

Exploring the Perspectives on Home-Based Palliative Care: A Systematic Literature Review

Nadia Sultanali Mushtaq^{*}

¹*School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan*

ABSTRACT

Background: Palliative care for the patient, in the comfort of their homes, can be enhanced by fully involving patient and family members in the decision-making process. Palliative care at home enables patients to spend their final moments in a familiar setting surrounded by family, reducing hospital readmissions and ultimately increasing patient satisfaction.

Objective: This study aimed to review the literature on home-based palliative care from the perspectives of patients and families, to identify their experiences and viewpoints.

Methods: A literature search was performed using the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) Strategy. While utilizing the PRISMA Strategy, literature was searched by different databases and manual sources. However, editorials and systematic reviews were excluded. A total, 680 records were identified through databases considering the time frame: July 2017-June 2023. Additionally, the literature search cleaned from duplication, pediatrics population, COVID-19-related, non-English, and use of technologies like telecommunication. At last, 06 articles were included for Systematic Review.

Results: Extensive research has focused on the experiences and perceptions of healthcare providers, including nurses, doctors, and community work professionals. Most of the articles were found on hospice care and nursing home care. It was pertinent to note that the majority of the work was found in the Western part of the world most specifically on cancer patients. However, very few studies were found on patients having palliative care at their homes with non-cancerous terminal illnesses.

Conclusion: Very limited studies were identified from the Middle East and the South Asian regions of the world on qualitative studies in exploring patients' and/or family members' perceptions of palliative care at home.

Keywords: *Home-based care, patient, family member, palliative care, perspective, experience.*

INTRODUCTION

Home-Based Palliative Care, HBPC, has proven to be effective in reducing hospital stays and optimizing patient care by addressing symptoms promptly [1, 2]. In 2008, the European Association for Palliative Care highlighted the essential values needed to provide quality palliative care at home [3, 5]. However, the burden on caregivers is significant, with many experiencing physical and psychological pain, as well as social, spiritual, and financial distress during the palliative care process [3, 6].

Health authorities emphasize that palliative care at home should fully involve patients and their family members in the decision-making process [7, 8]. Despite its benefits, challenges remain due to insufficient resources and support from healthcare providers, which hinder the delivery of high-quality care to patients at home [9, 10].

The Magnitude of Palliative Care Services in and across Pakistan

Palliative care is vital for enhancing life quality in serious illnesses, focusing on pain management, symptom relief, and emotional support. Yet, global disparities persist due to resource constraints and cultural variations in end-of-

life care [11]. Despite no significant change in mortality rates, this model improves peace of mind, prevents functional decline, and reduces the negative effects of hospitalization [12, 13]. In Iran, although charity organizations offer assistance to chronically ill patients, the lack of HBPC within the healthcare system poses noteworthy challenges [14]. In Switzerland, HBPC is provided by both governmental and non-governmental organizations [15]. Korea has a structure to provide modified care in collaboration with hospital and home health management [16]. This emphasizes comfort for clients and their families, as seen in the expanding market in the United States [17]. Studies predominantly conducted outside Pakistan, indicate a lack of emphasis among the Pakistani population compared to foreign countries and highlight a gap in local literature and knowledge.

Aim

With a comprehensive literature review, this study aims to explore patients' and family members' perspectives on palliative care at home.

METHODOLOGY

The literature search followed the PRISMA guidelines, using various databases and manual sources [18]. Cross-database indexing and using standardized terms like MeSH to ensure consistent and comprehensive retrieval of relevant information.

^{*}*Corresponding author: Nadia Sultanali Mushtaq, School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan, E-mail: nadia.mushtaq@outlook.com*

*Received: March 21, 2024; Revised: September 07, 2024; Accepted: October 11, 2024
DOI: <https://doi.org/10.37184/lnjcc.2789-0112.5.19>*

Table 1: Details of reviewed literature.

| S. No. | Author – Year of Publication | Country | Study Design | Sample Size | Proposed Framework | Medical Diagnosis |
|--------|--------------------------------------|------------------------------|---------------------------------|----------------------------------|--------------------|-------------------|
| 1 | Bilić <i>et al.</i> , 2022 | Croatia | Qualitative study | 8 spouses | No | All diagnosis |
| 2 | Oosterveld-Vlug <i>et al.</i> , 2019 | Netherlands | Qualitative study | 13 patients 14 family members | No | Cancer |
| 3 | Hyden <i>et al.</i> , 2020 | The United States of America | Descriptive design | 10 patients 10 family members | Yes | COPD |
| 4 | Salifu <i>et al.</i> , 2021 | Ghana | Qualitative design | 23 patients 23 family members | No | Prostate cancer |
| 5 | Horsfall <i>et al.</i> , 2017 | Australia | Qualitative-focused group study | 127 family members | No | All diagnosis |
| 6 | Nysaeter <i>et al.</i> , 2022 | Norway | Qualitative grounded | 9 patients | Yes | Cancer |

Inclusion

- More than 18 years of age of study participants
- Availing home health care for palliation
- Qualitative studies only

Exclusion

- Editorials and Systematic Reviews
- COVID-19 studies
- Non-English language literature
- Use of technologies in studies
- Interventional studies

In total, 680 records were identified through databases like SAGE, PubMed, and Cochrane by using the keywords; “Palliative Care”, “Home Health Care”, “End of Life Care”, “Patients’ Perceptive”, and “Family Perceptive about Care at Home”, and 10 additional records identified by considering the time frame: July 2017-June 2023. Furthermore, by using Endnote X9 software, all duplicates were removed, and a total of 298 records were identified as cleaned from duplications. Then, 298 records were screened for eligibility criteria.

Full-text articles were evaluated. In this respect, some pieces of literature were identified with abstracts only and not related to home health care; literature that

talked about nursing homes, hospice, and community care setups was excluded. 40 pieces of literature were identified with interventional studies. Identifying the prevalence of health issues related to constipation, pressure sores, psychological issues like depression and dementia, and nutritional status among home-bound patients, alongside 62 articles that were identified as out of scope, were excluded. At last, six articles were included for systematic review (Fig. 1).

RESULTS

The main focus of this study was on qualitative research related to home health care for palliation. Prioritizing qualitative studies allowed for a deeper exploration of patient and caregiver experiences, providing comprehensive insights into the contextual details of home palliative care. Notably, most of the available literature reviewed originated from outside Pakistan.

During the literature review, it was identified that most studies were conducted on patients’ family members, with or without the patient. Only one study focused on patients receiving palliative care services at home. Additionally, one study examined the perspective of

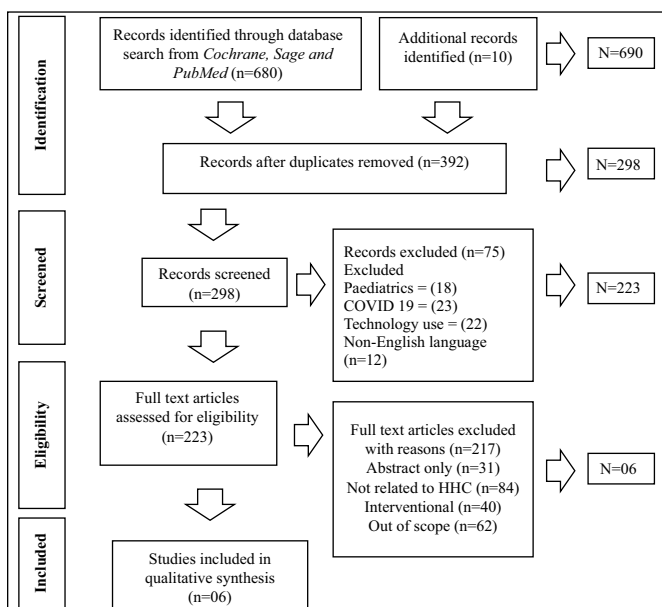


Fig. (1): Literature search strategy through PRISMA.

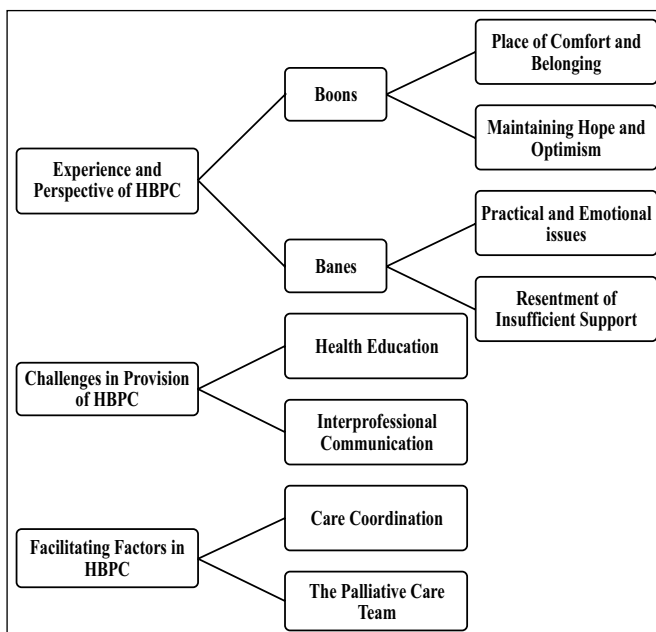


Fig. (2): Themes and categories.

Table 2: The findings of included studies.

| S. No. | Author – Year of Publication | Purpose of Study | Key Findings |
|--------|--------------------------------------|--|--|
| 1. | Bilić <i>et al.</i> , 2022 | To investigate anticipatory grief and the home-based palliative care experience among informal caregivers of spouses. | Spouse caregivers faced emotional, cognitive, and spiritual challenges associated with anticipatory grief. The experiences of all caregivers, emphasize the critical necessity for increased support and aid from healthcare professionals and other specialists engaged in delivering palliative care and assisting patients' families. |
| 2. | Oosterveld-Vlug <i>et al.</i> , 2019 | To explore essential elements of high-quality palliative care from patients and their relatives | Home-based palliative care requires medical expertise, accessibility, personalized attention, effective communication, streamlined procedures, and proactive engagement from professionals. Enhanced collaboration and simplified bureaucracy are vital. |
| 3. | Hyden <i>et al.</i> , 2020 | To investigate the viewpoints of Chronic Obstructive Pulmonary Disease (COPD) patients and their caregivers regarding palliative care delivered at home. | Patients and their caregivers identified several significant aspects of home-based palliative care, including cultural considerations, end-of-life care, ethical and legal considerations, education regarding medical assessment and future outlook, availability of medical care and symptom management. |
| 4. | Salifu <i>et al.</i> , 2021 | To investigate the difficulties experienced by patients and their family members in resource-limited environments when receiving palliative care at home. | Men with advanced prostate cancer faced issues like limited access to professional care, insufficient home care resources, limited disease knowledge, and medication access. Overburdened caregivers also acted as informal home caregivers, assessing symptoms, administering drugs, and providing care. |
| 5. | Horsfall <i>et al.</i> , 2017 | To examine the firsthand experiences of informal caregivers regarding end-of-life care provided in a home setting. | The home greatly impacts caregivers' well-being and their capacity to continue caring, as well as the ability of care networks to support one another. Participants emphasized that home represents comfort, belonging, and identity, with familiar objects. |
| 6. | Nysaeter <i>et al.</i> , 2022 | To investigate the desires for in-home care facilitating terminal patients with cancer to pass away at home, as expressed by adult patients in the late stages of palliative care. | The findings were summarized in a conceptual model depicting patients' consistent preference for home death despite health decline. Five related categories emerged: 1) Present-focused mindset, 2) Safety and autonomy, 3) Recognition and validation of identity, 4) Dependable, compassionate healthcare providers, and 5) Timely and adaptive care organization. |

exclusively spouses as care providers. In addition, two studies proposed conceptual frameworks to improve and organize palliative care services. Some studies explored participants' perspectives on their service provision to identify areas for improvement. Three studies focused exclusively on cancer patients, one study on patients with Chronic Obstructive Pulmonary Disease (COPD), and two studies included patients with various diagnoses, including different types of cancer (**Tables 1 and 2**). The results of the literature review identified major themes and categories (**Fig. 2**).

Experience and Perspective of HBPC

The literature review uncovered diverse experiences and perspectives from patients and families, with a few key boons and banes identified for HBPC.

Place of Comfort and Belonging

The significance of providing care in the familiar, personal environment of the patient's own home, significantly enhances their sense of security and comfort [19-22]. Patients often report that being surrounded by cherished belongings and familiar settings contributes to delicate stability and a greater sense of control over their end-of-life experience [23]. For families, this environment fosters a supportive and intimate space for meaningful interactions and shared moments [24]. Ensuring that the

home setting is adapted to meet palliative care needs while preserving the personal and emotive significance of the home is crucial for enhancing the overall quality of care and ensuring a compassionate, patient-centered approach [19].

Maintaining Hope and Optimism

The importance of fostering a positive outlook and delicate resilience among the challenges of advanced illness [24]. HBPC providers often focus on supportive interventions that help patients and families find meaning and maintain hope, even as they navigate complex care needs [22]. Strategies such as personalized care plans, open communication, and emotional support are crucial in sustaining a hopeful perspective [25]. By addressing the emotional and psychological aspects of care, HBPC creates an environment where patients feel valued and empowered, and families are supported in coping with the uncertainties of the palliative journey [19]. This approach not only contributes to a more fulfilling end-of-life experience but also helps in alleviating distress and enhancing overall well-being [23].

Practical and Emotional issues

In HBPC, both practical and emotional issues present significant challenges [25]. Practically, coordination among multiple healthcare providers and ensuring

consistent access to necessary resources can be difficult [19, 24]. Emotionally, patients and families may experience heightened stress due to the complexities of managing a serious illness at home. Feelings of isolation, caregiver burnout, and the emotional burden of witnessing a loved one's decline can impact the overall effectiveness of HBPC [21].

Resentment of Insufficient Support

Patients and families often experience feelings of helplessness and anger due to insufficient support and limited access to necessary medical equipment, medications, and professional care [24, 25]. These resource constraints can lead to frustration and despair as patients struggle to manage their symptoms effectively at home, further exacerbating the emotional and psychological stress on both patients and family members [21].

Challenges in Provision of HBPC

Provision of HBPC faces numerous challenges, particularly regarding the availability and adequacy of resources.

Health Education

Educating patients and their families about disease management, symptom control, and end-of-life care practices is crucial for effective HBPC [19, 21]. However, delivering comprehensive Health Education in a home setting can be difficult due to several factors. These include varying levels of health literacy, emotional stress, and the complexity of medical information that needs to be conveyed [25].

Interprofessional Communication

Interprofessional communication poses a significant challenge in the provision of HBPC [19]. Factors such as differing schedules, geographic dispersion, and varying communication styles can impede the timely exchange of crucial patient information [21]. Moreover, the absence of a centralized communication platform led to fragmented care and misunderstandings, potentially compromising patient safety and the quality of care provided [22, 24, 25].

Facilitating Factors in HBPC

In the literature review, another important theme identified as Facilitating factors for HBPC often includes care coordination and the involvement of a dedicated palliative care team.

Care Coordination

Ensures that all aspects of the patient's care are well-organized, with clear communication between healthcare providers, family members, and other caregivers [21]. This coordination is crucial for managing complex care needs and ensuring that the patient receives timely and appropriate support at home [19, 22].

The Palliative Care Team

Typically consisting of doctors, nurses, social workers, and other specialists, plays a vital role by providing expert guidance, managing symptoms, and addressing the physical, emotional, and spiritual needs of the patient [22, 24]. Together, these factors create a supportive environment that allows for high-quality, patient-centered care in the comfort of the patient's home [23].

DISCUSSION

The experiences and perspectives of patients and families engaged in HBPC are rich and varied, revealing a wide range of both positive and negative aspects inherent in this care. For many patients, the opportunity to receive care in the comfort of their own homes significantly enhances their overall sense of well-being and satisfaction. The familiar environment, surrounded by personal belongings, cherished memories, and loved ones, contributes to a profound sense of emotional stability and security [25]. This home setting provides not only a sense of physical comfort but also allows patients to maintain a sense of control over their end-of-life experience, which is often lost in more institutional settings. The emotional and psychological benefits of being in a familiar environment cannot be overstated, as it fosters a sense of belonging and can be a critical factor in a patient's overall quality of life during palliative care [26].

However, these benefits are not without confronts. While maintaining hope and optimism is essential to the overall well-being of patients and their families, it can be an overwhelming task amidst the realities of advanced illness. The uncertainty and unpredictability of a patient's condition often lead to fluctuating emotions, where moments of hope are interspersed with feelings of despair. HBPC providers, therefore, play a crucial role in fostering a positive outlook [27]. Through the development of personalized care plans, open and empathetic communication, and consistent emotional support.

Nevertheless, the emotional and practical complexities of managing care at home can lead to significant stress for both patients and caregivers [27]. The demands of providing care in a home setting often extend beyond the physical aspects of care, encompassing a wide array of emotional and psychological challenges. Practical issues such as coordinating among multiple healthcare providers, managing medications, and ensuring consistent access to necessary resources can be overwhelming for caregivers. These encounters are further compounded by the emotional toll that comes with witnessing the gradual decline of a loved one. Caregiver burnout is a real and pressing concern, as the constant demands of caregiving can lead to feelings of exhaustion, helplessness, and even resentment. The emotional burden on families is often intensified by perceived insufficient support from healthcare systems.

Limited access to medical equipment, essential medications, and professional care services can lead to frustration and despair, as families struggle to manage their loved one's symptoms effectively at home. These resource constraints not only compromise the quality of care provided but also exacerbate the emotional and psychological stress on both patients and caregivers, potentially leading to a diminished overall experience of HBPC [28].

The challenges in providing HBPC are multifaceted and require a comprehensive approach to address effectively. One of the critical issues identified is health education. Educating patients and their families about disease management, symptom control, and end-of-life care practices is essential for the successful implementation of HBPC. However, delivering this education in a home setting presents unique challenges. Factors such as varying levels of health literacy among family members, the emotional stress associated with caring for a seriously ill loved one, and the complexity of the medical information that needs to be conveyed all contribute to the difficulty of effective health education [29]. Without a clear understanding of the care processes and expectations, families may struggle to provide the necessary support, leading to suboptimal care outcomes.

Another significant hurdle in HBPC is inter-professional communication. The successful provision of home-based care relies heavily on the timely and accurate exchange of information between different healthcare providers [28]. The absence of a centralized communication platform can lead to fragmented care, where critical patient information is not shared effectively among the care team. This fragmentation can result in misunderstandings, errors in care delivery, and potentially compromised patient safety.

Despite these challenges, certain factors have been identified that facilitate effective HBPC, enabling a more positive and supportive care experience for patients and their families. Care coordination is one such factor, playing a vital role in ensuring that all aspects of a patient's care are well-organized and that communication is maintained between healthcare providers, family members, and other caregivers [30]. Effective care coordination helps manage the complexities of home-based care by ensuring that the patient receives timely and appropriate support across all dimensions of care—medical, emotional, and logistical. This coordination is particularly important in managing complex care needs, where multiple healthcare providers and services are involved.

The involvement of a dedicated palliative care team is another critical facilitating factor in HBPC. This multidisciplinary team typically consists of doctors, nurses, social workers, and other specialists who work

together to provide expert guidance, manage symptoms, and address the physical, emotional, and spiritual needs of the patient [31]. The palliative care team serves as the cornerstone of HBPC, ensuring that care is delivered in a holistic and patient-centered manner. By working closely with the patient and their family, the palliative care team helps to create a supportive environment that allows for high-quality care to be delivered in the comfort of the patient's home. This collaborative approach not only enhances the overall experience for patients and their families but also contributes to a more sustainable and effective model of home-based palliative care.

The study has limitations in that most reviewed literature comes from outside Pakistan, creating a cultural and contextual gap.

Future recommendations include conducting region-specific studies, especially in developing countries, to address local healthcare needs. Improving care coordination and communication among providers is crucial. Research can focus on implementing and evaluating best practices in HBPC. Advocacy for better policies and increased resources is essential to support palliative care services and ensure access to necessary equipment and medications.

CONCLUSION

Much of the work had been done on exploring the experiences and perceptions of health care providers like nurses, doctors, and community work professionals, and so on. Most of the articles were found on hospice care and nursing home care. It was pertinent to note that the majority of the work was done in the context of the western part of the world and most specifically on cancer patients. However, very few studies were found on patients having palliative care at their homes with non-cancerous terminal illnesses.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to Dr. Salma Rattani, Dr. Rafat Jan, Dr. Atif Waqar, Ms. Khairunisa Mansoor, and Ms. Sahrish Jalaluddin. I also wish to thank my study participants, colleagues, and friends for their invaluable contributions and support. Special thanks to my dear husband, Mr. Mushtaq, for his unwavering support and love.

AUTHORS' CONTRIBUTION

I take full responsibility for the study's conception and design, data collection, analysis and interpretation of results, and manuscript preparation.

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