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RESEARCH **Open Access**

Understanding the Multifaceted Roles of Families in Caring for Palliative Patients in the Community: A Systematic Literature Review

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Abstract
Enhancing family support in community-based palliative care is a growing global priority given the family's role as the primary caregiver for long-term palliative care patients in the community. This is a systematic literature review that aimed to synthesize recent evidence on the roles and contributions of families in caring for palliative patients in the community. A literature search was conducted through PubMed and ScienceDirect databases using the keywords “family role” OR “family support” AND “palliative” OR “palliative care.” The PEO framework guided the selection process, focusing on Population: families of palliative patients; Exposure: family caregiving roles; and Outcome: fulfillment of palliative care needs. Nine articles published between 2020 and 2025 met the inclusion criteria. The review identified diverse and interrelated family roles, including providing emotional and social support, delivering direct care, coordinating with healthcare professionals, engaging in decision-making and communication, and facilitating health education. Families also carried significant social and cultural responsibilities while adopting protective and adaptive coping strategies. The findings highlight that families are not merely companions but act as care managers, communicators, and educators who critically influence the quality of home-based palliative care. A unique insight from this review is the emphasis on the transitional phase from hospital to home as a crucial period requiring enhanced family capacity, structured coordination, and psychosocial support. Strengthening family education, telemedicine-based coordination, and community linkages emerges as a vital strategy to ensure holistic and sustainable palliative care delivery within community settings. Community nurses need to involve and meet the needs of families as clients in a nursing care plan that does not only focus on the needs of palliative patients.

Keywords: *Community Health Nursing, Family Role, Family Support, Palliative Care, Long-Term Care*

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1. INTRODUCTION

Advanced and terminal chronic illnesses such as cancer, heart failure, chronic kidney disease, and neurodegenerative diseases often lead to a decline in the quality of life of patients and their families. Family integration in the care of hospice patients nearing the end of life is a crucial component of the modern nursing paradigm (Kim & Kim, 2024). Developing and enhancing family support in palliative care is a priority in growing research. Families need to be involved in patient care plans through high-quality psychosocial support, especially during difficult situations such as serious illness and bereavement (Bork-Zalewska et al., 2024). Although numerous primary studies have addressed the management, therapy, and treatment aspects of palliative care patients, research specifically addressing family involvement in palliative care is also emerging. However, these findings are still applied in various studies with different focuses and contexts. A comprehensive synthesis of these research findings that encompasses and integrates the various roles of families in caring for palliative care patients in the community remains underdeveloped.

The World Health Organization reports that palliative care improves the quality of life for patients and their families, but access remains limited, particularly in low- and middle-income countries. Each year, approximately 4.4 million people in the WHO European Region, including 140,000 children, require palliative care. Services should be available in hospitals, hospices, and through home care teams, with a recommended number of services per 100,000 population (WHO, 2020). Globally, more than 56.8 million people require palliative care. The highest prevalence occurs in the elderly, at around 40%, in line with increasing global life expectancy. In Southeast Asia, approximately 17.1% of patients require palliative care, with cancer being the most common disease (20.4%). In Indonesia, the need for palliative care is recorded at around 0.35% (Kemenkes RI, 2023; WHPCA, 2020).

Palliative care was previously centered in hospitals or specialized facilities, but with increasing caseloads and limited capacity, care services have shifted to the community, with families as the primary caregivers. Research has found that families play a crucial role in palliative nursing care models, contributing significantly, along with patient, nurse, service, and technology factors, to effective palliative care. Family involvement is key to ensuring personalized and culturally sensitive end-of-life care in the community, which can impact patients' quality of life and quality of death (Agustini et al., 2025). Families have been positioned as key partners in providing palliative care to patients. The focus of palliative care has shifted from hospitals to community-based care, where families serve as the primary link between patients, healthcare providers, and the community. The transition from hospital to home is a critical moment that demands the family's ability to manage patient care. Challenges arise at various stages of the patient and family caregiver journey toward the end of life, including communication issues, limited time for caregiving, and a lack of appropriate support facilities. Patients and families face daily challenges due to life-threatening conditions and changing family dynamics, including traumatic experiences and feelings of grief when access to care is limited (Kallis et al., 2025).

Community-based home-based palliative care is a crucial need for the health of palliative care patients in the community because it can provide a comfortable and safe environment for terminally ill patients and their families, reducing stress and anxiety associated with hospitalization (Do Prado et al., 2024). Family experiences reflect the daily challenges of facing terminal illness, emphasizing the importance of a patient- and family-centered approach to care (Jacob et al., 2025). A comprehensive understanding of the family's role in palliative care is crucial to explore to provide empirical evidence regarding the family's important role in caring for palliative care patients in the community. The purpose of this study is to identify and summarize the results of various recent studies related to the role of the family in palliative care for patients in the community.

2. RESEARCH METHOD

This study was designed using a systematic literature review approach to identify and summarize various recent research findings related to the role of families in palliative care for patients in the community, The review process was conducted following established a systematic literature review procedures, including identification, selection, evaluation, and synthesis of relevant studies (Libório et al., 2023; Paul & Barari, 2022). Study question: What is the role of families in caring for palliative care patients in the community? Topic coverage: Various family roles in caring for palliative care patients in the community. Literature search: conducted in the international databases PubMed and Science Direct. The literature search was conducted using the keywords "family role" OR "family support" AND "palliative" OR "palliative care."

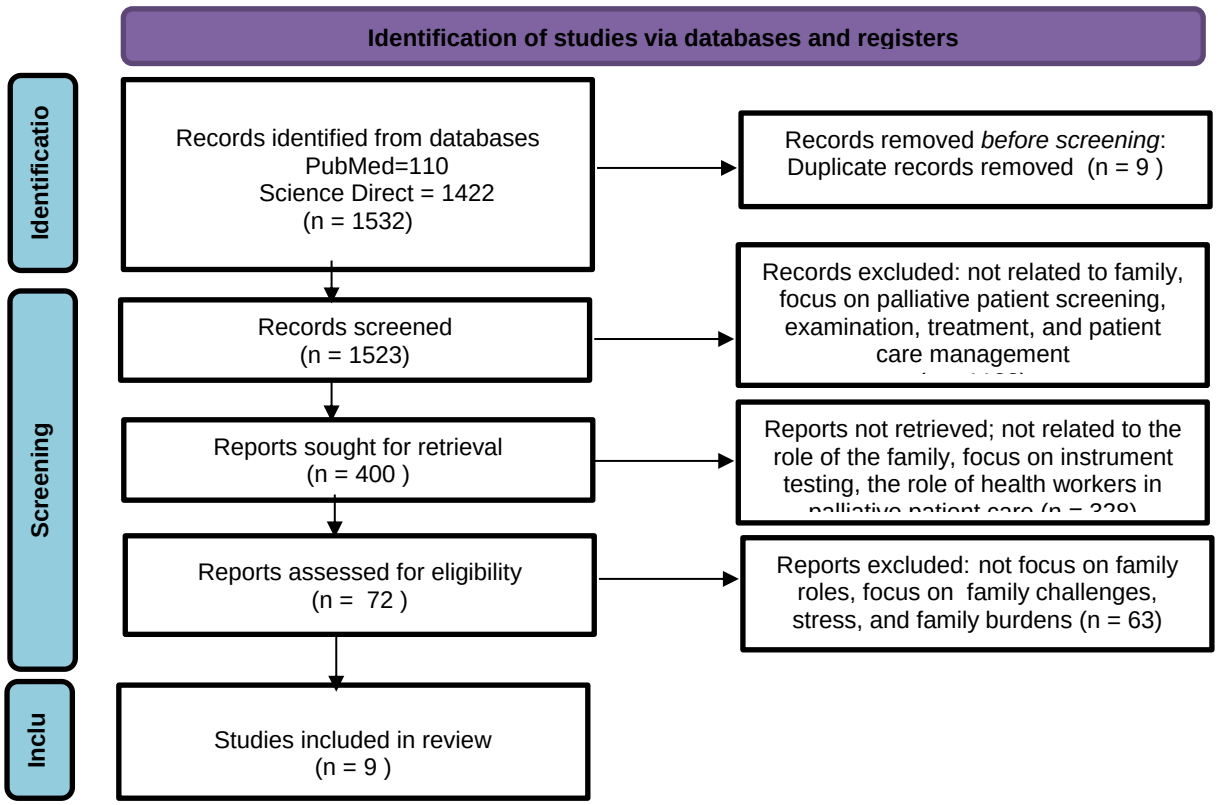

Figure 1 Prism diagram of article selection (Page et al., 2021)

Literature selection took into account the inclusion criteria conducted using the PEO approach, including Population, Exposure, and Outcome (Capili, 2020), Population: families of palliative care patients, Exposure: various roles played by families of palliative care patients, and Outcome: met the palliative care needs of patients. Only research articles published between 2020 and 2025 were considered. Article selection was conducted through database identification, title screening, abstract screening, and full-text reading (Page et al., 2021) (Figure 1). Data analysis was conducted descriptively through data extraction based on the researcher's name and year of study, country, study design, and sample size, and research results.

3. RESULTS AND DISCUSSION

A total of nine research articles were selected as literature to address the objectives of this study. Approximately 827 family caregivers of palliative care patients participated in the

primary research that served as the literature for this study. The families of palliative care patients came from various countries, including Ireland, Austria, Sweden, Indonesia, Germany, Canada, China, and several other countries, including Norway, Slovenia, Spain, Switzerland, and the United Kingdom (UK), or from three major continents: Europe, Asia, and the Americas.

Table 1. Various research findings related to the role of the family in caring for palliative patients in the community

Researcher (Year)	Country	Research design and Sample size	Results
(McCauley et al., 2023)	Ireland	Design: Qualitative Grounded Theory Sample: 15 patients and 21 families	The role of family support in palliative care is manifested primarily through the exchange of emotional support and support for involvement in care decision-making. The dynamics of support are influenced by a sense of reciprocal obligation and can manifest in the form of self-disclosure. These findings underscore the importance of psychosocial interventions that can facilitate supportive relationships between patients and their families as caregivers, thereby improving the quality of care and the well-being of both.
(Kreyer et al., 2024)	Austria	Design: Retrospective mixed methods Sample: 484 family	Effective support roles include information, ounselling, training, coordination, and referrals. Families have broad support needs, including support in caring for the patient and support for their own health and well-being. Key needs include time for themselves and assistance with coping with feelings or concerns
(Milberg et al., 2020)	Sweden	Design: Cross-sectional study Sample: 209 families	Six key factors were found to be most influential: support from extended family members, a sense of security in home palliative care, opportunities for caregivers to rest, family members living alone, being a child of the patient, which tends to be negatively correlated with feelings of support, and the perception that the patient also receives support from other family members. These findings underscore the relevance of

			Family Systems Theory in the palliative care context.
(Effendy et al., 2022)	Indonesia	Design: Qualitative Descriptive Sample: 12 patient families.	Families participated in home-based care supported by nurses. Home-based care is beneficial because it provides holistic care with a family-centered approach
(Azhar et al., 2025)	Germany	Design: a qualitative exploratory study Sample: 15 families	Family caregivers employ a variety of protective strategies, including social network engagement, information seeking, and life goal identification.
(A. Tan et al., 2021)	Canada	Design: Qualitative with an Appreciative Inquiry approach. Sample: 8 families, 26 home care team members, 1 patient, and 9 family physicians	Families build relationships of communication and collaboration with the healthcare team. The family doctor/patient relationship should be protected and encouraged by all healthcare providers, while greater system flexibility is needed to respond more effectively to patients. Caregivers need more education about the benefits of palliative care, as well as improved public discourse on mortality.
(Xu et al., 2024)	China	Design: Qualitative descriptive phenomenological study Sample: 15 families	Families play a central role in palliative care, especially during the transition from hospital to home care. Families are directly responsible for daily care tasks, such as pain management, medication administration, and basic patient care. They serve as emotional support providers, helping patients and themselves cope with the stress and challenges that arise during the transition. They serve as care coordinators, bridging communication between the hospital and the community, utilizing support networks and telemedicine services to ensure continuity and coordination of care.
(Martina et al., 2022)	Indonesia	Design: Qualitative study	Families play a key role in establishing open communication between the

		Sample: 31 participants, including 16 patients and 15 families	family and the patient, as well as with healthcare professionals, and communicating important information and perspectives on providing information, communicating bad news, and decision-making.
(Tripodoro et al., 2024)	Several countries, including Norway, Slovenia, Spain, Sweden, Switzerland, and the United Kingdom (UK).	Design: Qualitative descriptive study Sample: 48 families, 57 patients, and 53 healthcare workers.	Five themes were identified across countries: family as a limited care resource, active family role in decision-making, open communication with family, burden of care, and sociocultural mandates. Families play a crucial role in providing informal care during severe illness, often acting as the sole resource. Patients acknowledged the stress experienced by family caregivers, highlighting sociocultural influences, relational autonomy, burden of care, and the feminization of care.

Table 1 found that families have a variety of roles in caring for palliative patients in the community, including providing emotional support, involvement in care decision-making, informational support, counseling, training, coordination, and referrals, as well as providing a space for patients to get support from other family members, building communication and collaboration relationships with the health care team, having a central role during the transition from hospital to home care, being directly responsible for daily care tasks, bridging communication between the hospital and the community, utilizing telemedicine support networks to ensure continuity and coordination of care, sociocultural mandates, informal care during the terminal period, and the role of maintaining their own health

This study found and summarized that families play a central role in the care of palliative care patients in the community, especially during the transition from hospital to home. The family's role includes 1) emotional and social support: helping patients and themselves cope with stress, providing counseling, and involving extended family members; 2) Direct care and coordination: being responsible for daily tasks such as pain management, medication administration, and basic care, while also bridging communication between the hospital, community, and healthcare team, including the use of telemedicine; 3) Involvement in decision-making and communication: actively participating in medical decisions, establishing open communication with patients and healthcare professionals; 4) Informational and educational support: providing information, training, and education about the benefits of palliative care, as well as understanding mortality; 5) Socio-cultural burden and mandate: bearing the burden of patient care, often being the sole source of informal care, with social and cultural pressures emphasizing family responsibilities; 6) Protective strategies: utilizing social networks, seeking information, and finding purpose in life to support their role.

The role of family in emotional and social support is crucial in helping patients cope with the anxiety and uncertainty associated with palliative care due to terminal illnesses, while also supporting the caregiver's own psychological well-being (McCauley et al., 2023). Research has

found that palliative care patients face interconnected biological, psychological, and social challenges. Physical symptoms limit daily activities and independence, increasing dependence on family. Patients' social lives are affected by limited mobility, isolation, and the inability to participate in social activities as before, ultimately leading to frustration and psychological stress (Gonçalves et al., 2025). It is also important to expand the role and support to include family members who live far away to reflect and enhance the importance of social networks in satisfying palliative care (Milberg et al., 2020)

The family's role in direct care and coordination extends beyond performing daily care tasks such as pain management and medication administration, but also as a liaison between the patient, the hospital, and the community healthcare team (Xu et al., 2024). Research has found that family caregivers persist because of their sense of responsibility and compassion, with a desire to be involved in patient care, feel in control, and have their role recognized, while also requiring respite. Families require more intensive support from healthcare services, the implementation of person-centered care, psychoeducational interventions by nurses, and the development of tools to map family needs to ensure effective communication and support (Nysaeter et al., 2024). The use of technology such as telemedicine adds flexibility and continuity of care, in line with recommendations for home care integration (Xu et al., 2024)

Family involvement in decision-making and communication emphasizes the principle of relational autonomy, where the final decision rests not solely with the patient but is also influenced by interactions with family and healthcare professionals. This is crucial to ensure that the care provided aligns with the patient's and family's needs (McCauley et al., 2023; Tripodoro et al., 2024). The role of the family, good communication, and practical assistance are crucial factors influencing patient care. Nurses act as advocates and educators, balancing care delivery with realistic expectations (Israfil et al., 2025). Family involvement not only facilitates a shared understanding of the patient's condition and treatment options but also strengthens adherence to the care plan through shared accountability. Effective communication between nurses, patients, and families helps prevent misunderstandings, reduces conflict in decision-making, and supports ethical care that respects the family's cultural, social, and spiritual values (Ghosh et al., 2025; Kishino et al., 2022).

Information and educational support are important strategies for improving family competency in patient care and understanding the end-of-life process (Kreyer et al., 2024). Health literacy and specific training, such as symptom management and grief counseling, play a role in reducing anxiety and increasing caregiver preparedness (Xu et al., 2024). Well-implemented palliative and end-of-life care interventions can be beneficial in improving patient health status, reducing the burden on families as caregivers, and reducing symptoms of depression and anxiety in patients and families (Piamjariyakul et al., 2024). The integration of smart technology in palliative care supports a shift toward more personalized, efficient, and accessible care models. Technologies such as telemedicine and mobile applications can be options for providing information and training to families, proven to improve patient quality of life and reduce the burden on families as caregivers. To maximize these benefits, specialized training programs are needed to reduce the digital divide (Maguraushe & Ndlovu, 2024; Y. H. Tan et al., 2024). This study also highlights the significant socio-cultural burden and mandates that family members assume primary responsibility for care. This burden is not only physical and emotional but is also influenced by cultural norms that emphasize family obligations in caring for sick members (Tripodoro et al., 2024; Xu et al., 2024)..Cultural factors such as the involvement of religious leaders, concerns about death, and preferences for alternative treatments can influence family support in palliative care for patients (Israfil et al., 2025).

Families play a crucial role in developing protective strategies, including leveraging social networks, seeking additional information, and finding meaningful purpose in their role

as caregivers (Azhar et al., 2025). These strategies align with literature emphasizing the importance of caregiver coping and resilience in palliative care. Families' perceptions of home care are positive, and patients demonstrate adaptive coping skills. Support from healthcare professionals and family training aiscrucial to ensure appropriate care is provided to improve the patient's quality of life physically, socially, spiritually, and psychologically, while positively impacting the family and the patient as caregivers (Dasat et al., 2024). Overall, this study found and confirmed that the family's role in palliative care is highly multidimensional, encompassing emotional, practical, coordinative, educational, and cultural aspects. Support from the nursing, health care systems, and the community needs to be strengthened to ease the burden on families and ensure optimal quality care for palliative care patients (Abdel-aziz et al., 2025). Multiple indicators related to patients, nurses, families, health services, and technology use are essential in the palliative care model for patients requiring long-term end-of-life care (Agustini et al., 2025)

Clinical Implications for Community Nursing

The findings of this study emphasize that palliative care interventions must integrate families as active partners. Education, counseling, and social support programs should be targeted not only to patients but also to families as primary caregivers. Nursing interventions and health services need to support family engagement through supportive mechanisms such as telemedicine, cross-service coordination, and policies that can reduce unrealistic socio-cultural burdens on families and palliative care patients..

4. CONCLUSION

Families play a crucial role in providing palliative care in the community, particularly during the transition from hospital to home. Families assume a variety of roles, including offering emotional support, providing direct care, coordinating services, participating in decision-making, providing health education, and implementing adaptive coping strategies, often while facing significant social and cultural challenges. To enhance their caregiving capacity and symptom management skills, families require ongoing education and training. Effective coordination between families, hospitals, and healthcare professionals, facilitated through telemedicine platforms or structured communication systems, is crucial for achieving integrated patient care. Psychosocial support and strengthening community relationships are crucial for reducing the emotional and social burden experienced by families as primary caregivers of palliative care patients. Future research should focus on family-centered interventions and evaluate the role of families in caring for palliative care patients in the community. Cultural aspects and the integration of community technology are important aspects that need to be developed in further research.

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