data collection took place between October and November 2023, through open interviews, guided by a semi-structured instrument composed of two parts. The first aimed to identify the socioeconomic profile of the population studied and the second addressed the perspectives of the participants with the following guiding question: "would you like to hear from you how has the palliative care provided to you/your family member by the professionals of the Basic Health Unit been?". Auxiliary questions prepared by the authors were also asked to encourage the participants to reveal their perspectives on the phenomenon of interest.

Data collection took place until the moment when data saturation was identified, at which time the statements became repetitive and did not add a new explanation to the object of study. This occurred in the 8th interview, and two more interviews were carried out (one with a patient and one with a family member) to prove saturation. At this moment, it was also possible to identify the achievement of the objective initially proposed for the research, interrupting data collection.⁽¹²⁾

In order to capture the audio of the interviews, a voice recorder was used, so that the researcher could pay attention to the communication process with the participants and, at the same time, capture the conversation, with all the derivations of tones of voice, pauses and other aspects of non-verbal communication. In addition to the interviews, the study was complemented with a field diary, where the

researcher was able to record her impressions about the conversations and behaviors perceived, with a view to enhancing the analysis of the data collected.

It is worth noting that the main researcher, at the time of data collection and analysis, was a student in the last period of the nursing course and had experience with oncological patients in PC because she participated in an extension project with this focus. However, she had no previous connection with the potential participants of this research. The student was previously trained to carry out data collection and analysis and was directly supervised by two PhD professors with extensive experience in qualitative research, who regularly met to discuss the research process and reach consensus.

Data analysis was performed through Content Analysis, a thematic modality, proposed by Bardin.⁽¹³⁾ Content analysis consists of three basic stages, namely: pre-analysis, analytical description and inferential interpretation.⁽¹³⁾ In the pre-analysis, the organization of the empirical research material took place. It began with a general reading – "floating reading" – of all the material collected, which allowed the researchers, at first, to formulate the broader hypotheses and the determination of the corpus of analysis of the investigation.⁽¹³⁾

In the analytical description, the material that constitutes the corpus was submitted to an in-depth study, including the procedures of coding, classification and categorization of the statements, which was done through the use of different colors for nuclei of different meanings, followed by cutting and aggregation by semantic similarity of the data.⁽¹³⁾ Finally, the inferential interpretation was developed from the pre-analysis; however, it only reached greater density at this time, when significant categories were identified together with inferences and comparison with the current and current literature on the topic.⁽¹³⁾

Regarding ethical principles, it is noteworthy that all the precepts governed by resolutions 466/2012 and 510/2016 of the National Health Council were respected. The project was previously evaluated by the Ethics Committee of the signatory institution (Opinion Number: 6.332.099/CAAE: 73490523.0.0000.0104). The interviewees signed the Free and Informed Consent Form (FICF) in two copies of the same content. Anonymity and confidentiality of the information offered were guaranteed. All interviewees were identified with code names: the patients interviewed were identified with the letter "P" and the family members with the letter "F", followed by numerical order of entry into the study.

RESULTS

A total of 13 patients/family members were approached, with 3 refusals and 10 accepted, with no dropouts during data collection. Among the 10 participants, three were oncological patients in PC and seven were family members, five of whom were children and two grandchildren. All participants were female, aged between 18 and 60 years. With regard to religion, five declared themselves Catholic, three evangelicals and two had no religion. Regarding the way patients used the health service, two had health insurance, two others paid for some private care and six used the SUS exclusively. Regarding the level of education, one had completed elementary school, three had completed high school, two had completed higher education and four had completed higher education.

Regarding cancer of origin, among the participants who were patients and according to the report of family members about the loved one with cancer, four were breast, two were uterus, two were intestine, one bone and one soft parts. All of them had more than one organ with the presence of metastasis. Regarding the time of diagnosis, eight had been diagnosed for more than one year and two for less than six months.

After data collection and analysis, two thematic categories were identified: "Health care provided by Primary Health Care" and "Satisfaction with care despite obstacles perceived", as follows.

Health care provided by Primary Health Care

In this category, it was possible to identify that the work of PHC was directly related to the initial diagnosis process and the referral of the patient to the oncology service, in addition to the supply of medications and the scheduling of specialized tests.

[...] The request for treatment began, then she made the consultation, they referred her to oncology, she even did her treatment there at the hospital, there at the center. And then PHCU provided everything from medication, referral for examination and consultation [...] (F1)

[...] When they arrived at the health center, in the same week, they already referred them to the doctor. Next week, she was able to do the exams, it was very fast, very fast. The health agent who comes to the house helped me a lot [...] (F2).

[...] When it was time to find out, we took her straight to the health station. Then the doctor who attended asked for tests, diagnosed and referred her to start monitoring oncology. (F4)

Another relevant aspect highlighted by the participants was related to health promotion actions, since, based on consultations with health professionals, patients were able to modify lifestyle habits that impaired treatment.

For example, after she was consulted, the doctor and nurse prescribed the medications for her and emphasized the importance of treatment. She, despite being stubborn, began to change her habits and improved a lot [...] (F3)

Some participants pondered on the home visits carried out by the Family Health Strategy teams, associated with the strategy of delivering inputs and materials, for the continuity of care by the family in the home environment.

So, the CHW, the family network, the Family Health Strategy, always go to visit my grandmother [...] those days, my grandmother was not walking and needed the visits, so they would go to her house [...] (F4)

And, during the period that she was already in palliative care, we still looked for PHCU to try some visits at home. They came, helped us with the management, because the situation was very hard. They even offered diapers, all kinds of material to care for her at home [...] (F1)

In addition, care with the treatment of lesions resulting from the diagnosis of cancer or the treatment of the disease, associated with the supply of dressing materials, were also mentioned as important care received by PHC.

The health team of the unit was directly helping with the dressing issue [...] every 15 days, we went there. We achieved everything by receiving instruction from the nurses there on how to make the dressings. (F3)

[...] Then she put the Port-a-Cath and bandage, all here at the post. To clean the point, as my mother couldn't go to clean, they came here at home. (F2)

Based on the reports given by participants, it was possible to identify that the care provided to people with cancer in PC and their families in the context of PHC focused on referrals to specialists, in support of the initial diagnosis and treatment of the physical consequences of the disease.

Satisfaction with care despite obstacles perceived

In this category, the data were related to the understanding of the participants in relation to the ability of PHC professionals to care for oncological patients in PC and to monitor them continuously. Most of the interviewees mentioned that the professionals do not seem to be adequately trained to meet this demand, but that they still consider that the care was satisfactory.

No, I think they should be trained, because, look: they don't investigate, you have to pay. He only found out after doing so many tests, when I paid for a private consultation, because, at the health center, it wasn't solving anything, and the follow-up afterwards is also flawed [...] (P3)

They lack training, but I believe we are well served. There is always something to improve, but overall, their [health professionals] service has always been very good to her [patient]. (F7)

The professionals at the health unit did help. They came here a lot at home! (F6)

Some interviewees revealed that, although care is provided by PHC professionals, there is a significant delay in the implementation of care, causing care not to be provided and for them to choose to enter the health system through other services.

There, it is like this; there, it takes time, girl [...]. Once, I left there it was already 11 o'clock in the morning, there are a lot of people waiting! [...] That's why I go straight to the hospital. There, I know it won't take long. (P1)

[...] And then there is this delay in making an appointment. I posed three times, once in the morning, to be served, to open the post at seven in the morning. First, he went to make an appointment; then, it's [...] to make the consultation. I only know that it was three times, until I got this appointment. (P2)

Look: it's just that, in fact, my grandmother wasn't very well attended there. They don't offer this service, they take their time, take their time and pass it on. When I needed to, I went straight to the cancer hospital [...] (F5)

Since September 2019, we only found out in October 2020. It takes a long time to diagnose, and that complete exam should be available to these more fragile patients [...] (F1)

In addition to the lack of training of health professionals and the delay in providing care, some interviewees mentioned that the lack of human resources for general health care and PC was one of the factors that caused the lack of adequate information for families and generated dissatisfaction with the service.

They could be a little more agile, because when we searched, it still took a little while. There was no doctor available, there was no trained team to go home to talk about palliative care, talk about what cancer was, you know? Inform the family of how we could get through that situation. (F1)

They are very convoluted, it seems that they do not know how to explain any of this, cancer, or anything. They only took care of oxygen, but I only took care of cancer in the hospital [...] (P2)

Despite the weaknesses in the care found in some statements, which highlighted the delay in the time of care, the lack of guidance regarding PC and the lack of training of the professionals, the testimonies of the participants showed satisfaction with the care received, from the reception, through the therapeutic conversation, to the learning during the care.

They take care of the whole family. Thus, our case is different from that of a Brazilian family; And every time they want to check our economic and health situation, but I do feel satisfied! (F2)

Satisfactory! I learned a lot. Today, if you tell me that I have to take care of someone, I will for sure, and knowing a lot. They taught me a lot, about everything. (F7)

Oh, I say yes! Because it's the way it is, they did what was possible for them. They [health professionals] came here when they found out I was hospitalized, what they can do, they do. (P3)

In summary, it was identified that, despite the obstacles experienced for the effectiveness of care in the context of PHC, the participants consider the care as satisfactory.

DISCUSSION

The results of this study allowed us to identify that, according to oncological patients in PC and their families, PHC professionals offer care to them. However, little focus is given to PC actions per se, with care centered on the initial diagnosis, referrals to specialists, and physical care resulting from the disease and treatment. It is known that PC encompasses holistic care, in order to prevent and/or alleviate suffering related to physical, psychosocial, and spiritual factors.⁽⁶⁾ In the context of PHC, the purpose is to provide comprehensive and longitudinal care to patients in the terminal phase of life, whether at home or even at the UBS⁽¹⁾, which, to a certain extent, was not observed in the present study.

In this sense, the study in question revealed the weaknesses of health services in welcoming and providing PC. Even though there is already a growing demand from individuals who need to receive comprehensive health care aimed at therapeutic skills without focusing on cure, the statements exposed by patients/family members were strongly centered on the biomedical model, with an emphasis on medicalization, hospital care, curative actions, substantially ratifying the precariousness of the analysis of the multidimensional aspect of the individuality and collectivity of subjects.⁽¹⁴⁾

The role of PHC professionals in the context of PC aims to perform care at home, perform care techniques, guide families, provide psychological/emotional support and continuous monitoring of identified needs.⁽¹⁵⁾ Nevertheless, professionals generally work with the purpose of recovery and rehabilitation; however, when it comes to oncological patients in PC, death is imminent. Therefore, it is necessary to consider the promotion of quality of life and comfort of patients. In addition, professionals must extend support to the family, even in the process of coping with grief.⁽¹⁶⁾

The results showed that patients end up using specialized services more after diagnosis. On the other hand, it is observed that the care shared between professionals specialized in oncology and those of PHC can be as efficient and even more economical than the follow-up carried out exclusively by specialized services in cancer treatment.⁽¹⁷⁾ Despite the growing evidence that the integration of primary care in PC is an opportunity for high-quality cancer care, which is cost-effectiveness and much more acceptable to patients and their families, this integration is slow to take shape.⁽¹⁸⁾

In addition, few actions have been observed with the aim of improving PC activities, standardizing procedures and protocols, developing documentation and records, and updating the training of PHC health professionals in this area. Thus, it is unquestionable that the path to comprehensive, longitudinal, efficient and sustainable care by PHC is the result of the collaboration of a multidisciplinary team. However, it is equally true that each discipline of PHC (nursing, psychology, medicine and social work) must respond from its scope of professional practice to achieve the common goal of improving the health of people in oncological PC and their families.⁽¹⁹⁾

As identified in the present study, a phenomenological investigation carried out in Colombia with 17 dyads (patient-family member) demonstrated that there was a lack of proximity between the PHC nursing team and the patient with advanced cancer. The lack of emotional understanding and the dissatisfaction of psychological, social and spiritual needs were understood as the main generators of dissatisfaction among them, causing care to be focused only on biological treatment and the physical symptoms of the disease.⁽²⁰⁾

In addition to the care provided by PHC focused on the physical aspects of the disease or treatment, another factor mentioned by some participants was the delay in the time of care, emphasizing the long wait for consultations and for the release of exams. Such factors influenced the search for other health services and other complexities, with a view to providing effective care. The delay in scheduling and attending consultations in PHC and the failure to meet spontaneous demand are the main factors for low user satisfaction.⁽²¹⁾ Most of them understand that welcoming is a reference in the search for health services; because not feeling welcomed in their demands can generate dissatisfaction and abandonment of longitudinal follow-up of care.^(2,14)

It is known that people diagnosed with cancer, especially after the moment of palliation, usually gradually and increasingly, become dependent on their family members.^(19,22) This generates the need for the family to receive guidance to meet the daily needs of these patients, considering that most family members are unprepared for this, and it is up to the professionals to have the empathy and ethics to provide this type of guidance, equipping the family to experience this.⁽²³⁾ In addition, it is necessary for PHC professionals to be trained to provide this type of care.

However, based on the findings of the study and the current literature on the topic⁽²⁴⁻²⁵⁾, it was possible to recognize the important fragility in the process of education and qualification of PHC professionals, with regard to the care and follow-up of patients in oncological PC. This care is developed in a fragmented, isolated way and with limited access; Therefore, it is necessary for professionals to be sensitized and committed to the health of the population, recognizing the diversity of cases and contexts, providing the necessary care in a unique way.⁽²⁶⁾

PC have recently been inserted into Brazilian public policies, and there is still no policy that organizes and regulates these procedures. Therefore, in order for this care modality to be part of the daily routine of PHC, the doctrinal and organizational principles of the SUS are used, so that they can be implemented in health care, in user care and in the daily life of health units, with the purpose of ensuring the existence of this health care.⁽²⁶⁾ However, studies have stated that access to PC in PHC is still segregated, a reason that challenges managers and professionals in the search for alternatives aimed at improving access.^(7,19)

Thus, the present study instigates other researchers and health professionals working in PHC to seek strategies for patients in oncological PC and their families to actively participate in health care, ensuring their right as citizens and conscious decision-making. This has the potential for health actions to be offered correctly, in order to care for the user and his/her family, ensuring continued and longitudinal care, as recommended by the principles of the SUS.

On the other hand, it is necessary to consider that this study has limitations. The first of these refers to the fact that the participants were all female and mostly family members of patients in oncological PC. This circumscribes the findings to a gender analysis and focuses them mostly on a family perspective. Another limitation is related to the convenience sampling in terms of access on the part of the researcher, which is subject to selection bias, as only those who are more likely to contribute to the study accept to participate, and their experiences may be different from those who did not accept to participate.

Future research in the area may focus on addressing more oncological patients in PC, in addition to males and also PHC health professionals. This has the potential to broaden the understanding of the conceptions and experiences of terminal care in health services. In addition, educational intervention studies with PHC health professionals could be proposed to identify, methodologically, what would be the best strategy to offer content related to PC, in order to sensitize health professionals and, consequently, expand its application in daily work.

CONCLUSION

The results of this study allowed us to identify that the care provided by PHC health professionals to oncological patients in PC and their families is mainly marked by referrals to specialists, support in the initial diagnosis and treatment of the physical consequences of the disease. Despite the obstacles experienced, such as delays in providing care and lack of professional training, the participants perceived the care as satisfactory.

In turn, user satisfaction may not be related to receiving PC, but rather to the way they are welcomed in health services. This generates reflection on the relevance of deepening the discussion about this modality of care within the scope of PHC, because, if this care were present in the daily routine of PCHU, the professionals would make it possible to refer the PC to the demands currently present.

Regarding the contributions of this investigation, in terms of teaching, it is observed that it makes it possible to develop teachers and students still in the process of training in the health area to have access to a deeper knowledge of the experiences lived by patients and their families in the context of PC within the scope of PHC. In relation to nursing science, the results present relevant data for the scientific community and health professionals, so that they can recognize the need for PHC health services to reorganize themselves in order to bring PC into the context of the daily work process in the services.

CONTRIBUTIONS

Contributed to the conception or design of the study/research: Carvalho JMG, Sanguino GZ, Marcon SS, Luz MS, Murilho ABT, Oliveira LE, Barreto MS. Contributed to data collection: Carvalho JMG, Sanguino GZ, Marcon SS, Luz MS, Murilho ABT, Oliveira LE, Barreto MS. Contributed to the analysis and/or interpretation of data: Carvalho JMG, Sanguino GZ, Marcon SS, Luz MS, Murilho ABT, Oliveira LE, Barreto MS. Contributed to article writing or critical review: Carvalho JMG, Sanguino GZ, Marcon SS, Luz MS, Murilho ABT, Oliveira LE, Barreto MS. Final approval of the version to be published: Carvalho JMG, Sanguino GZ, Marcon SS, Luz MS, Murilho ABT, Oliveira LE, Barreto MS.

ARTICLE ORIGIN

Extract from the Course Conclusion Paper: Health care in Primary Health Care: perspective of patients in oncological palliative care and their families, presented to the Collegiate of the Department of Nursing of the State University of Maringá (UEM) in the year 2023.

REFERENCES

1. Ministério da Saúde (BR). Portaria nº 2.488, de 21 de outubro de 2011. Aprova a Política Nacional de Atenção Básica, estabelecendo a revisão de diretrizes e normas para a organização da Atenção Básica, para a Estratégia Saúde da Família (ESF) e o Programa de Agentes Comunitários de Saúde (PACS). Brasília: Ministério da Saúde; 2011.
2. Abrasco (Associação Brasileira de Saúde Coletiva). Desafios da APS no SUS no enfrentamento da Covid-19. Seminário Virtual Rede APS Abrasco [Internet]. Rio de Janeiro; 2020. Acesso em: 14 jul. 2023. Disponível em: <http://www.abeno.org.br/arquivos/downloads/ABRASCO.pdf>
3. Flores TG, Silva KF, Giaretton DWL, Weiller H, Pucci VR. Formação profissional: cuidado ao paciente oncológico sem possibilidade terapêutica na Atenção Básica. Rev APS. [Internet]. 2019;22(3). doi: <https://doi.org/10.34019/1809-8363.2019.v22.15931>
4. Paraizo-Horvath CMS, Fernandes DS, Russo TMS, Souza AC, Silveira RCCP, Galvão CM, *et al.* Identification of people for palliative care in primary health care: integrative review. Ciênc saúde coletiva [Internet]. 2022;27(9):3547–57. doi: <https://doi.org/10.1590/1413-81232022279.01152022>
5. Cordeiro FR, Medeiros JB, Fernandes VP, Giudice JZ, Arnemann CT. Clinical and sociodemographic profile of adults hospitalized in palliative care. Rev Enferm UFPI [Internet]. 2022;10(1): e766. doi: <https://doi.org/10.26694/reufpi.v10i1.766>
6. Castilho RK, Silva VCS, Pinto CS. Manual de cuidados paliativos da Academia Nacional de Cuidados Paliativos (ANCP). 3rd. Rio de Janeiro: Atheneu; 2021.
7. Rodrigues LF, Silva JFM, Cabrera M. Palliative care: pathway in primary health care in Brazil. Cad. Saúde Pública [Internet]. 2022;38(9):e00130222. doi: <https://doi.org/10.1590/0102-311XPT130222>
8. Clara MGS, Silva VR, Alves R, Coelho MCR. The Palliative Care Screening Tool as an instrument for recommending palliative care for older adults. Rev Bras Geriatr Gerontol [Internet]. 2019;22:e190143. doi: <https://doi.org/10.1590/1981-22562019022.190143>
9. Ribeiro JR, Poles K. Cuidados Paliativos: Prática dos Médicos da Estratégia Saúde da Família. Rev bras educ med [Internet]. 2019;43(3):62–72. doi: <https://doi.org/10.1590/1981-52712015v43n3RB20180172>
10. Malta DC, Andrade SSCA, Oliveira TP, Moura L, Prado RR, Souza MFM. Probability of premature death for chronic non-communicable diseases, Brazil and Regions, projections to 2025. Rev bras epidemiol [Internet]. 2019;22:e190030. doi: <https://doi.org/10.1590/1980-549720190030>
11. Abreu DMX, Araújo LHL, Reis CMR, Lima ÂMLD, Santos AF, Jorge AO, *et al.* Service users' perception about healthcare provided by teams participating in the National Program for Primary Care

Access and Quality Improvement in Brazil. *Epidemiol Serv Saúde* [Internet]. 2018;27(3):e2017111. doi: <https://doi.org/10.5123/S1679-49742018000300002>

12. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Soc Sci Med* [Internet]. 2022; 292(114523): <https://doi.org/10.1016/j.socscimed.2021.114523>.

13. Bardin L. *Análise de conteúdo*. 5th. São Paulo (SP): Edições 70; 2020.

14. Gomide MFS, Pinto IC, Bulgarelli AF, Santos ALP, Serrano Gallardo MP. User satisfaction with primary health care: an analysis of access and care. *Interface (Botucatu)* [Internet]. 2018;22(65):387-98. doi: <https://doi.org/10.1590/1807-57622016.0633>

15. Freire JR, Silva CBG, Costa MV, Forster AC. Educação Interprofissional nas políticas de reorientação da formação profissional em saúde no Brasil. *Saúde debate* [Internet]. 2019;43(spe1):86-96. doi: <https://doi.org/10.1590/0103-11042019S107>

16. Madsen R, Larsen P, Carlsen AMF, Marcussen J. Nursing care and nurses' understandings of grief and bereavement among patients and families during cancer illness and death – A scoping review. *Eur J Oncol Nurs* [Internet]. 2023; 62: 102260. <https://doi.org/10.1016/j.ejon.2022.102260>.

17. ElMokhallalati Y, Bradley SH, Chapman E, Ziegler L, Murtagh FE, Johnson MJ, Bennett MI. Identification of patients with potential palliative care needs: A systematic review of screening tools in primary care. *Palliat Med* [Internet]. 2020;34(8):989-1005. doi: <https://doi.org/10.1177/0269216320929552>.

18. Crimmins RM, Elliott L, Absher DT. Palliative care in a death-denying culture: exploring barriers to timely palliative efforts for heart failure patients in the Primary Care Setting. *Am J Hosp Palliat Care* [Internet]. 2021;38(1):77-83. doi: <https://doi.org/10.1177/1049909120920545>

19. Garcia-Vivar C, Elizondo N, Ambrosio L. Primary Care Nursing Is Essential to Fully Implement Survivorship Care Plans for Long-term Cancer Survivors and Their Families. *Cancer Nurs* [Internet]. 2019;42(3):177-8. doi: <https://doi.org/10.1097/NCC.0000000000000704>.

20. Hermosilla-Ávila AE, Sanhueza-Alvarado O, Chaparro-Díaz L. Palliative care and quality of life in patients with cancer during the terminal phase. A family/patient perspective. *Enferm Clin* [Internet]. 2021;31(5):283-93. doi: <http://doi.org/10.1016/j.enfcl.2021.04.002>

21. Santos AF, Rocha HA, Lima AMLD, Abreu DMX, Silva EA, Araújo LHL, *et al.* Contribution of community health workers to primary health care performance in Brazil. *Rev Saude Publica* [Internet]. 2020;54:143. <https://doi.org/10.11606/s1518-8787.2020054002327>

22. Benites AC, Rodin G, Leite AC, Nascimento LC, Santos MA. 'The experience of spirituality in family caregivers of adult and elderly cancer patients receiving palliative care: A meta-synthesis'. *Eur J Cancer Care* [Internet]. 2021; 30:e13424. <https://doi.org/10.1111/ecc.13424>

23. Konradsen H, Brødsgaard A, Østergaard B, Svavarsdóttir E, Dieperink KB, Imhof L, Luttik ML, Mahrer-Imhof R, García-Vivar C. Health practices in Europe towards families of older patients with cancer: a scoping review. *Scand J Caring Sci* [Internet]. 2021;35(2):375-89. doi: <https://doi.org/10.1111/scs.12855>

24. Hökkä M, Melender HL, Lehto JT, Kaakinen P. Palliative nursing competencies required for different levels of palliative care provision: a qualitative analysis of health care professionals' perspectives. *J Palliat Med* [Internet]. 2021; 1516-24. doi: <http://doi.org/10.1089/jpm.2020.0632>

25. Sarmiento WM, Araújo PCB, Silva BN, Silva CRDV, Dantas RCO, Vêras GCB. Formação acadêmica e qualificação profissional dos enfermeiros para a prática em cuidados paliativos. *Enferm Foco* [Internet]. 2021;12(1):33-9. doi: <https://doi.org/10.21675/2357-707X.2021.v12.n1.3805>

26. Boaventura J R, Pessalacia JDR, Martins TCR, Silva AE, Marinho MR, Neto PKS. Participation and social control in the politic context of palliative care: a theoretical reflection. *Rev Enf Cent Oeste Min* [Internet]. 2019; 9:e3433. Doi: <https://doi.org/10.19175/recom.v9i0.3433>

Conflicts of interest: No

Submission: 2024/01/17

Revised: 2024/12/19

Accepted: 2024/12/19

Publication: 2025/02/19

Editor in Chief or Scientific: Jose Wicto Pereira Borges

Associate Editor: Államy Danilo Moura e Silva

Authors retain copyright and grant the Revista de Enfermagem da UFPI the right of first publication, with the work simultaneously licensed under the Creative Commons Attribution BY 4.0 License, which allows sharing the work with acknowledgment of authorship and initial publication in this journal.