ORIGINAL ARTICLE

Exploring Quality of Life and Caregiver Burden in Palliative care

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CITATION

Srivastava K, Rathod H, Bhawalkar JS, Vishwakarma KS, Akhil R. Exploring Quality of Life and Caregiver Burden in Palliative care. Indian J Comm Health. 2025;37(2):208-216. https://doi.org/10.47203/IJCH.2025.v37i02.006

ARTICLE CYCLE

Received: 06/09/2024; Accepted: 15/03/2025; Published: 30/04/2025

ABSTRACT

Background: The increasing prevalence of non-communicable diseases in India has led to a growing need for palliative care. This study aimed to explore and analyse the factors contributing to the quality of life and burden experienced by caregivers of palliative patients in a metropolitan setting. **Methodology**: A qualitative phenomenological approach was employed, grounded in the interpretivist paradigm. Seven in-depth, semi-structured interviews were conducted with primary caregivers of palliative patients at a tertiary care hospital and Palliative Care Hospital. Purposive sampling was used, and data saturation determined the sample size. Interviews were audio-recorded, transcribed, and translated. Data analysis followed a hybrid approach, combining inductive and deductive methods. **Results**: Seven major themes emerged from the analysis. Caregivers reported significant deterioration in their quality of life, disruption of daily routines, and emotional distress. They faced challenges including physical and mental exhaustion, lack of respite, and financial constraints. Coping mechanisms included seeking emotional support and spiritual practices. Despite hardships, caregivers found satisfaction in witnessing improvements in their loved ones' conditions. They expressed concerns about future care arrangements and suggested better communication with healthcare professionals and respite opportunities. **Conclusion**: The study revealed that caregiving for palliative patients significantly impacts caregivers' quality of life and emotional well-being. While caregivers experience multiple challenges, they also find satisfaction in their role. To improve the caregiving experience, healthcare systems should focus on enhancing communication between healthcare professionals and patients, and providing respite options for caregivers. These findings can inform strategies to support caregivers and improve palliative care services in metropolitan settings.

KEYWORDS

Palliative Care; Caregivers; Quality of Life; Hospice Care; Caregiver Burden; Palliative Medicine; Qualitative Research

INTRODUCTION

For most part of the human history on earth, the world population was a miniscule fraction of what it is today. Over the past few years, world's population has gone through a remarkable transformation. Around the 18th century human race was around one billion. In the current global scenario, we have crossed the 8 billion mark. (1) The rise in population can be attributed to the improvements in medical services, better understanding of nutrition, sanitation to name a few. (2) Along with growing world population disease burden have also increased. A similar trend was seen all over the world. The current population in India is 1.44 billion.(3) Along with rising population, the prevalence of non-communicable diseases is on a rise. This can be attributed to shift in dietary habits, sedentary lifestyle, ageing population, increase in alcohol consumption and tobacco usage.(4) The burden of non-communicable diseases (NCDs) rising faster than that of communicable diseases like TB, HIV, and vector-borne or water-borne illnesses, India is going through a rapid health shift. It is believed that non-communicable diseases, such as diabetes, cancer, chronic respiratory conditions, and cardiovascular disorders, cause about 60% of all fatalities. Relatively more years of potentially productive life are lost as a result of NCDs. Over time, it is also anticipated that losses from heart disease, stroke, and diabetes-related early deaths will rise.(5) To tackle the issues of rising prevalence of NCDs, government of India had implemented national program for non-communicable diseases (NP-NCD), which includes disease like Diabetes, hypertension, Cancer, Stroke, Cardiovascular Diseases, Chronic Kidney Disease (CKD), Chronic Obstructive Pulmonary Disease (COPD) and integration of tuberculosis to the current program.(5)

The diagnosis and treatment of chronic or life-threatening diseases have a profound physical and psychosocial impact on patients and their families, particularly on family caregivers who are typically untrained or unprepared for this difficult duty. Family caregivers must adapt their families and their roles to meet the demands of caregiving, which can be daunting at times.(6) Put another way, families need to be resilient and put together their resources in order to respond to these circumstances in an adaptable manner. Family resilience is the ability of a family to effectively manage adversity so that each member can grow up in a loving, supportive, and cohesive environment. Cancer, or any other long-term illness, not only causes great suffering for the patient, but it also poses a serious challenge to the family, particularly in the areas of finances, social interactions, personal relationships, and mental health.(7)

Palliative medicine is a distinct branch of modern medicine, which mostly deals with chronic debilitating diseases. Palliative care can be defined as a specialised care for patients with chronic or life threatening diseases, with emphasis on alleviating the symptoms, pain and other related difficulties of the patient irrespective of the diagnosis or outcome.(8) The main objective of palliative care is to improve the quality of life of patient as well the family members. Palliative care differs from hospice care, which intend to provide end of life care only. Critical research published in the New England Journal of Medicine substantiate that Early introduction of palliative care along with diagnosis of disease is found to be very useful in improving the outcome of the patient.(9)

In a middle-income country like India, the need of palliative care is increasing day by day. Studies have showed that in Indian population, there is a significant physical and psychological burden among the caregivers of palliative patients. Burden manifest as stress, anxiety, depression and poor quality of life.(10,11) In Maharashtra, one of the most populated cities in India, is a home for around 128 million people. Maharashtra reported around 1.21 lakh new cases in 2023 alone,(12) with an increasing number of senior citizen population,(13) and other disease makes it important to develop a strategy for comprehensive management of these patients and their families. There are studies done to evaluate the quality of life and burden of the caregivers of palliative patients across different geographical locations of India. However, there is a lack of data that explain the quality of life and burden experienced by the caregivers of palliative patients in metropolitan cities. It is important to assess the quality of life and burden experienced by caregivers in these areas and the socio-demographical factors that influencing the outcome. It will help to strengthen the public health sector and to march towards the universal health coverage.

Aims & objective: To explore and analyse the underlying factors and dynamics that contribute to palliative caregiver’s quality of life and burden.

MATERIAL & METHODS

Study type & Study design*:* This study employed a qualitative phenomenological approach to explore the lived experiences of caregivers of palliative patients, focusing on their quality of life and perceived burden. This study was grounded in the interpretivist paradigm, which aligns with our phenomenological approach. This paradigm recognizes that the caregiving experience is subjectively constructed by individuals within their social contexts, and that our understanding of these experiences is inevitably shaped by the interpretive process of both participants and researchers.

The research team consisted of three investigators, including one with extensive experience in palliative care. This investigator's background enhanced the team's sensitivity to the expression of palliative caregiving but also necessitated careful reflection to minimize potential biases. Regular team discussions were held to maintain reflexivity throughout the research process.

Study setting: The study was conducted in a tertiary care teaching hospital and A Palliative Care Hospital in Western Maharashtra, which serves a diverse population of palliative patients and their caregivers. This setting was chosen to capture a range of caregiving experiences within the palliative care context.

Purposive sampling was used to recruit participants who could provide rich, in-depth information about their caregiving experiences.

Inclusion & Exclusion criteria: The inclusion criteria were, all primary care givers of palliative care patients irrespective of patient's treatment status, age, gender, caste, religion and socioeconomic status and able to communicate fluently in local language, English or a language known to investigators. Caregivers who refused to give consent for the study were excluded from the study.

Working definition: Primary caregiver was defined as the individual, who is responsible for providing care and support to a patient in home setting. He/ she should not be a professional hired under contract for providing care to the patient.

Ethical issues & informed consent: The study protocol was approved by the Institutional Ethical Committee of Tertiary care teaching hospital (Approval number: I.E.S.C/PGS/ 2022/205). Informed consent was obtained from all participants prior to their involvement. Participants were assured of confidentiality and their right to withdraw from the study at any time without consequences.

Strategy for data collection: In-depth, semi-structured interviews were conducted with each participant. An interview guide was developed based on themes identified from prior qualitative studies and relevant literature. The guide explored aspects of caregiving, quality of life, and caregiver burden. Inputs were included and a revised proforma was used as data collection tool. Each interview lasted approximately 25-50 minutes and was conducted at hospital setting, at the participant's convenience. Before the commencement of data collection, a pilot study was conducted and outcomes were subjected to evaluation.

Interviews were audio-recorded using a mobile phone recorder. Field notes were taken during and immediately after each interview to capture non-verbal cues and contextual information. Preliminary findings were shared with participants for feedback and to ensure our interpretations resonated with their experiences.

We initially aimed to recruit 10-15 participants but reached data saturation after interviewing 7 participants. No participants refused to participate. Data saturation was determined when no new themes or significant insights emerged from the interviews, as agreed upon by two independent researchers involved in the data analysis.

Audio recordings were transcribed verbatim into the local language. These transcripts were then translated into English by a bilingual researcher. To ensure accuracy, a portion of the translations was back-translated to the original language by an independent translator.

Data analysis: Data analysis followed a hybrid approach. Initial inductive analysis identified main themes based on prior qualitative studies and literature review. Subsequent deductive analysis of the transcripts yielded additional themes and subthemes. Manual coding was performed independently by two investigators. Regular discussions were held among the research team to challenge assumptions and explore alternative interpretations. Codes and themes were compared and refined through team discussions until consensus was reached. Detailed records of the research process, including analytical decisions, were maintained. The final thematic structure was reviewed by all team members to ensure it accurately represented the data.

RESULTS

In this study we conducted 7 in-depth interviews with the caregivers of palliative patients. Interviews were conducted till the saturation of data was attained. There were 2 caregivers of cervical cancer patients, one each of ovarian cancer, breast cancer, lung cancer, oral cavity cancer and mental health disorder. In this study, a few major themes and subthemes were emerged. (Table 1)

Table 1 Themes and sub-themes emerged from thematic analysis

Themes	Sub-theme
1. Impact on Quality of Life:	Deterioration in quality of life Disruption of daily routine and responsibilities
2. Emotional and Psychological Burden	Stress, anxiety, and tension Sadness and emotional distress Lack of Spiritual Solace
3. Caregiver Burden and Challenges	Physical and mental exhaustion Lack of respite and support financial constraints
4. Coping Mechanisms	Seeking emotional support

Themes	**Sub-theme**
	Spirituality and faith
5. Positive Aspects of Caregiving	Satisfaction and fulfilment
6. Future Concerns and Uncertainties	Worries about the future and care arrangements
7. Suggestions and Expectations for Improved Caregiving Experience	Better communication with patients' Respite for caregivers

1. Impact on Quality of Life:

This theme captures the significant impact that providing care has on the primary caregivers' overall quality of life.

a. Deterioration in quality of life:

The caregivers' quality of life was greatly affected by their caregiving duties and the emotional toll of seeing their loved ones suffer; this resulted in feelings of hopelessness and a questioning of their own lives' meaning.

"*It's very bad. Yes, sometimes I feel that I have given my entire life to all these struggles. What's the purpose of my life. It's all wasted."* (Participant 4)

"*Now I am living in 50-50 state. Some are good, some are bad and now I don't have work. I don't have money. I don't have much work to do as well."* (Participant 6)

"*In the beginning, her condition was good. But in the last 7-8 months, her condition has deteriorated. That's all."* (Participant 5)

Disruption of daily routine and responsibilities: The caregivers' daily routines suffered by the caregiving duties, which made them prioritize caregiving over other facets of their lives. An imbalance and tension resulted from this situation.

"*You can't go out at night because of this disease. I come home early. I get up at 5.30 in the morning and take care of my mother's medicines and household chores."* (Participant 5)

"I have my duties as a teacher. I have to do these duties (taking care of mother) as well. I am not able to do all of them. That makes me very tensed." (Participant 1)

"Now she develops water retention in stomach very frequently and needs hospital admission every time. That makes it difficult for me to adjust the work and my responsibilities " (Participant 5)

2. Emotional and Psychological Burden

This theme captures the significant emotional and psychological toll experienced by the caregivers, encompassing various aspects of their mental well-being.

Stress, anxiety, and tension: The caregiving responsibilities and the uncertainties surrounding their loved ones' health conditions led to heightened levels of stress, anxiety, and tension among the caregivers.

"*I feel very tensed when I think what the future would be? What will happen in the future? Most of the time I try not to think beyond that."* (Participant 1)

"*Yes, we do have arguments at home very often because of the disease. It's all because of tension. We get tensed. We face a lot financial problem. We face all kinds of problems. So that leads to unrest at home*." (Participant 2)

"*Sometimes you feel very anxious and goes into dark mood*." (Participant 6)

Sadness and emotional distress: The caregivers experienced profound sadness and emotional distress witnessing their loved ones' suffering, reminiscing about their past healthy state, and grappling with the uncertainties of the future.

"I feel sad sometimes. I think about old times when she was healthy. She was able to do all the household chores by herself without anyone's help. But now when I see her bed ridden most of the times, I feel very nervous." (Participant 1)

"When I see her in this situation, I feel sad sometimes. I think about old times when she was healthy." (Participant 1)

"*I just sit and cry. I don't feel like discussing about it with others. So, I just go to kitchen and cry sometimes."* (Participant 2)

"*I get some thoughts like, I don't want to live anymore, I want to die, that sort of thoughts. But later it will change to I should not surrender to all these pressures and tests. If I die, who will take care of my kids and all that. That helps me to cover up all my emotions."* (Participant 4)

Lack of Spiritual Solace: While some caregivers found solace in their spiritual beliefs, others expressed a lack of spiritual solace, questioning the existence of a higher power or the philosophical underpinnings of their beliefs.

"People have different views regarding spirituality. We have to do what we are supposed to do. Who even know that God exists. That all depend on the individuals." (Participant 7)

3. Caregiver Burden and Challenges

This theme encapsulates the various burdens and challenges faced by the caregivers, spanning physical, mental, and financial aspects of their caregiving responsibilities.

Physical and mental exhaustion: The caregiving duties took a significant toll on the caregivers' physical and mental well-being, leading to exhaustion, bodily aches, and a general lack of self-care.

"My whole body is aching. I can't stand for 10-20 minutes continuously. I have diabetes now. My appetite has reduced." (Participant 4)

"*It causes mental agony for the patient as well. I have to feed her, take her to the bathroom. I have to give her medicine at 2 in the night. My little sleep will get disturbed and I will be sleepy next day."* (Participant 6)

"*I can't blame anyone. I'm not able to sleep on time, eat on time, take care of myself properly."* (Participant 5)

Lack of respite and support:

The caregivers expressed a lack of respite and support, particularly for male caregivers, who found it challenging to provide certain aspects of care traditionally associated with female caregivers.

"If a female is taking care, it is easier. It causes mental agony for the patient as well." (Participant 6)

"I do think so. But there is no one to replace me. My sister is married and she has to take care of her family as well. My brother is younger to me, so it will be difficult for him to do this job. So, I just do it." (Participant 6)

"I'm a male caregiver, there comes some point where it becomes difficult to take care of my mother." (Participant 6)

financial constraints:

The caregivers faced significant financial constraints, often lacking the resources to afford better treatment options or manage the associated expenses, exacerbating their burden.

"I don't have any money. After this how will I stand on my own. That keep on running in my mind." (Participant 5)

"When my mother had a heart attack, we had to pay Rs. 9.5 lakhs for her. We didn't have that much budget. Because of that she didn't have any operation. We couldn't arrange the money." (Participant 2)

"Now I don't have work. I don't have money." (Participant 6)

4. Coping Mechanisms

This theme highlights the various coping mechanisms employed by the caregivers to deal with the emotional and psychological burdens of caregiving.

Seeking emotional support:

Many caregivers sought emotional support from their family members, friends, or support groups, sharing their worries and tensions to cope with the challenges they faced.

"Yes. We all talk to each other when we feel sad or anxious." (Participant 1)

"I talk to my friends. I can't talk to my brother as he is already in tension. So, I talk to my friends, share my thoughts with them and they help a lot." (Participant 7)

"My madams at massage center helps me the most."
(Participant 4)

Spirituality and faith: Some caregivers found solace in their spiritual beliefs and practices, turning to prayer, visiting places of worship, or strengthening their faith as a means of coping with the emotional challenges.

"My belief got stronger and I put all my hopes to God. I do go to temple once in a while and I feel relaxed and peaceful." (Participant 1)

"I have deep belief in God. I pray to him all the time." (Participant 4)

"I go to church. Pray to God for some time. I get a very much relaxed after visiting church." (Participant 4)

5. Positive Aspects of Caregiving

While caregiving undoubtedly presents numerous challenges, it is important to acknowledge the positive aspects that provide a sense of fulfilment and meaning to the caregivers' experiences.

Satisfaction and fulfilment

Despite the arduous nature of caregiving, the caregivers found solace and satisfaction in witnessing the well-being and contentment of their loved ones. These moments of respite from suffering served as a source of motivation and reward, reminding them of the significance of their efforts.

Seeing their loved ones free from pain, eating well, and engaging in daily activities brought a sense of joy and happiness to the caregivers, albeit amidst the challenges they faced.

These small victories in their loved ones' well-being provided a sense of fulfilment and reinforced the caregivers' commitment to their caregiving duties.

The caregivers derived a sense of satisfaction and purpose from witnessing even the slightest improvements in their loved ones' conditions, underscoring the positive aspects of caregiving that sustained them through their challenges.

"I feel happy when she eats well. I feel happy when is not having any pain. I feel happy, when she can walk without any pain." (Participant 5)

"*When she is happy, I feel the happiest. When she is devoid of pain, when she sleeps properly, when she eats food, I feel very happy."* (Participant 1)

"When they are better than yesterday, that's when I feel happy and satisfied." (Participant 7)

6. Future Concerns and Uncertainties

The caregiving experience was often accompanied by a sense of uncertainty and apprehension about the future, both for the caregivers themselves and their loved ones.

Worries about the future and care arrangements

The caregivers expressed deep-seated concerns about the continuity of care for their loved ones and their own well-being, should they be unable to continue providing care due to unforeseen circumstances.

The fear of leaving their loved ones without adequate care arrangements weighed heavily on the caregivers' minds, particularly in cases where they lacked a stable support system or financial resources.

The uncertainties surrounding their own future well-being and the potential impact on their loved ones' care added to the emotional and psychological burden experienced by the caregivers.

While some caregivers focused solely on the well-being of their loved ones, others acknowledged the need to address their own concerns and uncertainties about the future, highlighting the complex interplay between caregiving responsibilities and personal well-being.

"Yes, I am worried. I don't know who will take care of my children if I die. I don't have a house. I don't know where my children will go." (Participant 4)

"I get nervous thinking about what will happen in the future. My father lives alone and brothers live in three different places. I live alone in the house because of the duty." (Participant 1)

"I don't think about my future. I just want my children to be happy." (Participant 4)

7. **Suggestions and Expectations for Improved Caregiving Experience**

Throughout the interviews, caregivers provided valuable insights and suggestions that could potentially improve their caregiving experience and overall well-being.

Better communication with patients'

Effective communication between healthcare professionals and patients emerged as a crucial aspect in enhancing the caregiving experience.

The caregivers recognized the importance of open and transparent communication, as it could lead to a better understanding of the patients' needs and concerns, ultimately facilitating more effective care and support.

"I feel that if the they talk to patient little bit more, if they ask their problems and find solutions, it will be better..." (Participant 6)

Respite for caregivers:

The caregivers emphasized the need for respite opportunities, where they could take breaks from their caregiving duties to rejuvenate themselves, both physically and mentally.

The constant demands of caregiving often led to burnout and exhaustion, highlighting the importance of providing caregivers with opportunities for self-care and respite, ultimately improving their overall well-being and the quality of care they could provide.

The caregivers recognized the potential benefits of respite opportunities, not only for their own well-being but also for the overall caregiving experience and the quality of care they could provide to their loved ones.

"I wish that if there was a system of relieving caregivers for a few hours in a day, I could go out, have some fresh air, go for a walk and unclutter my mind and come back. It will improve my life as well as the caregiving I can provide." (Participant 6)

"But now staying 24 hrs here in bedside is kind of frustrating."(Participant 6)

DISCUSSION

In this study we conducted 7 in-depth interviews with the caregivers of palliative patients. Interviews were conducted till the saturation of data was attained. There were 2 caregivers of cervical cancer patients, one each of ovarian cancer, breast cancer, lung cancer, oral cavity cancer and mental health disorder. In this study, a few major themes and subthemes were emerged.

Impact of quality of life: This theme captures the impact of caregiving on the overall quality of life in a primary caregiver of palliative patients. Sub-theme we found are deterioration of quality of life and disruption in daily routine and responsibilities. Caregivers shared that their quality of life is significantly affected by the caregiving duties and the suffering of their loved ones takes a great emotional toll on their mental health. They explained that, as a result of this they often question their purpose in life and feels hopeless sometimes. Prioritizing the caregiving over personal life, they felt that their daily life gets affected a lot. This conflict leads to an imbalance in their life and leads to mental stress. This was consistent with the finding from other studies. In a study done by Ramasamy et al (14), who documented that caregivers of patients with advanced head and neck cancer experienced difficulties in prioritizing their physical health, including sleep, appetite, and overall well-being while providing care for the patients. Other studies done in Andhra Pradesh (15) Kerala (16), Mumbai (17), and in Iran (18), also revealed similar outcomes.

Emotional and psychological burden: In our study, the sub-themes emerged are stress, anxiety, and tension; sadness and emotional distress; lack of spiritual solace. Caregivers reported that, the responsibilities and uncertainties related to the prognosis of the patients leads to stress, anxiety and tension. A few of them revealed that the memories of the past healthy life of the patient leads to profound sadness and emotional distress. Caregivers reported a decrease in spiritual solace and sometimes they even question the existence of a higher power. This was in accordance with the findings from the studies.(16,14,17,18) In addition to this, in a study done among caregivers of PLHIV (15), revealed that stigma and discrimination further exacerbates the psychological burden they experience.

Caregiver burden and challenges: In our study, the major sub-themes emerged under this theme are, physical and mental exhaustion, lack of respite and support and financial constraints. Caregivers revealed that continuous caregiving leads to physical and mental exhaustion, bodily aches, and lack of self-care. Caregivers expressed lack of respite and support especially for male caregivers, which makes caregiving challenging sometimes. Another important challenge they were facing was financial constraints. Due to the caregiving duty round the clock, not able to go for regular works, lack of resources to afford better care and treatment, to find sources to manage other expenses exacerbates their burden. This observation was in agreement with other studies. The study by Taleghani et al (18), highlighted the physical and emotional stress of caregiving, including the impending fear of death and challenges in managing the symptoms without proper knowledge. In the study done by Ramasamy et al (14) and Kochuvilayil et al (16), they documented that economic impacts due to changes in work schedule and the high cost of care puts extra pressure over caregivers. This financial strain was pronounced in families with low socioeconomic status.

Coping mechanism: In this study, the sub-themes emerged under this themes are seeking emotional support, spirituality and faith. We found that caregivers sought emotional support from family, friends or support groups. They constantly share their worries and tensions with them to manage the challenges they faced. Some of the caregivers explained that they found solace in their spiritual beliefs and practices, turning to prayer, visiting places of worship and strengthening their faith as part of their survival through hardship. This was consistent with the findings of studies in Kerala (14), (16), where social and family support and financial supports from friends or relatives emerged as crucial factors in reducing stress. Paul et al (17) also noted that the importance of training in caregiving and emotional support, emphasizing the need for caregivers to feel competent and supportive in their roles.

Positive aspects of caregiving: In this study, the sub-themes evolved under this is Satisfaction and fulfilment. In spite of the challenges of caregiving, caregivers highlighted the moments of satisfaction and fulfilment when they witness the well-being and contentment of their loved ones, which acts as a source of motivation and reward and remind them the importance of their efforts. This was concordant with the other study outcomes. The study done among the caregivers of patients with advanced head and neck cancer (14) revealed that, caregivers who perceived themselves as providing good care reported a sense of relief and satisfaction.

Future concerns and uncertainties: The uncertainties and apprehensions about the future, both for caregivers and their loved ones, were an important theme in our study. Caregivers expressed their worries regarding the continuity of care, particularly in those without nay stable support system or financial resources. Some caregivers were prioritizing the well-being of their loved ones and others acknowledged the need to address their own concerns about future, which highlights the complex dilemma between caregiving responsibilities and personal well-being. This was similar to the experiences from the other studies.(14,16,18)

Suggestions and expectations for improved caregiving experience: In this study caregivers suggested better communication between healthcare professionals and patients, and need for respite care. Caregivers highlighted the need for respite opportunities, where they could take breaks from caregiving duties to relax themselves, both physically and mentally. They consider it will help them provide a better quality care for their loved ones as well. Caregivers from the study by Paul et al (17), suggested that bereavement support, training in vital caregiving skills and support during the final days of the patient will be useful to reduce the burden and improve the quality of life of caregivers.

CONCLUSION

In-depth interview with caregivers revealed that caregiving for palliative patients leads to significant deterioration in quality of life and disruptions in daily life combined with emotional distress such as stress, anxiety, and sadness. Caregivers experience multiple challenges including physical and mental exhaustion, lack of respite and support, and financial constraints, but find comfort in spirituality and mental support. In spite of these hardships, caregivers find satisfaction and fulfilment from witnessing their loved ones improve under their care. To improve the caregiving experience, caregivers suggest that having a better communication from healthcare professionals and provision of respite options.

RECOMMENDATION

We recommend that developing a comprehensive holistic support system that address the various aspects of caregiver burden, including emotional, psychological, physical and financial aspects is crucial. Implement and expand respite care services to allow caregivers regular breaks from their caregiving responsibilities will help to prevent burnouts and improve their quality of life. There is a need to create or enhance the existing financial support mechanisms for caregivers, such as subsidies, grants or low interest loans, to alleviate the economic strain of caregiving. Establish easily accessible counseling services and mental health services tailor made for caregivers of palliative patients and providing caregiver training programs can improve the quality of life of caregivers. Implement protocols for better communication between healthcare professionals, patients and caregivers, recognize and integrate spiritual support into palliative care programs, facilitate the creation of support groups or networks for caregivers to share experiences and coping strategies are the need of the hour.

LIMITATION OF THE STUDY

While we reached data saturation with a small sample size, a larger and diverse population might have yielded additional insights and perspectives. In this hospital based study, caregivers who are experiencing poor quality of life and burden who are unable to afford or access the care are left out, hence a community based study may differ from the outcome. The study provides a snapshot of caregivers experience at a single point of time. A longitudinal design could have captured how caregiver experiences change over the course of patient's illness trajectory. In in-depth interview, caregivers responded according to social and cultural norms, rather than true thoughts or feelings.

RELEVANCE OF THE STUDY

This study provides a relevant and context specific perspectives regarding the impact of caregiving on primary caregivers of palliative patients in Western Maharashtra. Through an in-depth evaluation of the experiences of caregivers, the study highlights remarkable emotional, physical, financial, and spiritual challenges faced by them, at the same time acknowledging their resilience and coping strategies. The study identifies the vital gaps in the existing healthcare delivery system and offers a realistic, caregiver-centered recommendations for improving healthcare support system. The findings emphasize the need for a holistic model that incorporates caregiver sensitive approach in palliative care planning, policy making and delivery.

AUTHORS CONTRIBUTION

All authors have contributed equally.

FINANCIAL SUPPORT AND SPONSORSHIP

Nil

CONFLICT OF INTEREST

There are no conflicts of interest.

ACKNOWLEDGEMENT

The authors extend our sincere gratitude to all the study participants for sharing their valuable time and experiences, which made this research possible. We also thank the various departments of Dr. D. Y. Patil Medical College, Hospital and Research Centre, and Vishranti Hospital, Pune, for their support and cooperation throughout the study.

DECLARATION OF GENERATIVE AI AND AI ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

The authors haven't used any generative AI/AI assisted technologies in the writing process.

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