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Caring for Hindu patients at the end-of-life: A narrative review

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Review Article

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Abstract

Objectives. This paper reviews the existing literature to identify specific challenges that may arise in the context of providing palliative and end-of-life (EOL) care for Hindu patients in the physical, psychological, and spiritual domains. We offer practical strategies where appropriate to mitigate some of these challenges. We review how the Hindu faith impacts EOL decision-making, including the role of the family in decision-making, completion of advance directives, pain management, and decisions around artificial nutrition and hydration (ANH) and cardiopulmonary resuscitation (CPR).

Methods. The PubMed, MEDLINE Complete, Cochrane, and Embase databases were searched for articles using the search strings combinations of keywords such as Palliative care, Hindu, Hinduism, End of Life Care, India, Spirituality, and South Asian. Once inclusion criteria were applied, 40 manuscripts were eligible for review.

Results. Our results are organized into the following 4 sections – how Hindu religious or spiritual beliefs intersect with the physical, psychological, and spiritual domains: and decision-making at the EOL.

Significance of results. Hindu beliefs, in particular the role of karma, were shown to impact decision-making regarding pain management, ANH and CPR, and advance directive completion. The complexity of Hindu thought leaves a significant role for interpretation and flexibility for individual factors in decision-making at the EOL.

Introduction

The experience of death and dying always takes on meaning for an individual beyond the biomedical reality, and religious or spiritual belief is one realm that constructs that meaning. Every culture in the world has developed practices and belief systems around caring for the dying. This is especially relevant in situations where values from an ancient faith tradition must be reconciled with modern technology. Research to date on the role of religion and spirituality in palliative care has centered on Abrahamic faith traditions. This review aims to explore the intersection of Hinduism with palliative and end-of-life (EOL) care.

Hinduism is a major world religion, with approximately 1.2 billion followers worldwide. In the United States, it is a fast-growing minority religion, with approximately 2.2 million adherents (Skirbekk et al. 2016). In order to provide effective palliative and EOL care for Hindu patients, clinical teams need to understand the ways that the Hindu religion conceptualizes EOL care, using insights gained both from India and the broader South Asian diaspora. Previous reviews that have examined Hinduism and palliative care included a systematic review on spirituality, divided into a relational, existential, and values dimension and found that religion (encompassing culture and practice) heavily informed what would be considered spirituality in other contexts (Gielen et al. 2015). Another summary article concisely highlighted key practical considerations for EOL care such as dietary restrictions, daily practices, EOL rituals, and interactions of traditional and Western medicine (Patel et al. 2020). Both these articles present different aspects of a much-needed view of Hinduism and palliative care. Our review builds on both of them by providing context for findings that are summarily mentioned in both to convey the full diversity of thought present within Hinduism. In analyzing the literature, we realized that there was often a gap between inferred outlooks based on the principles of Hinduism as opposed to the lived experience derived from primary studies, such as how a belief in the concept of *karma* impacts decision-making. We thus have a unique section on decision-making particularly for cardiopulmonary

resuscitation (CPR), pain management, artificial nutrition and hydration (ANH), and advance directive completion.

Hinduism has incredible diversity in regards to its philosophical traditions and cultural contexts, and thus does not have one defined doctrine regarding EOL care. This opens up a rich array of possibilities when interfacing with decision-making regarding palliative care and the life prolonging interventions of modern medicine. Analyzing the intersections of these 2 arenas is useful both for Hindu-diaspora serving healthcare practitioners, who may not be familiar with this aspect of their patients' background, and for practitioners of a Hindu background, who may need assistance mediating between the language of Western medicine and their own religious faith.

Methods

The PubMed, MEDLINE Complete, Cochrane, and Embase databases were searched for articles using the search strings listed below. Search strings were adapted from a previous systematic review on spirituality in palliative care services in India (Gielen et al. 2016). Additional search terms were added to cover the experiences of Hindus in countries outside of India. Articles published between 2000 and 2020 were included. Both peer-reviewed and non-peer-reviewed articles such as dissertations were included to capture the diversity of research on this topic. All study designs were included. After eliminating articles deemed not relevant with an initial title, abstract screening, and removal of duplicates, 54 articles remained. These 54 articles were then assessed against the exclusion criteria detailed below and then thematically grouped and analyzed; after multiple revisions for conciseness and relevance to theme, 40 articles were utilized. These articles are presented in Table 1 with keywords and designated as primary (qualitative and quantitative trials, narrative studies) vs secondary (reviews and summaries) sources.

Search strings included:

"Palliative care" AND "Hindu/Hinduism" "End of life care" AND "Hindu/Hinduism"

"India" AND "palliative care" AND "spirituality" OR "religion" "South Asian" AND "end of life care" OR "palliative care"

Reasons for exclusion:

- Reason 1: Primary subject sources did not include participants identified as holding Hindu beliefs and/or establish link between that identity and stated results.
- Reason 2: Primary subject research sources with participants from multiple faith backgrounds did not have the ability to distinguish which results pertained specifically to Hindu participants.
- Reason 3: Did not clearly identify patients as receiving palliative care, which can include EOL care but is not limited to it.

Results

Results are organized into the following 4 sections – how Hindu religious or spiritual beliefs intersect with the (1) physical, (2) psychological, and (3) spiritual domains; and (4) decision-making at the EOL. While there is interconnectedness between each, results were grouped in this way to cover the different domains within a holistic palliative care model (Puchalski 2006).

Physical domain

There are various practical considerations that should be kept in mind when caring for Hindu patients – these include complementary medicine, diet, external environment, and EOL rituals. Ayurveda is a traditional medicine practice that has roots in the Hindu tradition. The guiding principles of Ayurveda include understanding a person's physical and psychological constitution as some combination of 3 universal forces – vata (ether/air), pitta (fire), and kapha (earth). Each of these forces also corresponds to specific organ systems and physiological processes. Daily habits emphasized by Ayurvedic practice include avoiding combinations of certain foods (e.g., avoiding consuming grains and fruit together) or preferring to eat meals at certain times of the day for optimal digestion. Ayurveda also offers remedies for common symptoms which often utilize ingredients like ginger, clove, or turmeric. Medical professionals should pay special attention to any herbal supplements that a patient may be taking, as some supplements may cause drug-drug interactions or toxicities, e.g., curcumin (the active ingredient of turmeric) is an inducer of the cytochrome p450 pathway (Bhungalia and Kemp 2002; Patel et al. 2020). Hindu patients may face challenges with the food provided in settings where palliative care or hospice services are provided (e.g., nursing homes and hospitals). Food choices may be moral and spiritual choices as well, such as choosing a vegetarian diet due to a belief in ahimsa, which is a commitment to nonviolence. Hindus may also observe diets of sanctified food in which is offered to a deity prior to consumption or observe restrictions on certain items, (e.g., onions and garlic) (Shanmugasundaram and O'Connor 2009). A recent review article for palliative care clinicians caring for Hindu patients highlights the importance of keeping dietary restrictions in mind when prescribing medications that may have nonvegetarian ingredients such as gelatin and stearic acid; or artificial nutrition that may contain animal derivatives (Patel et al. 2020). Patients may also observe a fast from all foods or certain foods on particular days and may or may not take medication during that time (Patel et al. 2020). This should be discussed in an open way to avoid misunderstandings between the patient and the care team. It has been suggested that Hindu patients would appreciate access to institutional spaces designated for worship (Patel et al. 2020; Shanmugasundaram and O'Connor 2009). If possible, the body of the dying person should be as close to the ground as possible and pointing north, because this is believed to facilitate an auspicious death (Choudry et al. 2018; Firth 2005; Wiener et al. 2013).

According to Hinduism, the focus of one's attention at the moment of death determines one's destination after death. Thus, one's environment and consciousness at the final stage of life carry great importance. Sound carries special importance in many spiritual traditions and some evidence suggests that hearing is the last sense that leaves in a dying individual (Blundon et al. 2020). Thus, the dying Hindu patient should be offered a space for hearing sacred sounds. This can be done through live singing, chanting, reading sacred texts, or playing recordings (Choudry et al. 2018). It is a common practice for the family and/or greater community to surround the dying individual and engage in chanting and singing of sacred hymns. Practical arrangements that foster an auspicious departure may include giving the patient drops of water from the sacred Ganges river (Ganga) or placing a tulsi (holy basil) leaf in the patient's mouth (Patel et al. 2020; Shanmugasundaram and O'Connor 2009). One report described a case in which medical professionals prevented a family from giving drops of Ganga water

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Table 1. Categorization of Reviewed Sources

Subsection	Title	Citation	Keywords	Primary vs secondary literature
Physical Domain	Indian health beliefs and practices related to end of life	Bhungalia and Kemp 2002	Unavailable	Secondary
	Top ten things palliative care clinicians should know about caring for Hindus	Patel et al. 2020	Ayurvedic medicine; Hinduism; chaplaincy; palliative care; spirituality; yoga.	Secondary
	Palliative Care services for Indian migrants in Australia: Experiences of the family of terminally ill patients	Shanmugasundaram and O'Connor 2009	Cultural issues, Indian migrants, Palliative care, Terminal illness	Primary
	End-of-life: A Hindu view	Firth 2005	Unavailable	Secondary
	Cultural and religious considerations in pediatric palliative care	Wiener et al. 2013	Culture, Pediatric palliative care, Religion, Spirituality, Children, Ethnicity	Secondary
	An overview of the spiritual importances of end-of-life care among the five major faiths of the United Kingdom	Choudry et al. (2018)	Unavailable	Secondary
	Grieving tradition in a new land: Hindu death and dying rituals in America	Murato 2009	Unavailable	Secondary
	End of life care practices for Hindu patients during COVID−19	Chandratre and Soman 2022	COVID−19; Hinduism; end of life care; end of life care education; palliative care.	Secondary
Psychological Domain	What's important for quality of life to Indians–in relation to cancer	Chaturvedi 1991	Unavailable	Primary
	Spiritual concerns in Hindu cancer patients undergoing palliative care: A qualitative study	Simha et al. 2013	Cancer patients, Hindu, Karma, Palliative care, Qualitative study, Spirituality, Spiritual concerns	Primary
	Deathbed visions from India: a study of family observations in northern Kerala	Muthumana et al. 2011	Unavailable	Primary
	Spiritual perspectives and practices at the end-of-life: A review of the major world religions and application to palliative care	Bauer-Wu et al. 2007	Unavailable	Secondary
	Spirituality as an ethical challenge in Indian palliative care: A systematic review	Gielen et al. 2015	Ethics; India; Palliative care; Religion; Spirituality.	Secondary
	Pain and suffering as viewed by the Hindu religion	Whitman 2007	Pain, suffering, religion, spirituality, Hinduism, acceptance.	Secondary
Spiritual Domain	Development and psychometric assessment of a spirituality questionnaire for Indian palliative care patients	Bhatnagar et al. 2016	Factor analysis, India, Palliative care patients, Psychometric assessment, Questionnaire	Primary
	Prevalence and nature of spiritual distress among palliative care patients in India	Gielen et al. 2016	Spirituality, cancer, palliative care, India	Primary
	Signs of spiritual distress and its implications for practice in Indian palliative care	Bhatnagar et al. 2017	India; palliative care; spiritual distress; spiritual trust; spirituality.	Primary
	Indian philosophical foundations of spirituality at the end of life	Inbadas 2017	India; palliative care; spiritual distress; spiritual trust; spirituality.	Primary
	A time for listening and caring: Spirituality and the care of the chronically ill and dying	Puchalski 2006	Unavailable	N/A

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Table 1. (*Continued.*)

Subsection	Title	Citation	Keywords	Primary vs secondary literature
	Spiritual care therapy on quality of life in cancer patients and their caregivers: A prospective non-randomized single-cohort study	Sankhe et al. 2017	Spiritual care, Palliative care, Oncology	Primary
End-of-Life Decision-Making	East meets West: Cross-cultural perspective in end-of-life decision-making from Indian and German viewpoints	Chattopadhyay and Simon 2007	Unavailable	Secondary
	Traditional expectations versus US realities: First- and second-generation Asian Indian perspectives on end-of-life care	Sharma et al. 2012	cultural differences, end-of-life care, advance directives, immigrant health, qualitative research	Primary
	No easy talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients	Periyakoil et al. 2015	Unavailable	Primary
	Prospective end-of-life decision-making: A study of Asian Indian Hindu younger and older adults	Mohankumar 2009	Unavailable	Primary
	Hindu end of life: Death, dying, suffering, and karma	Thrane 2010	Unavailable	Secondary
	Can curative or life-sustaining treatment be withheld or withdrawn? The opinions and views of Indian palliative-care nurses and physicians	Gielen et al. 2010	Palliative care, humans, India, ethics, attitudes of health professionals	Primary
	Ethical dilemmas in palliative care in traditional developing societies, with special reference to the Indian setting	Chaturvedi 2008	Pain/drug therapy, ethics, spiritual care, medicine/traditional, developing countries/economics	Secondary
	Family-centered culture care: Touched by an angel	Hernandez 2019	Nursing, attitudes to death-ethnology, Hinduism, infant-newborn	Primary
	Perceptions of palliative care in a South Asian community: Findings from an observational study	Dosani et al. 2020	Unavailable	Primary
	The use of advance directives in a population of Asian Indian Hindus	Doorenbos and Nies 2003	Unavailable	Primary
	Dying at home: A qualitative study of the perspectives of older South Asians living in the United Kingdom	Venkatasalu et al. 2013	Ethnic minorities; South Asians; dying; end-of-life care; home	Primary
	Understanding advance care planning within the South Asian community	Biondo et al. 2017	advance care planning; minority groups; patient engagement; patient engagement research; qualitative research.	Primary
	Barriers to and facilitators of South Asian Indian-Americans' Engagement in advanced care planning behaviors	Radhakrishnan et al. 2017	Advanced care planning, focus group, South Asian Indians	Primary
	Elderly Indo- Caribbean Hindus and end-of-life care: A community-based exploratory study	Rao et al. 2008	Unavailable	Primary
	Hinduism and death with dignity: historic and contemporary case examples	Dewar et al. 2015	Unavailable	Primary
	End-of-life care beliefs among Hindu physicians in the United States	Ramalingam et al. 2013	Hinduism; do not resuscitate; end-of-life care; questionnaire; religiosity; withdrawal of life support.	Primary

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Table 1. (*Continued.*)

Subsection	Title	Citation	Keywords	Primary vs secondary literature
	An explanation and analysis of how world religions formulate their ethical decisions on withdrawing treatment and determining death	Setta and Shemie 2015	Unavailable	Secondary
	Perspectives of health care providers on US South Asians' attitudes toward pain management at end of life	Khosla et al. 2016	South Asians; cultural competency; hospices; pain management; palliative care; qualitative research; vulnerable populations.	Primary
	Hindu approaches to spiritual care	Chander and Lucinda Mosher 2019	Unavailable	N/A
	Negotiation, mediation and communication between cultures: end-of-life care for South Asian immigrants in Canada from the perspective of family caregivers	Weerasinghe and Maddalena 2016	South Asian immigrants; cultural beliefs; cultural sensitivity; end-of-life care; family caregivers.	Primary

to their dying relative who had just been taken off life support, because they thought the shock would cause her to die sooner. The family felt that the woman's soul was not free because final rites were not performed and expressed emotional guilt several years later for denying their loved one Ganga water (Firth 2005). This case has subsequently been cited as a cautionary example in the literature (Murato 2009). Medical teams should be made aware that Hindu families may wish to give drops of sacred water to the patient, and they should factor this in consideration when developing an EOL care plan. Many practicing Hindus living in diaspora countries may not have the sacred Ganga water or tulsi leaf easily accessible, especially in a crisis situation when the death of a family member is unexpected. Therefore, it may be helpful for the care team or chaplaincy service to have these items on hand, particularly if the hospital center serves a large population of patients identifying as Hindu. Both items can be purchased from Indian grocery stores or local temples, where available. They can be easily stored and only require a very small quantity per patient (Chandratre and Soman 2022).

Psychological domain

The prospect of terminal illness or death can be a source of great distress. Common concerns are a loss of identity or fear for the well-being of those who are left behind. Several studies mention the importance of "getting one's affairs in order" before the EOL as a protective factor against psychological distress (Chaturvedi 1991; Firth 2005; Simha et al. 2013). This can include practical responsibilities, but also may involve healing troubled relationships or achieving a sense of self-worth. Several authors suggest that the traditional South Asian extended family structure may contribute to a sense of self-worth and protect against social loneliness for dying patients, but this has not been empirically studied and may vary greatly with changing modern family dynamics in India and the diaspora (Simha et al. 2013).

A psychological manifestation given uniquely significant priority among Hindu patients are so called "deathbed visions," wherein individuals may experience visions or hallucinations at the EOL that are generally highly culturally specific. In a study of 104 participants in Kerala, it was found that Hindu patients had deathbed visions significantly more often than Muslim patients. Visions included religious figures, ghosts, animals or insects, or previously departed relatives. It has been suggested that the Hindu backdrop lends itself to deathbed visions because of a rich tapestry of stories about the transition period between lives (Muthumana et al. 2011). It is beneficial for the palliative care team to be familiar with deathbed visions for several reasons. First, to normalize visions when they are positive and comforting for the patient, understanding that they may provide reassurance to the surviving family of a peaceful departure of their loved one. Second, providers can give psychological support when deathbed visions arise that are highly distressing. Providers should also be prepared to differentiate between deathbed visions and delirium or psychosis. Finally, providers can use familiarity with these visions to help patients find meaning and hope in their EOL experience.

In Hinduism, karma is the belief that one's current actions determine the quality of one's future outcomes, with positive actions resulting in positive outcomes. Several patients cite their karma as an explanatory framework for their illness (Bauer-Wu et al. 2007; Gielen et al. 2015). In a study that administered a spirituality questionnaire to 300 cancer patients, 74.9% of them agreed that their illness was a consequence of karma. Indeed, nearly every article cited in this review has mentioned karma in some way, underscoring just how central it is to the Hindu context. However, this uniform belief in karma does not translate to a uniform application of karma; patients in fact draw on karma with extremely varied psychological, social, and embodied experiences of their illness. Viewing suffering as an impetus for detachment from one's physical identity can be beneficial as it brings a spiritual practitioner closer to the desired realization that they are not just their physical bodies, which may help a patient disassociate from their physical pain or illness (Whitman 2007). Conversely, thinking of one's past karma as the reason for one's pain may be associated with feelings of failure, futility, and self-blame. As 1 participant in a qualitative study of terminal cancer patients shared, "That is born in the mind. My mind sometimes asks what sin have I committed in which birth? I am not able to walk, and I cannot bear the pain. I then ask whom have I harmed? To which family? To whose children?" (Simha et al. 2013). Previous literature has shown that self-blame can lead to increased pain sensitivity (Wachholtz 2010). Thus, assessing patient for feelings of self-blame intertwined with a belief in karma may help in treating pain from a multidisciplinary perspective.

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Spiritual domain

The spiritual dimension of care deals with questions about connection to something larger than oneself, and how spiritual beliefs relate to suffering, illness, and death. Development of a questionnaire for palliative care patients in the Indian spiritual context found that belief in a transcendent power or entity was a defining feature of Indian spirituality (Gielen et al. 2016). Psychometric testing of this questionnaire in a sample of 300 cancer patients, 80% of whom identified as Hindu, revealed that higher pain scores were directly correlated with a greater degree of spiritual distress in patients (Bhatnagar et al. 2016). These patients also were more likely to be reconsidering their moral and religious values, derived less support from a religious relationship, and experienced stronger existential blame. In order to mitigate this spiritual distress, the authors recommended that a detailed spiritual history be incorporated in caring for Hindu patients at the EOL (Bhatnagar et al. 2017).

Due to the sheer diversity of traditions which have grown over thousands of years in a highly decentralized context that falls under the umbrella of Hinduism, it is helpful to focus on key philosophical principles to navigate in spiritual care of Hindu patients at the EOL: (1) personhood and (2) the purpose of human life and the meaning of death (Inbadas 2017).

Personhood

The crux of Hindu thought around identity views the self as an eternal, unchanging soul; the body and mental faculties are an external covering that the soul accepts as it transmigrates through various lifetimes. Various metaphors have been employed to understand the relationship between body and self, a prominent one being that of a chariot (body) and charioteer (self). Both are necessary for the human experience – but the soul is eternal while the body is destined to be temporary. In a study of 10 cancer patients, subjects spoke of resolving their earthly responsibilities and engaging in spiritual activities like participating in pooja (ritual worship) or looking at a photo of a Hindu deity as ways of investing in their eternal self and also providing relief and satisfaction in their current state (Simha et al. 2013).

The degree of spirituality and its impact on personhood in the face of serious illness varies. In a study that administered the previously mentioned spirituality questionnaire to 300 cancer patients, researchers grouped by degree of spirituality – "spiritually trustful," "intermediate," and "spiritually distressed." The authors found that women and those with low socioeconomic status were more likely to be in the "spiritually distressed" group. It was theorized that in the case of women, whose external identities and spiritual practice may be expressed through their central role as caretakers of the family, their terminal illness may precipitate a loss of identity and/or disconnection of their relationship with God and potentially their personhood (Gielen et al. 2016).

Purpose of human life and meaning of death

The circumstances surrounding death set up the next form that the soul will take and will potentially mark the completion of the birth and death cycle. In the Bhagavad Gita, a widely accepted authoritative Hindu text, the process of death is described as changing bodies, "As a person puts on new garments, giving up old ones, the soul similarly accepts new material bodies, giving up the old and useless ones" (Swami Prabhupada 1978). Thus, death is not regarded as the end of an individual's identity, but rather a disengagement from identifying with one's current self – navigating this transition can cause significant existential distress.

Spiritual practices familiar to the patient may provide solace and direction in navigating this discord. Specific spiritual therapies that the patient can engage in include chanting mantras, singing, prayer, reading sacred texts, and engaging in ritualistic worship, often called pooja. A chapter in a handbook for EOL spiritual care lists common mantras and prayers that may be chanted and may serve as a useful starting place (Puchalski 2006). The only example of a spiritual care "intervention" came from a single-cohort study in a group of 107 cancer patients undergoing concomitant cancer therapy and palliative care at a Hindu affiliated hospital (Sankhe et al. 2017). Participants were given the support of a comprehensive program labeled "MATCH" – Mercy, Austerity, Truthfulness, Cleanliness and Holy name. Components of this program included a vegetarian diet; refraining from intoxicants; spiritual counseling that encouraged open and straightforward dialogue; and prayers, meditations, and readings specific to the patient's existing religious and spiritual beliefs. The program included 1.5 hours per day with each patient – 30 minutes each of reading, chanting and counseling. To assess changes in quality of life and emotional affect, patients and caregivers completed the Functional Assessment of Cancer Therapy-General (FACT-G) at admission, discharge, and 2-, 4-, and 6-months post-discharge. There were significant increases seen in FACT-G scale scores in patients and caregivers, indicating greater spiritual well-being, at each of the intervals compared to baseline. While this study had no control arm to ascertain the effects of treatment alone, it provides a remarkable example of a targeted spiritual care program in the Indian and Hindu context.

EOL decision-making

Role of family members in decision-making

In South Asian cultures, there is a preference toward collective decision-making and differences in disclosure of information. Several studies have documented the tendency for family members to request that terminal diagnoses be withheld from the patient, owing to the belief that fear of a terminal diagnosis may result in a worse outcome (Chattopadhyay and Simon 2007). In reflecting on a family member from whom a terminal diagnosis had been withheld, 1 participant mused that "autonomy was not really a concept she valued" and "she didn't want to take on the burden of knowing everything and making decisions" (Sharma et al. 2012). The lack of control desired over information and decision-making may seem unusual from a Western perspective but is not uncommon in a culture that values collective decision-making. It has also been suggested that while Western cultures are generally more explicit, Eastern cultures tend to favor more implicit ways of being told that a patient is near the EOL (Periyakoil et al. 2015). However, it can also be argued that some patients may want extremely clear communication if they are approaching death, because they may wish to practically arrange for an auspicious death for themselves through practices such as those outlined above (Patel et al. 2020; Shanmugasundaram and O'Connor 2009). Examples have also been cited of family members who were very upset at a lack of clear communication that their family member was dying, because this prevented them from preparing for rituals surrounding death (Firth 2005). One first-generation Indian participant living in the United States shared that his view on disclosing a terminal diagnosis has changed since moving to the United States. In India, there was a strong support system to care for a dying person, and he felt

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that telling a patient would only serve to make the end of their life more difficult, whereas in the United States, he could not depend on such a support system and would want to know of a poor prognosis immediately, in order to make arrangements for himself (Sharma et al. 2012). This theme of diminishing social networks as a motivator for proactively engaging in EOL planning was also seen in a study of 100 older adults and 100 younger adult Indian Hindus in the United States (Mohankumar 2009).

Advance directive completion

There have been multiple reports of resistance to advance care planning among Hindus (Thrane 2010). A study of Indo-Caribbean Hindus found mostly positive attitudes toward advance care directives, but the actual rate of advance care directive completion was low suggesting underlying reasons for resistance that may not have been fully uncovered (Rao et al. 2008). In one Canadian study of 34 South Asian participants, a sizable minority (44%) felt that palliative care went against their cultural values and spiritual beliefs, and an additional 29% were unsure if palliative care aligned with these beliefs (Dosani et al. 2020). A study among Indian Hindus in the United States found that "having strong religious affiliation and a family decision- making style were significantly negatively correlated with advance directive completion" (Doorenbos and Nies 2003). It has been theorized that patients may be less likely to pursue advance care planning due to language barriers, power hierarchies in the family, and cultural beliefs about death being taboo or inauspicious to discuss (Venkatasalu et al. 2013). In a focus group study conducted in Canada, participants stated that filling out advance care planning forms felt like questioning the control of God. As one participant said, "We don't plan about death and severe health conditions as we believe it is not in our control. Discussing and preparing for it puts us in control rather than God and the higher power" (Biondo et al. 2017). A study interviewing South Asian Americans on advance care planning found that several participants had never been asked about advanced care planning in their interactions with medical care, while South Asian physicians shared that they often hadn't brought up advance care planning with patients due to constraints of time or cultural hesitance toward talking about death. Additional barriers cited in this study were an implicit trust in the oldest child to make decisions, and fear that signing an advance directive would result in being denied health care during traumatic events (Radhakrishnan et al. 2017).

Increasing participation of Hindus in advance care planning may require reframing the language around it. For a Hindu patient, cultural preferences toward collective decision-making may mean that language conveying autonomy and individual control may not resonate and may paradoxically discourage a patient from completing an advance directive. The ability to share one's wishes in order to approach death in a manner they would deem favorable and religiously aligned may be a better approach. One study shared a case in which a Hindu family wished to delay the removal of life support and allow for death until a time that was astrologically favorable, emphasizing the relevance of astrology in Hinduism (Dewar et al. 2015). While advance directives may not include such provisions per se, the example of a request to delay the removal of life support until an astrologically favorable time represents the use of modern medical technology in the service of a patient's religious and spiritual goals.

In a study sampling 293 Hindu physicians in the United States, 86% believed that their own religious belief did not influence their views on withdrawal of life support. Additionally, 79% of respondents had "adopted the US practice of discussing EOL care with the patient rather than primarily with the family," signifying greater acculturation and/or responding to the needs of the patient population they were serving (Ramalingam et al. 2013).

With regards to CPR, the soul in a Hindu context is thought to be physically located in the heart, so the loss of heart function (possibly along with concurrent loss of brain and lung function) may signify the initiation of the dying process (Setta and Shemie 2015). In a survey of Indo-Caribbean Hindus in the United States, participants lacked a precise idea of what CPR entailed, and assumed that after a trial of CPR, the patient would generally make a full recovery and return home (Rao et al. 2008). It is worth ensuring that culturally sensitive communication is available such that patients understand the statistically low likelihood of benefit from CPR for certain patients and the reality that CPR administration can be traumatic. It is also important to clarify that denying CPR in an advance directive does not preclude one from accessing other forms of resuscitative treatment, such as blood transfusions or intravenous fluids.

Pain management

Hindu beliefs around detachment, impermanence of the physical body, and acceptance of suffering as inevitable aspects of life have been suggested as useful coping mechanisms for Hindu patients experiencing pain (Whitman 2007). An American study of clinician perceptions of patients' use of pain management at the EOL reported that providers perceived South Asian patients to have greater reluctance to use pharmacological therapies compared with other patients. The 57 providers interviewed included physicians, physician assistants, chaplains, and social workers. Belief in karma, pain seen as weakness, and the desire for elderly patients to keep their mental faculties intact were hypothesized as reasons for their reluctance to accept analgesia (Khosla et al. 2016).

When considering the use of life-prolonging interventions, the concept of ahimsa (nonviolence) provides a relevant lens. The concept of ahimsa appears throughout a broad variety of Hindu sacred texts (Chander and Lucinda Mosher 2019). Ahimsa is not a simple call to avoid violence but requires a complex look at minimizing harm on a social, psychological, and spiritual level. In the context of EOL care and pain management, ahimsa is minimizing violence to one's most eternal self, the soul. The complexity of ahimsa can be honored by methods that prolong life, or that end life peacefully.

Similarly, the concept of karma also shapes decisions around pain management for patients and families in a dialectical manner. This is illustrated by an exchange between 2 focus group participants who were unsure of how their understanding of Hinduism applied to accepting pain relief, with 1 focus group member stating "According to Hindu philosophy, suffering is the result of your past.… So some people say, let that person suffer", while another member responded with, "But there is something available to reduce that pain so, are you doing the right thing or wrong thing?" Most participants echoed this sentiment and also stated the understanding that just because suffering results from one's karma does not mean pain relief should not be given at the EOL (Sharma et al. 2012).

Artificial nutrition and hydration

Many families may struggle with withholding ANH from a dying family member. In a study of the experiences of South Asian immigrants in Canada, the majority from a Hindu background, some caregivers felt that "force-feeding" a terminally ill person was the norm (Weerasinghe and Maddalena 2016). In Hinduism, there also

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exists the concept of prayopavesha, or fasting until death. It is difficult to know what proportion of Hindus with terminal illness actually follow this practice. It differs from suicide in that there is a strong element of community approval. Additionally, it is only for those with terminal illness who perceive that they are very close to death. It is observed by individuals who have fulfilled their duties and achieved a sense of contentment; it does not come from a place of fear or frustration, but is rather a strategic, calmly thought out practice (Murato 2009). Unlike the decision to withdraw nutrition on behalf of a dying, unconscious family member, prayopavesha is decided by a person who is still in a clear state of consciousness. Terminally ill persons for whom death is imminent may have traditionally fasted from food and water to prepare for their death. A related perspective is that "suspending artificial nutrition and hydration is sometimes supported because there will be fewer bodily fluids and the soul can more easily leave the body" (Setta and Shemie 2015). The decision to withhold artificial feeds in the setting of reduced appetite as a person nears their EOL may be easier to conceptualize for Hindu patients for whom fasting till death is culturally familiar.

Discussion

This review has organized the various perspectives offered in the literature about the relationship between Hinduism, death, EOL care, and palliative care. There was a broad range of evidence available (trials, theoretical explorations, patient narratives) and a lack of uniformly agreed markers in the study of Hindu religious and spiritual belief in the EOL care setting. A key theme emerging in each section was the discrepancy between theory and perceived application of essential Hindu values, and the consequent need for future empirical study to better understand some of these discrepancies.

There are multiple academic studies that offer karma as the primary operational framework used by Hindus to process death and dying (Chaturvedi 2008; Firth 2005; Gielen et al. 2010; Sharma et al. 2012; Thrane 2010). However, in some cases, the proposed arguments are based on a theoretical understanding of the philosophy that does not align with the applied practice, such as inferring that parents not expressing outward emotion at the death of a child is due to belief in karma (Hernandez 2019). It is crucial to avoid using only theoretical constructs to infer how Hindu patients may react to death or make decisions. As Gielen et al. explain, "Some Hindus are indeed of the opinion that suffering, and death are a consequence of karma. Yet, such theories may not always make acceptance of death easier. On the contrary, some Hindus may be convinced that their time has not yet come, and that therefore all possible life-prolonging treatments should be applied." Further, Gielen et al. state that none of the participants in their research have used the arguments regarding karma as support for withdrawing life sustaining treatment offered by Gatrad and Firth, 2 often cited voices in the field (Gielen et al. 2010). The danger of overstating the role of karma has historical precedent – early Western engagement with the Indian subcontinent showed both a fascination and abhorrence of the concept in ways that had practical consequences (Altman 2017). A belief in karma does not mean that Hindus do not experience the universal human emotions of grief, fear, and anxiety when confronting one's own death or that of a loved one, and research drawing primarily on a theoretical framework of karma may fail to temper an applied understanding with full consideration of the human dimension. An important future area of study is the exploration of perceived gaps in EOL care experienced by Hindu patients and their caregivers. A survey of care team members who interact with Hindu families regarding EOL decision-making on issues such as pain management, advance directives, withdrawing/withholding life-sustaining treatment may provide valuable insight. Additionally, the impact of religious and spiritually informed interventions, such as mantra chanting or meditative practices on physical or psychological distress, should be evaluated as a potential means of providing relief to this patient subset.

It is important to note that many of the studies cited in this article have been conducted outside the United States – the experience of Hindus in the American milieu and health care system is certainly unique and deserves to be explored further. In this review, no studies were found regarding the experience of Hindus not from a South Asian ethnic or cultural background. A 2014 Pew Research Forum study found that 4% of Hindus living in the United States identify as White (Hackett et al. 2014). The ways in which Hindus who are not of South Asian descent experience palliative care and EOL decision-making has not yet been investigated.

In conclusion, this review has sought to summarize key issues in the physical, psychological, and spiritual dimensions of palliative care as well as myriad issues at the intersection of EOL decision-making and Hinduism. It should be made clear that each person will have a unique set of considerations when making decisions at the EOL for themselves and their loved ones, and the examples provided in this paper are by no means exhaustive of all possible viewpoints. Additionally, individuals can reference principles discussed in this paper, whether it be ahimsa, karma, or a personal relationship with divinity, yet come to disparate conclusions regarding the best course of action. This versatility is a cornerstone of many belief systems, but is especially striking in Hinduism, as it emphasizes many philosophical constructs without a singular moral codification. This makes the work of cultural translation and engagement between Hinduism and EOL care especially relevant.

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