




General

Exploring the End-of-Life Experiences of Advanced Cancer Patients from India

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Objective

Paying attention to the socio-cultural characteristics of advanced cancer patients as they pass through the final stages of life can help healthcare professionals and mental health professionals assess the end-of-life experiences of terminally ill patients better. A comprehensive study of this population in the Indian context is helpful to devise individualized end-of-life care that aligns with their preferences and focuses on their comfort.

Method

The dataset comprised information-rich cases of 10 advanced cancer patients from Bangalore, India, selected using the purposive sampling method. The semi-structured interviews with the participants were audio-recorded, transcribed, and translated. Identification of patterns and commonalities in the dataset helped generate codes. The codes were used to narrow down to overarching themes.

Results

The standout themes were outlook on life, unfulfilled goals, end-of-life expectations, and death anxieties and attitudes to impending death.

Significance of Results

The study highlights the psychosocial and cultural needs of the patients in end-of-life care. How advanced cancer patients long for psychological care from mental health professionals and empathy from their loved ones. This study argues for renewed attention on the socio-cultural characteristics of terminally ill patients to enhance individualized care through culturally-competent interventions.

In the last decade alone, the number of cancer diagnoses has nearly quadrupled globally. From 10 million active cases in 2000, the International Cancer Research Agency (IARC) estimates the global burden of cancer at 19.3 million in 2020, including 10 million deaths. It is anticipated that the number of cancer patients would increase up to 50 percent by 2040 when compared to the global percentage increase between 2000 and 2020. By the year 2040, there could be as many as 30.2 million active cases worldwide.¹ According to the International Cancer Research Agency, one out of every 5 persons will get cancer during their lifetime. One out of eight men and one out of eleven women will die of cancer. Currently, over 50 million individuals, well within five years of cancer diagnosis, live with cancer. An aging world population and socioeconomic factors remain vital to understanding disease causation at all the different levels at which it operates.²

The burden of cancer is growing globally and there is palpable pressure on families, communities, and healthcare systems to cope with the increased burden of the disease.

The burden is disproportionate and many cancer patients do not have access to quick diagnosis and treatment, especially in developing countries weighed down by poverty and unpredictable incomes. In countries where numerous types of cancers are robust, early identification and effective treatment can increase the survival rate.¹

The recognition of terminal illness more often than not leaves a person shattered, turning his/her world upside down. Patients find themselves in intense shock and agony.³ Yun et al⁴ observe that when the bad news is communicated, patients experience misery (44.2%), depression (39.2%), frustration (28.0%), and a sense of loss (24.3%). Emotional distress and cognitive disturbances are frequent in patients with advanced cancers.

Unfortunately, in India, malignancies in a large percentage of patients are discovered when the disease reaches a tipping point, which translates to expensive treatment, increased morbidity, and death.⁵ Caught unawares in the terminal stages of a dangerous disease and left without any alternative, unsettling thoughts about dying become com-

mon. Several studies show that a range of common psychological reactions like anxiety, depression, psychiatric disturbances, etc. surface during the terminal stages of cancer.⁶ This could, in turn, lead to an increase in chronic pain, thereby attracting more aggressive medical attention, which is otherwise unnecessary.⁷ Along with the patients, the family members and friends also experience increased levels of stress and helplessness.⁸ In some patients, these trigger suicidal ideation or a desire for hastened death. Many patients manage to steer clear of stress in the twilight of their lives, while others develop a deepened sense of despair. Studies show that inculcating affinities towards spiritual well-being in deeply troubled patients might ease their stress and sharpen their coping mechanisms.⁹

However, there is a dearth of studies going into the experiences of terminally-ill patients passing through this crucial phase between life and death. Studying each patient's experiences and feelings during the final stages of life can help demystify the end-of-life experience. Each patient's perspective matters in devising the delivery of care that caters to individual needs.¹⁰ Hence, it would be helpful to study this category of population in India to devise better support for terminally-ill patients in the fag-end of their lives.

METHOD

STUDY DESIGN

This qualitative study employed thematic analysis to decipher patterns in the dataset. The thematic analysis allowed the researchers to identify shared meanings and experiences within the dataset. It involved organizing appropriate data and generating relevant themes from it. The important themes that emerged from the dataset were subject to detailed analysis.¹¹

SAMPLE AND RECRUITMENT

The researcher approached Karunashraya, a hospice facility at Bangalore providing free-of-cost palliative care to advanced cancer patients who are beyond curative treatment and the Karnataka Cancer Society Hospital in Bangalore city, India, to conduct interviews with the patients. The patients were screened with the approval of the ethics committee of Karunashraya. A purposive sampling method was employed to ensure that the dataset reflected information-rich cases. The hospice team helped in identifying such cases and the screening of each of the terminally-ill patient was done using the following criteria: Patients (1) should be 18 years or above, (2) should be aware of the diagnosis, (3) should be capable of communication, (4) should communicate in Kannada or English and (5) must have been at the hospice for at least three months to fully experience hospice care.

Out of the patients screened, ten patients (three males and eight females) fulfilled the criteria and were chosen for the interview. The screening process, on a couple of occasions, was affected due to unstable health, unwillingness, and reticence on the part of the patient/s. The criteria for exclusion ranged from (1) inability to communicate, (2) suffering from psychological disorders like dementia, schizo-

phrenia, clinical depression, etc. Demographic information of the participants like age, sex, occupation and so on were collected. The patients identified themselves by religion as Hindu, Christian, and Muslim, and were aged between 38 and 69.

DATA COLLECTION AND PROCEDURE

The data was collected from ten participants residing in Bangalore. As the investigator was new to the field of palliative care, she interned for 6 months at the hospice. During this period, the researcher assisted hospice workers in different aspects of palliative care and additionally picked up significant lessons in patient communication, interpersonal skills, questioning techniques, and communication strategies for different scenarios during the interview. Lectures, role-play, and rehearsals were also part of the training.

The investigator narrowed the dataset down to ten elected members of the population through the purposive sampling method. Before the interview, the purpose of the study was explained to the participants and their written consent was obtained. The investigator assured the members of the population of data integrity and the freedom to articulate their views. The rights of the participants were spelled out for clarity; they were free to withdraw participation any time and without giving any reason and choose to skip any question that they did not wish to answer. Doubts or questions raised by the participants were clarified.

The researcher established a working rapport with the participants to make them feel comfortable about sharing their personal experiences. The participants were given ample time to reflect and share their stories. The semi-structured interviews were coupled with open-ended questions which were framed based on literature review and expert opinion. Keeping in mind the language preferences of some of the participants, a professional Kannada translator was commissioned to undertake the translation. The structure of the interview, sequencing and thematic progressions were identical for both languages.

The interviews were conducted in English or Kannada and the Kannada interviews were translated into English later. The questions covered the patients' outlook of life, life goals, current preoccupations, views on good death, anxieties and concerns, and expectations of future care. Apart from the standard questions, impromptu questions were also posed to extract useful information when required. A few probing queries were occasionally posed for further clarification, for instance, 'can you tell me more about that?', 'please go on.', and 'can you describe that for me again?' This kind of gentle mediation helped to promote further explication of issues raised. To better understand the socio-cultural profile of the participants, socio-demographic information including age, occupation, education, religious orientation, etc., was also collected.

DATA PROCESSING AND ANALYSIS

Ten interviews were conducted, audiotaped, and transcribed verbatim by the researcher. Research analysis began from the data collection period and was completed in the course of the research period. The thematic analysis of the

dataset involved the following steps: (1) reading and re-reading the transcripts to capture all the minute details; (2) identification of recurring ideas, patterns, and commonalities in the dataset to generate codes; (3) devising themes and sub-themes from the codes; (4) review of themes by going back and forth between the recordings and transcripts to verify if the themes represented the specific dataset; (5) defining each theme; and (6) developing the draft report based on data analysis and subsequent edits. During the initial stages, the data was broken down into relevant categories based on participant experience and description of the hospice care. It was done to ensure that the main focus of research remained solely on end-of-life experiences. The second and third authors verified the themes and sub-themes for ascertaining the quality and credibility of the data.

ETHICS APPROVAL

This study was carried out with the necessary approvals granted by the ethics committee of Karunashraya, Bangalore, and the interviews diligently followed the ethical parameters laid down by the committee. The health conditions of the patients were accorded primary importance and if he/she was unable to continue for any reason the interview was discontinued immediately. Patients enjoyed the liberty to skip questions and pause, postpone, or call off the interview if they felt uncomfortable or needed a break. Following the interview, each patient was monitored and provided counseling by the hospice counselor to check for any adverse impact due to the interview.

SOCIO-DEMOGRAPHIC CHARACTERISTICS

Ten participants with a mean age of 50.2 (min 38 – max 69) took part in the study, of which six were females and four were males. The religious composition of the population was mixed. The sample was made up of six participants from the Hindu religious tradition, three participants from the Christian religious tradition, and one participant from the Islamic religious tradition. One patient could not complete the interview due to fluctuating health. The standard deviation of the age distribution was 12.10.

RESULTS

The study aimed to explore the end-of-life experiences of advanced and terminally ill cancer patients. The analysis is developed under 4 themes and with specific sub-themes within certain themes, which are illustrated using direct quotations from the population sample.

OUTLOOK ON LIFE

A common sentiment expressed by participants is that life had been tough on them, before and after the illness. One of the participants confessed that she had lost interest in life and living.

RL: *"It's okay but life's been cruel to me. I don't want to go on like this."*

Another participant, BG, voiced related concerns:

BG: *"The person next to me shouldn't feel annoyed. They shouldn't think, 'Good god, why is she cribbing so much? Her endless whining disturbs my sleep.' No one should ever feel like that about me. I should never be a burden on others."*

A growing sense of uneasiness with death at the center can diminish the joy and well-being of the individual. Life does not deliver any excitement to both RL and BG. Even before illness took over, RL found herself struggling in life. BG, on the other hand, is embarrassed about having to rely so much on others. Morita et al. looked at Japanese hospice inpatients to comprehend the nature of their existential distress. They looked at the recurring thoughts in such patients and found them distressing over their dependence on others; feeling miserable about being a burden on the family and friends. The sense of being socially non-functional push severely ill patients to count themselves as irrelevant.¹²

Interestingly enough, another participant wanted to make the most of what was left of it:

TJ: *"Of course, you want to enjoy life, you know"*

It was observed that this participant wanted to live the remainder of his life without any worries; he wanted to put everything behind him and savour each and every moment ahead. This can also be interpreted as a form of denial. Sometimes for some patients, denial works as a coping strategy, and while denial is not always advisable, it enables them to enjoy the present and reject all diversions.⁸ Zimmerman (2004)¹³ observes that when a fatal illness is originally discovered, denial is presumed to be an unconscious psychological condition that is natural and healthy, but becomes "maladaptive" and "pathological" after a certain amount of time had passed.

There are some patients who tend to adopt a banal approach and prefer looking at things with a tinge of dark humour:

BA: *"the moment they draw curtains or if a senior nurse enters the ward at night I know someone died. I'm not scared. I laugh about it saying I am next."*

This nonchalant attitude to death can help certain patients to cope with the backbreaking stresses that come with terminal conditions.

GOALS

The transcripts show that a majority of the patients dreamed of accomplishing certain goals before death, mainly short-term goals. Five sub-themes emerged under this category, viz., a) health goals, b) family goals, d) social goals, and e) no goals.

HEALTH GOALS

Conscious of uncertain turns life could take in times of a terminal disease, many participants reported that they aimed to stay as healthy as possible. Taking care of health became a priority to be able to concentrate on other aspects of life before death. For example, participant TJ shared:

"I have to be careful with my health, take medicines on time, and avoid things that bring me down. Keeping myself healthy will keep me happy and help me move on with life."

This participant stuck to timely intake of medicines. This indicates how much he would have enjoyed living life on his own terms. Although, he was in this difficult stage of life, his caution was second to none, especially about staying safe from harmful health choices. In some patients, there is a combination of nostalgia and regret working together prompting them to be more kind and compassionate. These mixed sentiments are reflected in patient CT:

"I just wish that I could become the old CT and live more. I also want to help other patients similar to me."

She wished to reclaim her old self, aspiring to be hale and healthy as before and help others. This, however, did not seem to arise from being in denial, but more out of a wish to relive the good old days. It is notable how physical wellbeing, more than wealth or other privileges, becomes a preeminent determinant of past wellbeing for terminally-ill patients. Studies have documented how patients emphasized the importance of physical and financial independence for a decent death.¹⁴

FAMILY GOALS

As the participants were aware of the limited time at their disposal, they were very concerned about their families and hoped well for their future. For example, CT shared:

CT: "I want to secure something for my daughter. This is my aim. My daughter and my parents are my priority."

Being aware of one's mortality encourages people to revisit relationships and settle hostilities of the past. Thoughts of compromise and pardoning are important components of mending broken relationships.¹⁵ Death, being the ultimate leveler, can diffuse many unresolved conflicts.¹⁶ Despite her deteriorating health, CT hopes to work towards securing her daughter's future and the wellbeing of her parents. According to participant NR, she would be delighted to take her grandchildren to school.

She expressed sadness over a few unfulfilled family goals, which weighed her down.

NR: "I wish to hold the hands of my grandchildren and take them to school and see my children scaling new heights. My son had cleared interviews for the Air Force and Forest Department, but it did not happen because of financial constraints. I feel for the success he could have had. Had it happened, we wouldn't be in Karnataka."

Another respondent was planning to register his land under his wife's name before anything happened to him. This was something that he felt would secure his wife's fu-

ture, ease his stress, and provide him with a sense of closure:

FM: "As with regards to my land, I have to register it under my wife's name or my brother will be granted the power of attorney. I need to have that taken care of."

Fulfilling unfinished business is like saying goodbye, having a sense of closure, and even preparing for death.¹⁷ Clinicians are aware of the importance of future milestones or "unfinished family enterprises" for dying patients that can influence their decisions and experiences and may even delay death. Studies have shown that major family events such as birthdays or major holidays are followed by deaths.¹⁸

SOCIAL GOALS

Besides family well-being, some participants were keen on doing something for society. Many participants in the study of Nissim et al. (2012)¹⁹ opted to volunteer for social causes, based on their wish to contribute to society. When individuals have something to contribute, they tend to be acknowledged or rewarded in return.

Participant BA shared:

"Personal and family goals apart, I wish to do something for society. I had this in mind earlier too and still feel the same."

The possibility of feeling useful by helping others in the same circumstances is something that many patients embrace. Some do this in the form of financial assistance to the poor or philanthropic gestures, while some others engage in civil-society-driven or community-based voluntary interventions. Patient CT and TJ shared:

CT: "I want to help other patients like me."

TJ: "I want to leave a message to humans, Help everybody, be nice to people, life is short."

BG: "If God gives me healthy, I want to be of service to orphans and the needy. I have endured a lot of pain in my life. Nobody should have to experience similar hardships."

Aware of chronic pain and difficulties, the participants wished to be of help to fellow patients. The willingness to help others is a sign of empathy, particularly voluntary services extended to other cancer patients stuck in a similar predicament. CT, TJ, and BG feel that their intervention can make a difference in the life of fellow human beings in pain or on the cusp of death, thereby adding value to the overall experience of their own death as well since they now find great meaning assisting others.

NO GOALS

Unavoidable circumstances related to any terminal illness characterised by chronic pain, such as the loss of control over one's life, being left out, and the mental turmoil, can leave patients in a state of bleak melancholy and lingering despair. Patients' concern that their lives aren't worth living if they have to live in pain may also trigger hopelessness.²⁰ Unrelieved cancer pain can heighten the patients' appre-

hensions and potentially jeopardize their degree of hope.²¹ Some participants didn't mince words:

BG: "What is the point of doing anything when death is so near?"

LK: "Nothing is important now. Never mind how many days are left for me, I am going to live them with a smile. I sometimes had thoughts of living like this and that. Now, I don't want to break my head over it."

Some of these comments could be interpreted as a plea for help wherein the individual is attempting to communicate the severity of her suffering and despair. Despair is linked to depression and a wish to die sooner.²² Disease discomfort can particularly unsettle individuals who have lived a self-sufficient life until they lost control of their lives.²³ Participants' overbearing sense of futility from the realization of impending death makes having any goal appear ludicrous. Their mental conditioning reinforces the notion that the future holds nothing except pain.

EXPECTATIONS FROM END-OF-LIFE CARE

Patients spelled out their expectations as to how they wanted to be cared for and what would be helpful as they prepare for their final lap.

MENTAL SUPPORT

Mental suffering is a standout feature among the most critical and possibly treatable obstructions in the dying procedure of patients in the advanced stages of their disease.²⁴ The participants of this study voiced their expectations of moral and emotional support from people around them. For example, BA shared:

BA: "More than any help with my disease, I need moral support. As I told you before, I feel like I have reached the climax."

Participant BA was acutely aware of his possible death to cancer and hence needed to feel morally and emotionally supported beyond any physical support.

Psychologists can help patients and families at four points in their lives: (a) before sickness occurs, (b) once disease is identified and therapies commence, (c) throughout the terminal illness and the dying process and (d) empowering devastated near and dear ones following the death of the patient.

Participant TJ echoed his need for useful advice and mental support:

TJ: "I need people to give me good advice and to be there for me as a source of mental support."

Participant TJ was looking up to his dear ones for mental support and to handhold him through a trying phase of his life. Psychologists/counselors should be able to make an intervention for such patients by guiding them towards a good death. However, despite the significance of distinguishing and treating end-of-life challenges of the mind, mental health clinicians get less instruction or role in the

assessment or treatment of psychological issues in the terminally ill.²⁴

MEDICAL CARE

For patients approaching death, some of the significant palliative goals include guaranteeing professionally informed end-of-life care, time to time assessments and management of death uneasiness, and a decent death.²⁵ The first comprehensive attempt at defining 'good death' was by O'Neil (1983)²⁶. According to him, "good death is one in which the timing of death is suitable and proper, the person is in control of the dying process, those associated with the dying circumstance observe essential moral standards and the death style of the individual is logical."

A good death is a key consideration in end-of-life care. According to the Institute of Medicine, a good death is defined as "a death which has no association with distress and suffering for both the patients and caregivers." Also, the death should align with 'cultural, ethical and clinical standards'.²⁷

The participants of this study lavished praise on the Karunashraya hospice for the kind of medical attention they were being provided:

BA: "They helped me a great deal right from the time I got admitted. I hope I will continue to receive such care in the future also."

BG: "They are looking after me so well and there is no hint of pain. I would say they are doing more to me than God. Karunashraya is like Vaikunta (God Vishnu's abode) to me. Even my daughter or mother wouldn't be able to provide such good care."

But the problem arises when crafty definitions fail to translate into practical guidance. Simply put, good death can be achieved by creating the necessary conditions which enable the patient to look forward to a few weeks of meaningful life rather than making it look like only minutes are left at the disposal of the patient.¹⁸

CONCERNS WITH APPROACHING DEATH

The patients expressed a few concerns, attending to which could potentially give them immense satisfaction in the twilight of their lives.

FINAL DISPOSITION

Participants expressed concerns regarding what might happen to their corpses after they die and whether their corpses would be disposed of appropriately. Some expressed their wish to donate their body for medical research. For example, participant BA said,

BA: "I would like to donate my organs. What should I do? What is the procedure?"

The participant had requested the hospice personnel to guide him on body donation, indicating how strongly he felt about it. Another participant expressed her anxieties about

lying in the coffin. Thoughts about the funeral drove her fearful. She had also stopped attending them. RL said,

RL: "I keep telling my son, when I die, don't put me on ice. I don't like anything cold kept under my body. He says, "Ma, leave me alone. Don't talk rubbish." I have told him not to bury me, instead, I can be cremated. Never throw sand on me and bury me. I won't be able to breathe. All these things are on my mind. I hear that in many cemeteries they remove your clothes and sell your body parts and bones for a price!"

AFTER-LIFE IMAGINATION

Spiritual and existential concerns in the context of illness and death refer to how people find meaning, purpose, and worthwhile suffering. These concerns may be specifically religious, but even those without religious beliefs observe moral and ethical convictions with which they ascribe meaning and purpose to life. This has been recognized over the years by the healthcare profession.¹⁸

Death had triggered thoughts of the afterlife in the participants of this study as well and the intensity of these thoughts varied from individual to individual. These had strong associations with the degree of their religious faith and spiritual seeking. Most of the participants were preoccupied with what they might do after death, and often-times, puzzled, and unaware of the road ahead. Some patients are inclined toward spirituality and life after death, while some others found great satisfaction in philosophical explorations into the meaning of life and death.

For example, participant RL mentioned:

RL: "I always wonder where I would go when I die. Where will I be? I imagine myself dying and being taken up into the sky and the unknown. Maybe, I could stand next to my body and watch people carrying out the cremation."

Insightful and empathetic handling of these concerns should allay the fears of many patients as this can enhance their psycho-spiritual wellbeing on the road to death.

NO CONCERNS

Some participants found it easier to spend the little time left without worrying too much about death. TJ and CT had related views on the subject:

TJ: "I don't want to think about it (giggles). I don't want to think about death."

CT: "It simply takes a minute to be born or to die. Nobody has control over their birth and death. We should fully keep living it till we have it in us."

CT consciously stayed away from thinking about death. He feels that such thoughts can only breed negativity and compound the burden. Interestingly, both participants showed no sign of depression or despair or suicidal thoughts. It was more of an approach, a coping strategy, that they preferred to adopt over others, and that which made them more comfortable. While there is an element of denial in this approach, it is only partial and the patients seem to be fully aware of what's going to be their plan of action and the reasons for doing it a particular way.

DISCUSSION

The study found that the awareness of living with a terminal illness left the population sample of this study shattered. The illness has turned their world upside down, leaving them fragile with a flurry of emotional outbursts and mental outbreaks.³

The news of impending death changes the patient's perceptions about life,²⁸ exposing them to psychological distress, deteriorating health, and faster death.²⁹ Physical distress and emotional difficulties add to the negative impact of the disease. Mahon and Casperson³⁰ observed that terminally ill patients developed a stronger appreciation for life than before. In this study, paradoxically, it was observed that patients' appreciation for life only diminished as they confronted the realities of living with a dangerous disease. The fact that time was in short supply encouraged them to focus on enjoying whatever little was left of it and be dismissive of misgivings and apprehensions.

It has been observed that patients tend to discover some meaning in their illness, with about 30% to 90% of the patients reported to be positively affected in some manner. Some patients grow spiritually and mend their relationships. They became more focused on friends and family, and less preoccupied with professional success. Many patients went about addressing their unfinished businesses before their illness took over completely.³ The patient's will to fulfill personal goals is associated with a sense of wellbeing and contributes to reducing psychological distress.³¹ This was observed in the participants of this study as well, all of whom, despite having an incurable illness, wished to be on pain management and sought emotional and mental support.

Patients must be empowered, through mental health professionals, to cope with an uncertain future and make most of the little time left to achieve goals, settle financial affairs, mend relationships, and co-exist with their families. The awareness of restricted time may encourage some patients to organize their present and future lives efficiently.³² As indicated by several studies, finding meaning and hope for terminally ill patients are associated with having good relationships and meaningfully connecting with family, friends, and healthcare professionals.³³

Psychologists can help bridge the gap and play a vital role in identifying various factors that are of concern to the patients, thereby improving assessments and the efficiency of intervention strategies that can address death anxiety.³⁴ A terminal illness could be physically and emotionally stressful for patients as well as their families. It liberally breeds diverse emotions like fear, anger, helplessness, depression, adjustment and anxiety disorders.³⁵

Doctors recommend consulting a psychologist to deal with depression and anxiety.³⁶ A bond of understanding is established between the patient and the counselor from whom the patient draws strength. This could be because the patient is usually exposed to social and emotional isolation, and, therefore, the emotional release through uninhibited expression or empathetic listening in the presence of a psychologist can provide relief from stress and generate the necessary strength for coping. The counselors can further alleviate the distress of the patients by listening to

their end-of-life plans, whether they have considered end-of-life care, their preferred manner of death, what happens to their possessions after death, and so on.

As seen with the population sample of this study, some patients feel the need to be useful to society. Two concerns chiefly fuel their desire to engage with society: firstly, the participants had been through substantial physical pain and mental stress and wished to help people like them. Secondly, having gone through the vicissitudes of life, they now have the advantage of hindsight. They are all the more convinced that the human race should live in peace and harmony, a piece of advice that they wished to pass on to younger generations.

For most patients, a potential death encounter means getting on with completing their unfinished businesses in terms of family and relationships. Securing the financial future of their dear ones becomes a priority and sometimes it comes with simply acknowledging that nothing more could be added to what has been achieved so far. Besides, reviewing one's life could help a person take important decisions and make some crucial choices. The overall process could bring about positivity and enhance the feeling of goodness during the final days of life, and perhaps enable the patient to approach death with courage and optimism.³⁷

Hope can play a vital role in terminal cancer treatment as it has proven therapeutic value.³⁸ The population sample of this study expressed the need for mental support from counselors, family, relatives, or doctors. This is indicative of their efforts to discover hope around them. Hence, an oncologist looking at a patient should also screen for mental and emotional distress in the process of determining effective treatment protocols.³⁹ Further, if mental and emotional disturbances are not addressed on time, it can, in the long run, can further erode the patient's quality of life.

According to a study, communication and emotional support are two important factors for building a sense of well-being. Research on end-of-life care has shown that nearly one-half of all the patients come to terms with their illness when death is near. Chronic illness acceptance is a predictor of low distress levels.⁴⁰ Studies have also shown positive associations between acceptance of the diagnosis and improved psychological outcomes.⁴¹

While some patients tend to find a sense of meaning and hope as death approaches them,⁴² some negatively approach their prognosis and see their current life situation in a meaningless light. This often goes together with the gradual erosion of all hope.¹² There is a well-established correlation between the desire to die and depression.⁴³ Patients should be trained to cope with impending death to overcome negative psychological impulses and meet them head-on.⁴⁴ According to Moestrup and Hansen,⁴⁵ when terminally ill patients were asked about death, they mentioned that fantasizing about favourable scenarios in the afterlife helped them deal with death to an extent. Such conceptions of the afterlife are determined by the degree of faith, ideology, and cultural background of the patient.

It was found that some of the participants of this study anticipated something good to come out of death. Terminally ill patients find positivity in psycho-spiritual wellbeing and may choose to deepen their self-awareness, sense of faith, and relationships. As the patients were acutely con-

scious of having a terminal illness, it gave rise to spiritual concerns like the meaning of life and the possibility of an afterlife.⁴²

In this study, however, it was observed that the participants chose not to venture much into the realm of the spiritual and instead preferred making most of the time left. Some patients could peacefully coexist with their illness having found internal strength to cope with pain and eventual death and, therefore, preferred to live out the remainder of their lives without muddying waters.⁴²

As this study points out, valuable insights on the end-of-life experiences of terminally ill patients can be extracted from advanced cancer patients. Studies have shown that during the final months and days of the terminal illness, patients long for individualized care that aligns with their preferences and focused on their comfort.⁴² Each patient undergoes various experiences depending on his/her illness, but overall, there are a few concerns common to all patients. Learning from their expectations and experience can help health professionals in devising clinical and psycho-spiritual protocols for ensuring a good death for the terminally ill, apart from tailoring specific interventions that cater to individual needs and that of the families.

LIMITATIONS AND FUTURE DIRECTION

To the best of the researcher's knowledge, no study has relied on the socio-cultural factors of advanced cancer patients of India to devise individualized end-of-life care that aligns with the preferences of terminally-ill patients and focused on their comfort; however, there exist certain limitations to the study, like the small size of the sample (which was due to dearth of patients who offered to cooperate for in-depth interviews). The sample may not be representative of a larger audience or conducive to generalizations, as it is drawn from a specific region and conducted at two specialized institutes from the same city. Another limitation is that the data was coded by a single author. Hence, the reading and interpretation may not be as rich as those generated by multiple coders.

The findings of this study may help construct transformative interventions for terminally ill patients. Future researchers may study a larger sample from different parts of the country to arrive at relevant generalizations.

CONCLUSION

This study has shed light on the diverse experiences of advanced cancer patients in the twilight of their lives. The study found that paying close attention to the socio-cultural orientation of the terminally-ill patients can help devise individualized end-of-life care that aligns with their preferences and focused on their comfort, thereby increasing the chances of good death. The population sample of this study expressed genuine concerns about their mental health, as they sought mental support from psychologists and empathy from their family and loved ones. Further, empathetic and individualized medical care was appreciated. A majority of the patients nursed goals concerning their health, family, and society, while a few participants indi-

cated no desire or goals because they seemed futile when faced with death. Some patients expressed their anxieties over a dignified final disposition, while some others were worried about the afterlife. Contrary to popular expectation, spiritual formulations and philosophical conceptions of the meaning of life or life after death occupied the minds of only a minority.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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