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Burden of Care: A Study of Caregiver Experiences in Managing End-of-Life Care for Cancer Patients with Sensory Disabilities in India

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This study explored the challenges experienced by six end-of-life caregivers of four cancer patients with sensory disabilities - two with visual impairments and two with speech and hearing impairments - in India. Purposive sampling and in-depth interviews were used to illustrate the everyday challenges caregivers encountered, the communication barriers, and the burden of making decisions. The study also attempted to explore how the caregivers, comprising wives, children, and siblings of the respective patients, maneuvered in a medical system that failed to offer a disability-sensitive healthcare milieu. The findings revealed significant emotional stress, ethical dilemmas concerning making decisions, and a serious communication gap both within residential and medical institutions. This research emphasized the urgency in addressing the distinctive needs of this population at the institutional and policy level as it was the family members, more often than not, who ensured equitable and compassionate end-of-life care for patients with disabilities.

Keywords: end-of-life care, indian caregivers, sensory disability, advanced-stage cancer, communication barriers

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1. Introduction

For patients and their families, advanced-stage cancer would always present immense challenges, particularly when associated with sensory disabilities, such as visual, speech and hearing impairments, which have a great impact on the process of understanding, decision-making, and communicating. Although caregivers, primarily the family members, play a crucial role in bridging the information and emotional gap between patients and medical professionals, they also endure emotional, financial, and psychological stress that is amplified by a general disability-insensitive atmosphere under the medical institutions. Disclosure of diagnosis and discussion on the prognosis would be crucial for planning a palliative treatment regimen, but truth-telling and communication become extremely challenging with patients with sensory impairments. In India, healthcare professionals' inadequate training in disability-sensitive communication makes it more difficult for caregivers to maintain transparency without shattering the patient emotionally.

With an emphasis on communication, truth-telling, and decision-making difficulties, this study has examined the experiences of six end-of-life caregivers of four cancer patients who had sensory impairments. It sought to draw attention to structural obstacles and the necessity of inclusive, disability-sensitive palliative care strategies, highlighting the moral conundrums faced by caregivers as they were found desperately attempting to strike a balance between patient autonomy and emotional protection.

The importance of the research resides in its capacity to guide improved procedures and policies that might assist patients and caregivers with sensory disability. In order to create a more inclusive healthcare milieu, which would prioritize the well-being of both patients and caregivers, this study aimed to discover these disparities and promote compassionate, equitable care recognizing the unique difficulties confronted by disabled patients and their families.

2. Literature Review

This research attempted to explore the experiences of caregivers in India who were studied assisting advanced-stage cancer patients with sensory impairments, focusing on the challenges they face in communicating, telling the truth, and making decisions. The research on caregiving in the context of terminal disease and sensory impairments has been assessed in this review of the literature, with a focus on how these two complex experiences intersected in the Indian healthcare system. It drew attention to the gaps in our present knowledge and the need for studies that would specifically address the difficulties this vulnerable population experienced.

The significant effects of terminal disease on patients and their families were well documented in the literature (Broom et al., 2016; Carlander et al., 2011; Hudson et al., 2013). Providing care for someone dying would be a difficult job that frequently entailed heavy emotional, financial, and physical demands. As they would deal with the challenges of managing their loved one's ailment, arranging medical care, and offering emotional support, caregivers commonly suffer from stress, anxiety, despair, and exhaustion (Harrop et al., 2014; Lewis, 2014). Numerous aspects of caregivers' burden were studied, such as how it affected their financial security, social connections, and mental and physical health (Grov et al., 2005; Kirkendall et al., 2012; McLaughlin et al., 2014; Stenberg et al., 2010). Caring in India was frequently and firmly anchored in cultural and familial traditions, with family members, especially women, taking on most of the caring duties (Mondal, 2022; Muralidharan et al., 2024). The stresses faced by caregivers might be exacerbated by this cultural emphasis on family caregiving, particularly in the absence of sufficient support networks.

The difficulties of providing care would greatly increase when a terminal illness was accompanied by sensory disabilities, such as hearing, speech, or vision impairment. Patients with sensory disabilities might have trouble communicating, have limited access to information, and be unable to take part in decision-making (Tuffrey-Wijne et al., 2016). It could be particularly difficult for caregivers of people with sensory impairments to comprehend their loved one's unique requirements, offer them the right care, and ensure their overall well-being. Several research concluded that caregivers for people with disabilities would report feeling more stressed and burdened than those who attended patients without disabilities (Grov et al., 2005; Michael, 2008).

These difficulties were exacerbated in the context of terminal illness, as patients and caregivers might get overwhelmed by the disease's progressing nature and the growing demand for complex medical care (Tuffrey-Wijne et al., 2016).

Speaking the truth about a terminal diagnosis has been a difficult moral dilemma, especially for patients who were suffering from sensory impairments. The literature emphasized the value of candid and open communication in end-of-life care, as well as the patient's right to be informed and involved in care decisions (Back et al., 2009; Epstein & Street, 2007; Street et al., 2009; Towers & Glover, 2015). However, accessibility, communication techniques, and cultural sensitivity must all be carefully considered when conveying sensitive information to people with sensory impairments. When communication proved difficult, caregivers frequently faced the challenge of striking a balance between openness and the need to shield their loved ones from emotional harm (Harrop et al., 2014). Communication strategies in India might be influenced by cultural norms and beliefs surrounding death and dying. For example, many families might choose to keep patients from knowing the whole truth about their illness (Mondal, 2022; Muralidharan et al., 2024). For caregivers attempting to negotiate the difficulties of telling the truth in the backdrop of sensory impairments, and the established philosophy of benevolence over the patient's autonomy might pose additional difficulties (Mondal, 2022).

Complex medical decisions regarding treatment alternatives, and palliative and end-of-life care would frequently involve literal life-and-death decision-making while dealing with terminal illness. To assist patients in these decisions, to speak out for their needs, and to honor their desires, caregivers were essential (Tuffrey-Wijne et al., 2016). Also, individuals with sensory impairments might find it difficult to engage in decision-making, and it caused more burden to their caregivers. On behalf of their loved ones, caregivers might have to make tough choices, frequently without assistance or clear direction from medical experts (Kirkendall et al., 2012; McLaughlin et al., 2014). Several studies highlighted how crucial shared decision-making and patient autonomy are to end-of-life care (Epstein & Street, 2007; Street et al., 2009). But following that might be especially difficult when patients have trouble communicating and caretakers lack the tools and support that they need (Towers & Glover, 2015). The difficulties faced by caregivers have further been compounded by the fact that palliative care services are still not widely available in India (Mondal, 2022; Muralidharan et al., 2024), especially for those with disabilities.

Within the healthcare system, end-of-life caregivers of patients with sensory impairments frequently face substantial systemic obstacles. Healthcare professionals might not be prepared to handle the distinctive demands of this population because of their limited training in disability-sensitive communication (Tuffrey-Wijne et al., 2016). Misunderstandings, poor communication, and insufficient care could result from this. Available literature has emphasized the necessity for healthcare workers to receive better training on culturally sensitive care, communication techniques, and disability awareness (Iezzoni et al., 2021; Kirkendall et al., 2012; Kuenburg et al., 2016; McLaughlin et al., 2014; Shakespeare et al., 2019). Although the need to increase disabled people's access to healthcare is becoming more widely acknowledged in India, considerable work is required to meet the unique requirements of people with sensory impairments who are simultaneously dealing with terminal diseases.

Research focusing particularly on the experiences of caregivers of terminally ill patients with sensory disabilities in India is severely lacking, even though studies have examined many facets of caregiving, terminal disease, and sensory disabilities. Very few studies have examined the convergence of these complicated experiences and mostly have concentrated on particular forms of disability or selected features of caregiving (Tuffrey-Wijne et al., 2016). By offering a thorough depiction of the difficulties experienced by caregivers in this setting, this study has sought to close this knowledge gap. It has specifically looked into the difficulties caregivers encountered in telling the truth and communicating with very advanced-stage cancer patients with sensory disabilities; how sensory impairments affected the patients' and caregivers' capacity to participate in palliative treatment and end-of-life care decision-making; the systemic obstacles caregivers confronted in the Indian healthcare system, such as the absence of disability-sensitive training among medical professionals and dearth of communication tools;

and the moral conundrums caregivers faced when trying to strike a balance between patient autonomy and the need to shield loved ones from emotional suffering. This research has aimed to offer insight that might have an impact on the creation of policies, development of disability-sensitive practices, training programs for healthcare professionals, and interventions aimed at assisting caregivers and raising the standard of care for the susceptible group. The ultimate goal of this research was to advance more compassionate and inclusive end-of-life care that acknowledged the particular difficulties faced by patients with disabilities and their families.

3. Methodology

Study Design

In this study, a qualitative research approach has been implemented to explore the lived experiences and challenges encountered by six caregivers in their day-to-day engagement with advanced-stage cancer patients with sensory disabilities in India. These six caregivers are close family members of four patients, two with visual and two with speech and hearing impairments, two men and two women with the age range of 58 to 71 years (Table 1). As this study investigates the everyday struggle of caregivers in communicating, decision-making, and overcoming the structural barriers in a broad disability-insensitive milieu, which involves severe emotional, financial, and mental anxiety, the qualitative study design, with semi-structured interview, has been deemed appropriate because of its exploratory and comprehending nature. As in the semi-structured interview, the researcher "asks informants a series of predetermined but open-ended questions" (Ayres, 2008, p. 810), this method offers "more control over the topics of the interview than in unstructured interviews… (and) there is no fixed range of responses to each question" (ibid.). A questionnaire including fifteen open-ended questions was used to conduct in-depth interviews with the participants. As the study sought to elucidate the nuances of the everyday challenges encountered by a specific group of caregivers, the questionnaire employed a variety of question types, from broad inquiries like "What are some of the biggest challenges you face as the primary caregiver?" or "How do you cope emotionally?" and specific questions like "Do you think the healthcare system is equipped to handle patients with disabilities effectively?" or "Can you share a specific experience that highlights the structural inadequacy?" to prescriptive questions like "What do you think would have been a better option for communication?"

Table 1: Patients' demographics

	Gender	Age	Type of Disability	Type of Cancer
Patient-1	Male	71	Visual impairment	4th stage liver cancer
Patient-2	Male	63	Hearing and Speech impairment	4th stage Lung cancer
Patient-3	Male	58	Hearing and Speech impairment	4th stage Lung Cancer
Patient-4	Female	67	Visual impairment	4th stage Breast Cancer

The Participants

Among the ten caregivers approached, only six of them, three women and three men, agreed to participate in this study with the assurance of complete anonymity. The ages of the participant caregivers, all of whom were residents of the state of West Bengal in India, ranged from 25 to 57 years (Table 2). As, cancer is a great taboo in India with a substantial number of patients being unaware of their disease due to the practice of non-disclosure or benevolent deception over patient's autonomy (Mondal, 2022), getting participants for any social research on cancer has proven to be a challenge. As the research specifically centered around the caregivers who were attending to advanced-stage cancer patients with sensory disability, the sampling was purposive. With the reassurance that the patients would not be bothered as the research focused solely on the caregivers, six close family members of four patients consented to be interviewed for this study. Participant A, who was the wife of Patient-1, Participant B and Participant C who were the wife and son of Patient-2 respectively (Table 2), were approached through a hospice only after confirming their consent. The other three participants, Participant D, and Participant E who were the son and daughter of Patient-3 respectively, and Participant F who was the brother of Patient-4, were recruited through individual contacts of the researchers. The interviews with the participants were conducted at their respective homes during the period from September 2023 to April 2024.

Table 2: Caregiver's Demographics (n = 6)

Caregiver	Gender	Age	Relation to Patient
Participant A	Female	57	Wife of Patient-1
Participant B	Female	54	Wife of Patient-2
Participant C	Male	29	Son of Patient-2
Participant D	Male	30	Son of Patient-3
Participant E	Female	25	Daughter of Patient-3
Participant F	Male	57	Brother of Patient-4

Ethical Considerations

Ethical approval was acquired from the University Human Research Ethics Committeeat the beginning of the research. As three participants were approached through a hospice, an institutional approval letter was procured before starting the interviews. And, as the other three participants were recruited separately through personal connections and not under any institutional setup, there was no scope or requirement to procure any institutional ethical committee clearance. Written consent and approval with the signature of each participant were ensured from each participant before enlisting them by clearly outlining the objectives of this research in minute detail. A distress protocol was employed to mitigate any harm inadvertently caused by the agony of recounting their anxiety and grief.

Data Analysis

Following the completion of each interview, the participant received a transcription of the audiotaped data for approval. To evaluate and find recurring themes in highly descriptive conversations, the dataset has been manually coded. Following Braun and Clarke (2006), the coding process was divided into six stages: familiarizing with the data; generating initial codes; searching for themes; evaluating themes into significant groups; identifying and naming themes to create a narrative; and connecting quantitative and qualitative data for producing the final report. This study used grounded theory, an inductive method for data analysis in which observations were compiled into conceptual categories that were then reassessed in the research environment to gradually improve and link to more conceptual classifications (Schutt, 2019). The process of drafting the report commenced once the coding was completed and the data segments were analyzed.

4. Findings

Following Braun and Clarke's six-phase framework for doing thematic analysis (2006), three major themes emerged from the interviews with six caregivers who were providing end-of-life care for cancer patients with sensory impairments: the day-to-day challenges of caregiving, communication barriers, and the inequitable healthcare system. The emotional, moral, and structural challenges that carers have encountered when delivering end-of-life care were revealed by these narratives, highlighting the pressing need for systemic changes and disability-sensitive practices.

The Day-to-Day Challenges of Caregiving

The experience of caring for a loved one with terminal disease is intense and emotionally taxing, particularly when end-of-life care involves patients with sensory impairment. The participants of this study expressed a variety of difficulties, such as making ethical quandies in truth-telling, dealing with the severe emotional stress of decision-making, and stressful handling of finances.

Ethical Quandaries in Truth-Telling

One overwhelming revelation of this study was the nature of truth-telling to advanced-stage cancer patients in India. Among the four patients, whose caregivers were interviewed for this study, none were aware of the terminal stage of their cancer. Two of the four patients (Patient-1 and Patient-3) were even completely unaware that they had cancers and were undergoing treatments believing that they were diagnosed with some benign forms of tumor.

When determining whether to inform their loved ones of the disheartened prognosis, caregivers frequently encountered difficult moral qualms. 57-year-old Participant A, the primary caregiver, and wife of the 71-year-old advanced-stage liver cancer patient with visual impairment, revealed: "I was unsure of how to disclose to my husband that he was only going to have a few months left. I was worried that the news would destroy him and add more to his misery and confusion as he was unable to read the medical records. He is still grappling with his vision loss that transpired a couple of years back due to the complications of diabetes. I kept wondering if it would be better for him to know everything and then, decided against disclosing anything about the cancer."

Caregivers frequently face this conundrum as they have been found attempting to strike a balance between the moral precept of autonomy and the established benevolent deception that dictates protecting their loved ones from emotional suffering. This outlook was shared by 54-year-old Participant B, wife of the 63-year-old advanced-stage lung cancer Patient-2 with hearing and speech disabilities: "I had to decide how much to disclose because of his disability as after decades of being with him, I still found this situation impossible to articulate. While I did not want to deprive him of hope, I also did not want to tell him a complete lie, so I informed him about the cancer, but lied about its stage."

Emotional Stress of Decision-Making

Partial or zero disclosure, which was frequently caused as a response to the patients' disabled conditions, often heightened the caregivers' emotional burden in making decisions on behalf of their close one's end-of-life care. The weight of these choices was meticulously explained by 29-years-old Participant C, the son of a 63-year-old advanced-stage lung cancer Patient-2 with hearing and speech disabilities, as he said, "Every choice has felt like a life-or-death situation for me and mom (Participant B), like is it better to transition to palliative care or continue radiotherapy and chemotherapy, and without much of my dad's information? I often question whether I am acting in my father's best interests. I am sure mom is going through similar emotional upheaval."

Similar opinions on self-reproach and anxiety were revealed by 30-year-old Participant D, the son of the 58-year-old advanced-stage lung cancer patient with hearing and speech disabilities, as he articulated, "I felt guilty whenever I had to decide without my father's knowledge. Seeing him trying to assess the situation constantly and the resultant frustration is heartbreaking for me."

Seeing his father struggling and being confused with his physical discomforts, frequent hospital visits, and numerous pathological tests, he and his younger sister, Participant E, decided to misinform him that he had been diagnosed with a benign tumor that was curable. They collectively resolved to make every medical choice on their father's behalf and shared a great sense of emotional stress and guilt for making decisions on their own.

These narratives of all participants have illustrated a universal mental strain, loneliness, and sense of remorse that caregivers endured in their decision-making responsibilities.

Financial Difficulties

For all the participants, financial challenges were a major point of concern. Palliative care became more expensive as they had to design it keeping in mind the specific needs of disabled patients. For example, in the process of hiring a home care attendant for Patient-1, his wife, Participant A, had to pay extra charges for the patient's visual impairment. In her words, "During the daytime hours, I had to hire a specialist nurse from a daycare center as I go to the office. They charged me almost double the rate the moment I said the patient was visually disabled. This alone is proving to be the most expensive part of the palliative care. To arrange money for all these, I had to sell some of my jewels and take out a loan."

The financial difficulties were also highlighted by 57-years-old Participant F, who is the younger brother and sole caregiver of the 67-year-old advanced-stage breast cancer patient with a visual disability, when he said: "As we live in a semi-urban locality, and the local healthcare center has no cancer facility available, we travel 5-6 hours every week for diagnostic tests, oncological consultations, and palliative treatment at the cancer center in the metropolitan city. As my sister developed visual impairment due to damage in the optic nerve just a few years ago, we cannot travel by public transport and the expenses of hiring a car every week for traveling this long is a huge problem."

Communication Barriers

In delivering high-quality end-of-life healthcare, effective communication is elemental. However, in this research, it has been found that sensory disabilities for patients proved to be a major obstacle preventing them from fully realizing their prognosis and treatment procedures. The caregivers for the two patients (Patient-2 and Patient-4 who were partially aware of their diagnosis), despite their sincere efforts, failed short of explaining complicated medical information to them. This added more frustration for the caregivers who were already burdened by the day-to-day challenges.

Barrier in Communicating Prognosis and Treatment Regimens

Even though all the participants of this study have unequivocally expressed their concerns about the difficulties in communicating the prognosis and complex treatment procedures to patients with sensory disability, the caregivers of patients with speech and hearing disabilities found it further arduous. For instance, Participant D and Participant E, the son and daughter of Patient-3 with hearing and speech disabilities, expressed these barriers as the main reasons behind not disclosing the diagnosis to their father. As Participant E explained, "Telling the truth about his diagnosis is a one-time challenge, but we could not fathom how to communicate the details of his prognosis and treatment regimen on a day-to-day basis. That is certainly one major cause behind non-disclosure."

Even for family members of those patients who were partially aware of their conditions, it was a challenge to communicate complex medical information. Participant C, the son of Patient-2 with hearing and speech disabilities, expressed it lucidly, "The doctors would explain things to me as they don't know how to communicate with my father, and I don't know how to convey the technical elements of the treatment procedures to my father. After every single visit to the doctor, Dad becomes irritated since he is constantly trying to comprehend what is happening around him. This communication gap often makes his interaction with me and my mother (Participant B) emotionally taxing. And for days, sometimes weeks, a sense of frustration and depression looms around me and mom."

Absence of Communication Tools

The participants have pointed out how there was a complete absence of sign language interpreters, voice assistance equipment, Braille materials, and other disability-assistive technologies in medical institutions. It has also been reported that this insufficient availability of resources often left patients with sensory disability vulnerable, and more dependent on their caregivers. This in turn burdened the caregivers as they felt incapable and helpless. Participant C has explained this through the experience during his visit to the hospital with his father, "We do not expect a sign language expert to be present, and the doctors are also not familiar with sign language, so I always serve as a go-between. But most of the time, I fail to understand the medical jargon, and everything following that gets lost in translation" Participant F emphasized the scarcity of accessible communication resources for his elder sister, Patient-4 with visual disability. He said, "My sister can read simple texts in Braille. As her vision loss was a gradual process, it allowed her some time to learn Braille. But, here no Braille materials, audio resources, or voice assistance equipment are available. I try to read her whatever possible."

Inequitable Healthcare System

Another concern regularly raised by the caregivers was the inadequate and ill-equipped healthcare system that was supposed to address the unique requirements of patients with sensory disabilities.

Insufficient Training of Healthcare Professionals

Five of the six participants voiced apprehensions about the lack of knowledge that healthcare professionals exhibited when it came to communicating with patients who have sensory impairments. As Participant A, wife of Patient-1 with visual disability articulated, "The doctors and nurses often appeared uneasy when engaging with my husband. They were fidgety and talked too fast."

For patients with speech and hearing impairments, as reported by several participants, experiences of similar unprofessionalism were reflected by the amateurish attempt of medical personnel who appeared ill-equipped while communicating with disabled patients. For example, Participant B said, "The cancer ward nurses seemed unsure how to interact with my husband. They always interacted with me instead of him, even though he was the patient."

The inadequacy in the training of healthcare professionals turned into a major point of concern for Participant E when she witnessed insolence and indifference during her visit to the emergency ward with her father, Patient-3 with hearing and speech disability. She recounted, "My father was in excruciating pain, and the hospital employees were unable to interpret his gestures. Despite my father's extensive familiarity with sign language, they were able to comprehend it. They persisted in asking him questions out loud, and when he was unable to reply, they simply assumed that he was not being cooperative or that his suffering was not severe.

They even did not listen to me and hours passed before they handed him pain medication. We were both traumatized by the encounter. It helped me realize that even when patients have the ability to communicate in their own ways, the healthcare system is ill-equipped to deal with them.”

While asked whether he had ever experienced insensitivity or indifference from any medical personnel, Participant C, caregiver of Patient-2 promptly replied, “Regretfully, yes. After learning that my father is hard of hearing and nonverbal, they sometimes act impatiently and derisively. I was once handed over a prescription by a doctor who refused to provide me with a detailed explanation of the treatment plan. That evidently seemed apathetic to our hardships. There are a few doctors who are sincerely sympathetic, I must mention, but the general experience is miserable.”

Systemic Gap in Palliative and End-of-Life Care Availability

The absence of communication tools, which have been recorded under the broad theme of communication barriers, was also mentioned as a systemic lapse in palliative and end-of-life care accessibility. It has also been observed that patients and caregivers, especially those from low-income or rural backgrounds, were affected further by these structural deficiencies. This became evident when Participant F, the caregiver of Patient-4 with visual disability, emphasized how these hardships were amplified by their inconvenient existence in a semi-urban area. He conveyed, “The small town we live in lacks any end-of-life care services that could have assisted with the special needs of my sister. And to cover the systematic gaps, we are relying on relatives and friends.”

Overall, the findings highlighted the complex difficulties confronted by those who were providing end-of-lifecare for cancer patients withsensory impairments. Their experiences were mostly characterized by ethical quandaries, emotionaldistress, and financial pressure, which were exacerbated by institutional deficiencies in healthcare and communication obstacles. In ensuringthat these patients had access to care, narrowing thecommunication gaps, and advocatingfor them, caregivers were indispensable. These revelations underscored the critical need for structural changes to support patients and caregivers, provide them with accessible palliative care services, and introduce disability-sensitive training for healthcare professionals.

5. Discussion

The findings of this study offered insight into the complex struggles confronted by those who provided end-of-lifecare for cancer patients with sensory impairments. These difficulties were categorized into three main themes: day-to-day challenges, communication barriers, and inequitable healthcare system. Every participant emphasized severe flaws in the current healthcare system in India and highlighted the pressing need for changes at structural and policy levels to support patients and caregivers better. The following discussion will place the findings in the context of these three themes and try to frame recommendations for improving healthcare deliverance.

The Day-to-Day Challenges of Caregiving

Consistent with previous studies that emphasized the struggle between preserving patient autonomy and shielding patients from psychological suffering (Broom et al., 2016), this study also echoed how the caregivers struggled to make the difficult moral decisions in choosing whether to inform their loved ones of their fatal diagnosis and hopeless prognosis. In India, truth-telling to cancer patients is a debated issue as the majority of the patients are either completely or partially unaware of their diagnosis (Chaturvedi et al., 2009; Mondal, 2022), and disability added more to this practice of non-disclosure based on the primacy of benevolence and munificence over patient autonomy. These conundrums aligned with research on truth-telling in palliative care, which highlighted the importance of tailored and culturally appropriate disclosure strategies (Clayton et al., 2007; Fallowfield et al., 2002; Fujimori & Uchitomi 2009).

Following an earlier study on caregiver burden, which explored how making decisions has been a significant source of stress and guilt for caregivers (Grov et al., 2005), the participants of this research also expressed how psychologically and emotionally overburdened they felt in the process of day-to-day decision making that could change a patient’s life, especially when patients were unable to express their preferences in clear terms. It alsodemanded an urgent implementation of improved support networks to assist caregivers psychologically.

The recurrent topic of financial burden, as expressed by the participant frequently, was in line with research showing how expensive caregiving was, especially in low and middle-income nations (Stenberg et al., 2010). The burden was made worse by the healthcare system's lack of funding, which left caregivers to bear the expenses without any structural assistance.

Communication Barriers

The communication barrier was a recurring theme in this study as participants suffered an utter sense of helplessness and feelings of isolation due to their inability to adequately convey complicated medical procedures and information to their respective patients with sensory disabilities. These difficulties align with prior studies that emphasized how crucial good communication was to end-of-life care specifically, and palliative treatment in general (Back et al., 2009; Epstein & Street, 2007; Street et al., 2009; Towers & Glover, 2015). The availability of qualified interpreters and sign language experts was the systemic change that caregivers strongly demanded as they often felt incompetent while communicating with the patients in the process of discussing their complicated conditions.

As accessible communication tools and assistive technology were crucial to effective healthcare settings (Muthu et al., 2023; Senjam & Mannan, 2023), the lack of accessible and disability-sensitive communication options, including audio resources, voice assistance technology, digital communication equipment, and Braille materials ended up denying the patients with vision, speech and hearing impairments, the access to their own treatment, which compromised their dignity and autonomy and left the caregivers frustrated. Unsurprisingly, the participants unequivocally expressed the urgent need for better communication techniques in medical environments to effectively assist individuals with sensory impairments.

Inequitable Healthcare System

While studies strongly advocated for healthcare providers to undergo disability-sensitivity education and training (Iezzoni et al., 2021; Kuenburg et al., 2016; Shakespeare et al., 2019; Tuffrey-Wijne et al., 2016), significant inadequacies in the Indian healthcare system were established by the study, with a notable absence of disability-sensitive communication training for healthcare professionals. Doctors and nurses, in general, communicated with the caregivers rather than the patient, an alienating experience that left the patients frustrated and resulted in a strained relationship with the caregivers. This reflected the same findings of Shakespeare et al. (2019), who explored the widespread ignorance and incompetence of medical personnel in meeting the unique needs of patients with disability, which frequently, as reported by the participants of this study too, resulted in suboptimal treatment. By improving communication skills, such training would ease the strain on caregivers and guarantee that patients with sensory impairments receive the respect and dignity they deserve.

Another significant obstacle was the existence of systemic disparities in palliative care accessibility. Accessing palliative care treatments for patients with sensory impairments was a challenge for many caregivers, especially in rural or low-income areas. As participants revealed their concern about traveling far to avail facilities that could meet the special needs of their respected patients with disabilities, it mirrored the studies focused on disparities in access to end-of-life and palliative care, especially for marginalized groups (Hawley, 2017; Connor et al., 2020). It demanded systemic and policy changes to overcome these gaps to integrate disability-sensitive practices and increase access to palliative care services.

6. Conclusion

Following its objectives, this research managed to explore the significant obstacles encountered by the end-of-life caregivers of cancer patients with sensory impairments in India. The day-to-day logistical and ethical challenges, moral conundrums, obstacles in communication, and structural flaws in the healthcare system made their job immensely difficult, which often resulted in a sense of loneliness and depression. The ubiquitousness and extent of these struggles have emphasized how urgent the need for systemic changes to better assist caregivers and patients with sensory disabilities ensuring a fair and considerate medical ambiance. Only a more inclusive structure and focused policy could guarantee a reduced burden for the caregivers.

Recommendations

The findings of this research have important ramifications for both practice and policy.

As a genuine lack in the end-of-life care of cancer patients with sensory impairments has been confirmed at the structural level, there is immense scope for improvement to provide disability-sensitive healthcare services. To achieve that, healthcare professionals need to be trained in disability-sensitive communication, and accessible communication methods, such as audio resources, sign language interpreters, and Braille materials should be available for every patient with a disability. There is also an urgent need to make palliative and end-of-life care available for every patient, especially those living in rural or low-income areas to close the systemic gaps in accessibility. Access to improved support networks, such as financial aid, counseling, and accessible emergency care would make the healthcare system more equitable for everyone and reduce the pressure on caregivers.

Limitations

This current study deals with a small size of sample, a future study with a larger number of participants might add more dimensions to the findings. Also, future research can examine how disability intersects with other demographic identities, such as age, gender, religion, caste, level of education, and socioeconomic status to illustrate how particular difficulties are experienced by specific marginalized groups.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

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