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ORIGINAL ARTICLE

PERFORMANCE OF THE PRIMARY CARE NURSING TEAM IN PALLIATIVE CARE: THE PERSPECTIVE OF FAMILIES

Fernanda Cristóvão Martins*
Nara Marilene Oliveira Girardon-Perlini**
Luiza de Senna Iensen***
Isabella Siqueira de Souza****
Silvana Bastos Cogo*****
Naiana Oliveira dos Santos******
Cínthia Cristina Oliveski*******

ABSTRACT

Objective: To explore families' perspectives on the performance of the primary care nursing team in palliative care. **Methodology:** A qualitative, descriptive study. Data were collected in 2021 through semi-structured interviews with six families who received palliative care in Basic Health Units in a municipality in the interior of Rio Grande do Sul. The data were analyzed using thematic analysis. **Results:** Three themes were identified: Families' perceptions of nursing care, which address how nursing care in palliative care is delivered; Factors influencing families' perspectives, highlighting changes related to the pandemic, care centered on medical actions, care coordination by other services, and insufficient primary care; and Families' perspectives on care, focusing on beliefs surrounding illness as well as aspects they consider necessary to improve care. **Final considerations:** Nursing performance is perceived as limited, revealing gaps in care due to staff shortages, the absence of home-based care by the team, and insufficient follow-up of families. However, this performance appears to be largely invisible due to the prominence of other services within the care network, with which there is weak coordination, compounded by precarious conditions for meeting palliative care demands.

Keywords: Primary health care. Palliative care. Family. Nursing.

INTRODUCTION

The transition in the epidemiological profile highlights the global rise in chronic noncommunicable diseases (NCDs), including cardiovascular diseases, neoplasms, chronic respiratory diseases, and diabetes *mellitus*, as leading causes of morbidity and mortality. In Brazil, the current epidemiological scenario is characterized by the predominance of NCDs such as hypertension, diabetes *mellitus*, and cancer (1).

In this context, beyond the suffering experienced by individuals and their family members, the public health system becomes overburdened across all three levels of care due to high demand, the chronic nature of these conditions, and the increased costs and resources required for their management(2).

Revised in 2014, the National Health Promotion Policy (PNPS) adopts Primary Health Care (PHC) as the main entry point for its implementation, considering the network's coverage capacity and its articulation with other specialized levels of health care(3). Thus, the PHC team is responsible for coordinating comprehensive care for patients with chronic conditions(3-4).

NCDs associated with worsening health conditions often mark disease progression and a lack of response to disease-modifying therapies, resulting in the need for palliative care (PC). The World Health Organization (WHO) defines PC as a multidisciplinary approach to care that aims to improve the quality of life of patients and

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*Nurse. Graduate student in Family Health. Santa Rosa, Rio Grande do Sul State, Brazil. E-mail: fecrmartins@hotmail.com. ORCID iD: 0000-0002-1293-9707
**Nurse. Post-doctorate in Nursing. Associate Professor IV, Department of Nursing and Graduate Program in Nursing, Federal University of Santa Maria (UFSM), Santa Maria, Rio Grande do Sul, Brazil. E-mail: nara.girardon@gmail.com. ORCID iD: 0000-0002-3604-2507
***Undergraduate Nursing Student. ScientificInitiationScholarship. UFSM, Santa Maria, Rio Grande do Sul, Brazil. E-mail: luiza.sennaiensen@acad.ufsm.br. ORCID iD: 0009-0007-6432-488X
****Undergraduate Nursing Student. ScientificInitiationScholarship. UFSM, Santa Maria, Rio Grande do Sul, Brazil. E-mail: isabella.siqueira@acad.ufsm.br. ORCID iD: 0009-0005-9227-0191
*****Nurse. Associate Professor I, Department of Nursing and Graduate Program in Nursing, UFSM, Santa Maria, Rio Grande do Sul, Brazil. Email: silvanabastoscogo@gmail.com ORCID iD: 0000-0002-1686-8459
******Nurse. Adjunct Professor, Department of Nursing and Graduate Program in Nursing, UFSM, Santa Maria, Rio Grande do Sul, Brazil. Email: naiana.oliveira@ufsm.br ORCID iD: 0000-0002-5439-2607
*******Nurse. PhD student in the Graduate Program in Nursing UFSM, Santa Maria, Rio Grande do Sul, Brazil. Email: cinthia.oliveski@gmail.com ORCID iD: 0000-0002-5381-9461

their families in a comprehensive manner when facing a life-threatening illness, through the prevention and relief of suffering, early identification of complications, and the assessment and management of pain and other physical symptoms, as well as social, psychological, and spiritual needs(4).

Illness imposes stressful situations and requires continuous readaptation in the lives of patients and their families. In this context, the family can be understood as a group that identifies itself as such, composed of individuals connected by biological, affective, or affinity ties, who share a sense of belonging and are committed to one another, as well as common values, beliefs, knowledge, and practices(5).

Having a family member with a chronic illness can lead to changes in family functioning and role performance, especially when home-based care is required. This experience involves a complex process marked by emotional, cognitive, practical, and social support challenges. Anxiety and uncertainty about the future, the need for knowledge and skills to provide care, along with insufficient guidance and the lack of continuous communication, highlight the need for comprehensive care focused on the family-patient dyad(6).

In this context, it is the responsibility of the PHC multiprofessional team, particularly nurses, to plan and deliver care actions grounded in palliative care principles. However, significant difficulties and challenges hinder the incorporation of palliative care into the PHC setting. These include the practical disarticulation of the health care network, which compromises continuity of care, as well as shortages of material resources, inadequate professional training, and insufficient working conditions for the multiprofessional team(7). As a result, the implementation of palliative care in PHC remains fragmented, reflecting the multiple challenges faced by professionals, ranging from individual-level issues to structural limitations, in addition to the lack of effective public policies and the absence of clearly defined care management protocols(7).

Palliative care can be provided across all levels of the health care system. At the home level, it is directed toward individuals who are bedridden and is delivered by PHC teams and the Better at Home Program. Specialized outpatient services are responsible for promoting longitudinal care, while emergency services and Emergency Care Units (UPAs) focus on managing acute symptom exacerbations(8).

In this context, the family is a central and indispensable component of the palliative care philosophy. Elements such as psychological and emotional support, empathetic communication, active listening, clear information about the clinical condition of the person receiving care, and a welcoming approach are key aspects that can guide nursing interventions(8).

Regarding scientific production on palliative care in primary health care, an integrative review identified that nursing professionals are responsible for carrying out a range of activities which, in partnership with the multiprofessional palliative care team, contribute to promoting the well-being of patients with conditions that have no therapeutic possibility of cure, as well as to providing expanded care for their families(9).

Regarding the role of nurses in palliative care within primary health care, another integrative review indicates that, in PHC, nurses contribute to patient care through general competencies such as observing and describing signs and symptoms and establishing bonds with patients and their families. However, the review concludes that nurses demonstrate superficial knowledge of palliative care in the PHC context, highlighting the need for continuing education to strengthen their performance in palliative care(10).

In view of these outcomes, it is evident that studies addressing the perspectives of families assisted in primary health care also represent a gap in knowledge that needs to be addressed. Therefore, considering current public policies that advocate for the articulation of comprehensive patient care and include foundations for the organization of palliative care within the health care network, it is necessary to understand how these services are perceived by those who use them, as a means of generating evidence to better guide and improve their implementation.

In view of the above, the following question arises: What is the families' perspective on the performance of the primary care nursing team in palliative care? Accordingly, this study aimed to explore the perspectives of families regarding the performance of the primary care nursing team in palliative care.

METHODOLOGY

This is a qualitative, descriptive study conducted in the territories of four of the 20 physical units of Basic Health Units (UBS) and Family Health Strategy (ESF) services that comprise Primary Health Care in a municipality in the interior of Rio Grande do Sul. The study followed the guidelines of the COnsolidatedcriteria for REporting Qualitative research (COREQ).

This municipality is geographically located in the northwestern region of the state, bordering Argentina, with an estimated population of 76,963 inhabitants(11). Primary Health Care is organized according to a territorialized model, with a focus on family-centered care and the social context, as established by the National Primary Care Policy (PNAB). Currently, the municipality has 20 health units distributed across urban and rural areas, with Primary Care teams covering an estimated 89.17% of the population(12). These data demonstrate the broad reach of primary care services in the municipality and therefore justify the choice of this setting for the development of the study.

The participants were families referred to the municipality's primary care services who were experiencing the chronic illness of a family member receiving palliative care, regardless of diagnosis. As an initial selection procedure, the UBS and ESF units were randomly selected. Subsequently, health professionals from the selected units were consulted to identify families within their coverage areas who lived with an adult family member presenting some degree of functional dependence and receiving palliative care.

For participant selection, the following inclusion criteria were established: patients classified as receiving palliative care, who were assisted by the nursing team of the UBS/ESF in their respective territories; who presented indications of functional dependence; and who were 18 years of age or older. To assess the patients' level of dependence, the Barthel Index was applied. This instrument consists of ten items related to activities of daily living (ADLs) and yields scores ranging from 0 to 100 points(13). Patients classified as having total (0-20), severe (21-60), or moderate (61-90) levels of dependence were included. Exclusion criteria comprised the presence of pain, nausea, vomiting, fatigue, cognitive impairment, or other self-reported discomforts that could hinder the application of the scale and subsequent participation in the interview.

The criteria for the selection of family members included self-identification as part of the patient's family and being 18 years of age or older. The exclusion criterion was the presence of cognitive impairment, such as compromised orientation or verbal coherence, identified during the initial conversation with the interviewer at the time of the invitation to participate in the study.

Patients who met the established criteria were invited, together with their families, to participate in the interview. Contact with the referred individual and their family was established through home visits, accompanied by a community health agent or another member of the health care team. During these visits, the objectives of the study and the form of participation were explained, and the invitation to take part in the research was formally presented.

This process resulted in the selection of six patients. Of these, three participated in the interviews, while three were excluded based on the criterion of incapacity due to their clinical condition. Regarding family members, all six individuals invited agreed to participate in the study.For the interviews, it was agreed that they could be conducted during the same meeting, without the presence of a team member or community health agent, or scheduled for another day, according to the participants' preference. The number of participants was defined by data saturation, identified through the repetition of information and the achievement of the objectives proposed in the study(14).

The interviews were conducted in the second semester of 2021with patients and family members together, lasted an average of 40 minutes, and were carried out by the first author of the study, a nursing student with experience as a scientific initiation scholarship holder. A semi-structured interview guide was used, addressing issues related to perceptions of the care provided by the nursing team in the context of palliative care.With participants' authorization, the interviews were audio-recorded and later transcribed for analysis. In interviews conducted jointly with patients and family members, questions were strategically directed to ensure that both participants were able to express their perspectives. It should be noted, however, that the interview transcripts were not validated by the participants.

The collected data were analyzed using the thematic analysis (TA) technique. TA is a method that involves examining a data set, whether derived from interviews, focus groups, or a series of texts, in order to identify recurring patterns of meaning. In this study, an inductive approach was adopted through a coding process in which themes and/or categories were generated directly from the data. This technique comprises six phases for operationalizing the thematic analysis process: familiarization with the data; generation of initial codes; searching for themes; reviewing themes; defining and naming the themes; and producing the final report(15).

In the first phase, the interviews were transcribed verbatim. The second phase involved the construction of initial codes from the data, which were organized into groups sharing similar patterns. In the third phase, these codes were gathered and classified into potential themes. The fourth phase consisted of reviewing and refining the themes and subthemes. In the fifth phase, the themes and subthemes were defined and named, and a detailed analysis was developed for each theme, identifying the underlying narrative and its relationship with the study objective and research question. Finally, in the sixth phase, a logical, concise, and coherent report was produced, thereby validating the analysis(15).

The project was approved by the municipality's Teaching and Research Center (NEP) and by the Research Ethics Committee (CEP), under Opinion No. 4,465,843. There were two refusals to participate, and all participants who agreed to take part signed the Informed Consent Form (ICF). To ensure anonymity, participants were identified by the letters F (family member) and P (patient), followed by numbers corresponding to the order of the interviews.

RESULTS

Six families participated in the study, totaling nine participants, including three patients and six relatives. Among the six users identified as family references, three were female and three were male. Participants' ages ranged from 38 to 71 years. Regarding the underlying conditions that led to the indication for palliative care, three patients had neoplasms, while the remaining three presented sequelae of traumatic brain injury, sequelae of cerebrovascular accident, and Alzheimer's disease. According to the Barthel Index, four users demonstrated total dependence and two demonstrated moderate dependence.

Regarding the family members, all were primary caregivers. Five family members were female and one was male. Ages ranged from 34 to 68 years. In terms of marital status, two were married, two were single, one was divorced, and one was widowed. Three family members reported being evangelical, two Catholic, and one Mormon. Additionally, three family members reported being retired, one worked as a caregiver for ill individuals, one was a homemaker, and one was unemployed. Regarding family income, two family members reported an income of one and a half minimum wages, two reported two minimum wages, one reported variable income associated with a government benefit, and one reported an income of seven and a half minimum wages.

Analysis of the interviews resulted in three themes, which are described below.

Families' perception of the nursing team's care

The first theme describes how nursing care, care practices, and interventions related to the chronic illness process were developed within a palliative care approach. The care described by the families encompassed both subjective and objective dimensions. Families identified that the establishment of a bond with the nursing team was materialized through the practices adopted during the investigation and diagnostic definition, as well as throughout the therapeutic process over the course of the illness.

> She was referred for examinations, and cancer was identified. We underwent several tests. (F1)

> When we consulted a private physician, whom we paid for the appointment, he requested an examination costing 800 reais. We then sought care from the physician at the primary health unit, who was able to arrange the examination through the public health system. Subsequently, the physician and a nurse visited, followed by another nurse who came to our home to see him. We have been well cared for, and I have no complaints. (F2)

Families mentioned care actions focused on clinical aspects, highlighting the effectiveness of the nursing team's assessment of the patients' physical conditions. They emphasized that these assessments were aimed at identifying symptoms requiring management, particularly pain. Such evaluations were conducted both at the health unit and during home visits.

> When I experienced severe pain, I went there, and they gave me medication for pain relief.(P1)

> I mentioned recently that she was experiencing pain, and the nurse said she would ask the physician to increase the dosage. Subsequently, the dose was increased to be administered more times per day. (F3)

Care directed toward pressure injuries was also perceived, as families reported that the nursing team identified risk factors and provided guidance on the necessary preventive care.

> The nurse said that if he had a wound on his body or a rash, we should inform them, and then they would arrange a mattress of that type.(F4)

> This oil was very effective for his condition. I have seen many people develop severe skin rash, and he did not. (F2)

Families highlighted the manner in which guidance regarding the care of the family member was provided and considered it positive. However, they also reported situations in which guidance could be improved to better address the specific needs of both the patient and the family.

> They advise giving the medication at the correct time, as well as meals. They also tell us that, if necessary, we should go to the health unit. Whenever we notice any change, we are supposed to seek care at the unit. (F4)

> Professionals from the center could come here to teach me how to handle the oxygen. The person who instructed me was the one who delivered the oxygen cylinder and the tubing... (F3)

The validation of families' experiences is evidenced in the recognition of the subjective dimension of care, which is present when the team acknowledges the needs arising from the users' life contexts. Difficulties in accessing the health system, the unit's resources, and the scheduling of examinations and or consultations were recognized by the team and, consequently, families' access to these services was made more flexible.

> The physician was able to arrange the examination through the public health system. It helped. It was a great support. She knew that we each earned only one salary, and she provided this assistance. (F2)

> My daughter usually goes there to request the prescription, but she can also call to ask for it. The community health agent visited us and will speak with the nurse so that we can simply call to request the ambulance when he needs to go for exams. (P3)

The reports also indicate attitudes that legitimize the autonomy and uniqueness of family experiences. There are circumstances in which guidance and counseling on therapeutic alternatives are provided, while the decisions made by the family regarding treatment are validated and respected.

> They recommended cancer treatment, but she refused because it would require removal of her breast, which she did not want. Therefore, the only option was to prescribe painkillers, anti-inflammatory drugs, and other analgesics. That was it, there was nothing else to be done. (F1)

> It is a form of support. If you go there when you need it, you receive care. Whether it is medication or a prescription, you just go there and obtain it. (F2)

> They give me advice, telling me not to do anything foolish, things like that. (P2)

Factors influencing the perspective of families

The second theme describes factors that, according to family reports, may distort and even hinder the perception of care provided by the nursing team. These factors include social distancing measures and the expansion of remote care resulting from the pandemic, as well as the establishment of a fragile bond with primary care professionals.

In the context of family care, the pandemic emerges as a factor that reshaped care dynamics, accounting for changes arising from adaptations in health services aimed at preventing the spread of COVID-19. In many cases, these adaptations involved a reduction in the number of professionals providing face-to-face care.

> They are not coming now because of the pandemic. But from time to time, they do come to visit her. (F1)

> They haven't come. The doctor is working from home, right? She doesn't come here anymore because it seems she is in a risk group. (F6)

> I asked the doctor (doctor's name), as soon as he arrived, to schedule an appointment. They said, 'We'll schedule it right away,' but so far nothing has happened... (F3)

The care model centered on medical professionals contributed to families directing their responses and their perception of the care provided at the unit primarily toward physicians' performance. Families also perceived the actions of other members of the healthcare team as being dependent on medical decisions, frequently associating the expectation of problem resolution and the definition of their care needs with the physician's responsibility.

> The doctor has seen me there several times in a row because of the itching. They treated me very well. (P3)

> We go to the health unit for everything, except for her cancer problem, which is the doctor's responsibility. If she suffers, we have to go straight to that doctor. (F5)

> With the nurse from the Melhorem Casa program, whatever is needed, he comes here. If he has any doubts, he calls the doctor immediately. The care is excellent; I have no complaints. (F6)

As care and follow-up for individuals receiving palliative care occur across different levels of the healthcare system, whether hospital-based or outpatient, families tend to identify as their primary reference the service sought during acute situations. Consequently, they do not recognize primary care as playing a direct and central role in family care.

> The strongest bond is with the hospital; that is where we go directly. (F5)

> If I see that the situation is serious, I take her to the emergency care unit (UPA). (F3)

> It is always the Melhorem Casa team that comes. I never do anything without calling them first. (F6)

The performance perceived as insufficient in primary care services was reflected in families' perceptions of gaps in care, such as the shortage of professionals, the absence of the team in home care, and limited family follow-up. Families associated service inefficiency with the high demand for care, the wide range of services provided to families within the territory, and organizational problems related to medication dispensing, delivery of test results, and appointment scheduling.

> They said there is no nurse. So I don't know why the health center is even open. I needed antibiotics, and they sent me a prescription for an antidepressant, which I had already taken. (F3)

> I think it's difficult for them to come to our home. When you go to the health center, you are well attended inside. But this home follow-up—I would actually like it, because if they came, it would be welcome. Still, I don't have much confidence in that aspect, you know?(F5)

Families' expectations about care

The third theme contrasts the reality of how care provided by the nursing team was delivered with how families wished it to occur. For some families, these expectations were shaped by their beliefs and the personal meanings attributed to illness, revealing perspectives for change and suggestions they considered appropriate regarding the team's performance.

Illness-related beliefs referred to personal and popular understandings of the illness process and ways of acting upon it, often grounded in previous experiences. Families considered, for example, the possibility of incorporating alternative treatments into the therapeutic approach to alleviate symptoms, such as the use of teas and medicinal plants.

> She went to get some teas yesterday. We brought aloe, and we brought another one. She applies coffee grounds because she believes it will get better. (F1)

> I wanted them to talk about what we could do at home to help, to relieve the pain, to apply something there. (F4)

Families' expectations regarding potential improvements in care were associated with different patterns of performance by primary health care (PHC) professionals, as a discrepancy was perceived between services provided at the health center and those delivered through home visits. Home visits conveyed a greater sense of security and credibility among families when compared with other forms of care. However, families reported that professionals often conducted home visits only when accompanied by students or interns.

> Home visits would be good for us to talk and receive support. (F5)

> The nurses from the Best at Home program ask, 'Do you need anything? Cotton balls? Alcohol? Whatever you need, just ask.' This is something the staff at the health center don't even ask. (F3)

> I think there is a lack of dedication. They could easily come here once a week, but they only come when there is an intern to bring along. (F6)

DISCUSSION

The construction of palliative care across different levels of care is complex and faces several challenges in its implementation. When confronting the difficult trajectory of an incurable disease, such as cancer, nursing plays a fundamental role in providing care that ensures dignity for both the patient and their family(16). In this regard, the findings of the present study indicate that a care-centered attitude adopted by the nursing team may represent a positive factor in fostering bonds and providing support in the face of adversities arising during a family member's illness.

In the context of home-based palliative care, nursing practice, in collaboration with the multidisciplinary team, has the potential to contribute to improved quality of life for patients and to serve as a source of support and information for families. With this purpose, care strategies directed toward families and caregivers aim to guide coping with the disease and, above all, to prevent clinical complications, identify symptoms, and support decision-making(17).

It is noteworthy that, in this study, several factors influenced families' perspectives regarding the performance of the primary care nursing team in palliative care. These included the COVID-19 pandemic, which was ongoing during data collection; the perception of medically centered care; the coordination of care by another service within the healthcare network; and shortcomings identified in relation to primary care services.

In the context of the pandemic, family care was compromised due to social distancing measures, a reduction in home visits, and fear of seeking healthcare facilities. In this scenario, families experienced discontinuity of care and were unable to rely on the support of institutional and governmental agents or the health system, which was overloaded and on the verge of collapse. Consequently, professionals found themselves operating within a "weak network," exposed to situations of profound helplessness(17,18).

The biomedical model that still predominates in the healthcare system, anchored in the centralization of medical activities, influences how families perceive nursing work. In this study, as well as in others conducted with primary health care (PHC) users, families demonstrated difficulty in recognizing nurses' professional autonomy within the actions performed, frequently focusing on medical activities(19,20). The superficial understanding of nursing contributions is evident in families' diffuse references to general guidance, wound care, and medication administration, often associating these practices as subordinate to medical responsibilities.

Considering that primary care has limitations in managing chronic conditions that require higher technological density, the referral and counter-referral system, which should work as a strategy to establish care flow within the healthcare network and support shared therapeutic planning to ensure continuity of care, is often underutilized(21,22). As a result, from the families' perspective, the lack of interaction among services constitutes a gap that fragments and weakens care.

From this perspective, a study shows that, particularly in cancer care, there is discontinuity in the information necessary for patient care within counter-referral services (23). Consequently, breakdowns in communication between different levels of healthcare can directly harm patients and their families by compromising the long-term continuity of primary care. This finding was also identified in a study conducted with nurses focusing on the care coordination attribute, in which communication failures between services were perceived by both families and healthcare professionals(24).

Although families do not identify primary care as the main reference point for palliative care, they recognize it as a setting that provides support and resolution for other healthcare demands, seeking it when necessary. This perspective expressed by participating families reinforces the role of primary care as the entry point to users' therapeutic trajectories within the public health system, particularly for individuals with chronic conditions(25).

When faced with life-threatening situations that lead to dependence and involve limited therapeutic options for disease treatment, families often feel powerless and constrained in their caregiving possibilities and symptom relief. As a result, they reflect on the care received and, based on their beliefs and prior experiences, consider alternative resources that might support the care of their ill family member. These expectations are sometimes related to therapeutic options beyond conventional PHC practices, including the use of medicinal plants as a complementary approach to symptom relief, which expands family caregiving resources, is easily accessible, and allows greater autonomy in care(26).

Amid perceptions related to the care received, comparisons between care provided by primary care and home care nursing teams reveal differences in service characteristics and professional performance. With regard to home care, a study conducted with family caregivers of cancer patients found that the sense of security conveyed by healthcare professionals fosters credibility in patient care and positively influences the sharing of caregiving responsibilities. The presence of the healthcare team in the home was highlighted as one of the primary sources of support for families(27).

In summary, families' perspectives on the performance of nursing teams providing palliative care within the primary care setting encompass dimensions of care that can directly influence family quality of life. Although some perceptions differ, they allow for the identification of aspects that require strengthening within health units and care practices, so that the illness experience faced by families may be dignified and humanized, in accordance with the principles guiding the nursing profession and the Brazilian public health system(28).

In summary, it is observed that the families' perspective on the performance of the nursing team that develops palliative care in the primary care scenario addresses dimensions of care that can directly influence the quality of family life. Although some perceptions are divergent, it is understood that they allow the identification of aspects to be strengthened in health units and care, so that the illness experienced by families is a dignified and humanized experience, as proposed in the principles that guide the profession and the Brazilian public health system.

FINAL CONSIDERATIONS

Experiences related to the illness process of a family member receiving palliative care give rise to unique perspectives that reflect the viewpoints of those who experience and receive care. Home visits, in particular, are perceived as practices that enable the strengthening of bonds, recognition of the family's actual caregiving conditions, and facilitation of access to and monitoring of health status. Within this context, the primary health care (PHC) nursing team, in its strategic role in family care, is recognized as a provider of clinical care and resources, acting to relieve symptoms and validate the challenges and suffering experienced. Simultaneously, however, nursing work is rendered less visible due to the protagonism attributed to other professional categories.

In this scenario, there is a clear need to ensure continuity of care for users in palliative care by PHC nursing teams, even amid the complex and fragmented flows of health care networks. The urgency of consolidating palliative care within the primary care sector is also evident, particularly through professional training aimed at a more needs-oriented approach to users and their families. Promoting the appreciation of nursing work and ensuring professional autonomy are processes that directly impact the quality of care, emphasizing humanized practices and fostering improvements in quality of life.

Accordingly, this study sought to value family perceptions within the context of nursing professionals' performance in palliative care, with the aim of contributing, through critical reflection, to the improvement and qualification of professional practice. Furthermore, the development of additional studies focused on palliative care in PHC, especially those addressing the nursing team, is essential to deepen the understanding of existing challenges and to envision new possibilities for advancing palliative care within the primary care setting.

Finally, one limitation of this study is its conduct during the COVID-19 pandemic, which, to some extent, restricted access to families and the collection of data that might more comprehensively represent families receiving palliative care within the municipality's health services. Additionally, the limited number of participating families constrains the generalizability of the findings. Nevertheless, considering municipalities with similar characteristics, the results may be applicable to other contexts and family settings.

ATUAÇÃO DA EQUIPE DE ENFERMAGEM DA ATENÇÃO BÁSICA EM CUIDADOS PALIATIVOS: PERSPECTIVA DE FAMÍLIAS

RESUMO

Objetivo: Conhecer a perspectiva das famílias sobre a atuação da equipe de enfermagem de atenção básica em cuidados paliativos. **Metodologia:** Pesquisa qualitativa e descritiva. Os dados foram coletados em 2021, por entrevistas semiestruturadas, com seis famílias que recebiam atendimento paliativista em Unidades Básicas de Saúde de um município do interior do Rio Grande do Sul. Os dados foram submetidos à análise temática. **Resultados:** Organizaram-se três temas: A percepção das famílias acerca do cuidado de enfermagem–o qual aborda como se desenvolve a assistência de enfermagem em cuidados paliativos; Fatores que influenciam na perspectiva das famílias – que destaca as mudanças pandêmicas, o cuidado focado na atuação médica, a coordenação do cuidado por outros serviços e a insuficiência da atenção básica; e As perspectivas da família sobre o cuidado –que estão voltadas para as crenças que envolvem o adoecimento, bem como o que consideram melhorias ao cuidado. **Considerações finais:** A atuação da enfermagem é percebida como limitada, evidenciando lacunas no cuidado, devido à falta de profissionais, ausência da equipe para o cuidado domiciliar e acompanhamento familiar insuficiente. No entanto, parece estar invisibilizada pelo protagonismo de outros serviços que compõem a rede e com a qual estabelece articulação deficitária, somada às condições precárias para atender às demandas paliativistas.

Palavras-chave: Atenção primária à saúde. Cuidados paliativos. Família. Enfermagem.

ACTUACIÓN DEL EQUIPO DE ENFERMERÍA DE LA ATENCIÓN PRIMARIA EN CUIDADOS PALIATIVOS: PERSPECTIVA DE FAMILIAS

RESUMEN

Objetivo: conocer la perspectiva de las familias sobre la actuación del equipo de enfermería de atención primaria en cuidados paliativos. **Metodología:** investigación cualitativa y descriptiva. Los datos fueron recogidos en 2021, por entrevistas semiestructuradas, con seis familias que recibían atención paliativa en Unidades Básicas de Salud de un municipio del interior del Rio Grande do Sul/Brasil. Los datos fueron sometidos al análisis temático. **Resultados**: se organizaron tres temas: La percepción de las familias sobre el cuidado de enfermería - que trata cómo se desarrolla la asistencia de enfermería en cuidados paliativos; Factores que influyen en la perspectiva de las familias - que destaca los cambios pandémicos, el cuidado enfocado en la actuación médica, la coordinación del cuidado por otros servicios y la insuficiencia de la atención básica; y Las perspectivas de la familia sobre el cuidado - que están dirigidas a las creencias que involucran la enfermedad, así como lo que consideran mejoras al cuidado. **Consideraciones finales:** la actuación de la enfermería es percibida como limitada, evidenciando lagunas en el cuidado, debido a la falta de profesionales, ausencia del equipo para el cuidado domiciliario y acompañamiento familiar insuficiente. Sin embargo, parece estar invisibilizada por el protagonismo de otros servicios que componen la red y con la cual establece articulación deficitaria, sumado a las condiciones precarias para atender las demandas de cuidados paliativos.

Palabras clave: Atención primaria a la salud. Cuidados paliativos. Familia. Enfermería.

REFERENCES

1. Wehrmeister FC, Wendt AT, Sardinha LMV. Inequalities and chronic non-communicable diseases in Brazil. Epidemiol. Serv. Saúde. 2022; 31(spe1): e20211065. DOI: https://doi.org/10.1590/SS2237-9622202200016.especial.

2. Malta DC, Gomes CS, Barros MBA, Lima MG, Almeida WS, Sá ACMGN, et al. Noncommunicable diseases and changes in lifestyles during the COVID-19 pandemic in Brazil. Rev. Bras. Epidemiol. 2021; 24: e210009. DOI: https://doi.org/10.1590/1980-549720210009.

3. Ministério da Saúde (BR). Portaria GM/MS nº 2.446, de 11 de novembro de 2014. Redefine a Política Nacional de Promoção da Saúde. Brasília, DF: Diário Oficial da União, 2014; 1(220): 68. Disponível em: https://pesquisa.in.gov.br/imprensa/servlet/INPDFViewer?jornal=1&pagina=68&data=13/11/2014&captchafield=firstAccess.

4. World Health Organization. Palliative care: factsheet. Geneva: World Health Organization; 2018. Disponívelem: http://www.who.int/mediacentre/factsheets/fs402/en/.

5. Girardon-Perlini NMO, Hoffmann JM, Begnini D, Mistura C, Stamm B. A família frente ao adoecimento por câncer de mama. R. Enferm. UFSM. 2016; 6(3): 360-370. DOI:http://dx.doi.org/10.5902/2179769220893.

6. Xu Y, Liu Y, Kang Y, Wang D, Zhou Y, Wu L, et al. Experiences of family caregivers of patients with end-of-life cancer during the transition from hospital to home palliative care: a qualitative study. BMC Palliat Care. 2024; 23(230): 1-9. DOI: https://doi.org/10.1186/s12904-024-01559-4

7. Santos MCL, Souza ARND, Anderson MIP. Palliative care in Primary Care: the perspective of physicians and nurses who are tutors of Residency Programs in the Family Health Strategy. RevBras Med Fam Comunidade. 2023; 18(45): 3345. DOI: https://doi.org/10.5712/rbmfc18(45)3345

8. Ministério da Saúde (BR). Portaria GM/MS nº 3.681, de 7 de maio de 2024. Institui a Política Nacional de Cuidados Paliativos - PNCP no âmbito do Sistema Único de Saúde. Brasília, DF: Diário Oficial da União; 2024; 1(98): 215. Disponível em: https://pesquisa.in.gov.br/imprensa/jsp/visualiza/index.jsp?data=22/05/2024&jornal=515&pagina=215.

9. Silva TC, Nietsche EA, Cogo SB. Palliative care in Primary Health Care: an integrative literature review. Rev. Bras. Enferm. 2022; (75): e20201335. DOI:https://doi.org/10.1590/0034-7167-2020-1335.

10. Fonseca LS, Carvalho BC, Santos HO, Silva JM, Santos JCO, Ferreira LLL, et al. Nursing work in palliative care in Primary Health Care: integrative review. Rev. Bras. Cancerol. 2022; 68(1): e071383. DOI: https://doi.org/10.32635/2176-9745.RBC.2022v68n1.1383.

11. IBGE – Instituto Brasileiro de Geografia e Estatística. Panorama: Santa Rosa, Rio Grande do Sul, Brasil. 2022. Disponível em: https://cidades.ibge.gov.br/brasil/rs/santa-rosa/panorama.

12. FUMSSAR. Relatório de gestão da saúde 3º quadrimestre e anual 2023. Departamento de Planejamento. Documentos internos, 2023. Disponível em: <https://www.fumssar.com.br/?p=26773>.

13. Minosso JSM, Amendola F, Alvarenga MRM, Oliveira MAC. Validation of the Barthel Index in elderly patients attended in outpatient clinics, in Brazil. Acta Paul Enferm. 2010; 23(2): 218-23. DOI:https://doi.org/10.1590/S0103-21002010000200011.

14. Minayo MCS. Amostragem e saturação em pesquisa qualitativa: consensos e controvérsias. Revista Pesquisa Qualitativa. 2017; 5(7): 1-12. Disponível em: https://editora.sepq.org.br/rpq/article/view/82/59

15. Rosa LS, Mackedanz LF. A Análise Temática como metodologia na pesquisa qualitativa em educação em Ciências. Atos pesqui. educ. 2021; 16: 8574. DOI: https://doi.org/10.7867/1809-0354202116e8574.

16. Willing KB, Farão EMD, Fonseca ADG, Alvim ALS, Nazareth JB, Paiva ACPC. Cuidados paliativos na oncologia sob a óptica da enfermagem: desvelando saberes e práticas. R. Enferm. Cent. O. Min. 2025; 15: e5593. Disponível em: http://www.seer.ufsj.edu.br/recom/article/view/5593/3618

17. Maia AES, Grello FACG, Cunha KC. Sociodemographic andclinical profileof cancerpatients registeredin thehome visiting program of a public hospital. Rev. Bras. Cancerol. 2021; 67(2): e05864. DOI: https://doi.org/10.32635/2176-9745.RBC.2021v67n2.864.

18. Maia BB, Oliveira-Cardoso EAD, Risk EN, Pillon SC, Santos MAD. Eating disorders, COVID-19 and reconfigurations of care: challenges for shared management of health professionals. Estud. Psicol. (Campinas). 2025; 42: e230055. DOI: https://doi.org/10.1590/1982-0275202542e230055

19. Sousa MF, Santos BMP, Paz EPA, Alvarenga JPO. Complexidade das práticas da enfermagem na Atenção Primária à Saúde. Enferm. Foco. 2021; 12(Supl.1): 55-60. DOI: 10.21675/2357-707X.2021.v12.n7Supl.1.5211

20. Ribeiro DFS, Gaspar DRFA, Santos LP, Silva MBT. The nurse's professional identity on the primary health care users perception. Rev. Bras. Enferm. 2022; 75(3): e20200974. DOI:https://doi.org/10.1590/0034-7167-2020-0974.

21. Oliveira CCRB, Silva EAL, Souza MKB. Referral and counter-referral for the integrality of care in the health care network. Physis (Online).2021; 31(1): e310105. DOI: http://dx.doi.org/10.1590/S0103-73312021310105.

22. Santos RC, Bispo LDG, Ferreira LLL, Souza JLS, Jesus LS, Teixeira V, et al. Reference and counter-reference in the Brazilian national health service: challenges for integrality. Rev. Atenção Saúde. 2021; 19(69): 51-65. DOI: https://doi.org/10.13037/ras.vol19n69.7614.

23. Beltrão TA, Ramalho MNA, Barros MBSC, Silva FMC, Oliveira SHS. Acompanhamento de pessoas com câncer por enfermeiros da atenção primária. Rev. Cubana Enferm. 2019; 35(4): e3011. Disponível em: http://scielo.sld.cu/scielo.php?script=sci_arttext&pid=S0864-03192019000400006.

24.Stochero AV, Petter EB, Brum LB, Silva CB, Soccol KLS, Santos NO. Perspective of nurses from the family health strategies on the attribute coordination of attention. Ciênc. cuid. saúde. 2024; 230. DOI:https://doi.org/10.4025/ciencuidsaude.v23i0.68734.

25. Castro CP, Sala DCP, Rosa TEC, Tanaka OY. Atenção ao câncer de mama a partir da suspeita na atenção primária à saúde nos municípios de São Paulo e Campinas, Brasil. Ciênc. Saúde Colet. 2022; 27(2): 459-470. DOI: https://doi.org/10.1590/1413-81232022272.42012020.

26. Bonow CT, Ceolin T, Lopes CV, Zillmer JGV, Vargas NRC, Heck RM. Medicinal plants used in self-care by people with cancer in palliative care. Texto Contexto Enferm. 2020; 29: e20190329. DOI: https://doi.org/10.1590/1980-265X-TCE-2019-0329.

27. Maffei B, Arrieira ICO, Ferreira RA, Cardoso DH. Coping strategies of caregivers of patients receiving palliative home care. Psicol. teor. prat. 2019; 21(3): 303-322. DOI: https://doi.org/10.5935/1980-6906/psicologia.v21n3p303-322.

28.Moraes ACSG, Santana ME. Needs offamily caregiversand therole ofnurses inoncological palliative care: integrative literature review. Rev. Bras. Cancerol. 2024; 70(2): 1-13. DOI:

https://doi.org/10.32635/2176-9745.RBC.2024v70n2.4560

Corresponding author: Nara Marilene Girardon-Perlini. Avenida Roraima, nº 1000. Centro de Ciências da Saúde, prédio 26. Bairro Camobi. Santa Maria, Rio Grande do Sul, Brasil, CEP 97105-900. (55) 9 9973-5986.nara.girardon@gmail.com

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