

Family Caregivers' Dilemma while Providing Palliative Care to Elderly Patients

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Abstract

Elderly patients receiving palliative care are terminally ill, thereby requiring an increasing amount of caregivers' time and attention. Caregivers often face diverse issues and challenges while performing caregiving tasks. The purpose of this paper is to systematically investigate the challenges that trigger family caregivers' dilemmas while providing palliative care to their elderly patients. The sample size was 10 respondents (family caregivers) who were purposively selected by the researchers from hospital-based palliative care settings and home-based palliative care settings. The finding of this study presents the existing and emerging dilemmas confronted by the caregivers of the elderly receiving palliative care. The caregivers in both settings reported elderly patients' reluctance to perform daily exercises and medication. The caregivers in the hospital-based palliative care setting mentioned the patient's desire to go home, while the caregivers in the home setting needed extra assistance to manage the care needs of the elderly patients. The paper also highlights the implications for social workers functioning in palliative care settings. In conclusion, caregiving for an elderly patient is a very arduous and demanding task. Family caregivers grapple with many day-to-day challenges which creates dilemma in providing quality palliative care to their elderly patients. They try to fix their dilemmas by looking at the issue through a medical lens and discussing it with professional palliative care providers.

Keywords: Caregivers dilemma, Elderly Patients, Palliative Care, Caregiving Challenges

Introduction

The International Association for Hospice and Palliative Care (IAHPC) developed a consensus-based definition of palliative care that emphasizes holistic care for individuals with serious health-related suffering due to acute illnesses. It focuses on addressing the physical, emotional, social, and spiritual needs of patients and their family caregivers.⁽¹⁾ Palliative care involves pain management and symptom control by a multidisciplinary team which includes professionals and family caregivers.⁽²⁾

Family caregivers play a crucial role in improving the quality of life of their patients and alleviating their suffering by providing the best possible care to them. They bear the responsibility of various tasks which include physical care, emotional support, medication, coordination with healthcare professionals, and overall management of care.⁽³⁾ The family caregivers manage all these aspects of patient care while also dealing with their own personal and psychological struggles.⁽⁴⁾

Caring for a terminally ill patient needing palliative care can be tough and presents a unique

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set of challenges. The key challenges faced by family caregivers in providing palliative care to patients lead to physical exhaustion, emotional distress, financial constraints, and balancing multiple roles and responsibilities. The family caregivers may feel overwhelmed by the complexity of care, the intensity of emotions, and the demands of their role. They may struggle to understand patients' needs, preferences, and wishes leading to decision-making dilemmas related to the overall management of care.⁽⁵⁾

The increasing need for intensive caregiving among the elderly population has led to a growing demand for palliative care.⁽⁶⁾ The need for providing palliative care to elderly patients is growing as their numbers rise globally and India holds one-fifth of them. The confluence of demographic aging and the increasing prevalence of non-communicable diseases presents obstacle to the healthcare framework in India.⁽⁷⁾ A study conducted in Delhi has demonstrated that there exists a demand for palliative care in North India at a rate of 1.5 per 1000 individuals within the population.⁽⁸⁾

Previous research in palliative care has shown evidence of its effectiveness on patients' health, improved quality of life, and better caregivers' experiences.⁽⁹⁾ The Lancet Commission report also highlights the importance of integrating palliative care into mainstream healthcare systems.⁽¹⁰⁾ Even though palliative care in India has been around for 30 years, there's no comprehensive nationwide policy.⁽¹¹⁾ The notable endeavors in palliative care have been majorly achieved through community-owned services.⁽¹²⁾

In India, where there is a rapidly growing aging population and limited palliative care services, there is a need to research and gain practical insights into the challenges and opportunities for improving the state of palliative care. There is a lack of diversity in research studies on palliative care, with an under-representation of elderly patients and their caregiver's needs. Thus focusing on these issues, the article aims to create an evidence base on provision of palliative care to the elderly patients in India and open doors for further research on the topic in larger settings.

Materials and Methods

The goal of the study was to observe and provide a comprehensive report concerning the dilemmas encountered by the family caregivers of elderly patients receiving palliative care in New Delhi. The design of the study was descriptive. The sample size was 10 respondents who were purposively selected by the researchers from hospital-based palliative care settings and home-based palliative care settings. The study was conducted by interviewing these respondents from ten different households. Each of the respondents was the primary family caregiver either self-identified or identified by the elderly patient. Using a structured interview schedule the respondents were asked closed as well as open-ended questions regarding palliative care being received by their elderly patient. The findings of the study were analyzed in the light of the theoretical and empirical literature reviewed and then systematically arranged under different themes. The respondents' anonymity and confidentiality were ensured throughout the study. The limitation associated with the article is its reliance on small primary data, limited access to secondary data, and potential undiscovered bias of the researchers.

Results and Finding

Profile of the respondents:

Based on the responses listed in Table 1, the mean age of the family caregivers was calculated to be 44.5 years ranging from 26 years to 59 years of age. The 80 percent of these caregivers were females, majorly daughters. The data illustrates that the mean age of the elderly patients' was 76.9 years of age. The 70 percent of the elderly patients were females of age 75 years or above. Six of the ten elderly patients were of age 75 years or above needing round-the-clock attention from caregivers irrespective of the palliative care setting. Only five households had an annual income of less than 3 lakhs per annum.

Table 1: Demographic data of elderly patients and their family caregivers

Household ID	Elderly			Caregiver		Relation of Caregiver with Elderly	Income less than 3 lakhs
	Age	Gender	Is Frail	Age	Gender		
1	88	Female	Yes	29	Female	Granddaughter-in-law	No
2	80	Male	Yes	48	Female	Daughter	No
3	86	Female	Yes	26	Male	Grand Son	Yes
4	79	Female	No	42	Female	Daughter	No
5	81	Female	Yes	45	Female	Daughter	Yes
6	80	Female	Yes	47	Female	Daughter-in-Law	No
7	75	Female	Yes	56	Female	Daughter	No
8	73	Female	No	38	Male	Son	Yes
9	66	Male	No	59	Female	Spouse	Yes
10	61	Male	No	55	Female	Spouse	Yes
Average	76.9			44.5			

Dilemma in Hospital-Based Palliative Setting:

One of the primary dilemmas caregivers face is balancing between the elderly patient's wishes and their health necessities.⁽⁵⁾ The elderly patients may have a particular choice while the caregivers might have a different one. These situations give rise to certain dilemmas hampering the decisions crucial to the elderly patient's care. The following set of dilemmas was reported by the caregivers of elderly patients receiving palliative care in hospital-based settings:

1. **Daytime Napping:** Several studies have suggested that sleeping attributes change as people age. These changes in the sleeping pattern are influenced by various factors.⁽¹³⁾ According to the data from the present study, four out of the five elderly patients receiving hospital-based palliative care were found to sleep during the day and stay awake at night. They normally fail to take their day medicines as they are asleep. The daytime napping also made it hard for the caregivers to adjust their rest schedules. The caregivers saw a lack of night-time sleep as unhealthy, which could affect a person's overall health. Previous studies have also suggested that sleep deprivation among

elders during hospitalization is often and may lead to worse health outcomes.⁽¹⁴⁾ Hence, the caregivers couldn't decide if they should allow the patient to sleep during the day or disrupt their daytime naps thus creating the caregivers' dilemma concerning the sleeping pattern of the elderly patients.

2. **Longing for Home:** Hospitalization is a phase of acute social isolation and loneliness.⁽¹⁵⁾ Almost all the five caregivers agreed that their elderly patients felt lonely and missed their homes in hospital-based palliative care settings. The patients asked the caregivers how much longer their hospital stays would be and when could they go home. The caregivers asked questions to themselves if they should let the elderly patient return home or keep them in the hospital for continued care. Hence, the caregivers struggled with the dilemma of whose decision to follow- the professional's advice to be at the hospital or the elderly patients' wishes to be treated at home.
3. **Financial struggles:** Healthcare expenditure plays a significant role in shaping decisions regarding medical care.⁽¹⁶⁾ Three out of the five caregivers of hospitalized elderly patients shared that they struggled with the

financial cost of caregiving. Those caregivers who were expensing around Rs.3000/- daily and had an annual income of less than 3 lakhs per annum were uncertain to continue hospital-based palliative care. The caregivers were caught in a dilemma of whether to spend any more money at the hospital or switch to home-based palliative care to balance finances.

Dilemma in Home-Based Palliative Setting:

The caregivers of elderly patients who receive palliative care at home are faced with a multitude of challenges. Previous studies have indicated that elder caregiving challenges are majorly associated with the physical, social, and psychological demands of caregiving duties.⁽¹⁷⁾ These challenges produced dilemmas for the caregivers which are outlined below:

1. **Physical challenges of caregiving:** Taking care of someone can be physically tough. It often depends on the health and needs of both the person being cared for and the caregiver.⁽¹⁸⁾ The caregivers reported that they helped the elderly patients with activities of daily living such as bathing, and toileting, and help with getting up, making them sit, or changing clothes. Three out of the five caregivers stated that they needed help from other family members with tasks such as lifting and transferring. These three respondents were the female caregivers of elderly patients aged over 70 years. They required another person to assist them unlike in a hospital where nurses and ward boys are available to help. Therefore, the caregivers faced a dilemma regarding shifting the elderly to a hospital-based setting or continuing the care at home.
2. **Struggling with guilt and doubt:** Studies suggest that caregiving causes psychological strain and leads to emotional distress for the caregivers.⁽¹⁹⁾ Thus the caregivers can have a hard time deciding the best care approach for their elderly patients. Two of the five caregivers considered that the quality of palliative care service is compromised by being home-based. Professionals care providers, typically visit elderly patients every two weeks, so most of the caregiving is entrusted to the family caregivers. Patients getting home-based palliative care usually

receive less professional assistance and more informal help from family caregivers.⁽²⁰⁾ The caregivers experienced guilt about not doing enough for the elderly patient. The caregivers weren't sure if they could give good palliative care at home or shift the elderly patient to a hospital setting to avail more of professional care services. This was a hard choice for them thus creating dilemma and emotional distress regarding the care decision.

Dilemma in both the Settings

Caregiving for elderly patients in hospitals as well as home-based palliative care can both be challenging. The below-mentioned challenges common to both settings created dilemmas for the caregivers:

1. **Reluctance to perform daily exercises and towards medication:** The caregivers reported their struggle with the elderly patients to make them follow medical advice. Six of the ten elderly patients who were mostly female and above 70 years of age often resisted taking medication and doing exercises prescribed by their professional caregivers. The elderly patients resisted arguing they already had enough medicines or lacked the strength for physical activities. This made it hard for caregivers to know how to best take care of them. A similar study also highlighted the issue of medication non-adherence among older adults.⁽²¹⁾ This resistance left the caregivers unsure whether to push them to keep up with their health routines or to give in to the patient's wishes, hence creating a dilemma for the caregivers.
2. **Forgetfulness:** As people get older, they often start to forget things.⁽²²⁾ The study reports that six of the ten elderly patients above the age of 75 years kept forgetting things. They often couldn't remember when they took their medicine, exercised, or ate a meal. The elderly patients would ask the caregivers to repeat activities that were already performed. This caused an increased sense of responsibility, irritability, and stress for the caregivers. This made it hard for the caregivers to handle the caregiving duties with ease. Thus creating a dilemma whether the caregivers should continue the elderly patients' care or assign professional caregivers for their patient.

Addressing Dilemmas

Addressing these dilemmas requires support and collaboration among healthcare professionals, patients, and their caregivers. The caregivers consulted with professionals like doctors, nurses, psychologists, and social workers for advice on handling these dilemmas. These professionals helped the family caregivers to navigate through important decisions to improve the overall well-being of the elderly patients along with respecting their wishes.

Implications for Social Workers

Social workers in palliative teams play a vital role in providing high-quality care. They provide psychosocial and emotional support as team members. They can bridge the gap between caregivers and professional care providers by encouraging communication and shared decision-making. They should equip themselves with the knowledge, skills, and resources to impart adequate training and education to the family caregivers. The social workers can also help generate awareness among the masses signifying the importance of palliative care for the elderly, and involve in advocacy and other macro-level practices.

Conclusion

The present study sheds light on the dilemmas faced by the family caregivers of elderly patients receiving palliative care in home and hospital-based settings. The study observed that the three major challenges faced by family caregivers were elderly patients' reluctance to perform exercises and take medication, longing for home when hospitalized, and loss of nocturnal sleep. Caregivers who were economically sound and caring for patients with fewer health complications experienced fewer significant dilemmas than those caring for elderly patients above 75 years of age and with co-morbid conditions. The research findings imply that the dilemmas faced by caregivers in providing palliative care to elderly patients are complex and multifaceted. To make informed decisions regarding the patient's care, it is vital to consider the patient's wishes and health requirements.

In conclusion, providing care for the elderly can be a daunting and exhausting task, which can deplete the emotional and physical resources of the caregivers. This, in turn, creates challenges for caregivers leading to dilemmas and difficulties in deciding on care provision. Further research is needed to explore this topic in larger and more diverse populations to inform the development of evidence-based practices.

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Ethical Clearance: The study was conducted in ethical and responsible manner which includes obtaining informed consent from participants, maintaining anonymity and confidentiality.

References

1. Justino ET, Kasper M, Santos KDS, Quaglio RDC, Fortuna CM. Palliative care in primary health care: scoping review. *Rev Lat Am Enfermagem.* 2020;28:e3324.
2. Seamark D, Ajithakumari K, Burn G, Devi PS, Koshy R, Seamark C. Palliative care in India. *J R Soc Med.* 2000 Jun;93(6):292-5.
3. Prasad P, Sarkar S, Dubashi B, Adinarayanan S. Estimation of need for palliative care among noncancer patients attending a tertiary care hospital. *Indian J Palliat Care.* 2017;23(4):403.
4. Cejalvo E, Martí-Vilar M, Merino-Soto C, Aguirre-Morales MT. Caregiving Role and Psychosocial and Individual Factors: A Systematic Review. *Healthcare.* 2021 Dec 7;9(12):1690.
5. Chaturvedi SK. Ethical dilemmas in palliative care in traditional developing societies, with special reference to the Indian setting. *J Med Ethics.* 2008 Aug 1;34(8):611-5.
6. Dr. A. Jayaraman. A Study on Caring Perception of Informal Caregivers of Elders. *Res Humanit Soc Sci.* 2017;7(17).
7. Sahoo PM, Rout HS, Jakovljevic M. Consequences of India's population aging to its healthcare financing and provision. *J Med Econ.* 2023 Dec 31;26(1):308-15.
8. Kaur S, Kaur H, Komal K, Kaur P, Kaur D, Jariyal V, et al. Need of palliative care services in rural area of Northern India. *Indian J Palliat Care.* 2020;26(4):528.

9. Gaikwad A, Acharya S. The Future of Palliative Treatment in India: A Review. *Cureus* [Internet]. 2022 Sep 23 [cited 2023 Aug 2]; Available from: <https://www.cureus.com/articles/109172-the-future-of-palliative-treatment-in-india-a-review>
10. McDermott E, Selman L, Wright M, Clark D. Hospice and Palliative Care Development in India: A Multimethod Review of Services and Experiences. *J Pain Symptom Manage*. 2008 Jun;35(6):583-93.
11. Laabar TD, Saunders C, Auret K, Johnson CE. Palliative care needs among patients with advanced illnesses in Bhutan. *BMC Palliat Care*. 2021 Dec;20(1):8.
12. Patel F, Sharma S, Khosla D. Palliative care in India: Current progress and future needs. *Indian J Palliat Care*. 2012;18(3):149.
13. Li J, Vitiello MV, Gooneratne NS. Sleep in Normal Aging. *Sleep Med Clin*. 2018 Mar;13(1):1-11.
14. Stewart NH, Arora VM. Sleep in Hospitalized Older Adults. *Sleep Med Clin*. 2018 Mar;13(1):127-35.
15. A R. The interface of loneliness, hospitalization and illness. *Nurs Palliat Care* [Internet]. 2017 [cited 2023 Jul 31];2(6). Available from: <http://www.oatext.com/the-interface-of-loneliness-hospitalization-and-illness.php>
16. Williamson SB. Caring for our patients - fact or legend - an economic view. *Curationis*. 1981 Sep 26;3(4):55-6.
17. Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family Caregiving for Older Adults. 2020;
18. Mamom J, Daovisan H. Listening to Caregivers' Voices: The Informal Family Caregiver Burden of Caring for Chronically Ill Bedridden Elderly Patients. *Int J Environ Res Public Health*. 2022 Jan 5;19(1):567.
19. Schulz R, Sherwood PR. Physical and Mental Health Effects of Family Caregiving. *AJN Am J Nurs*. 2008 Sep;108(9):23-7.
20. Campbell CS, Black MA. Dignity, Death, and Dilemmas: A Study of Washington Hospices and Physician-Assisted Death. *J Pain Symptom Manage*. 2014 Jan;47(1):137-53.
21. Resnick B. Medication adherence: Interventions over the past 40 years. *Geriatr Nur (Lond)*. 2020 Nov;41(6):667-8.
22. Arai H, Satake S, Kozaki K. Cognitive Frailty in Geriatrics. *Clin Geriatr Med*. 2018 Nov;34(4):667-75.