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Patients' and caregivers' needs in palliative care from the perspective of home care providers: A qualitative study

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ABSTRACT

Background & Aim: Palliative care is an approach designed to enhance the quality of life and alleviate suffering associated with life-threatening illnesses. It should also be included in Home Care Services. This study aimed to identify the needs of patients in palliative care and their caregivers from the perspective of Home Care Service providers.
Methods & Materials: This qualitative research study was conducted with a multidisciplinary team of providers under the Home Care Service program in the interior of São Paulo state, Brazil. Data were collected through semi-structured interviews and analyzed using the Content Analysis method.
Results: Three categories emerged from the provider's narratives: insufficient knowledge about palliative care, the needs of patients in palliative care, and the needs of caregivers of patients in palliative care. Additionally, nine subcategories were identified: palliative care as end-of-life care, palliative care as an opportunity to provide comfort measures, lack of palliative care training for the multidisciplinary team, pain management, nutrition, emotional support, and psychological care, presence of family members, psychological support, and assistance in care management.
Conclusion: This study identified the needs of patients in palliative care and their caregivers from the perspective of Home Care staff. The primary needs of patients, as identified by the staff, encompassed both physical and psychosocial support, including the presence of family members. For these patients' caregivers, staff emphasized the importance of psychological support and assistance in managing care. The study highlights the importance of continuous education in the home palliative care setting that recognizes the needs of both patients and caregivers.

Introduction

Palliative care (PC), as defined by the World Health Organization (WHO), is an approach aimed at improving quality of life and relieving suffering through the early identification and treatment of physical, psychological, and spiritual issues experienced by both patients and their families as a result of life-threatening illnesses (1).

PC has gained research interest due to demographic and epidemiological transitions, particularly the aging population (2). PC is considered a fundamental human right, and everyone should have equitable access to it. In 2019, 56.8 million individuals required PC, largely due to conditions such as cancer (28.2%), HIV (22.2%), brain diseases (14.1%), and dementia (12.2%) (1).

In Brazil, there are currently 234 PC services, 52.6% of which are integrated into the Unified Health System (UHS), the Brazilian public health system. With a population of 203 million, this translates to one public PC service for every 1.4 million Brazilians, underscoring the urgent need for national improvement and expansion of these services (4). In 2024, the Ministry of Health determined that around 625 thousand Brazilians are in need of palliative care (8). The Brazilian National Primary Care Policy includes PC within the scope of Primary Health Care. Home care (HC) can be provided under these PC services (5).

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HC delivers a diverse range of healthcare specialties, including rehabilitation, illness prevention, treatment, and health promotion, provided by a multidisciplinary team within a patient's home. It humanizes care with a comprehensive, patient-centered approach, while offering economic benefit through reduced hospitalizations and overall cost reductions for public health services and patients. Delivering PC in the home setting offers further benefits, including access to multidisciplinary support while allowing patients to remain within their familial and social context. This approach helps prevent recurrent, often unnecessary, hospitalizations and offers emotional support to both patients and their families. This system demands competent professional and non-professional caregivers capable of providing comprehensive care (6,7).

The UHS offers the Home Care Service (HCS) program, whose goals include reducing hospitalizations and lengths of stay, promoting patient-centered care and autonomy, and providing ongoing education. HCS is delivered by the Multidisciplinary Home Care Team and the Multidisciplinary Support Team, consisting of nurses, doctors, psychologists, social workers, pharmacists, nutritionists, dentists, occupational therapists, physical therapists, and speech therapists (5,7).

HCS established the "Better at Home" Program, which oversees the planning, implementation, organization, supervision, team composition, and continuous education of the HCS (5). Continuous education of the healthcare team in HC is crucial, as these providers guide family members and other caregivers who provide regular daily care to PC patients. This education must encompass skill development to address ongoing changes to medication management, hygiene, feeding, and other daily care tasks (6,9).

To contextualize Brazil’s home-based palliative care (HBPC) system globally, several international studies highlight the variation in provider and caregiver perspectives on HBPC across different income settings. In low-income countries (LICs), educational interventions for HBPC carers tend to prioritize psychosocial over spiritual or social components, and are most often driven by nursing professionals (23). Structural barriers such as inadequate access to opioids, lack of standardized clinical pathways, and minimal policy prioritization challenge HBPC implementation in LICs. Yet, when family caregivers are supported by providers, home-based models are effective in LICs (25).

In contrast, a recent U.S.-based study identified structural barriers to HBPC referrals, including fragmented pay structures, misperceptions of PC among providers, and electronic health record limitations (24). Across settings, provider burnout, poor coordination, and unmet informational and practical needs for carers remain consistent concerns (26). These global insights offer a comparative lens to contextualize the Brazilian experience, illustrating its unique structural challenges in delivering effective HBPC.

Reflection on the experiences of healthcare staff in the healthcare setting fosters an understanding of their roles in primary care, the collective resources available to support their practice, and systemic conditions that influence their capacities (10). Given the proximity in which the HC team works with patients and their caregivers, they are uniquely positioned to witness the day-to-day lives and to recognize their needs. The present study, therefore, aimed to identify the needs of patients receiving PC and their caregivers from the perspective of HC staff.

Methods

This study employed a qualitative, exploratory, and descriptive approach. The report was conducted in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (11).

The study took place at the HCS in Jardinópolis, São Paulo, with data collection conducted between February and March 2024. The Jardinópolis HCS was established to rehabilitate, promote, and protect family health. Access to this service may be initiated by provider referral or self-referral. Within the “Better at Home” Program, this service provides guidance to the family/caregiver, encourages the development of caregiving skills, promotes patient autonomy and PC, and integrates healthcare services with the family (12).

The sample selection of the HCS multidisciplinary team was based on the following inclusion criteria: holding a healthcare qualification and having worked in the HCS for at least six months. Professionals on leave for any reason during the data collection period were excluded.

Team members were invited to participate in the study through direct contact at their workplace, forming a convenience sample. Interviews were conducted in a private space at the same institution where the study was carried out, at a time chosen by the participants to minimize work disruptions.

Semi-structured interviews were used to collect data, offering flexibility for participants to express their worldviews while being guided by a list of predefined questions in a private setting at their convenience, minimizing work disruption (13). To develop the guiding questions, a narrative review was conducted on the topic of PC in HC.

The interviews were structured around the following key questions: What do you understand about PC? What are the main needs of PC patients in the home setting? What are the main needs of caregivers of PC patients in the home setting? Sociodemographic and professional data were also collected for characterization. It is worth noting that these questions served as starting points for the dialogue and were further explored based on the participants' narratives, in order to foster a comprehensive understanding of the phenomenon under investigation.

Participants were informed about the study and provided their consent by signing two copies of the Free and Informed Consent Form (ICF), one of which was retained by the participant and the other by the researcher. Interviews were digitally audio-recorded and transcribed in full.

All interviews were audio-recorded with consent, fully transcribed, and anonymized using professional titles and codes (e.g., Registered Nurse [RN]). Data were analyzed using Content Analysis (14), which involves: (1) pre-analysis, (2) material exploration, and (3) treatment of results, inference, and interpretation. Coding and categorization were conducted manually using spreadsheets. Theoretical saturation was reached after the sixth interview, when recurring narratives, codes, and meanings were observed with no emergence of new themes. The seventh interview confirmed the redundancy of content. Saturation was determined following the principle of exhaustiveness, where empirical material ceases to contribute new relevant information (14).

Given the specificity of the empirical field—a public home-based palliative care service with a single, locally scoped team—and the depth of the interviews conducted, the sample proved adequate to achieve theoretical saturation, a central criterion in qualitative research, and to generate sufficiently rich data to support the emerging analytical categories (27, 28).

The multidisciplinary composition of the team enabled the capture of a plurality of perspectives, which enhanced the understanding of the phenomenon in its complexity. This heterogeneity was regarded as a methodological strength, as it allowed for the triangulation of viewpoints within the empirical corpus itself, contributing to the interpretative validity of the findings (29, 30).

The study was approved by the Research Ethics Committee (REC) of the Ribeirão Preto School of Nursing under CAAE 74404523.9.0000.5393 and protocol number 6.575.645. All ethical principles were followed in accordance with Resolution 466/2012 of the Brazilian National Health Council (15).

Results

The interviews were conducted at various times, both in the morning and afternoon, and lasted approximately 30 to 40 minutes. Seven professionals participated in the study: one physician, one nurse, three licensed practical nurses, one speech therapist, and one physical therapist. One participant was male (14.28%) and six were female (85.72%). The time since graduation ranged from 10 to 31 years, and their experience in the specified service ranged from 2 to 10 years. This sample included the entire HCS team in Jardinópolis, consisting of only seven professionals.Based on the data obtained from participants' interviews, three thematic categories and nine subcategories emerged, as illustrated in Table 2.

Table 1. Demographic characteristics of participants. Source: Author, 2025.

Code	Occupation	Gender	Years since graduation	Years in home care
P	Physician	Male	12	6
PT	Physical Therapist	Female	31	10
LPN1	Licensed Practice Nurse	Female	10	2
LPN2	Licensed Practice Nurse	Female	18	10
LPN3	Licensed Practice Nurse	Female	13	10
RN	Registered Nurse	Female	15	10
ST	Speech Therapist	Female	17	2

Table 2. Categories and subcategories.

Categories	Subcategories
Inadequate knowledge of palliative care	• Palliative care as end-of-life care • Palliative care as an opportunity to provide comfort measures • The lack of palliative care training for the multidisciplinary team
Needs of patients in palliative care	• Pain management • Nutrition • Psychological support • The presence of family members
Needs of caregivers of patients in palliative care	• Psychological support • Assistance in managing care

Limited knowledge about palliative care

The data revealed a discrepancy in participant perspectives. Three interviewees stated that only a minority of PC patients were treated by HCS, while four reported that most patients under HCS care were palliative. This highlights an incomplete understanding of PC's definition and scope, as all HCS patients are considered palliative. Such a knowledge gap could hinder the identification of patients needing a PC approach.

Lack of palliative care training for the multidisciplinary team

A significant gap in the training of multidisciplinary team professionals regarding PC was observed. Many professionals expressed insecurity about the topic, citing insufficient training during their formal education. Additionally, several team members reported challenges in fully grasping PC concepts. These findings underscore the need for ongoing education and professional development in PC to enhance the skills and competencies required for comprehensive, compassionate care for patients with complex needs.

Despite being part of the team for 10 years, we have never stopped studying palliative care, but there is still a lack of a broader perspective among the team itself. I believe that palliative care encompasses much more than we currently understand. I think all professionals still need to engage in continuous training (PT).

I did not feel very well-prepared; I had very little exposure to palliative care (...). I think the path forward is through more training and learning (ST).

Palliative care is still an enigma because it doesn't always come with a palliative care diagnosis from the hospital; we are the ones who need to enter the home and assess the situation. We need to be continually educated in this area because that is what Home Care (HCS) entails (...) (RN).

Palliative care as end-of-life care

The interviews revealed that a significant proportion of participants (42.85%) exclusively associated PC with end-of-life care. This limited perception demonstrates the need for greater awareness and education on the broader scope and benefits of PC, not only during the terminal phase but throughout the illness trajectory.

It's end-of-life care, right? For the patient, right? It's not what everyone says, the old opinion that, oh, it's to hasten the patient's death. No, that's not the goal of palliative care (...) (P).

To provide care for your terminally ill patient, ensuring they do not suffer (LPN1).

What I understand is that, unfortunately, when the patient reaches a stage of the illness where there is no improvement and no possibility of a good recovery… (LPN2).

Palliative care as an opportunity to provide comfort measures

Five of the seven interviewees demonstrated an understanding of PC that included promoting comfort measures for patients. This perception highlights PC as a significant opportunity to provide relief and well-being for patients.

Palliative care is, in fact, about providing comfort measures to ensure a full end-of-life experience, without any invasive procedures or interventions that could prolong the patient's life. Rather, it focuses on the patient living in this moment, free from any invasive measures (P).

So, we step in to offer care that provides comfort, right? (LPN2).

I understand palliative care as providing comfort (...). Comfort can mean staying at home, placing a feeding tube at home, administering medication at home, and avoiding the need to transport the patient (...). I think it's about comfort at home, being close to loved ones (LPN3).

I believe palliative care is about offering comfort, not necessarily at the end of life, as we have patients who remain in palliative care for extended periods(...) (RN).

It is my role to bring comfort when possible and ensure quality of life in the patient's final moments (...) (ST).

The needs of patients in palliative care

The interviewees demonstrated an understanding of the broad range of palliative patients' needs within the HC setting. This finding supports a holistic approach to PC. Comprehensive care for this patient population should encompass symptom management and extend to consider emotional, social, and spiritual needs, thereby providing comprehensive support throughout the course of the illness.

Pain management

Five interviewees identified pain as one of the primary symptoms presented by patients receiving PC at home. These findings underscore the importance of an effective approach to pain management in HBPC that includes appropriate assessment and treatment strategies to ensure the relief of patients' suffering.

Look, mostly it's pain, right? There's a lot of it (LPN1).

Their greatest need is pain relief because many complain of pain, so alleviating it is their biggest need at home (LPN3).

Pain is the first thing they complain about; that's what I see most often (RN).

In relation to palliative care, I believe it's mostly about managing pain through medication (ST).

Taking a broad view of care and determining what is most crucial for a palliative care patient. Sometimes it will be pain (PT).

Nutrition

Three of the interviewed professionals highlighted nutrition as a challenging aspect of care and emphasized the importance of providing comfort through food. This reflects the complexity of ensuring proper nutrition and overall well-being in this context.

(...) more focused on providing comfort through food (ST).

Inability to eat (...). I think this is what we encounter most often and where we focus the most to provide comfort (RN1).

Sometimes it's about nutrition. Other times, it's simply about organizing things when everything feels so chaotic (PT).

Emotional support and psychological care

The interviews highlighted the importance of emotional support and psychological care for patients receiving PC at home. Two professionals emphasized that fully understanding patients' needs requires providing proper emotional support and psychological care to help them cope with emotional vulnerabilities. This underscores the need for a patient- and family-centered approach to PC that addresses not only physical needs but also emotional and psychological concerns.

Especially psychological support, right? (...). From a healthcare perspective, they are theoretically well-served. Our municipality is somewhat lacking, actually quite lacking, in psychological services (P).

Typically, the primary needs at admission are emotional support. In an initial evaluation, I see both the patient and the family as in need of care. They have so many needs, both physical and emotional (PT).

Family presence

Two interviewees emphasized the importance of family members' presence and support as a major need for patients in PC. This observation highlights the fundamental responsibility that family members play in the care process, providing not only emotional support but also actively participating in the physical and practical care needs of patients. This understanding underscores the need to involve and support family members as an integral part of the PC team, aiming to enhance the patients' quality of life and comfort during this vulnerable stage of their lives.

I think their greatest need is to be close to their family, receiving love, care, and attention, but many won't have that (LPN3).

(...) heightened need for nutritional comfort and family support (ST).

The needs of caregivers of palliative care patients

Interviews with HCS professionals emphasized the vital role caregivers play throughout the disease trajectory of PC patients. Often, family members, these caregivers provide direct care, maintain a close bond, and offer constant support. Understanding their needs is essential for providing adequate assistance, highlighting the importance of an approach focused not only on patients but also on caregivers, acknowledging their crucial role.

Psychological support

Psychological support was identified as the primary need for caregivers by four of the seven interviewees. This support includes the need for compassion, emotional backing, and other psychological challenges. These findings emphasize the importance of addressing the emotional and psychological needs of caregivers of palliative patients in the HC setting.

(...) It's really about psychological issues, right? They need support (P).

Their main need is support. Emotional support (...). The public health system provides some support. It offers dietary support and technological coverage for wounds. But what about human support? That's missing (PT).

It's attention. You have to give them attention, listen to them, hear what they have *to say, their worries, their sadness—they often feel lost* (LPN1).

(...) The concern is about being able to provide comfort to the patient. I think it's mostly about exhaustion and mental strain (LPN1).

Assistance in care management

A key issue identified was the lack of caregiver skills in managing patient care, leading to improper task distribution, which contributes to physical, emotional, and financial strain. Many caregivers lack healthcare training, leaving them ill-equipped to provide adequate care. This underscores the importance of training and guidance for non-professional caregivers to ensure competence, safety, and quality care.

Often, caregivers have to stop working. And financially, how do they manage that? (...) This must be addressed: the caregiver, the burden of care, and the physical, emotional, and financial strain (PT).

Exhaustion, feelings of isolation. Usually, most of the family steps away, and it all falls on one person, who becomes overwhelmed (RN).

They ask for help. They say, "I don't know what to do, how will I take care of them? I can't do this, I need help." We help as much as we can, but we can't be there 24 hours (...). It always falls on one person, and that person becomes overburdened (LPN3).

(...) Sometimes they don't know what to do when the patient is very ill (LPN1).

I think it's a difficult time, so just having a professional willing to answer questions, explain, and guide makes a huge difference. They clearly need this. I believe that proper guidance at this time makes all the difference (ST).

Discussion

The HCS team performs a critical role in supporting PC patients and their caregivers. The provision of HBPC by these professionals offers a more humanized approach to care (16).

This study identified a significant gap in professionals' knowledge, largely due to insufficient education in PC. This PC knowledge gap has been demonstrated in high-income countries (HIC) HC teams, suggesting it is not unique to Brazil or LICs (24). However, PC remains underemphasized in the curricula of many healthcare programs in Brazil, including medicine and nursing, a potential opportunity for intervention. This reflects a broader pattern in the Brazilian healthcare education system, where PC is often viewed as optional, hindered by systemic underfunding and a lack of curricular integration. These structural challenges hinder the development of ethical, holistic, and human-centered competencies needed for effective PC, limiting professionals' preparedness (17).

The misconception among providers that PC is solely end-of-life care is not uncommon; this aligns with the experiences reported in our study. This narrow understanding can lead to a late introduction of care, typically only after curative options are exhausted. Promoting early PC integration improves symptom prevention and enhances patient quality of life (18).

Professionals in this study often conceptualized PC as a set of practices aimed at promoting patient comfort. This aligns with Comfort Theory, which defines comfort as the fulfillment of needs across physical, psychological, social, cultural, spiritual, and environmental domains. Applying this framework helps clarify the multidimensional nature of comfort in PC and underscores its role as more than symptom control—it is about fostering relief, ease, and transcendence tailored to the individual patient (19).

Promoting comfort in this holistic sense encourages greater social interaction and improves quality of life, especially at the end of life. Understanding comfort within this theoretical model helps professionals deliver care that is sensitive to the uniqueness of each patient, as highlighted during care providers' interviews. HBPC is an important moment for providing comfort measures.

In this study, the primary demand identified by professionals was pain management. Pain is a physically and emotionally distressing experience, shaped by the patient's individual experiences. It significantly impacts quality of life and causes considerable discomfort for patients with chronic illnesses, requiring the implementation of personalized strategies to alleviate suffering (21,22).

Moreover, the importance of nutrition stands out as a fundamental need for patients. Nutrition encompasses not only physiological aspects but also integrates cultural, social, and emotional elements, which are intrinsically linked to care and quality of life. It plays a key role in the comfort of PC patients. Comfort feeding involves adapting food choices and feeding practices to individual preferences, textures, and emotional needs. This approach strengthens relational bonds and creates moments of connection and dignity (20).

Professionals also highlighted the importance of emotional and psychological support. Through empathetic dialogue, patients are encouraged to share their experiences and fears, fostering trust and strengthening therapeutic relationships. These interventions not only support symptom management but also humanistic aspects of PC—key components of Comfort Care Theory (19,21).

Across income settings, psychological support has taken priority in caregiver education. However, in LICs, social and spiritual aspects of these interventions are largely overlooked in comparison to HICs. This discrepancy with LICs could be due to cultural perceptions and local norms where spirituality is intertwined with social identity and community (25).

Nursing staff play a fundamental role in the implementation and research of HBPC caregiver education (23). This presents an opportunity for professional development of the nursing role in Brazil, wherein community-oriented providers supervise caregiver education that encompasses psychological support for both the patient and the carer, and addresses the social and spiritual dimensions of PC with cultural competence.

Home-based care also allows patients to remain close to their families, a key need emphasized by professionals. The presence of loved ones enhances emotional security and promotes a sense of continuity and identity (9). Research suggests that in LICs, familial caregivers are more common than in HICs (25). The challenges commonly faced by family-caregivers—ranging from emotional strain to practical overload—were clearly described in our findings (22).

Relationships between patients and their family caregivers are marked by a range of complex emotions, including love, gratitude, fear, and guilt. These emotional dynamics are often intensified in PC, where caregivers face considerable physical and psychological strain due to patients' high levels of dependence (9). Without appropriate training and support, this burden can compromise both caregiver well-being and the quality of care delivered. Global evidence suggests that health provider support for caregivers is especially important in LICs for effective HBPC and should prioritize structured education, practical guidance, and emotional support to reduce stress and enhance care quality (17,22). In Brazil, however, such support mechanisms remain limited, particularly in primary care. Strengthening provider involvement in caregiver support may be key to improving outcomes in HBPC.

This study has some limitations. The small sample size reflects both the limited availability of professionals in the study setting and the non-participation of larger municipalities, many of which declined due to institutional overload. As the data were collected in a single HCS unit and based solely on self-reported accounts from professionals, the findings may be influenced by social desirability bias and are generally limited in their applicability. Additionally, the perspectives of patients and caregivers were not included, which restricts the possibility of triangulation and a broader understanding of palliative care needs. The analysis, while in-depth, may also reflect a narrow contextual reality shaped by specific service characteristics. Moreover, structural barriers in Brazil's healthcare system—such as regional inequalities and restricted access to care, particularly among vulnerable populations—likely influenced both the feasibility and the scope of the research. Nonetheless, the insights generated offer an important contribution to the scarce body of literature on home-based palliative care in low- and middle-income countries, particularly by highlighting frontline professionals' perspectives that are often overlooked yet essential for informing practice and guiding policy improvements.

Conclusion

This study identified the key needs of PC patients and their caregivers from the perspective of healthcare professionals in Brazil's healthcare system. Professionals emphasized pain management, nutrition, emotional and psychological support, and family presence as central patient needs. For caregivers, psychological support and assistance with care management were identified as key needs.

The findings also underscore the importance of ongoing PC education within the HCS. A stronger grasp of PC principles allows providers to better assess needs, formulate care strategies, and deliver confident, compassionate care.

Finally, an individualized approach remains essential. Recognizing the unique physical, social, spiritual, and psychological challenges of each patient and caregiver enables more responsive care. While these insights are rooted in the Brazilian context, they resonate with global discussions on the importance of provider training and integrated support in improving the quality of life throughout the PC journey.

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Conflicts of interest

The authors declare no conflict of interest in this study.

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