Demonstrating The Importance of Cultural Considerations At End-Of-Life Utilising The Perspective of Indian Patients With Cancer

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Abstract

Purpose

To contrast with an Australian study, this study aimed to understand Indian cancer patients' hopes and beliefs about the end-of-life, particularly focusing on how this informed their preferences regarding end-of-life treatment. In India, individuals' lives are mainly guided by culturally driven practices of doing right by one's family and believing death is predetermined.

Methods

Indian patients (25) diagnosed with advanced incurable cancer and aware of their prognosis participated in semi-structured interviews exploring their hopes as they approached the end-of-life. The interview also sought to understand patients' views and beliefs about DNR orders and euthanasia. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis.

Results

Two major themes were identified: (i) a desire for living or dying comprising sub-themes of perceptions of current responsibilities, and, having a fighting spirit versus feelings of despair, and (ii) God was the ultimate decision-maker of life and death. Further, patients understood that a do-not-resuscitate order meant euthanasia and responded accordingly. Some patients reported hoping for death due to the pain and resultant suffering. However, patients did not talk about euthanasia openly, instead choosing to describe it within a larger framework of life and death.

Conclusions

Indian patients reaching the end-of-life valued their family responsibilities which determined their desire to live or die. However, all patients believed that God decided on their life and death. It is important to consider cultural perspectives on DNR or euthanasia, and to address patients' pain management needs towards the end-of-life.

1. Introduction

The current inquiry followed the recognition that studies (by IO and JE) on hope and attitudes towards Do Not Resuscitate (DNR) orders among Australian patients with advanced cancer had cultural limitations [1–5]. Indian patients were considered an apt comparison group for cross-cultural research due to the paucity of relevant research emerging from India, the increased Indian migrant population in Australia (Australian Bureau of Statistics, 2018), and contrasting social norms (e.g. access to medical care, views on life, death, and religion, and familial structures) [6].

Hope is multifaceted [7, 8]. As patients with cancer reach end-of-life many transition from a “hope for a cure” to a “hope for a good death”, often relying on their religious or spiritual backgrounds to cope with their impending death [3, 8]. Hopelessness in this context stems mainly from physical suffering, because of cancer pain, towards the end-of-life [9] and is frequently related to depression, a desire to hasten death, and suicidal ideation [10].

The International Agency for Research on Cancer GLOBOCAN reported that in India, the 2018 5-year prevalence of cancer was 2258, 208 with 784, 821 deaths [11]. In India, patients associated cancer with inevitable death, reporting feelings of hopelessness during their cancer trajectory [12]; particularly those receiving palliative care [13]. As with Australian patients [3], Indian patients’ interpretation of hope influenced their medical preferences and decisions within the contexts of hope being present or absent (i.e., as a noun): if there was a hope for recovery or cure they wished to engage in medical treatment; if there was no hope they favoured forgoing treatment [14]. Mishra et al. reported that a primary concern among Indian cancer patients was their family’s well-being or stability, especially in terms of settling their children (e.g., educating their children, leaving them some wealth/inheritance and getting them married) [15].

Key to Indians’ conceptualizations of life and death is the understanding that death is in God’s hand, and thus that it is not an individual’s right to make decisions regarding euthanasia or withholding life-preserving interventions [16]. Indians tend to have a shared belief about attaining an auspicious death [17], principally guided by fulfilling one’s social commitments or *dharma* [18]. These beliefs are dissimilar to Westernized societies, such as Australia, where patients wanted to have, and exercise, the right to make advance directives, that is, to stipulate their preferences for end-of-life care (including via DNR orders) [1–4]. Moreover, although the Supreme Court of India in 2018 legalized ‘passive euthanasia’ under strict guidelines [19], active euthanasia is not legalized in India.

The aims of this study were: (i) to determine the hopes, beliefs and experiences at the end-of-life of Indian patients with incurable cancer, (ii) to inform legislation/policy on advance directives and end-of-life care through culturally appropriate analyses, and (iii) to promote cross-cultural comparisons regarding end-of-life experiences and decision-making.

2. Methods

2.1 Participants

Twenty-five Indian patients (*male* = 18; *mean age* = 50 years) diagnosed with incurable cancer were interviewed at a cancer specialty hospital in Hyderabad, India, which provided ethical approval for the study (Table 1).

Table 1
Patients' demographic and medical details

Characteristic		Frequency
Mean age		50.2 years
Age range		27–72 years
Gender	Male	18
	Female	7
Marital Status	Married	23
	Single	2
Number of children	None	1
	1–3	19
	4 and above	4
Religion	Hindu	21
	Muslim	4
Employment status	Employed	13
	Non-employed	10
Education level	Primary (i.e., 10th grade)	11
	Secondary (i.e., 12th grade)	4
	Undergraduate degree	4
	Postgraduate degree	3
	Not educated	3
Primary disease site	Lung	8
	Stomach	3
	Colorectal	3
	Prostrate	3
	Breast	2
	NHL	1
	ALL	1
	Cervix	1

Characteristic		Frequency
Endometrium		1
Tongue		1
Metastasis	Yes	23
	No	2

2.2 Procedure

Using purposive sampling, patients were recruited at the hospital by MC, an Indian psychologist trained in qualitative research, after explaining the study objectives. Inclusion criteria were that the patient (i) was diagnosed with incurable cancer, (ii) was aware of their poor prognosis, (iii) did not have any prior psychiatric conditions (as reported by the patient and/or family carer), and (iv) could speak English, Hindi or Telugu (regional language). Twenty-five of 83 patients approached agreed to participate in the study and gave written consent.

2.3 Interviews

After collecting demographic data, semi-structured interviews were conducted in the hospital, at the patients' cubicle/room or in the deputy medical officer's rooms. Twenty-two interviews were conducted in Telugu, 2 in English, 1 in Hindi. All interviews (*average length* = 33 minutes) were tape-recorded and transcribed following a translation and back-translation process (see Table 2 for interview topics and sample questions). As two authors only speak English, the transcripts were analysed in English, thus enabling all authors to contribute to data analysis and development of themes. However, words which were especially evocative and rooted in cultural context (e.g., the Telugu term *sumangali*) were retained with their English meaning provided in brackets in the interview transcript. Data saturation [20] was achieved at the 20th interview but additional interviews were conducted to confirm that no new information was evident within participants' accounts.

Table 2
Interview schedule

Topic	Sample questions
Hopes	<p>What are you hoping for right now?</p> <p>What do you hope for yourself and your family?</p> <p>How do your experiences with cancer relate to your current hopes?</p>
Beliefs about a do-not-resuscitate order	<p>What are your thoughts on withholding medical treatments such as CPR at the end-of-life?</p> <p>In what circumstances would a do-not-resuscitate order be appropriate for you?</p>
Beliefs about euthanasia	<p>What are your thoughts about euthanasia?</p> <p>What does euthanasia mean to you?</p> <p>During what times or situations during your illness do you think about euthanasia?</p>

2.4 Analysis

Transcripts were analysed using interpretative phenomenological analysis (IPA) allowing examination of the lived experiences of individuals from their distinctive frames of reference or viewpoints [21]. Each transcribed and translated interview was read by all the authors and data analysis was conducted by MC and JE. These authors read and re-read the transcripts, identifying any independent, specific aspect of patients' experiences, dividing them into meaning units which were then assigned a code (e.g., current responsibilities). Following discussion and clarification of their interpretations of the developing patterns across these codes, the authors independently clustered the codes to represent a coherent theme, or sub-ordinate theme. The authors collectively grouped sub-ordinate themes on the basis of topic and content similarity to develop super-ordinate themes, revisiting the original transcripts to ensure these themes were consistent with the corresponding, original meaning unit. Thus, the analysis allowed for total immersion, reflection, and collaboration on the part of the authors, strengthening the analytical process. Pseudonyms were used for all quotes. Pauses in transcribed speech are indicated by ellipses.

3. Results

It is common in India for family carers to accompany patients to the hospital and play an active role in their medical decision-making, on behalf of the patient [22, 23]. Nearly half (45) of the approached patients' family carers refused permission to discuss the patient's poor prognosis or their thoughts on a DNR order and euthanasia, explaining that they felt the interview would cause emotional trauma to the patient, "give them ideas", or precipitate difficult conversations with the carer. Reasons cited by the remaining 13 patients who declined participation included being too tired or not having enough time.

Despite explaining that an aim of the study was to explore Indian patients' perceptions and beliefs about DNR orders, all patients interpreted these as euthanasia and responded accordingly (without using the word "euthanasia" though some used the term "mercy-killing"). Two superordinate themes emerged from the analysis: (i) a desire for living or dying and (ii) God as the ultimate decision-maker (see Table 3 for illustrative quotes with these themes).

Table 3
Quotations

Theme	Subtheme	Quotations
Desire for living or dying	Perceptions of current family responsibilities	<p><i>Seventy years is more than enough to live. Till 50 years you're working. After those, 10 years or so you can enjoy your retired life, after that you'll only be eating up whatever was earned. There's no use anyways. (Venkat, male, 53 years)</i></p> <p><i>When you have children you help them grow, get them married that is enough and satisfying. (Kanchana, female, 58 years)</i></p> <p><i>Even if I die, they will give my son my post. They will be able to live happily because they will get around twenty lakhs that is all I want I will be happy. Only when I have thought of me not being able to help my children is when my soul fights. That problem is solved so I am happy and because of that, I was able to live happily for a year and I may die this year. (Nitish, male, 49 years)</i></p> <p><i>Yes, all my desires have been fulfilled. Everything is over. My sons are married. They have children. My husband is a good man. So I want to die. I want to die in front of my husband's eyes. I want to die as a sumangali. (Ramya, female, 57 years)</i></p> <p><i>Gayatri (female, 42 years): Yes, I do not want treatment and I feel that is the best way and the treatment is not going to benefit me.</i></p> <p><i>First Author: Why do you feel that you not taking treatment is the best?</i></p> <p><i>Gayatri: When a person is alive, he has to achieve something in life if he cannot achieve anything it is no use living (sobs).</i></p> <p><i>My life has to be extended at least one more year for my wife and children. That is only my desire. I do not have any desire about property. There is nothing for my wife and children, ... we do not have even own a house. We do not have nobody's co-operation, help, and we are poor. I do not have anything Madam (crying). (Trinad, male, 38 years)</i></p> <p><i>I should settle my children and then I am ready to face (death). I was not scared before, I used to think as I am taking treatment I will be fine very soon. But now I don't have that much hope. (Sanjeev, male, 56 years)</i></p>
	Fighting spirit versus despair	<p><i>I told that as much as possible I may live. I told that I got that courage, moral courage or mental courage to take that one. I have to take chance of recovery. There's a .001% chances maybe to recover. I don't want to lose that chance. (Lokesh, male, 64 years)</i></p> <p><i>We should face whatever problem that comes your way. I need to fight and throw this disease from my body. Otherwise it will eat me. I will fight because I have willpower. (Dilip, male, 58 years)</i></p> <p><i>It's not about cancer...it's not, it's not...anything else. It's your day-to-day life. If you don't have hope, you don't have life. (Bharat, male, 32 years)</i></p> <p><i>Anything could happen anytime. However, I feel my condition is fine and my health is cooperating well with me, I am in no condition to give up. (Even though) the results in the report, the doctor told that there is</i></p>

Theme	Subtheme	Quotations
		<p><i>no cure ... in spite of (my) belief that I will be cured...for sure. (pause) The thought of me not getting cured is never on my mind. (Nitish, male, 49 years)</i></p> <p><i>If the disease can't get cured by English medicines (i.e., biomedicine), Ayurvedic medicines will have chance for curing the disease. (Bhanu, male, 33 years)</i></p> <p><i>I asked the doctor... when am I going to die...? Why should I come to the hospital? I do not have to come to hospital. I will not take treatment. Why unnecessarily take it? I will suffer at home and die there itself. Why should I come here and face all these problems? Merely waste...What I am telling it is unnecessary to come here, that's why I asked the doctor, ... these injections, medicines... These are all problematic. That's why my mind thinks like that (about wanting euthanasia). (Anasuya, female, 59 years)</i></p> <p><i>That much painful (long pause), if I use pain killer, then the pain reduces...for that. If doctor tells, I would have helped him to make it (mercy-killing) happen. "Whatever you want to do, please do. Send me with no pains." (long pause) It's because I can't bear this pains. I have no fear. (Ram, male, 35 years)</i></p> <p><i>Once, to me after 3 chemos, they gave 3 more, and then they gave 2 more. That time my legs used to give more pain like, someone is cutting my legs with a blade, and then I thought of giving up my life... I used to cry, "Why should I live this life!" I felt like committing suicide... I felt that much pain. During those chemos it was like hell. That time I felt like committing suicide by jumping from a height. We can't do anything. Even the doctor ... in the final stages...can't do anything. (Madhu, female, 44 years)</i></p> <p><i>Sometimes I feel that, "How many days I have to suffer? Why doesn't this get cured? How many days I have to live with these sufferings?" Sometimes I feel death is better than suffering...unable to bear these sufferings. (Ganesh, male, 62 years)</i></p> <p><i>At the moment...I won't hope. I want to go home...to be honest, I want to go home...without any...problems...to be...with...my children and wife because...everyday...suffering...enough. (Vasudev, male, 72 years)</i></p> <p><i>Our India does not allow that, right? When he is alive and is in such a state even he experiences lot of difficulties and will have to live through that, now instead of that he will be going in no time happily. However, in India...I feel that is not in practice.It will not be practiced as it is an extreme step. (Nitish, male, 49 years)</i></p> <p><i>No developed country will agree for it. The image of the government will come down in the public view. Individually it may be accepted for few. It is as if the government has failed. (Ranjith male, 59 years)</i></p>

Theme	Subtheme	Quotations
God is the ultimate decision maker		<p><i>Keeping faith in God that's it, and taking treatment, after all...it is God's decision. There is nothing in our hands. Getting this disease is not in our hands, so, we need to be strong. (Madhu, female, 44 years)</i></p> <p><i>The thing is...it is there...so...to save the life...very much important. Ultimate authority...is...the Almighty is there...to save or not save. He is there...this all integrated in His plan...we can't see... He has His plan. (Ananth, male, 57 years)</i></p> <p><i>I have good faith in Allah and...until and unless Allah permits no one can take your life. Israel'ala Islam has to come and take your spirit, the rooh [Urdu word meaning "spirit"]. No-one has come. (Ali, male, 51 years)</i></p> <p><i>Trust in God. Nothing else. Keep praying to God and spend time, we can only keep trying it out...but anything is only after putting all burdens on God. So I trust in God. Any improvement is worth it...isn't it? It's the grace of God. With his grace at any given time some miracle may happen right? (Mahesh, male, 27 years)</i></p>

3.1 Desire for living or dying

This theme comprised two subthemes: perceptions of current family responsibilities; and having a fighting spirit versus feelings of despair.

3.1.1 Perceptions of current responsibilities

Most participants expressed their desire for living or dying through articulation of their existing responsibilities towards their family, with parents expressing concerns about “settling” or providing for their children. Patients believed that if their children were married, were working or had completed their education (making them likely to secure work), and would inherit property from their parent, then their familial duties were completed. Fulfilling these responsibilities, being “useful” to their family, helped patients feel prepared and ready to face death.

Some gender differences were observed. For example, married women spoke about being “lucky” if they died before their husbands, while widows spoke about the purposelessness of living. Most participants who expressed a desire to live longer were younger and male. They considered that they had not fulfilled their duties towards ensuring their family’s future, and spoke of feeling dejected, devastated, or in despair, that their family would not be taken care of after their death.

3.1.2 Fighting spirit versus despair

Some participants displayed a fighting spirit, whilst others felt despair in the face of their incurable cancer, both shaping their desire to live or die. “Fighting” the cancer was primarily reported by male participants, often fuelled by hope and courage. They believed that not “giving up” a “chance” or having “will-power” were key to overcoming the disease. Most patients conceptualized hope as finding a cure for cancer, with ‘having hope’ perceived as the mechanism through which one displayed the “life” within

themselves. Conversely, thinking or feeling one might not be cured was not entertained because this was viewed as a sign of surrender to the disease. In the face of a poor medical prognosis, many patients actively sought alternative traditional methods to cure cancer, thus demonstrating their fight for life.

Nine patients, however, felt that dying would be “better,” stating that mercy-killing (i.e., euthanasia) was “good to have” as an option. A key reason for wanting death was physical pain. Patients reported that pain limited their functional well-being (e.g., “sitting forcibly due to leg pain”) and negatively impacted upon their physical well-being (e.g., “there is no day or night for pain; don’t feel like eating, sleeping...”). Some felt miserable as “twenty-four hours continuously it is (the pain) making me suffer”. This suffering prompted existential anguish (e.g., “For how long... for how many more days should one suffer like this?”) prompting most to view death as something that was common to all humankind (“anyhow one day we all will die”), and holding that it made no difference if death was hastened to escape the suffering. Some reported that their pain was so intense that it removed their hope to live and made death a welcome relief from their daily difficulties. However, all patients felt that their country (i.e., India) would not let them opt for mercy-killing, even though this was “a good option” that would “free” them from suffering. This belief referred both to the legal aspects of euthanasia (i.e., euthanasia is illegal) and to the prevalent social norms that ending one’s life was wrong. Some patients believed the social norms around mercy-killing were so negative that legalizing it could bring a government “down”.

3.2 God is the ultimate decision-maker

Irrespective of patients’ religion or desires to live or die, all saw God as the ultimate decision-maker, believing that life and death were in His hands and He had a plan for them. Patients further believed that if they had “God’s blessings” or if God “picked” them, then their life will be prolonged. Therefore, patients were willing to “see how many days God would give” them since God knew the correct time to “take” them. In this manner, patients came to terms with their diagnosis and lack of control over disease outcome and reconciled their desires for life or death by placing these in the hands of God.

4. Discussion

4.1 Main findings

A strong influence on the desire to live or die was whether family responsibilities were fulfilled, arising from a socio-culturally driven discourse in India on the role and meaning of being a parent [24]. Embedded in the notion of dharma (justice/truth), doing right by one’s family is believed to be a crucial step on the path to *moksha* (salvation), the ultimate goal of human life [18]. Although emerging from Hindu philosophy, these precepts have been absorbed into the Indian way of living over centuries. Chakkarath argues that the transportation of religious beliefs into social values and structures has rendered the boundaries between religion and society nearly non-existent, dating back to the sage Manu’s *manava dharma shastra* (a compilation of “rules of conduct”) in the second century BC [18]. Parents in India—particularly fathers—are obligated to provide for and protect their children which translates to educating the child well enough to be employed and marrying them off [18, 24, 25].

For women, a less compelling but equally important path to moksha is a responsibility to die as a *sumangali* (a married woman), an auspicious facet of womanhood which positions her as a *soubhagyavathi* (a fortunate woman) [26, 27], who is expected to perform various rituals (e.g., *karwa chauth*) to prolong their husband's life [26] and ensure their *sumangali* status. Being *sumangali* also indicates her commitment to her family and her good fortune. In this study, female participants may have interpreted their life and death in terms of their marital status. Married women viewing death as a sign of their virtuousness and the widowed women as a relief from their feelings of worthlessness, which helps them cope with their impending death. Despite India's burgeoning modernity, these findings reveal socio-culturally ingrained notions around power and gender.

Contrasting this, only male participants demonstrated a fighting spirit, holding that hopelessness constituted surrender to the cancer. Hope was a resource for fighting cancer in the Australian study but there were no gender differences [1, 4]. It is possible that the desire to maintain a fighting spirit reflects powerful male stereotypes of being courageous or resilient in the face of misfortunes [28] but seeing them relatively unprepared to accept inescapable loss or adversity. In India, there is a strong expectation that men should uphold a fearless and stoic attitude when encountering difficulties or hardships and this is an expected coping strategy [29]. These findings challenge previous psycho-oncology research in India reporting that cancer patients have a pessimistic and fatalistic attitude towards cancer [30, 31]. However, they may be understood through the *sense of coherence* (SOC) theoretical framework proposed by Antonovsky which explains how individuals handle crisis or adversity [32]. This framework consists of 3 components of comprehensibility (i.e., the crisis/adversity is explicable), manageability (i.e., one has resources to handle the demands the crisis/adversity places on them) and meaningfulness (i.e., these demands are worth the individual's emotional investment) [33]. Previous qualitative research argued that adopting a fighting spirit helps patients to view cancer as a challenge and lends them a sense of purpose or meaning [34, 35]. Similarly, patients in the current study may be both finding and demonstrating value in their life (i.e., meaning) by fighting for it.

Strikingly, pain, which compromised quality of life and caused existential anguish, was the only experience which brought about a favourable attitude towards euthanasia among some participants in this study. These findings concur with previous research in Asia suggesting that pain during the end of life was a prominent and compelling reason for wanting to hasten death, precluding attainment of a good death [36, 37]. Patients coped with this wish to hasten death by rationalizing it as a common facet of human life. Interestingly, though Elliott and colleagues [1, 4] noted that patients with cancer hoped to live without pain, they did not observe any link between changes in hope attributable to pain, suggesting that perhaps Australian patients may have access to better pain management than Indian patients. However, pain was associated with endorsement of euthanasia as well as wishing, or attempting, to die [2]. In a systematic review and meta-ethnography on understanding the desire to hasten death, Rodríguez-Prat and colleagues reported that suffering was a central theme affecting patients' physical, psychological, social, and existential domains, whilst negatively impacting on patients' self-identity and self-respect—two fundamental areas of one's sense of self [38]. Similarly, patients in this study perceived suffering to undermine their personhood, taking away their self-control and replacing it with helplessness, and, in

some cases, resulting in suicidal ideation. Despite this, all believed that mercy-killing was socially unacceptable, suggesting the pervasive nature of this societal norm in India. This belief was not unfounded: research with Indian doctors [39], nurses [40], and patients [41] reported strong disapproval of euthanasia. This was due in part to the cultural reluctance to talk about death, because discussing one's mortality is an *apashagun* (inauspicious) [19]. Interestingly, while some patients in the current study endorsed euthanasia, they felt that legalising it would reflect badly upon the Indian government. This shows that they were unaware of the ongoing national debate in India on the legalization of passive euthanasia [42]. However, they also equated the concept of DNR orders (to limit cardiopulmonary resuscitation) with euthanasia. Most Australian patients did not confuse these topics and typically favoured both [2, 4]. It seems plausible that the influence of socially driven values on the topic of euthanasia may overshadow or even shape the law in India; at a minimum, legislators will need to consider the broader socio-cultural fabric of India.

Notwithstanding patients' desire to live or die, all believed that this was a decision left to God with no significant role for them. Spiritual coping is a well-researched and key coping mechanism among Indian cancer patients [43]. However, these findings are in sharp contrast to those of Olver and colleagues (2002, 2008) who reported that patients wished to exercise the right to decide how they died and viewed it as their responsibility to do so [2, 4]. These contrasting findings indicate the need for, and benefits of, cross-cultural research, in formulating end-of-life policy.

To our knowledge, this is the first qualitative study emerging from India to shed light on how God is conceptualized in the contexts of the end-of-life. Patients described God's power over them vividly, often referring to God as the one who gave them life, has rights on how and when they die, and who provides all-powerful support in the face of imminent death. This perceived support from God took several forms: attributing an external locus of control for the cancer and poor prognosis, creating a sense of dignity (i.e., feeling they might be chosen if their life was extended) and, most importantly, working to provide an anchor during times of despair. Therefore, it is likely that assigning decisions about life and death to God was not a sign of passivity or fatalism among these patients, but a source of strength, meaning, hope and an opportunity to feel tethered to something greater than oneself.

4.2 Implications

The current study indicates minimal state support available for Indian citizens, as evident in patients' strong sense of responsibility towards their families and their encounters with pain. Government action to enable improved pain management is required. It may be that the philosophizing of religious scriptures masks the limited social security in India such that families are expected to fend for themselves should a crisis befall them. Consequently, this sense of parental responsibility may function as a politically endorsed mechanism to encourage beliefs in the dharma cycles. Future research should unpack patients' needs, perceptions, and expectations of government support in order to inform policy development and practice regarding end-of-life care.

Additionally, there is a need to provide psychological support to Indian patients at the end-of-life, and communication skills training for care seekers and providers as shown by female patients' reasons for desiring death, male patients' adopting a fighting spirit, reports of existential suffering due to pain. It may be useful to introduce gender-specific support groups; for example, support groups for men can aim to balance their fighting spirit with a realistic understanding of their prognosis to better prepare them for their impending death. Support groups for women could center on exploring their feelings regarding living and dying as a social/family experience, to counter any devaluing of their own life.

Recommended skills for doctors include asking patients nearing death about pain, empathizing with the ensuing suffering, exploring patients' quality of life, and identifying and referring patients in psychological distress to a psychologist or counsellor. Introducing conversations about God at a particular point in the illness trajectory can help patients to utilize their faith in God as a coping tool. Skills for patients can include strategies to help them share their experiences with pain with the doctor and ask questions on pain management. Those experiencing existential anguish may benefit from psychotherapies such as *dignity therapy* which focusses on the suffering caused in dying by affirming the individual's sense of dignity, thus reducing psychological and existential distress [44].

Finally, apart from conceptualizing hope as a resource for fighting disease/death, these study findings contrast with previous research on hope and attitudes towards DNR orders [1–3] among Australian cancer patients. This underscores the need for, and benefits of, cross-cultural research in elucidating differences and similarities in perspectives on end-of-life experiences and decision-making. Future research should explore the role of acculturation regarding these concepts and practices among Indian immigrants living in Australia or elsewhere, to understand the extent to which one's culture of birth and that of their host country shape these perceptions.

4.3 Strengths and limitations

This study used a qualitative methodology, and although offering a rich understanding of the end-of-life experiences of Indian cancer patients, in order to generalise the findings, quantitative research could further examine the extent of and relationships between pain, coping, psychological distress, and attitudes towards euthanasia and DNR orders. More detail is required on patients' ability to obtain pain relief, given evidence that nearly 97% of Indian cancer patients have poor or no access to pain-relieving drugs such as morphine, despite court orders to improve the availability of these drugs [45]. Future research should explore end-of-life experiences among Indian women in different relationship statuses, such as singles and divorcees. Other aspects of patients' advance planning (e.g., financial) could also be examined. Finally, future research will also benefit from exploring care providers' (family and doctor) experiences of, and views on, caring for a patient at the end-of-life, pain management, euthanasia, and DNR orders.

5. Conclusions

The study findings revealed two key themes. Patients' desire for living or dying comprised perceptions of current responsibilities, beliefs about being a *sumangali*, having a fighting spirit, personal encounters with

pain, and the subsequent suffering/despair; and patients' beliefs in God saw them place the decision to live or die in God's hands. Furthermore, patients understood DNR orders as euthanasia. The findings suggest a need to improve Indian policy and clinical support for pain-relief, provide additional psychological services, and elicit patients' beliefs about God before end-of-life planning. Finally, further research is needed to determine how acculturation may contribute to perspectives on end-of-life and DNR orders among Indian migrants living in Australia and elsewhere.

Declarations

Funding: This study was funded by Cancer Council Australia.

Conflicts of interest: IO is a Senior Associate Editor of Supportive Care in Cancer

Availability of data and material: Data will be stored for 15 years and available on request from the corresponding author.

Code availability: Not applicable

Author contributions: Study conceptualization and material preparation were performed by MC, JE and IO. Data collection was conducted by MC. Data analysis was done by MC and JE. The first draft of the manuscript was written by MC and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics approval: This study was conducted in compliance with the hospital ethics regulations where the data was collected. All procedures performed in studies involving human participants were in accordance with the ethical standards. The study was approved by the Director of the hospital where the data collection was conducted.

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Consent for publication: The patient information sheet provided information on the intent to publish the data, which was incorporated into the informed consent form as well.

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Figures

Figure 1

Thematic map