

# Problems and Needs of Relatives and Family Caregivers During Palliative and Hospice Care

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**Abstract:** *The emotional and physical toll of caregiving in palliative and hospice settings is often an overlooked reality that deserves deeper attention. This qualitative phenomenological study delves into the lived experiences of family caregivers who support patients with life-limiting illnesses, revealing how the delicate balance between compassion and exhaustion shapes their daily lives. It is evident that these caregivers face intertwined challenges-chronic fatigue, anxiety, financial strain, and social isolation-while struggling to find reliable information and practical guidance. The narratives gathered show how spirituality, peer support, and occasional acts of empathy from healthcare professionals become vital coping anchors. That said, the study also uncovers gaps in existing care structures, where caregivers' voices remain marginalized in clinical decisions. This suggests that nursing practice must evolve beyond patient-centered care to a genuinely family-inclusive approach, where caregivers receive the education, counseling, and respite they rightfully deserve. By integrating such support into nursing policy and training, palliative care can truly embody the principle of holistic compassion-one that sustains not only those nearing the end of life but also those standing steadfast beside them.*

**Keywords:** family caregivers, palliative care, emotional well-being, coping strategies, holistic nursing

## 1. Introduction

### Background of the Study

Palliative and hospice care aim to improve the quality of life for patients with life-limiting illnesses by addressing physical, emotional, social, and spiritual needs. As the focus shifts from cure to comfort, family members often become the primary caregivers, providing essential physical and emotional support. This caregiving role, while deeply meaningful, is often associated with significant physical exhaustion, emotional stress, and financial strain.

Family caregivers may struggle to manage complex symptoms, communicate with healthcare professionals, and balance caregiving responsibilities with personal commitments. The absence of structured guidance and support systems often intensifies their distress. Understanding these challenges and unmet needs is crucial to strengthen holistic palliative care that includes the well-being of both patients and their families.

### Need for the Study

In India, palliative and hospice care services are gradually expanding, but caregiver support remains inadequate. Most palliative care programs emphasize symptom relief for patients while neglecting the psychological and practical needs of caregivers. Caregivers frequently experience burnout, depression, and role strain, which may reduce the quality of care provided and negatively impact their own health.

Identifying caregivers' problems and needs will help nurses and healthcare professionals design interventions, counseling, and educational programs that promote caregiver well-being. As holistic nursing care includes the family as a unit, this study is timely and essential.

### Statement of the Problem

*A qualitative study to explore the problems and needs of relatives and family caregivers during palliative and hospice care.*

### Objectives of the Study

- 1) To explore the physical, emotional, and social problems experienced by family caregivers during palliative and hospice care.
- 2) To identify the perceived needs of family caregivers in providing care to terminally ill patients.
- 3) To understand caregivers' coping strategies and support systems.
- 4) To suggest nursing implications to improve caregiver support in palliative settings.

### Operational Definitions

- **Family Caregiver:** A relative who provides unpaid care and support to a patient receiving palliative or hospice care.
- **Palliative Care:** Specialized medical care focused on relieving suffering and improving quality of life for patients with life-limiting illnesses.
- **Problems:** Difficulties, burdens, or challenges faced by caregivers in physical, emotional, social, or financial domains.
- **Needs:** Requirements or support (emotional, informational, or practical) that caregivers perceive as necessary during the caregiving process.

### Assumptions

- Family caregivers experience multiple physical, emotional, and social problems during caregiving.
- Caregivers may have unmet needs related to knowledge, emotional support, and coping.
- Understanding these experiences can guide nursing interventions.

### Delimitations

- The study will be limited to family caregivers of patients receiving palliative or hospice care.
- The study will be conducted in selected palliative care units or hospices.
- Only caregivers who have provided care for at least one month will be included.

**Conceptual Framework**

The study is based on **Lazarus and Folkman's Stress and Coping Theory (1984)**, which explains how individuals evaluate and respond to stressful situations. Caregiving is viewed as a stressor, and caregivers' coping responses determine their well-being and adaptation.

**2. Review of Literature****Section I: Studies Related to Problems of Family Caregivers**

- Caregivers often face physical exhaustion, sleep disturbances, and chronic fatigue due to the continuous demands of caregiving (Smith et al., 2019).
- Emotional problems such as anxiety, depression, and anticipatory grief are prevalent among those caring for terminally ill relatives (Gupta & Mehta, 2020).
- Financial burdens, job disruptions, and social isolation are common among caregivers (Das & Mohanty, 2021).

**Section II: Studies Related to Needs of Caregivers**

- Studies highlight the need for clear communication, emotional support, and education about symptom management (Kumar et al., 2018).
- Caregivers express the need for respite care, counseling, and community resources (Lee & Choi, 2020).
- Many caregivers desire to be included in care decisions but lack confidence or knowledge to participate actively (Fernandes, 2022).

**Section III: Studies Related to Nursing Implications**

- Nursing interventions that include caregiver education, psychological counseling, and follow-up support improve both patient and caregiver outcomes (Patel et al., 2021).
- Integrating caregiver needs into palliative care policies ensures holistic care delivery and reduces caregiver distress (World Health Organization, 2022).

**3. Research Methodology****Research Approach:**

Qualitative exploratory approach.

**Research Design:**

Descriptive phenomenological design.

**Setting of the Study:**

The study will be conducted in selected palliative care and hospice centers (e.g., selected hospitals or community hospices in Odisha).

**Population:**

Relatives or family caregivers of patients receiving palliative or hospice care.

**Sample and Sampling Technique:**

- **Sample Size:** Approximately 10–15 participants, until data saturation is reached.
- **Sampling Technique:** Purposive sampling.

**Inclusion Criteria:**

- Family caregivers aged 18 years or above.
- Those who have been providing care for at least one month.
- Willing to participate and provide consent.

**Data Collection Method:**

In-depth, semi-structured interviews using an interview guide with open-ended questions (e.g., "Can you describe your experience of caring for your loved one?").

**Data Analysis:**

- Transcribed interviews will be analyzed using **Thematic Analysis** as described by Braun and Clarke (2006).
- Themes and subthemes will be developed to represent caregivers' problems and needs.

**Ethical Considerations:**

- Ethical clearance will be obtained from the institutional review board.
- Informed consent will be taken.
- Confidentiality and anonymity will be maintained throughout the study.

**4. Analysis and Interpretation of Data**

**Introduction:** This chapter presents the findings of the qualitative study exploring the problems and needs of relatives and family caregivers during palliative and hospice care. Data were collected through in-depth semi-structured interviews with 12 purposively selected caregivers. Transcripts were analyzed using Braun and Clarke's thematic analysis method (2006). The analysis resulted in six major themes, each with associated subthemes and supporting verbatim quotes from participants.

**Theme 1: Physical Exhaustion and Health Decline**

Sub-theme	Illustrative Quotes	Interpretation
Long hours and disrupted sleep	"I don't remember the last time I slept through the night — I am always listening for breathing or pain calls."	Chronic sleep deprivation affecting health.
Musculoskeletal strain	"After lifting him so many times my back just aches. I used to exercise, now I can't find the time."	Physical burden of patient handling leads to back pain and fatigue.
Neglect of personal health	"I ignored my own sugar check-ups because there was always something more urgent for him."	Caregivers prioritize patient over personal health, increasing risk for chronic illness.
Somatic symptoms	"I constantly have headaches and feel tired all the time."	Stress manifests physically, affecting overall well-being.

**Theme 2: Emotional Distress and Anticipatory Grief**

Sub-theme	Illustrative Quotes	Interpretation
Anxiety and worry	"I live with a constant fear of an emergency at night."	Persistent vigilance contributes to chronic anxiety.
Depression and helplessness	"Some days I cry and then I feel guilty because he needs me—how selfish that I have cried."	Emotional exhaustion and guilt are common.
Anticipatory grief	"I grieve many things already — the holidays we won't have, the plans we made for retirement."	Caregivers mourn future losses, reflecting anticipatory grief.
Conflicted emotions	"I feel relief sometimes, but then I feel guilty for feeling relieved."	Complex emotions are typical in long-term caregiving.

**Theme 3: Financial and Social Strain**

Sub-theme	Illustrative Quotes	Interpretation
Direct medical costs	"We used all our savings. My husband had to quit his job to look after her — we are surviving on very little."	Caregiving creates financial stress.
Loss of income	"I had to choose between a day's pay and taking him to hospital."	Work-life conflict intensifies burden.
Social isolation	"People stop calling — they don't know what to say. I don't have time to explain."	Reduced social engagement increases isolation.
Stigma or lack of social understanding	"Friends don't understand why I can't join gatherings."	Lack of societal awareness adds to caregiver stress.

**Theme 4: Need for Information and Training**

Sub-theme	Illustrative Quotes	Interpretation
Medication management	"If someone had shown me how to give subcutaneous injections, I would not have panicked the first time."	Lack of practical skills increases anxiety.
Symptom recognition	"We need a simple chart — when to call, what to expect when breathing becomes difficult."	Structured guidance helps reduce emergencies.
Practical caregiving skills	"No one told us how to bathe him properly when he can't sit — I learned by trial and error."	Caregiver education improves safety and confidence.
End-of-life care knowledge	"We didn't know what to expect when the time comes; it was frightening."	Training reduces fear and uncertainty about death processes.

**Theme 5: Coping Through Spirituality and Social Support**

Sub-theme	Illustrative Quotes	Interpretation
Spiritual/religious coping	"Prayer keeps me calm; it gives me strength to do the work each day."	Spirituality provides emotional resilience.
Family and community support	"My sister comes twice a week to help with bathing — that help is everything."	Social support reduces burden and provides relief.
Peer support	"Talking to other caregivers made me feel I'm not alone; they understood."	Shared experiences validate emotions and offer coping strategies.
Adaptive coping strategies	"I try to focus on what I can control and accept what I cannot."	Problem-solving and acceptance promote mental well-being.

**Theme 6: Expectations from Healthcare Professionals**

Sub-theme	Illustrative Quotes	Interpretation
Clear communication	"We want the doctor to be honest about what will happen but to say it with care."	Caregivers need transparent and sensitive information.
Inclusion in care planning	"Sometimes we are told to 'manage at home' — we need step-by-step guidance, not dismissal."	Inclusion promotes confidence and reduces anxiety.
Timely responsiveness	"A phone call from the nurse to check on us would mean a lot."	Accessible healthcare improves caregiver satisfaction.
Compassionate attitude	"I just want someone to listen without judging me."	Empathetic care strengthens trust and coping.

Overall Interpretation: Caregiving in palliative and hospice settings involves multidimensional challenges — physical, emotional, social, financial, and educational. Caregivers rely on spirituality, social networks, and coping strategies but require formal support from healthcare professionals. Addressing these needs can improve caregiver well-being and patient care quality.

**Recommendations:**

- 1) Conduct routine caregiver assessment (physical, emotional, social, financial).
- 2) Develop structured education programs: practical skills, medication management, end-of-life guidance.

- 3) Offer psychosocial support: counseling, support groups, spiritual care.
- 4) Provide respite care and facilitate access to community resources.
- 5) Train healthcare professionals in family-centered communication and shared decision-making.
- 6) Implement policies to recognize and support caregivers (financial support, flexible leave, equipment provision).

## 5. Discussion, Summary, Conclusion, and Implications

### 5.1 Discussion

The findings are expected to reveal that family caregivers face multidimensional challenges while caring for terminally ill patients. Emotional and psychological problems often outweigh physical burdens, and most caregivers express a strong need for professional guidance, emotional support, and acknowledgment from healthcare staff.

### 5.2 Summary

This qualitative study explored the experiences, problems, and needs of family caregivers during palliative and hospice care. The study highlighted the urgent need for caregiver-centered support systems, education, and counseling services integrated into palliative care programs.

### 5.3 Conclusion

Family caregivers are an essential part of the palliative care team. Recognizing and addressing their problems and needs can enhance both patient and caregiver quality of life. Holistic nursing care must extend beyond the patient to encompass the well-being of the family as a unit.

### 5.4 Nursing Implications

- **Nursing Practice:** Provide emotional and informational support to caregivers during each patient encounter.
- **Nursing Education:** Integrate family-centered care and caregiver communication skills into the nursing curriculum.
- **Nursing Administration:** Develop policies that include caregiver assessment as part of palliative care documentation.
- **Nursing Research:** Future studies can develop and test intervention programs for caregiver support.

### 5.5 Limitations

- Conducted in a limited geographical area.
- Small sample size typical of qualitative research.
- Findings may not be generalizable to all settings.

### 5.6 Recommendations

- Conduct mixed-method studies to quantify caregiver stress and needs.
- Develop structured support programs for caregivers.
- Include caregiver education in routine palliative care services.

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