



Prognostic Discussions in Advanced Cancer: A Qualitative Thematic Analysis of Patients' and Caregivers' Experiences in a Tertiary Cancer Center in India

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Abstract

Introduction Advanced cancer poses unique difficulties for patients, caregivers, and health care providers. Prognostic discussions are pivotal in shaping care decisions during this stage. These conversations involve health care professionals conveying disease progression, expected outcomes, and estimated life expectancy. Research consistently underscores the pivotal role of prognostic discussions in advanced cancer care, and most existing research stems from developed countries, necessitating the exploration of experiences within the Indian context.

Objective The aim of this study is to identify the themes and patterns that emerge from the narratives of patients and caregivers surrounding prognostic discussions.

Materials and Methods Using a qualitative methodology, participants were drawn from the palliative care clinic via a purposive sampling in this prospective qualitative study. Semi-structured interviews were conducted, and thematic analysis was employed to understand patient and caregiver experiences. Ethical considerations were adhered to throughout, obtaining informed consent and ensuring anonymity.

Results Findings from 21 participants revealed five themes shaping prognostic discussions: perception and understanding of prognostic information, emotional impact, decision-making and treatment preferences, communication with providers, and cultural and religious influences. Patients struggled to comprehend complex medical terms, while caregivers played essential roles in aiding understanding. Both groups grappled with intense emotions upon learning of limited life expectancy, impacting decision-making. Effective communication and involvement of caregivers in discussions were pivotal, and cultural and religious beliefs shaped the perspectives on death.

Conclusion This study emphasizes the intricate emotional landscape of patients and caregivers during advanced cancer prognostic discussions. It highlights the need for

Keywords

- ▶ caregivers
- ▶ palliative care
- ▶ prognosis
- ▶ prospective studies
- ▶ communication
- ▶ perception

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health care providers to undergo specialized communication training, prioritize shared decision-making, and respect cultural contexts. However, the study's limitations warrant future research for broader generalizability and long-term impact assessment.

Introduction

Cancer continues to be an important global health challenge, affecting millions of lives worldwide.¹ In India, cancer is one of the leading causes of morbidity and mortality, with a growing burden of advanced-stage cases.² Advanced cancer, often characterized by a poor prognosis, presents unique challenges for patients, caregivers, and health care providers. As patients enter the palliative care phase, the focus shifts from curative treatments to relief from symptoms, improving the quality of life, and supporting patients through their end-of-life journey. Prognostic discussions are critical in guiding patient care decisions during this time. These discussions entail health care providers communicating information about a patient's disease progression, expected outcomes, and likely life expectancy. However, these conversations are often complex and emotionally charged, requiring skillful and compassionate communication from health care providers. Additionally, patients and their caregivers bring their fears, hopes, and cultural beliefs to the table, influencing how they perceive and respond to prognostic information.³

The literature consistently highlights the critical role of prognostic discussions in guiding patient care decisions during the advanced phase of cancer. By fostering open communication, informed decision-making, and patient-centered care, these discussions have the potential to improve the quality of life for patients and their families, promote realistic treatment choices, and optimize resource allocation in advanced cancer care. However, much of the research is from the developed countries.⁴

Understanding the experiences of patients and caregivers with prognostic discussions is of paramount importance in the Indian health care landscape. This qualitative research delves into the critical aspect of prognostic discussions within the context of advanced cancer, employing a constructionist and interpretive framework to gain valuable insights into the lived experiences of patients and their caregivers. Through qualitative exploration, we seek to identify the recurring themes and patterns that emerge from the narratives of patients and caregivers. We employed thematic analysis to help uncover the underlying complexities and nuances surrounding prognostic discussions.

Methods

This is a prospective qualitative research study. The participants were selected using purposive sampling to ensure diversity in experiences. Accrual followed till data saturation.

Inclusion and exclusion criteria: All adult patients with advanced cancer (stage III or IV, relapsed, refractory cancer) referred to a palliative care clinic at an Indian tertiary cancer

center over the period from April 2019 to June 2021 were included in the study. Patients who were clinically unstable to go through the study procedure were excluded. Only one caregiver per patient was approached to participate in the study. Caregivers who had been providing care for at least 6 months and were ≥ 18 years were included. Incomplete interviews were excluded from the study.

Primary and secondary outcomes: The main outcome centered on patients' and caregivers' understanding and interpretation of the prognostic information shared with them. The secondary outcomes encompassed the unaddressed needs surrounding the sharing of such information, coping mechanisms, as well as the impact of societal, cultural, and religious elements on their choices and preferences regarding treatment.

Patients were assessed at the time of the first contact with the service. Demographic and clinical data were gathered from charts. Semi-structured interviews were engaged to capture comprehensive and intricate insights into their interactions with prognostic discussions. Employing open-ended inquiries, the study aimed to probe emotions, thoughts, and engagements with health care providers during these conversations. The transcripts underwent thorough examination, coding, and categorization to pinpoint recurring themes tied to patient and caregiver experiences with prognostic discussions.⁵

In this study, qualified medical professionals skilled in qualitative research diligently worked to mitigate biases stemming from personal attributes, qualifications, participant relationships, assumptions, and engagement with research participants. Interviews occurred in a distraction-free clinic side room, devoid of time constraints. Notably, researchers took meticulous notes on participant remarks and their reflections during interviews, with all discourse conducted exclusively in Hindi, a language in which the investigators were proficient. This linguistic congruence between investigators and participants played a pivotal role in facilitating effective communication and comprehension (**► Supplementary File S1**, available in the online version only).

To faithfully capture spoken interactions, audio recordings were scrupulously transcribed in Hindi, preserving the subtleties, tones, and nuances inherent in the original spoken language. This step was paramount in upholding the authenticity of conversations and preventing any loss of meaning during transcription. Furthermore, to enable a comprehensive understanding of the amassed data, the transcribed Hindi text underwent a systematic translation into English. This translation process enlisted skilled bilingual translators who employed a rigorous forward-backward translation method. This method initially translated the transcribed Hindi text into English by one group of translators, followed by another group translating the English version back into

Hindi. By comparing this second Hindi version with the original transcription, any disparities or meaning deviations between languages could be identified and rectified. This iterative process ensured a high level of reliability and validity in the translated content.

The analysis employed a thematic approach to scrutinize interview data, uncovering recurrent patterns and themes. The method of constant comparison was applied, aligning new data with existing findings to refine and elaborate emerging themes.⁶ Regular assessment ensured that new data either introduced novel insights or fortified previously identified themes, culminating in data saturation.⁷

Statistical Analysis

Statistical analysis were conducted including descriptive statistics (frequency, mean, and median), using Microsoft Excel.

Ethics

All procedures performed in studies involving human participants were per the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The institutional ethics committee approved this research (IEC/1018/3128/001 dated October 08, 2018).

Results

The study included 21 participants, categorized as follows: 15 caregivers responsible for advanced cancer patients and 3 pairs of patients and caregivers. They were denoted as participant 1 (P1) to participant 21 (P21). Caregivers comprised 3 wives, 3 husbands, 6 sons, 1 son-in-law, 2 daughters, 1 father, and 2 brothers, with 1 interview per category. Patients had a median age of 62 years (range: 40–58 years), while caregivers had a median age of 57 years (range: 35–78 years). In terms of gender, 28.6% were females and 71.4% were males. Marital status indicated that 90.5% were married or living with a partner, with 9.5% being widowed. Regarding education, 28.6% completed junior high school, 52.4% were high school graduates, 9.5% had some college or vocational school education, 4.8% held a college or university degree, and another 4.8% had a graduate degree or professional training. Employment status showed that 42.8% were full-time employed but had lost their jobs, 19% were part-time employed but lost their jobs, 9.5% were homemakers, 23.8% were unemployed, and 4.8% were retired. In terms of household income, 57.1% earned less than INR 10,000, 38.1% earned INR 10,000 to 40,000, and 4.8% earned between INR 40,000 and 75,000. Among patients, 33.3% had breast cancer, and 66.7% had thoracic cancer. All patients (100%) had stage IV cancer diagnoses (► **Table 1**). The study delved into participants' experiences through thematic analysis, uncovering five pivotal themes: (1) perception and comprehension of prognostic informa-

Table 1 Participant characteristics (N=21)

Characteristic	n (%)
Age (y)	
18–39	1 (10.3)
40–49	5 (17.2)
50–59	6 (17.2)
60–69	5 (34.5)
70–79	4 (20.7)
Sex	
Female	6 (28.6)
Male	15 (71.4)
Marital status	
Married and living with a partner	19 (90.5)
Widowed	2 (9.5)
Highest education	
Junior high school	6 (28.6)
High school graduate	11 (52.4)
Some college or vocational school	2 (9.5)
College or university degree	1 (4.8)
Graduate degree or professional training	1 (4.8)
Employment status	
Employed full-time, lost job	9 (42.8)
Employed part-time, lost job	4 (19)
Homemaker	2 (9.5)
Unemployed	5 (23.8)
Retired	1 (4.8)
Household income	
Less than INR 10,000	12 (57.1)
INR 10,000–40,000	8 (38.1)
INR 40,000–75,000	1 (4.8)
Cancer type (patients, n = 3)	
Breast	1 (33.3)
Thoracic	2 (66.7)
Cancer stage (patients, n = 3)	
Stage IV	3 (100)

tion, (2) emotional impact of prognostic discussions, (3) decision-making and treatment preferences, (4) communication with health care providers, and (5) cultural and religious influences.

Theme 1: Perception and Understanding of Prognostic Information

The first theme explores how patients and caregivers perceive and comprehend prognostic information conveyed by health care providers. Many patients found it challenging to understand medical jargon and prognostic terms, leading

to feelings of confusion and uncertainty. Caregivers often play a crucial role in translating medical information and making it more accessible to patients.

Subtheme 1: Patient's Perspectives

Patients expressed mixed emotions when receiving prognostic information, ranging from shock and denial to acceptance and preparation for the future. Some patients found it empowering to have a realistic understanding of their prognosis, allowing them to make informed decisions about their care.

Patient (P8) said that he is happy with the prognostic discussion: "I am happy you told this to me, I am feeling lighter ... doctor used to talk about this drug and that drug, but you told me about my life. I am happy."

Patient (P9): "Yes, I am happy to know. I am thinking whatever life is remaining it should be with smile and happiness ... with care they are taking of mine."

Patient (P11) reported fulfillment with their life: "There's nothing left as experience for me ... I lived 70 years. Now there is nothing left to experience more"

Subtheme 2: Caregiver's Perspectives

Caregivers also shared their experiences in supporting patients during prognostic discussions. They expressed the delicate balance between providing hope and maintaining honesty about the patient's condition. Additionally, caregivers discussed their struggle to maintain emotional composure while offering support to their loved ones.

Caregiver (P6): "What to say now? He is in a lot of pain, we don't sleep the whole night, and he is incontinent now."

Caregiver (P7): "I don't feel good about this discussion ... you talked about his life expectancy ... what to say now? He is in a lot of pain."

Caregiver (P10): "Diagnosis was not made early ... she was getting water accumulation repeatedly in the abdomen ... we only came to know it after a major surgery."

Theme 2: Emotional Impact of Prognostic Discussions

The second theme delves into the emotional impact of prognostic discussions on both patients and caregivers. Receiving news of a limited life expectancy elicited intense emotional responses, including anxiety, sadness, and fear of the unknown.

Subtheme 1: Patient's Emotions

Patients described feelings of grief and a sense of loss for the life they once had, coupled with a desire to cherish the time they had left with their families. The emotional turmoil often influenced their decision-making process regarding treatment options and end-of-life care preferences.

Patient (P15): "Doctor has told me that my disease is incurable now ... and I can sense that my life is limited now ... after knowing initially was mentally and physically stressed and in fear. I cried too ... I have too many responsibilities of family."

Subtheme 2: Caregiver's Emotions

Caregivers experienced a unique emotional burden, characterized by feelings of helplessness, guilt, and grief. Many caregivers struggled with the responsibility of providing care while dealing with their emotions, which often impacted their mental well-being.

Caregiver (P1): "I am very sad ... my heart is very sad ... I still feel he will live a long life ... I still wish he should live more."

Caregiver (P13): "I just felt that if I would have brought him earlier, he would have received good treatment. We were late"

Caregiver (P14) reported, "You told me this ... you did good ... but ... I am tensed after knowing this ... how I will live without him ... (a long silence) ... will there be no treatment?"

Theme 3: Decision-Making and Treatment Preferences

This theme explores how prognostic discussions influenced patients' decision-making processes and treatment preferences.

Subtheme 1: Patient's Decision-Making Process

Patients emphasized the importance of being actively involved in decisions related to their care. A comprehensive understanding of their prognosis allowed them to make choices aligned with their values and priorities.

Patient (P4): "Doctor has told me that my disease is incurable now ... I have responsibilities to my family ... I should start making provisions for them so that they can live when I am gone."

Subtheme 2: Caregiver's Role in Decision-Making

Caregivers described their supportive role in helping patients make informed decisions. They provided emotional and practical support throughout the decision-making process, ensuring the patient's choices were respected and followed.

Caregiver (P13) was happy: "When I was told earlier by the oncologist that my father will live for about 6 months to a year only, I decided not to go for chemotherapy and will work for his comfort now ... After knowing his life ahead, I am working in every aspect to fulfill his wishes."

Caregiver (P19): "It's not in our culture to say you're going to die. I don't even want to accept myself still. I know that she is ill, but I'm still thinking you never know. Miracles may happen or something. It's hard, but I will never tell her. She doesn't know now. She doesn't know. I don't think I would like her to know because she'll be scared or something. But in our culture, you never say to the patient."

Theme 4: Communication with Health Care Providers

The fourth theme highlights the significance of effective communication between patients, caregivers, and health care providers during prognostic discussions.

Subtheme 1: Patient–Provider Communication

Patients valued health care providers who communicated with compassion, honesty, and empathy. The quality of the patient–provider relationship notably influenced patients' ability to process and cope with prognostic information.

Patient (P8): Prognostic discussion helped him to look into his future, but at the same time, concern about the future of his family was his main concern: “What will happen to me is in god's hand; it's his wish ... it's matter of sadness ... I came to this hospital and was not cured ... I am prepared for this now ... I already stopped thinking about the past now. I am worried about my family”

Subtheme 2: Caregiver–Provider Communication

Caregivers emphasized the need for health care providers to involve them in the discussions about the patient's prognosis and care plan. Transparent communication with caregivers fostered trust and facilitated coordinated care.

Caregiver (P16): “When I heard this, I was shocked ... I am shaken ... I was determined I wouldn't give up ... now I will give her happiness as much as I can.”

Caregiver (P17): “Yes ... you told the scenario with her ... her cancer is not curable ... I was shocked after hearing ... (silence ... looks a bit frustrated ...) ... we will give her medicine to relieve her pain.”

Caregiver (P2): “Experience is like ... I was in follow-up till date ... information was like everything is going proper ... he is on chemo tablets and health was improving too. Yesterday we had a test and an infection has happened ... so we are in a different place today”

Caregiver (P3): “I felt good about this discussion because no doctor has told this much detail about his life expectancy. You are doing good things by telling such information ... many people give many opinions but what you have told me is reality ... now I will try to take care of him in the best possible way.”

Caregiver (P5): “I feel good about this discussion ... if you can tell the life expectancy of the patient in future, it will be good for caregivers ... now we know ... so we will fulfill her wishes”

Caregiver (P17): In favor of such a prognostic discussion, as he feels that it will prepare him for the future: “Actually you did right ... because if it would have happened suddenly, we might have felt more troubled ... whatever we came to know now ... we are prepared ... Now we know the possibility of scenarios with her ... We will face all those problems. Due to this, we will feel less shocked eventually.”

Theme 5: Cultural and Religious Influences

The final theme explores how cultural and religious beliefs influenced patients' and caregivers' experiences with prognostic discussions.

One patient and one caregiver reported their feelings about future perspectives during the prognostic discussion.

Subtheme 1: Impact of Culture on Prognostic Discussions

Indian families play a central role in caregiving and decision-making, considering cultural values and familial obligations. Language, metaphors, and reliance on traditional healing practices also shape how patients and caregivers perceive and cope with prognosis.

Example of emphasizing stoicism and acceptance when facing serious illness or death, with the belief in karma and acceptance of fate playing a role: Patient (P12)—“So my cancer is considered very, very dangerous and I shouldn't say my cancer ... I believe in God. God says that in everything that comes out of your mouth, you always have to say positive about us. The more we say about negative things, the more that negativity will come to us.”

A different example where the participant discussed openly about prognosis, fears, and hopes: Caregiver (P21)—“You're left in a state of uncertainty because no one can give you a definitive answer. You're constantly in fear, if you will get a call from the hospital that he is no more. You cannot share within the family; it's just a waiting game.”

Subtheme 2: Religious Coping Mechanisms

Religion provided comfort and hope to many patients and caregivers facing terminal illnesses. Religious beliefs influenced their coping mechanisms and perspectives on life and death.

Caregiver (P18): “I'm a religious person, as in I believe that there is a higher power looking out for my family. God has been helping us throughout this whole illness, and whatever happens will happen for good.”

Patient (P20): “Telling ‘my God, my God’ became more frequent compared with the past. I talked to my God. Now I have more attention toward God, maybe 3 times or maybe 10 times more.”

Structured Discussion**Main Findings/Results of the Study**

The outcomes of this study illuminate the complex and multifaceted nature of discussions centered around prognosis in advanced cancer. This research underscores that when patients and their caregivers are confronted with the harsh reality of a limited life expectancy, they traverse a diverse spectrum of emotions and obstacles. These intricate dynamics emphasize the crucial role that health care providers play in understanding the subtleties embedded within these discussions, allowing them to deliver care that is both personalized and compassionate. The researchers played a crucial role in approaching the emotionally intense areas with professionalism and sensitivity. They provided support and guidance to both the patients and caregivers, acknowledging the difficult psychological state they were experiencing. The researchers ensured that their interactions were compassionate and that they helped professionally and ethically throughout the study.

What This Study Adds

The emotional landscape experienced by patients and caregivers is profound and intricate.⁸⁻¹¹ The revelation of a limited

life expectancy triggers a cascade of feelings ranging from fear and anxiety to sadness and confusion. Caregivers, often close family members or friends, are equally entwined in this emotional journey, grappling with their emotions while striving to provide the best possible support. This study underscores that the interplay of emotions and challenges in this context is intricate and multifaceted, demanding health care providers be attuned to a wide range of human experiences.

Given the substantial emotional toll borne by both patients and caregivers in this challenging phase, it becomes evident that a critical need exists for integrating comprehensive psychosocial support and counseling services into the framework of palliative care protocols. This inclusion is vital to ensure that the mental and emotional well-being of patients and caregivers is thoughtfully addressed alongside their medical needs. The study highlights that the holistic care approach should encompass not only physical comfort but also emotional solace, thereby improving the overall quality of life during these difficult times.

At the heart of this approach lies the concept of shared decision-making.¹²⁻¹⁶ This intricate process serves as a pivotal bridge between patients' treatment preferences and their deeply rooted values and aspirations. The study stresses that health care providers must recognize the significance of involving patients and caregivers in this decision-making process. This integration empowers patients to have a voice in their care, aligning medical choices with their personal beliefs and desires.

For this approach to be successful, health care providers must master the art of effective and empathetic communication during prognostic discussions. The relay of information should be clear, compassionate, and comprehensible to all parties involved. The study underscores the importance of health care providers possessing the skill to convey complex medical information in a way that resonates with patients and caregivers, reducing confusion and facilitating informed decision-making.¹⁷

Furthermore, the study underscores the importance of acknowledging the influence of cultural and religious factors. Cultural norms and beliefs surrounding death and dying played a role in shaping patients' and caregivers' reactions to prognostic information. Certain Indian cultures emphasize stoicism and acceptance when facing serious illness or death. Families may maintain a calm demeanor, focusing on practical matters and avoiding emotional expression. The belief in karma and acceptance of fate play a role in this approach.¹⁸ Other cultural groups encourage emotional expression. Families openly discuss prognosis, fears, and hopes. Indian families often play a central role in caregiving and decision-making. Collective family discussions consider cultural values, familial obligations, and the desire to protect the patient from distressing information.¹⁹ Religion and spirituality shape end-of-life perspectives. Hinduism, Buddhism, and other spiritual beliefs influence how individuals perceive death, the afterlife, and the acceptance of mortality. Rituals, prayers, and metaphors related to illness and suffering are integral to the cultural context.²⁰ Patients come from diverse backgrounds, each with their unique perspectives on matters of death and dying. Health care providers must recognize and respect these differences, ensuring that care is tailored to honor

patients' individual beliefs and values. This cultural sensitivity enriches the patient-provider relationship, fostering an environment of trust and understanding.²¹⁻²⁶

Implications and Recommendations

To enhance communication between health care providers and advanced cancer patients, specialized training in delivering sensitive news with empathy is essential. Integrating palliative care education into medical training empowers professionals to offer patient-centered care. Cultural competence training within palliative care equips providers to respect diverse cultural perspectives. Patient-centered care, involving patients and caregivers in decision-making, fosters a more empathetic approach to cancer care.

Significance

This study bridges the gap between the medical community and advanced cancer patients. Insights from patients and caregivers guide health care providers, policymakers, and researchers in understanding the challenges of terminal illness. Exploring emotional and cultural dimensions in prognostic discussions, it informs communication strategies prioritizing the patient's perspective. This enhances empathetic conversations, aiding informed decisions and improving end-of-life care. Additionally, it informs tailored training programs for palliative care professionals, fostering compassion and inclusivity.

Limitations and Future Directions

This study, while insightful, has limitations, including a small sample size and potential recruitment biases, and inadvertent delay due to the coronavirus pandemic. In response to the pandemic, we implemented measures to mitigate its impact on the study like adapting data collection methods to align with safety protocols and extending the data collection period to address any potential influence of the pandemic on the data. Despite that, we encountered reluctance from potential participants and managed to recruit 15 caregivers and 3 pairs of patients and caregivers for our study. The sensitive nature of the topic led to many declining participations. Additionally, contextual constraints in a tertiary cancer center in India (such as time limitations, transportation issues, and emotional stress) influenced willingness to participate. However, data saturation was achieved, allowing us to explore research questions thoroughly. We believe that our focus on qualitative depth compensates for the limited sample size, justifying our approach. However, future studies could explore strategies to enhance recruitment and address these challenges to involve a larger and more diverse participant pool for broader insights. The long-term effects of prognostic discussions on patients and caregivers need in-depth investigation. Furthermore, assessing the effectiveness of communication training for palliative care providers can refine future programs.

Conclusion

In conclusion, understanding the experiences of patients with advanced cancer and their caregivers in prognostic discussions is crucial for delivering patient-centered care in the palliative

care setting. Effective communication, emotional support, and cultural sensitivity are vital in fostering a compassionate and understanding health care environment for patients and caregivers facing terminal illnesses. By addressing the challenges identified in this study, health care providers can notably improve the cancer care experience in India.

Patient Consent

Ethics and Consent

This research was conducted according to the World Medical Association Declaration of Helsinki. We have conformed to the ICMJE recommendations for the conduct, reporting, editing, and publication of scholarly work in medical journals, and have stated in the methods section the relevant ethics committee or IRB-provided approval. This study obtained ethical approval from the institutional review board of the Tata Memorial Hospital (registered Clinical Trials Registry: India/2019/03/018141). Informed consent was obtained from all the participants before conducting the interviews, and anonymity and confidentiality were ensured throughout the research process.

Data Sharing

Data are available with the corresponding author and can be shared on reasonable request.

Authors' Contributions

Substantial contributions to the conception or design of the work and acquisition, analysis, or interpretation of data for the work were made by A.T., A.G., and M.A.M. Drafting the work and revising it critically for important intellectual content were done by A.T. and A.G. Final approval of the version to be published was given by all the authors. A.T., A.G., and M.A.M. agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Conflict of Interest

None declared.

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