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Unseen Burdens: The Hidden Struggles of Primary Caregivers in Palliative Care Environments

Aspin R.

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ABSTRACT

Background: Palliative care aims to enhance the quality of life for patients with life-limiting illnesses. While much attention is given to patient comfort, the vital role of primary caregivers often family members who provide continuous physical and emotional support is frequently overlooked. These caregivers face a multitude of hidden struggles that include emotional exhaustion, physical fatigue, social isolation, and financial strain.

Objectives: This study aims to explore the lived experiences and hidden burdens of primary caregivers in palliative care environments. It seeks to understand their emotional, physical, social, and financial challenges, identify coping mechanisms, and gather their suggestions for support.

Methods: A qualitative phenomenological research design was employed. Primary caregivers of patients receiving palliative care were selected using purposive sampling. In-depth, semi-structured interviews were conducted until data saturation was achieved. Thematic analysis was used to analyze the narratives and identify recurring patterns and themes.

Results: Emerging themes included emotional vulnerability, disrupted personal lives, lack of formal support, cultural expectations of caregiving, and adaptive coping strategies such as spiritual reliance and informal peer support. Many caregivers reported neglect of self-care, anxiety, anticipatory grief, and a desire for structured support systems including respite care and psychological counseling.

Conclusion: The study reveals that caregiving in palliative care settings entails profound, often invisible burdens. There is a critical need to integrate caregiver focused support services within the palliative care framework. Recognizing caregivers as co-recipients of care, rather than mere providers, can contribute significantly to holistic and compassionate palliative care.

KEYWORDS

• Caregiver burden • Palliative care • Lived experience • Qualitative study • Emotional distress • Support needs • Coping strategies

AUTHOR'S AFFILIATION:

Professor Cum Vice Principal, Fatima College of Nursing, Gorakhpur, Uttar Pradesh 273014, India.

CORRESPONDING AUTHOR:

Aspin R., Professor Cum Vice Principal, Fatima College of Nursing, Gorakhpur, Uttar Pradesh 273014, India.
E-mail: nursing@aspinr.com

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INTRODUCTION

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems. In this context, caregivers, often family members, play a vital role by providing sustained emotional, physical, and practical support to the patients. However, their silent suffering frequently goes unnoticed in the larger healthcare narrative. These primary caregivers serve as the backbone of palliative care, particularly in home based or resource limited settings, yet their experiences remain inadequately addressed or studied in depth.[1]

Caring for terminally ill patients can be both rewarding and emotionally devastating. The dual responsibility of tending to the complex needs of patients while managing their own personal lives places caregivers under immense pressure. This often leads to caregiver burden, a multifaceted stress response that may include emotional exhaustion, anxiety, depression, sleep disturbances, and social withdrawal. The progression of the patient's illness intensifies the psychological load on caregivers, resulting in grief, anticipatory loss, and sometimes trauma that can persist even after the patient's death. Despite these challenges, caregivers continue to offer unconditional care, driven by love, obligation, or cultural expectations, often at the expense of their own health and well-being.[2]

In India, where cultural norms emphasize family responsibility for the care of ill or elderly members, the role of informal caregivers is particularly significant. However, they receive minimal institutional support, counseling, or formal training. The societal tendency to regard caregiving as a duty rather than a need for skilled care adds to the neglect of caregiver support mechanisms. Many caregivers in India, especially women, tend to sacrifice career, personal aspirations, and even their own health to prioritize caregiving duties. The lack of structured caregiver support programs, respite care, or psychological counseling facilities exacerbates this issue.[3]

Several studies have explored the medical and emotional needs of palliative patients, but qualitative investigations into the lived experiences of caregivers are limited. A deeper understanding of their struggles ranging from financial burdens, role conflict, emotional burnout, to social isolation is essential to inform policy and practice. Qualitative inquiry is particularly suitable to explore the nuanced and subjective experiences of caregivers, providing a platform for their voices to be heard authentically and empathetically.[4]

The World Health Organization has emphasized the need for family centered care and holistic support in palliative environments. As caregiving is often delivered in home settings, caregivers frequently serve as surrogate health professionals, learning procedures and handling medication, yet their emotional resilience is rarely evaluated. Unattended caregiver distress can affect the quality of patient care, leading to burnout and compromised decisions. Thus, recognizing and addressing caregiver burdens is not just an ethical necessity but also a healthcare priority.[5]

In this light, the present study, "Unseen Burdens: The Hidden Struggles of Primary Caregivers in Palliative Care Environments," aims to explore the hidden dimensions of caregiving through qualitative methods. By documenting and interpreting caregivers' lived experiences, this study seeks to contribute to a more compassionate and comprehensive palliative care model that not only addresses patients' needs but also supports and uplifts their caregivers. This research may also guide healthcare professionals, policymakers, and social workers in designing targeted interventions for caregiver support, stress relief, and resilience-building.[6]

Problem Statement

Palliative care focuses on improving the quality of life of individuals with life-limiting illnesses, yet the role and experiences of primary caregivers who provide daily, sustained, and emotionally intensive support remain largely overlooked. In many settings, especially in India, caregiving responsibilities are primarily assumed by family members with minimal formal training or institutional support. These caregivers are exposed to a multitude of hidden struggles including emotional exhaustion, social isolation, financial burden, and lack of self-care, which often go unrecognized in clinical practice. The silence surrounding their

experiences contributes to unmet psychosocial needs, potentially compromising both caregiver and patient outcomes.

Despite the growing global emphasis on holistic palliative care, there exists a gap in qualitative research exploring the lived experiences, perceived burdens, and coping mechanisms of these caregivers. Understanding their hidden challenges is crucial to developing caregiver-centered support systems and policies. Therefore, this study aims to explore and document the subjective struggles faced by primary caregivers of palliative care patients, thereby illuminating the invisible dimensions of caregiving and informing comprehensive palliative care practices.

Objectives of the Study

1. To identify the emotional, physical, social, and financial challenges experienced by primary caregivers of palliative care patients.
2. To understand the coping mechanisms and support systems utilized by these caregivers.
3. To explore the impact of caregiving on the personal lives and mental well-being of primary caregivers.
4. To gather caregivers' suggestions for improving palliative care support services and caregiver resources.

Operational Definitions

1. **Primary Caregiver:** For the purpose of this study, a *primary caregiver* refers to an individual (usually a family member or close relative) who assumes the major responsibility for providing physical, emotional, and/or practical support to a patient receiving palliative care. This person may or may not have formal training and is not necessarily a professional healthcare provider.
2. **Palliative Care Environment:** *Palliative care environment* refers to the setting in which palliative care is provided. This includes homes, hospices, or hospital-based palliative units where the focus is on improving the quality of life of patients with life-limiting illnesses by alleviating pain and distressing symptoms.
3. **Hidden Struggles:** *Hidden struggles* denote the internal, often unspoken challenges faced by caregivers. These include emotional stress, psychological trauma, physical exhaustion, financial hardship, social isolation, and role conflict, which are not always visible or acknowledged by the healthcare system or society.
4. **Caregiver Burden:** *Caregiver burden* is defined as the multidimensional strain experienced by the caregiver due to prolonged caregiving duties. This includes physical fatigue, emotional distress, financial strain, and reduced personal time, which collectively impact the caregiver's quality of life and well-being.
5. **Lived Experience:** *Lived experience* refers to the personal, first-hand accounts of caregivers regarding their day-to-day realities, thoughts, feelings, and challenges while caring for a palliative patient. These subjective experiences are explored using qualitative methods such as in-depth interviews.

METHODOLOGY

Research Approach and Design

The present study adopted a qualitative research approach using a phenomenological research design. Phenomenology was appropriate for this study as it aimed to explore and understand the lived experiences and hidden struggles of primary caregivers in palliative care settings. This approach enabled in-depth exploration of subjective feelings, meanings, and perceptions that are often not captured through quantitative methods.

Research Setting

The present study was conducted at Fatima Hospital, Gorakhpur, a healthcare institution that provides palliative care services to patients with chronic and life-limiting illnesses. The hospital serves both urban and rural populations from the surrounding regions and includes a dedicated team of medical and nursing professionals involved in long-term patient care.

Primary caregivers of patients receiving palliative care at Fatima Hospital were identified and approached for participation. Data collection was carried out in a private and quiet setting within the hospital premises to ensure participant comfort and confidentiality.

For caregivers unable to meet in person, provisions were made to conduct interviews telephonically or via video conferencing, based on convenience and consent.

Population

The target population was**primary caregivers of patients receiving palliative care**, who are involved in day-to-day caregiving and emotional support.

Sampling Technique

A **purposive sampling** technique used to select participants who meet the inclusion criteria and can provide rich, relevant, and diverse information.

Sample size

A total of **12 primary caregivers** of palliative care patients were included in the study. These participants were selected purposively from Fatima Hospital, Gorakhpur, as they met the inclusion criteria and were willing to share their caregiving experiences.

Selection criteria

Inclusion Criteria

- Primary caregivers aged 18 years and above.
- Caregivers providing care to palliative patients for at least one month.
- Caregivers who are willing to participate and provide informed consent.
- Caregivers who can communicate in English or Hindi.

Exclusion Criteria

- Caregivers with diagnosed psychiatric illnesses that may affect participation.
- Paid caregivers or professional healthcare workers.
- Caregivers unwilling or unable to provide consent or participate in an interview.

Data Collection Method

Data collected through **semi-structured, in-depth interviews** using an interview guide developed by the researcher. Interviews conducted in a private and quiet setting, either face-to-face or via phone/video call. Each interview last approximately 30–45 minutes with participant consent. Field notes also be maintained to capture non-verbal cues and contextual information.

Data Collection Tool

1. **Interview Guide**: Consisting of open-ended questions designed to explore various dimensions of caregiver burden, emotional and physical challenges, coping strategies, and suggestions for support.
2. **Demographic Data Sheet**: To collect participant background information such as age, gender, relationship to the patient, duration of caregiving, and living arrangement.

Data Analysis

Data wasanalyzed using **thematic analysis**, following Braun and Clarke's six-step framework:

1. Familiarization with data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Verbatim transcripts of the interviews were coded manually. Themes were developed inductively, and illustrative quotes from participants were included to enrich interpretation.

Ethical Considerations: Ethical approval was obtained from the Institutional Ethics Committee prior to data collection. Informed consent was taken from all participants. Confidentiality, anonymity, and voluntary participation were ensured. Participants were informed of their right to withdraw at any stage without any consequences.

CONCEPTUAL FRAMEWORK

This study is guided by **Roy's Adaptation Model** and **Lazarus and Folkman's Transactional Model of Stress and Coping**, both of which help to conceptualize the caregiver's experiences in the context of stress, burden, and adaptation.

RESULTS

A total of **12 primary caregivers** participated in the study. Thematic analysis of their narratives revealed **five major themes** and corresponding subthemes that captured the hidden burdens and coping mechanisms of caregivers in palliative care environments.

Table 1: Thematic Summary of Lived Experiences of Primary Caregivers in Palliative Care Settings

Theme	Description
Emotional Exhaustion	Caregivers experienced chronic emotional fatigue, anxiety, sadness, and anticipatory grief due to prolonged exposure to terminal illness and the stress of watching their loved ones suffer.
Disrupted Personal Life	Participants reported major disruptions in their daily life, including quitting jobs, losing personal time, isolation from friends and social life, and neglect of their own health and well-being.
Physical & Financial Strain	Physical exhaustion from caregiving tasks and financial burden due to medical expenses and loss of income were significant stressors faced by most participants.
Inadequate Support Systems	Many caregivers reported inadequate guidance from health professionals post-discharge, absence of follow-up care, and lack of emotional or psychological support services.
Adaptive Coping Strategies	Despite the challenges, caregivers adapted through religious faith, acceptance of the situation, self-motivation, and informal support from family or community, which helped them manage caregiving stress.

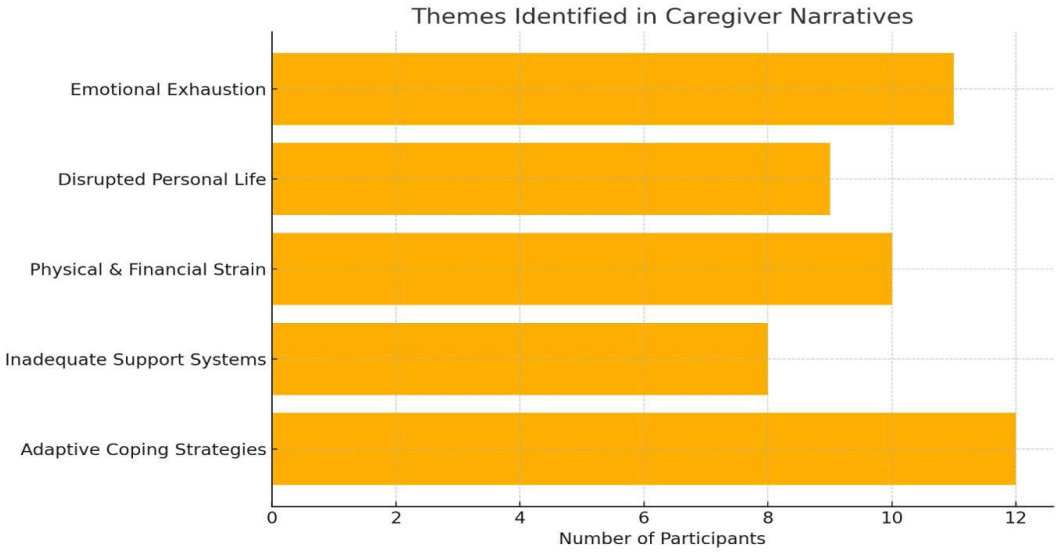

Figure 1: Themes identified in caregiver narratives

SUMMARY OF FINDINGS

The findings revealed that primary caregivers experience deep emotional, physical, and social burdens in silence. Despite lacking professional support, many developed spiritual or personal coping mechanisms. These results highlight the urgent need for caregiver centered interventions within palliative care programs.

DISCUSSION

The findings of this qualitative study revealed that primary caregivers in palliative care settings experience significant emotional, physical, social, and financial burdens that are often invisible and unacknowledged. The emergent themes emotional exhaustion, disruption of personal life, physical and financial strain, inadequate support, and adaptive coping highlight the multidimensional challenges caregivers face throughout the caregiving journey.

Emotional distress was one of the most prominent themes. Participants frequently expressed anticipatory grief, helplessness, and psychological fatigue. These findings are consistent with Manchia *et al.* (2021), who observed that caregivers often experience anxiety and depressive symptoms due to the prolonged uncertainty and decline associated with terminal illness. This distress is intensified by the lack of formal psychological support systems.[7]

Disruption in personal and social life was another major finding. Participants had to sacrifice careers, education, and relationships. Similar observations were made by Sharma (2016), who emphasized that caregivers often experience social withdrawal and role conflict, particularly among women who are culturally expected to be primary nurturers. These changes result in loss of identity and increased isolation.[8]

Physical and financial burdens further compound caregiving stress. The current study found that caregivers frequently experienced fatigue, back pain, and chronic sleep deprivation, similar to findings by Essue*et al.* (2017). Moreover, economic strain due to loss of income or high treatment costs emerged as a major concern. These burdens were especially severe in low-resource households with limited access to affordable healthcare or social assistance.[9]

A striking insight from this study was the inadequate institutional and emotional support for caregivers. Many reported being discharged from hospitals with minimal guidance or follow-up. LeLaurin (2020) highlighted similar concerns, suggesting that caregivers often feel abandoned after discharge and are left to navigate complex care situations alone.[10]

Despite these adversities, many caregivers demonstrated resilience through coping mechanisms such as prayer, acceptance, and peer support. This supports Kazemi (2021) stress and coping theory, where emotional and problem focused coping help individuals adapt to chronic stressors. These mechanisms, though valuable, are often insufficient to fully counterbalance the intense caregiving burden.[11]

IMPLICATIONS OF THE STUDY

For Nursing Practice:

- Nurses should include caregivers in the palliative care plan by providing regular education, counseling, and home-care instructions.
- Community health nurses can play a crucial role in identifying caregiver distress and connecting families with psychosocial resources.

For Policy and Administration:

- Policies should be framed to offer structured support systems for caregivers, such as respite care, caregiver training, and home visits.
- Financial assistance and health insurance policies must explicitly cover informal caregiver needs and services.

For Research:

- More in-depth qualitative and longitudinal studies are needed to understand how caregiver burdens evolve and what interventions can sustainably support them.
- Future studies can also explore gender-based differences and caregiving in rural vs. urban contexts.

CONCLUSION

This study illuminated the complex, often hidden burdens faced by primary caregivers in palliative care environments. Caregivers silently endure emotional trauma, physical fatigue, social isolation, and financial hardships while dedicating themselves to the well-being of their loved ones. Their resilience and coping strategies reflect strength, yet these alone are not enough to protect against burnout and long-term psychological harm.

Recognizing caregivers as co-recipients of care not just supporters is essential in delivering holistic palliative care. There is an urgent need for caregiver inclusive policies, emotional support services, and community based interventions to alleviate their invisible suffering. By amplifying their voices through this study, we hope to pave the way for more compassionate, inclusive, and sustainable models of palliative care.

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