Original Article

"End-of-Life Care is more than Wound Care": Health-Care Providers' Perceptions of Psychological and Interpersonal needs of Patients with Terminal Cancer

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Abstract

Aim: People diagnosed with cancer and in end-of-life care may have a range of needs. These needs may be inadequately expressed, recognized, or responded to by family members and health-care providers. The present study aimed at exploring health-care providers' perceptions of the interpersonal needs, psychological needs, and unfinished business among terminally ill cancer patients during the end-of-life care. **Methods:** The sample consisted of 11 health-care providers, including physicians, counselors, social workers, and nurses from the end-of-life care settings in Bengaluru, India. A cross-sectional qualitative design was used and involved semi-structured interviews and focus group discussions. **Results:** Thematic analysis identified themes related to health-care providers' perceptions of patients' prominent interpersonal needs, psychological needs, and expressions of "unfinished business" and their perspectives and experiences. There were three themes related to psychological needs and concerns: (i) experience and expression of negative emotions, (ii) mental health concerns, and (iii) confronting mortality. Three themes emerged in the domain of interpersonal connections: (i) support and closer connections with family, (ii) disconnection from family relationships, and (iii) building new connections at the hospice. Two themes were identified related to unfinished business: (i) types of unfinished business and (ii) addressing unfinished business. The findings also highlighted health-care providers' perspectives and experiences: (i) need for expanded end-of-life care training and (ii) experiences of emotional labor. **Conclusions:** The findings have implications for comprehensive training of health-care providers and for assessment, support, and care services in palliative care settings in India.

Keywords: Cancer, health-care providers, palliative care, psychological needs, unfinished business

INTRODUCTION

There have been efforts to develop an end-of-life care policy in India to ensure quality care, a "good death," and professional guidelines that are grounded in sociocultural realities.[1] As an extension of palliative care,[2] the end-of-life care aims at an empathic attentiveness to the meaning and experience of suffering of each patient.[3] The relief of suffering in the dying involves going beyond alleviation of physical pain to encompass "total pain"; the sum of the patient's physical, psychological, social, and spiritual pain.[4] Research has found that higher psychological distress and lower social support are associated with higher pain levels among persons with cancer.[5] A life-limiting illness is associated with many changes such as the loss of defining roles of parent and spouse, loss of control over one's body, loss of one's dignity, and these may be more difficult to deal with than the physical pain.[6]

A comprehensive end-of-life care plan shifts from the disease perspective and values an understanding and affirmation of the "whole" person with unique needs and preferences.[1] The goal of end-of-life care is, therefore, to improve the quality of life of both patients and families by providing nursing, psychosocial, and spiritual support. This "work of dying[7]" involves a process of life review and health-care providers may be involved in facilitating the completion of unfinished tasks. Research with Indian patients diagnosed with terminal cancer indicated that pain, physical health, finances, and the

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future were the most commonly reported concerns.[8] In a recent study,[9] 30 participants from 16 palliative care centers shared their views about the end-of-life care services relevant for the Indian setting. While a majority supported the importance of communication about the dying process and helping patients express their wishes, feelings, beliefs, faith, and values, some participants believed that this was not possible or relevant in the Indian setting.

The increasing incidence of cancer in India, with over 80% presenting at Stages III and IV,[10] adds to the existing complex challenges in the provision of palliative/end-of-life care services in the country.[11] There is inadequate training for health-care providers in the assessment and sensitive response to an array of physical and psychosocial needs of patients. In addition, there is a paucity of research on the concerns and needs of patients with cancer when death is imminent. Although professional health-care providers are on the frontline, providing complex and critical services, there is limited information on their perceptions and experiences of patients' needs and expectations. These needs may be concealed, expressed indirectly or directly, and may also be underrecognized or remain unaddressed.

The present study was planned to increase the understanding of patients' psychological and interpersonal needs, concerns, and internal struggles at the end of their life. As part of this research, the information was collected from the patients and health-care providers. This paper looks through the lens of health-care providers' perceptions during their work at palliative care centers.

METHODS

Sample

The sample included 11 health-care providers working at palliative care centers for a minimum duration of 6 months, with work roles that involved direct contact with patients. The health providers included six counselors, two physicians, two social workers, and one nurse from two end-of-life care settings; Karunashraya Palliative Care, Bengaluru, and Ave Maria Palliative Care, Mangalore.

The majority of the health-care providers were women (90.9%), with their ages ranging from 35 years to 54 years (mean = 35.36; standard deviation [SD] =10.59). While six of the health-care providers had postgraduate degrees in psychology, social work, or nursing, two other health-care providers had doctoral degrees in psychology/social work, and the physicians had MBBS degrees. Most of the health-care providers (63.6%) did not have any formal training or education in end-of-life care. Their levels of experience in an end-of-life care setting ranged from 18 months to 3 years. The large proportion of their time at work was spent in direct contact with patients (Range: 21 h to 56 h per week; mean = 33.64, SD = 11.7).

Measures

Health-care providers' perceptions of patients' needs – Focused group discussion guide/semi-structured interview guide.

A focused group discussion (FGD) guide with probe questions was developed to obtain health-care providers' perceptions of patient's psychological and interpersonal needs and concerns. The questions were planned for use either in a focused group discussion or in individual interviews with the health-care providers.

Health-care providers were encouraged to discuss their perceptions of patient's psychological and interpersonal needs. They were asked to reflect on their personal experiences with patients and family members and share narratives of recent or salient interactions to support their views. The domains of inquiry explored the patterns of needs and concerns expressed by patients during the end-of-life care; these include psychological and emotional needs and those arising from relational and familial concerns. Health-care providers were asked questions about patients' expression of their needs in terms of how, when, where, and to whom this was directed. Their impressions about factors related to patients' sharing or disclosures were gathered. Their experiences, in responding to either their patients' direct disclosures or their own understanding of patients' needs, were also elicited. The questions also focused on the barriers to and difficulties in addressing these needs, as well as the role of personal qualities and experience levels of health-care providers. Finally, probes examined the perceived training needs for health-care providers working in end-of-life care.

Procedure

Ethical approval was sought for this study, and permission was obtained from the two institutions engaged in end-of-life care.

Two individual interviews with health-care providers were conducted in the pilot phase to help plan the probes for focused group discussion guide. The questions for health-care providers were finalized based on the feedback provided by the participants in the pilot phase and two experts' opinion. The first expert was a Professor of Psychiatry who has completed an international fellowship in psycho-oncology from the Memorial Sloan Kettering Cancer Centre, New York, and has been involved in research and training in the area of palliative care. The second expert was an emeritus consultant in palliative medicine who is the Director of Education and Research in a palliative care setting in Bengaluru.

Written informed consent was obtained from the health-care providers at the two end-of-life care centers, who met the inclusion criteria for participation in focus group discussions (FGDs). Two groups were finalized for FGDs, each consisting of six members, representing diverse disciplines related to end-of-life care. The second FGD could not be conducted due to clinical emergencies and unexpected professional commitments. Of the six health-care providers who had provided consent for participation, five agreed for an individual interview at a convenient time, based on their work schedules. The FGD took around two hours to complete, and the individual interviews were 30–40 min long. As a moderator, the first author ensured a safe environment where all participants could narrate their experiences, opinions, learnings, suggestions, and engage in a healthy discussion with fellow participants. Detailed notes were recorded, maintaining anonymity of the participants, and the researcher outlined personal reflections about the content and processes, after completion of the FGD and each individual interview. The FGDs and the individual interviews were audio recorded and transcribed.

Analysis

Thematic analysis was used to analyze responses on FGD and individual interviews.[12] This method has been widely used to provide in-depth understanding of individual experiences. The first author familiarized himself with this methodology by extensive reading of published research using the method. The first author was supervised by the coauthors who were trained mental health professionals with substantial academic teaching, clinical, and research experience.

The first step in data coding involved the development of broad topic areas as domains or themes by reviewing the responses; these included narratives, phrases, examples, and long exchanges between the participants and the patients. The next step involved the construction of core ideas that formed specific categories under each domain. The first author and the coauthors read the transcripts to review the core ideas in each domain and arrived at a final consensus on the coding through discussion. The core ideas across all the responses were identified.

With continuous references to each response, comparisons were made across the various domains, categories, and core ideas. This analysis process involved close discussion between the researcher and the guide. Many initial categories and core ideas were changed and merged after discussions.

RESULTS

Three domains emerged from the analysis of all the responses, namely, psychological concerns, interpersonal connections, and unfinished business. The emergent themes are described below in Table 1.

Psychological needs and concerns

The themes related to psychological needs and concerns are discussed below.

Experience and expression of negative emotions

Health-care providers observed a range of difficult and distressing emotions experienced by patients. These negative emotions included guilt about being responsible for the illness due to habits such as smoking or personal attributes such as "durahankara" (ego) or guilt about the inability to fulfill their role responsibilities. The health-care providers also felt that their attempts to address patients' guilt feelings were ineffective. Patients expressed multiple fears during their interactions with health-care providers. The FGD and interview revealed that some patients experienced anger and hostile aggressive feelings toward select family members (e.g., in-laws) but did not appear to have an outlet or effective way to express their anger. While some patients would become quiet and isolated, others sought more attention from health-care providers.

Table 1: Health-care providers' perceptions of their patients' psychological needs and concerns, unfinished business interpersonal connections, and their perspectives and experiences

Domain	Themes	Core ideas
Psychological needs and concerns	Experience and expression of negative emotions	Negative emotions turned inward (e.g., guilt, fear, and remorse) Negative emotions turned outward (e.g., anger and aggressive feelings and attention-seeking behavior)
	Mental health concerns	Anxiety Depression and suicidal thoughts
	Confronting mortality	Reactions to the idea of death Questions about spirituality and faith Disclosure and knowledge about impending death
Interpersonal connections	Support and closer connection with family	Need for more time with family and desire to go home Need for sexual intimacy with the spouse
	Disconnection from family relationships	Wish for detachment and avoidance of family network Sense of rejection, abandonment, and threats from the family
	Building new connections at the hospice	Relationship with health-care providers Health-care providers as mediators
Unfinished business	Types of unfinished business	Recapitulation and regrets about life choices Roles and responsibilities Repair and reconciliation Saying goodbye and leaving a legacy
	Addressing unfinished business	Responses from patients, family, and health-care providers
Health-care providers' perspectives and experiences	Expanded training needs	End-of-life care training related to breaking bad news, dealing with patients' emotions and needs, religious and subcultural beliefs, and rituals
	Emotional labor	Emotional difficulties Compassion fatigue

Mental health concerns

Health-care providers observed mental health concerns such as increased levels of anxiety and depression. Instances of suicidal intent and attempts were described by health-care providers – "*We had a patient in the ward. We spent a whole day talking to her and her family, and in the evening she attempted suicide because of the unbearable pain.*" One of the health-care providers described an incident where the patient asked his wife to participate in a suicide pact with him. Cultural beliefs about the afterlife seemed to be an influence; "*They say, if we die together maybe we can be together in the next life too. If I die alone, my wife and children will be left behind, and I will never meet them again*." Such situations were experienced as extremely challenging by health-care providers who worked closely with persons in palliative care.

Confronting mortality

Health-care providers recognized diverse *reactions to the idea of death* and felt that each patient has his/her unique experience in approaching death. Shifts within the cycle of acceptance and denial were evident, and there are fears about dying alone or what awaits them in the afterlife. Some patients insist on investigations that are not required, and health-care providers noted that family members also wish to adhere to all last wishes to ensure that the "*soul does not come back after death*."

In the words of one of the health-care providers, "*They see their own mortality. They all know they are going to die soon, but don't know when. Those who are aware of it, they see death in everything. Seeing someone die in the hospice, they experience their own death. They ask us to change the ward, they don't sleep the whole night.because it is too early for them to embrace death*." Those patients who had moved closer to accepting death, conveyed specific wishes for their postdeath ceremonies, and a desire for a "*a normal and respectful death*," either at home or in the presence of family members.

Health-care providers observed challenges to patients' religious and spiritual beliefs during the end-of-life stage; some patients stopped praying to God, felt punished by God or questioned the "injustice" of the diagnosis, or changed their religious orientation. Equally, the FGD/interview participants experienced how spiritually-orientated coping strategies were a source of strength for many patients as well. Overall, they felt that these approaches should be inculcated in end-of-life care, as something that would resonate with many patients.

Despite the presence of fluctuating denial among many patients, health-care providers shared their observations about patients' desire for more *knowledge and timely disclosure* of their illness and prognosis. This was seen as something that would facilitate completion of tasks and wishes and help in their preparation for death.

Interpersonal needs and concerns

The themes related to interpersonal needs are discussed below.

Needs for support and closer connection with family

Health-care providers observed that patients expressed their needs for more *visits from family* members and *more time* with spouse, children, and other close relatives. Many asked for visits to their homes to meet members of their family.

Health-care providers described their understanding of *sexual intimacy needs* among some patients. These patients often concealed their needs for fear of negative reactions. One participant recounted her patient's words; "*What would others think if they come to know.he is dying but still wants sex at this phase*." A receptive attitude by health-care providers facilitated these discussions; patients clarified their fears about the illness being contagious and disclosed that body image concerns were deterrents to the initiation of sexual intimacy with the spouse. These included loss of body weight, hair loss, and postmastectomy concerns, among others.

Health-care providers discussed patients' concerns about barriers to meeting their needs for sexual intimacy within the hospice setting: these included the absence of private rooms, nonavailability of their partner at the hospice, and the perceived attitude of other patients/caregivers/health professionals.

Disconnection from family relationships

Health-care providers also highlighted how a small proportion of patients actively avoided contact with family members or refused to go home. There were diverse reasons for this; fears that children would not recognize them or would be fearful of their appearance, fears that the illness was contagious, the lack of medical and care facilities at home, and wanting to avoid members of the extended family to their decline in financial status.

Some participants' responses indicate a need to be respected. In the words of one of the patients, as narrated by the participant, "*Why are people coming and peeping at me? I don't like people coming and seeing me. I know I am sick and unwell, but I don't want everyone to come and see me like a museum piece.*" They say, "*I am not fine.How will I go and mingle with others*."

Some patients expressed their wish for conscious detachment and an opportunity for quiet reflection. They requested health-care providers not to allow family visits at the hospice saying, "*I need to think about my life. I don't want to be distracted by anyone*."

Health-care providers described their observations of disconnection from the family, despite the patients' need for a closer connection. They spoke of incidents where patients experienced rejection from family members who did not want to take them home. Health-care providers reported about the loosening of family bonds; "*They feel separated and isolated by the family and society…they ask us if this illness is contagious. Why are people not touching us and talking to us?*" On rare occasions, family members threatened patients if they expressed the need to go home; "*They threatened her* *and said, in case you request the doctors for discharge, we will leave you on the streets*."

Building new connections in the hospice

The responses indicated that patients sought to meet their interpersonal needs through new relationships with health-care providers at the hospice. One of the care providers narrated an experience at the hospice, "*There was a patient who will not speak anything, but wanted me to sit beside his bed for almost an hour. You have to just make sure that you are there with him*." For most patients, a close confiding relationship with the health-care providers became an important support at the hospice; a space for sharing personal and family difficulties, their needs, and last wishes. Health-care providers, particularly the nursing staff and counselors, also developed special attachments with some patients.

The health-care provider may also be asked to play a mediating role between patient and the family and are called upon to communicate what the patient is unwilling to do directly. On occasion, patients compared the behaviors of the health-care providers and family members. For instance, one health-care provider described what the patient said, "*When the doctors are able to come and sit down and talk to us for hours, why can't my children come and talk to me even for few minutes?*"

Unfinished business

The themes related to unfinished business are discussed below.

Types of unfinished business

In this category, five core ideas were identified; recapitulation and regrets about life choices, roles and responsibilities, repair and reconciliation, and saying goodbye and leaving behind a legacy.

The participants reported that patients typically recollected past memories and expressed regrets over life choices and incomplete goals. Some of these were past regrets and perhaps could not be changed, for example, regrets over conflict and separation from family of origin due to their marriage of choice. Others were regrets such as not persevering for a government job and having no opportunities for doing things differently in the future.

The patients revealed their concerns about unfinished responsibilities and tasks. These included concerns about legal issues, for example, one patient wanted to file a case against someone who owed him money. Various responsibilities were based on the life stage of the patients; an elder brother wanted to take care of the marriages of younger siblings, a grandparent wanted to complete the task of buying jewelry for her children, a father wanted to complete building a house for his sons to live in. In fact, health-care providers described how patients experienced a loss of control if other members began to take on their tasks and responsibilities during the hospice stay.

The need for reconciliation and repair of interpersonal conflicts were prominent during the end-of-life stage. Health-care providers described how patients almost seem to "wait to die," as they tried to meet or communicate with family members to seek or obtain forgiveness and achieve closure to their "unfinished business."

The participants' responses also indicate patients' desire to say goodbye to all their loved ones, leave behind a legacy and be remembered. Some wanted to address this need by gifting their grandchildren money or jewelry that had been kept aside or by writing letters with messages for each close family member.

Addressing unfinished business

Health-care providers discussed instances where patients proactively addressed their unfinished business, either by going home, from the hospice by instructing family members or by enlisting help from others. In situations, where addressing unfinished business was not possible, this was extremely distressing to patients and was often reflected in less communication and withdrawal from others as well as in lowered pain tolerance.

While family members were largely supportive in responding to patients' needs to complete some tasks and fulfill their wishes, often the onus seemed to be on the health-care providers. The study participants described a range of ways, in which they facilitated the completion of "unfinished business"; facilitating meetings with estranged family members, delivering apology letters to persons after death of the patient, facilitating marriages of children at the hospice bedside, and helping a patient meet a famous local film star.

Health-care providers' perspectives and experiences

Most health-care providers highlighted a need to expand training in end-of-life care to address sensitive issues such as breaking bad news, dealing with intense emotions, and addressing the array of patient care needs. In the words of one of the participants, "*I feel end of life care is more than wound care. It's about dealing with patients' emotions, especially negative emotions such as anger, resentment, guilt, hostility. We need training in managing these*." Some of the health-care providers emphasized that comprehensive training for end-of-life care needs to include information about difficult subcultures and religions and their rituals around death and dying.

Equally, the care providers recognized their struggles with their own emotions such as anger, sadness, helplessness, and guilt. They mentioned instances where they were unable to respond to patients' needs such as providing financial help or ensuring safety and well-being of the surviving spouse. One participant spoke about an interaction with a patient; "*I still have that guilt feeling. She just asked for a banana, but I didn't give her because she was a diabetic. I couldn't fulfil her last wish*." Two other participants shared their thoughts, "*Sometimes, I feel how much we do for them, but still they are unhappy*;" "*We also get angry with them, if they say something bad about us despite doing so much*." Care providers also described close attachments with some patients and going out of their way to spend time with them and respond to their needs. They spoke of their experience of difficult emotions after the death of these patients.

Discussion

The findings of the present study illuminated health-care providers' perceptions of the prominent psychological and interpersonal needs and concerns of their patients in end-of-life care.

The health-care providers in this study demonstrated sensitivity to the experience of negative emotions and mental health vulnerabilities among their patients as they approached the end stage of their lives. While patients experienced a range of distressing negative emotions, anger and aggressive behaviors were most challenging for health-care providers to deal with. While anger is an expected part of the dying process,[13] it can evoke difficult responses among care providers if they personalize the patient's anger or get enmeshed in the relationship.[14] Understanding anger as a defensive coping mechanism and using advanced communication skills can help in reaching out to angry dying patients more empathetically and effectively.[14]

Studies in the Western and Indian context have reported the presence of depression, anxiety, and hopelessness during the terminal phase of the illness.[15-17] With the focus on alleviation of pain and other medical complications, it is possible that these psychological needs remain unrecognized, underreported, or inadequately addressed.[18] The use of measures for the rapid assessment of depression, anxiety and common psychosocial concerns, adapted for use in India, has been recommended.[19] Palliative care staff would need ongoing training and support in dealing with the psychological needs of their patients and effective networks with mental health practitioners where required. Initiatives such as "Measuring what Matters"[20] provide recommendations for the assessment and documentation of emotional or psychological needs in palliative care settings.

The health-care providers bore witness to their patients' struggles with mortality and their questions about their faith and the existence of God. In cultures like India, family members and health-care providers may collude to hide information about the diagnosis and prognosis, in order to protect the patient from the pain of confronting death.[21] More recently, though there is a recognition that patients in India, particularly those who are younger and more educated, would want to be informed about the closeness and inevitability of their death.[22] This can help them reconcile their "unfinished business," express their needs and preferences, and experience what they construe as a "good death."[23,24] George[25] highlighted that *how* sensitively the disclosure is made is perhaps more important than *what* is said. In addition, the issue of *when* is also critical; there must be time for the person to make some choices in a situation of powerlessness and uncertainty. According to Byock,[6] it is important for persons to acknowledge and say five things at the end of life – Goodbye, I love you, Thank you for loving me, Forgive me, and I forgive you. The findings of the present study mirrored some of these five tasks, with patients expressing needs for spending time, saying goodbye, taking care of loved ones' needs, and leaving objects of memory for family members, along with attempts at repair and reconciliation. Similar to the findings in Western contexts,[26] the patients may also contemplate about the place of death and what needs to be done after death.[26] Palliative care practitioners are often closely involved in facilitating the process of mean-making,[27] taking care of unfinished business, and reconciling to things that are difficult to address directly or completely. In a collectivistic, pluralistic, and traditional society like India, care providers need to be cognizant of varied religious and subcultural belief systems, and each patient's position along the intersections of dimensions of class, religion, caste, community, language, age, and gender.[28] The importance and close involvement of family calls for training and skill in effective communication with family members.[29] Larson and Tobin[30] discussed how to overcome barriers and use effective strategies to have meaningful end-of-life conversations that can facilitate closure and completing personally salient tasks. They also emphasize the need for health-care providers to initiate these conversations in a sensitive and culturally appropriate manner, instead of solely in response to patients' disclosures.

The participants' responses revealed that patients had divergent interpersonal needs; strong wishes for support, time, and deeper connections with their families as well as active avoidance or detachment from relational bonds. George[25] argues that in collectivistic cultures like India, the presence of family and friends can help the person feel less alone in the experience of dying. Patients' request to go home or the wish to be with family and die at home may reflect strongly held cultural beliefs and practices about death.[31] The need for belongingness and sexual intimacy with the partner emerged as an unmet need in the present study. The participants reported the hesitations the patients have in discussing these concerns: body image concerns, fears about rejection from the partner, less communication about sexual needs, and other issues concerning sexual well-being have been researched most often among women with breast cancer.[32,33] Clearly, there are barriers to discuss sexuality concerns in palliative care settings, although the expression of intimacy needs might be particularly vital at this stage, when relationships with loved ones are time limited.[34] Research in palliative care populations has indicated that patients want to discuss their intimacy-related concerns with their care providers.[35] Training should be expanded to include practical ways of incorporating this into assessment and interactions between patients and care providers.[36] What is essential is an openness and sensitivity to such dialogs with patients and reflection on any personal or cultural attitudes that could impede such conversations. Hospice settings also need to consider possible arrangements for the provision of privacy for expression of sexual needs.[34] Health-care providers recognized varied reasons for patients' avoidance and detachment from interpersonal relationships. Sensitive discussions with patients may reveal reasons that can be addressed; for instance, misconceptions or fears about family members' reactions or responses to the illness and its' effects. Myths about the contagious nature of cancer have been documented in community-based research in India, more likely among persons who are older, with lower educational levels and from lower socioeconomic strata.[37] Similar misconceptions among some patients (and family members) were noted by health-care providers in the present study. Addressing these misconceptions in the hospice would be a partial measure, and there is a need to plan public campaigns that would have a wider reach and a more sustained impact. Worryingly, health-care providers also observed that some patients were isolated and their need for relatedness and support were met by rejection and threats from family members. These findings may be understood to some extent as stemming from misconceptions about the illness, caregiving burden, and economic strain, in a country which does not have an adequate public health system and insurance cover.

Patients built strong interpersonal connections with the health-care providers at the hospice and depended on them for emotional and instrumental support. The provision of compassionate care and empathetic engagement with patients is central for good palliative care. The concept of "emotional labor"[38,39] describes the relational and emotional aspects of the work done by health-care providers in palliative care. This requires both absorbing others' emotions and calibration of one's emotions and makes them vulnerable to "compassion fatigue,"[40,41] the repetitive cycles of connecting closely with patients and their emotional needs, and then having to disconnect in the face of their inevitable death, can put care providers at risk for burnout. The findings suggest that health-care providers need comprehensive training, sustained use of self-care practices, and ongoing support, as part of systemic processes in palliative care centers.

The use of a qualitative lens to explore the experiences and perspectives of health-care providers is a strength of this exploratory study, but there are some limitations in the study design as well. The sample included participants from only two palliative care centers in South India, and the emergent themes may not reflect all the needs and concerns of persons in end-of-life care. The profile of patients at the palliative care centers and their socioeconomic, religious, and subcultural backgrounds can influence their dominant needs and concerns. Spiritual needs are an important aspect of the end-of-life's journey;[42,43] however, this domain was not specifically explored in the present study. Although open discussion of health-care providers' perspectives was encouraged during the FGD, it is possible that professional hierarchies might have influenced the communication. Involving the health-care providers in rechecking the themes after the analysis would have enhanced the validity of the research findings.

Conclusions

Further research could examine and integrate the perspectives from patients, family members, and health-care providers. The use of brief bedside screening tools for comprehensive assessment of patients' biopsychosocial-spiritual needs has been recommended,[44] and these findings can inform the development of a culturally contextualized measure. Such research has important implications for more effective training, assessment, and support and care services in palliative care settings in India.

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Conflicts of interest

There are no conflicts of interest.

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