

SPIRITUAL CARE IN PALLIATIVE CONTEXTS: PERSPECTIVES FROM HINDU FAMILY CAREGIVERS – A SCOPING REVIEW

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Abstract

This scoping review examines spiritual care in palliative settings from the perspective of Hindu family caregivers, utilizing articles from ProQuest, ScienceDirect, and PubMed, and applying the Joanna Briggs Institute Critical Appraisal Tool. By analyzing eleven studies published between 2019 and 2023, we uncover how Hindu spirituality influences care at the end of life, highlighting themes such as the Concept of Death, Spiritual Needs, and Caregiving Challenges. Findings reveal the critical role of family in providing spiritual support, the blend of religious rituals with caregiving, and the array of challenges faced by caregivers, including emotional and financial burdens. The review advocates for palliative care models that integrate Hindu spiritual practices, addressing the need for culturally sensitive care that respects the spiritual beliefs of Hindu patients and their caregivers. Ultimately, this review underscores the necessity of a holistic approach to palliative care that accommodates spiritual needs within Hindu families. It advocates for the inclusion of transcultural care principles, especially significant for Muslim nurses who are prominently represented in the profession. By integrating these insights, healthcare providers can offer culturally sensitive and spiritually respectful care to patients of diverse backgrounds. This approach not only bridges cultural divides but also enriches the palliative care experience for all involved..

Keywords: Hindu spirituality, Palliative care, Family caregivers, Spiritual care challenges, Cultural sensitivity in healthcare

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INTRODUCTION

Spirituality is defined as the quality or state of being spiritual, often associated with religious questions and values. It is also used in a non-religious context to denote the comprehension of fundamental moral and existential questions about the nature of the soul. The Cambridge Dictionary describes spirituality as involving deep feelings and beliefs of a religious nature, rather than the physical aspects of life. Similarly, the Oxford Advanced Learner's Dictionary defines it as being connected with religion or the human spirit. Meanwhile, the Collins English Dictionary views it as the state or quality of being dedicated to God, religion, or spiritual matters, especially in contrast to material or temporal concerns. Hence, spirituality encompasses a unique approach to religion or prayer.

According to Hussain (2020), in Islam, spirituality is characterized by a relationship with Allah that influences individual values, the sense of meaning, and relationships with others. It includes beliefs in Allah and His prophet, judgment day, rituals, daily behavior, and knowledge, rooted in love that is informed by knowledge and manifested in living according to Sharia law.

Spirituality from a Western perspective is broader and may or may not include religion. Clyne et al. (2019) and Puchalski et al. (2009) describe it as an aspect of humanity concerning how individuals seek and express meaning and purpose, and their connectedness to the moment, self, others, nature, and the significant or sacred. Nolan et al. (2011), as cited by Laranjeira et al. (2023), consider spirituality a dynamic aspect of life related to expression and the search for transcendence, meaning, and purpose. Furthermore, Laranjeira et al. (2023) reference Evangelista et al. (2016), noting spirituality also involves a belief in a higher entity and is associated with more humanistic and person-centered care.

In the context of Hinduism, spirituality extends beyond mere ritualistic practices to encompass a comprehensive understanding of life, death, and beyond. Hindu spirituality is characterized by its emphasis on the eternal cycle of life (samsara), the law of cause and effect (karma), the ultimate goal of liberation (moksha), and a profound connection with the divine, which permeates every aspect of life and the universe (Shukla, 2022).

Palliative care focuses on managing pain and other uncomfortable symptoms to enhance comfort for patients with incurable illnesses. The World Health Organization (WHO) defines palliative care as an approach to improve the quality of life of patients and their families facing life-threatening illness challenges. Studies, such as Blaževičienė et al. (2020), assert that palliative care is vital to health and human dignity, representing a fundamental human right. It employs an interprofessional team approach to address the physical, psychosocial, and spiritual needs of patients, including those with life-limiting diagnoses. Within palliative care, understanding and catering to the spiritual needs of Hindu patients and their family caregivers necessitates a deep appreciation of these concepts. Spiritual care in this setting involves not only addressing the existential and emotional challenges faced by patients and families but also integrating religious rituals, prayers, and the teachings of dharma (duty/righteousness) that offer comfort, hope, and meaning at the end of life.

Aim of Scoping Review

In the field of palliative care, the spiritual well-being of patients and their families is of utmost importance in ensuring high-quality end-of-life care. However, there is a significant gap in the literature on how to address these spiritual needs across different cultures and religions, especially within Hindu communities. Hinduism is a complex religion with unique beliefs and practices that provide a distinct perspective on spiritual care, yet it remains underexplored in current palliative care research.

This scoping review has a dual aim of filling the knowledge gap and shedding light on how Hindu family caregivers perceive, engage with and fulfill the spiritual care needs of their loved ones in palliative care settings. It is critical to understand these dynamics to inform and enhance palliative care practices that are culturally sensitive and spiritually aligned with the values of Hindu patients and their families. Moreover, the diversity within Hindu practices and beliefs necessitates a comprehensive review to capture the breadth of experiences and expectations in spiritual care at the end of life.

This scoping review aims to consolidate existing research on spiritual care from the viewpoints of Hindu family caregivers. Its objective is to identify research gaps and recommend strategies to integrate Hindu spiritual practices into palliative care models. The review aims to contribute significantly to the development of more inclusive, respectful, and effective palliative care practices that acknowledge and honour the spiritual beliefs and needs of Hindu patients and their caregivers.

METHODOLOGY

Search Engine

The literature search was conducted using guidelines and online databases including ProQuest, ScienceDirect, and PubMed, accessible through the IIUM library subscription. The search focused on scholarly articles pertinent to the topic under review.

Search Strategies

a) Keyword

The keywords to find the related articles are “(spirituality care OR spiritual sensitivity) AND (palliative care OR end-of-life OR terminally ill) AND (Indian OR Hindu) AND (caregiver OR family) AND perspective”.

Table 1: Sample, Phenomenon of Interest, Design, Evaluation, Research Type (SPIDER) Framework Table

SPIDER	Initial terms
Sample	Hindu family caregiver
Phenomenon of Interest	Spiritual care in palliative care

Design	Interview and Questioners
Evaluation	Experiences
Research type	Qualitative study and Quantitative study

b) Inclusion and Exclusion Criteria

Eligible articles were identified by reviewing titles and abstracts, focusing on full-text academic journal articles available in English, published between 2019 and 2023, and specifically addressing spiritual care in palliative settings among Hindu or Indian patients. Exclusions were made for articles not fully accessible.

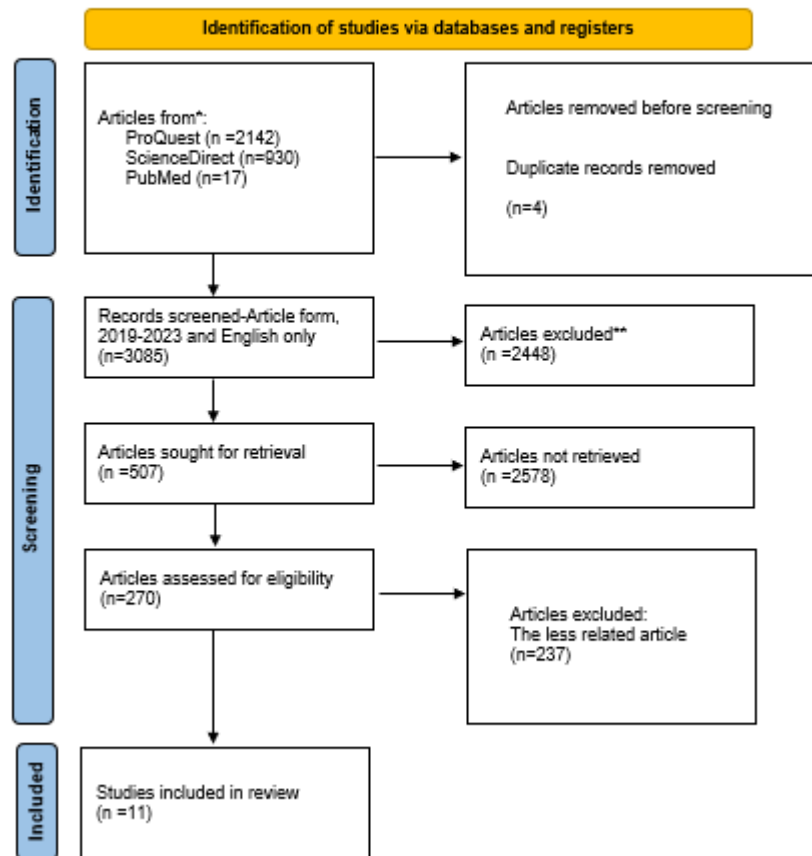


Figure 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Table

CRITICAL APPRAISAL

The Joanna Briggs Institute (JBI) Critical Appraisal Tool, comprising structured checklists of eight questions, was used to critically appraise the selected studies. This tool facilitated the

evaluation of the studies' validity, quality, credibility, methodology, and findings.

LITERATURE REVIEW MATRIX

Table 2: Literature Review Matrix

Title, author, year of publication	Research method	Research objective/questions	Dependent / Independent variables, statistical test, research tools	Participants characteristics (sample size, inclusion and exclusion criteria)	Research findings	Limitation
<p>Demonstrating the importance of cultural considerations at end of life utilizing the perspective of Indian patients with cancer (Chittem et al., 2022)</p>	<p>Qualitative study</p>	<p>The objective of this research is 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.</p>	<p>Semi structured interview</p>	<p>-The participants of this study are 25 Indian patients diagnosed with incurable cancer at a cancer specialty hospital in Hyderabad, India. -The inclusion criteria are was diagnosed with incurable cancer,</p>	<p>The results show 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. (ii) God</p>	<p>The limitation is further examined the extent of and relationships between pain, coping, psychological distress, and attitudes towards euthanasia and DNR orders.</p>

				<p>aware of their poor prognosis, did not have any prior psychiatric conditions, could speak English, Hindi or Telugu (regional language).</p>	<p>was the ultimate decision-maker of life and death. Furthermore, 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.</p>	
<p>I Don't talk about my distress to others; I feel that I have to suffer my problems. ..' Voices of Indian women with breast cancer: a</p>	<p>Qualitative study</p>	<p>To explore the psychological distresses experienced by Indian women with breast cancer living in Kerala, South India, during and after treatment</p>	<p>semi-structured one-to-one interviews.</p>	<p>The participants are 20 consenting women undergoing treatment for breast cancer.</p>	<p>The result shows three major themes emerged from the data. - The first major theme was 'far-reaching psychological distress'.</p>	<p>The limitation is due to the diverse nature of the culture of the country, the data cannot be considered</p>

<p>qualitative interview study. (Daniel et al., 2021)</p>		<p>and to understand better what helped to relieve or increase these distresses.</p>			<p>This included anxiety, guilt, anger, and depression in response to the disease and physical side effects of treatment and issues relating to body image. - The second major theme was 'getting on with life'. Women tried to make sense of the disease, by actively seeking information, the role of medical professionals, and their practical adaptations. -The third</p>	<p>completely representative of the South Asian population.</p>
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					major theme was the 'support system strongly based on family, friends, faith, and the community which affect them positively as well as negatively.	
<p>“End-of-Life Care is more than Wound Care”: Health-Care Providers’ Perceptions of Psychological and Interpersonal needs of Patients with Terminal Cancer. (Pinto et al., 2019)</p>	<p>A cross sectional qualitative design</p>	<p>To explore health-care providers’ perceptions of the interpersonal needs, psychological needs, and unfinished business among terminally ill cancer patients during the end-of-life care.</p>	<p>semi-structured interviews and focus group discussions .</p>	<p>The participants are 11 health-care providers working at palliative care centres for a minimum duration of 6 months.</p>	<p>The result shows thematic analysis identified themes related to this study. -There were three themes related to psychological needs and concerns : (i) experience and expression of negative emotions , (ii) mental</p>	<p>The limitations are sample included participants from only two palliative care centres in South India, and the emergent themes may not reflect all the needs and concerns of</p>

					<p>health concerns, and (iii) confronting mortality .</p> <p>-Three themes emerged in the domain of interpersonal connections: (i) support and closer connections with family, (ii) disconnection from family relationships, and (iii) building new connections at the hospice.</p> <p>-Two themes were identified related to unfinished business: (i) types of unfinished</p>	<p>persons in the end-of-life care.</p>
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					<p>business and (ii) addressing unfinished business. -The findings also highlighted health-care providers' perspectives and experiences: (i) need for expanded end-of-life care training and (ii) experiences of emotional labor.</p>	
<p>Indian Cancer Patients' Needs, Perceptions of, and Expectations from their Support Network: a Qualitative Study. (Chawak et al., 2020)</p>	<p>Qualitative study</p>	<p>To understand Indian cancer patients' needs and expectations from their support network.</p>	<p>Semi structured interview.</p>	<p>-The participants are 26 cancer patients undergoing treatment at a hospital in Mumbai, India. -The inclusion criteria</p>	<p>The result shows four major themes emerged which are: (i) role of the oncologist including their primary medical</p>	<p>Firstly, the data was collected in the city of Mumbai which is a large city in India with a unique population</p>

				<p>was patients who were able to communicate in Hindi, English, or Marathi .</p> <p>-The exclusion criteria was Patients with advanced cancers and below the age of 18.</p>	<p>decision maker, communicating with authority versus spending time with patients</p> <p>(ii) role of the immediate family including being emotionally present and supporting them in medical adherence</p> <p>(iii) role of relatives and friends including giving advice and providing tangible aid and services.</p> <p>(iv) role of other cancer patients including help with coping with the illness.</p>	<p>profile.</p> <p>- Second , this study focused on patients' perceptions and expectations of their support network in terms of their support needs but not on how the patients went about obtaining this support .</p> <p>-Third, the present study cannot determine whether patient s' needs and expectations of their support network</p>
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						<p>k change over time.</p>
<p>“So, when a woman becomes ill, the total structure of the family is affected, they can’t do anything ...” Voices from the community on women with breast cancer in India: a qualitative focus group study. (Daniel et al., 2022)</p>	<p>Qualitative study</p>	<p>To understand the cultural context within which Indian women with breast cancer living in India, experience psychological concerns from the perspectives of healthcare professionals, volunteers, and church members.</p>	<p>semi-structured focus groups</p>	<p>The participants are 45 people from 5 focus groups conducted in South India (clinicians 2 groups and lay public (3 groups)).</p>	<p>The result showed three major themes psychosocial issues related to diagnosis, psychosocial impact of cancer treatment and coping with diagnosis and treatment and seven sub themes emerged from the groups.</p>	<p>The limitation was Christian church.</p>
<p>Challenges in the Provision of End-of-Life</p>	<p>Qualitative study</p>	<p>Not applicable</p>	<p>Not applicable</p>	<p>Not applicable</p>	<p>Not applicable</p>	<p>The limitations are the differences</p>

<p>and Palliative Care to Ethnic Nepali Refugees. (Najjar and Hauck, 2020)</p>						<p>nces in the complex caste system of Nepal are also not well evaluated in the current literature. The healthy migrant effect may result in a refugee population with significantly different perspectives than nonrefugees as well.</p>
<p>A Qualitative Study on Palliative Needs of Stroke Patients in an Indian Tertiary Care</p>	<p>Qualitative study</p>	<p>To describe treating doctors' perspectives on the palliative needs of stroke patients in India.</p>	<p>Interview guide.</p>	<p>The participants of the study are 17 doctors at St. John's Medical College Hospital</p>	<p>The result shows eight themes emerged based on the interview. The eight themes</p>	<p>Not applicable</p>

<p>Setting - Doctors' Perspective. (Lloyd et al., 2019)</p>				<p>l, a tertiary care hospital in South India.</p>	<p>are functional disability, physical burden, psychological needs, social issues, caregiver burden, counseling-an unmet need, spiritual needs and issues at the end-of-life care.</p>	
<p>Perceptions and meanings of living with Parkinson's disease: an account of caregivers lived experiences. (Bhasin and Bharadwaj, 2021)</p>	<p>Qualitative study</p>	<p>To understand the experiential and existential impact on the lifeworld of caregivers.</p>	<p>In-depth personal narrative interviews</p>	<p>10 caregiver participants in India.</p>	<p>The results show six themes emerged: a) Becoming a caregiver : Undertaking immeasurable and unrelenting responsibilities. b) Rising patient-hood of one's family</p>	<p>The limitations are the data in the present study were obtained from participants inhabiting urban and metropolitan scenario from the</p>

					<p>member: pain of losing the person in the patient. c) Experi- ence of altered tempo- ral ity: living in pain with the uncer- tain- ty and dura- tion of the dis- ease. d) Encoun- tering mean- ing- less- ness: dwind- ling faith in prin- ciple s of life. e) Exist- ing as a “Be- ing For” and not “Be- ing With”: a care- giver ’s self- e- stran- ge- ment and blur- ring of Identi- ty f) Self- Preser- vat- ion through</p>	<p>upper middle class, seek- ing treat- ment at the cen- tral hospi- tals of the capi- tal. Thus, the find- ings should not be taken to be a repre- senta- tive pic- ture of the entire popu- lation of peo- ple iden- tify- ing as care- giv- ers. to Parkin- son’s Dis- ease</p>
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					brief moments of respite: coping with caregiving.	
Cancer Pain Experience Through the Lens of Patients and Caregivers: Mixed Methods Social Media Study. (Filipponi et al. 2023)	A descriptive and quantitative analysis of qualitative data	This study aimed to (1) reveal the unmet needs of both patients and caregivers. (2) detect the emotional activation associated with cancer pain by analyzing the textual patterns of both users.	Data were collected following Pushshift Reddit API Documentation	Not applicable	The results show: The language used for describing experiences related to cancer pain and expressed needs differed between patients and caregivers. For patients (agglomerative coefficient=0.72) For caregivers (agglomerative coefficient=0.80)	The limitations are given that the data were retrieved from an online social network, demographics, and user personal characteristics (eg, personality, anxiety, depression, etc) were missing from the analysis.
perceptions of Caregiving by	Qualitative study	To explore the self-appraisal concept of	through in-depth, semi-structured	12 participants family	The result show 6 themes	Limitations is the data

<p>Family Caregivers of Older Adults with Dementia in Iran: A Qualitative Study. (Farhadi et al. 2022)</p>		<p>caring based on the experience of family caregivers of older adults with dementia.</p>	<p>interviews.</p>	<p>caregivers of elderly with dementia.</p>	<p>emerged: a) Perceived burden. b) Satisfaction with care c) Personal growth d) Care-giving gains e) Philosophy of care f) Loss and threat</p>	<p>were gathered. based on a qualitative methodology with a small sample size through purposive sampling, limited to an Asian community.</p>
<p>What Spirituality Means for Patients and Families in Health. (Gardner et al. 2020)</p>	<p>Qualitative study</p>	<p>To strengthen understanding of the value of spiritual care offered in health settings.</p>	<p>Semi-structured interviews.</p>	<p>The participants are 24 patients, and 10 family members were interviewed.</p>	<p>The results how themes emerged: a) Being treated as a person b) Being reminded of who you are, what you are capable of c) Being able to have conversations about what matters to You</p>	<p>The limitation is the study took place in a hospital in a city in Victoria, Australia. This hospital is in a community with limited cultural diversity. This means</p>

					<p>d) The importance of maintaining contact with Family and friends and related networks</p> <p>e) religious affiliations and practices</p> <p>f) Valuing music</p> <p>g) Nature/being Out in the world</p> <p>h) Contact with animals</p> <p>i) Activities with Others</p> <p>j) Accessible information and practical support</p>	<p>the study may not show how well the hospital includes people with very different religious or spiritual beliefs.</p>
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RESULT AND DISCUSSION

In the literature search across ProQuest, ScienceDirect, and PubMed, we initially identified 3089 articles. After removing duplicates and non-relevant studies, 3085 articles remained. Screening abstracts and applying inclusion criteria—full-text availability, English language, and publication dates between 2019 and 2023—narrowed the selection to 270 applicable articles. From these, 11 articles were chosen for in-depth analysis in this study, leading to the identification of key themes

which will be discussed in the following sections.

Concept of Death

Studies reveal nuanced understandings of death in India, reflecting diverse cultural and religious beliefs. Pinto et al. (2019) highlights a policy aimed at ensuring a dignified end-of-life experience, recognizing the individual's unique needs and the importance of holistic care that includes emotional and spiritual support. Research in Bengaluru with palliative care center participants underscores the mixed feelings surrounding death, from acceptance and fear of dying alone to hopes of being reunited with loved ones in the afterlife.

Chittem et al. (2022) delve into the Hindu belief system where death is seen as predetermined by divine will, emphasizing duty fulfillment and spiritual liberation (moksha) as essential to a good death. Rituals and social responsibilities play a crucial role in this understanding, influencing perceptions of death positively.

Najjar and Hauck (2020) discuss how Hindu philosophy views death as a natural transition, leading to an acceptance of non-aggressive end-of-life care practices. The incorporation of traditional Hindu rituals into palliative care in Nepal, including the establishment of end-of-life facilities within ashrams, demonstrates the integration of religious practices in palliative care.

Comparatively, the Muslim perspective aligns life and death with Allah's will, highlighting a predestined time of death and the pursuit of a dignified end (khusnul khatimah).

In summary, Hinduism and Islam offer distinct views on death and the afterlife, influencing end-of-life care practices. Hindu beliefs in reincarnation, karma, dharma, and moksha contrast with the Muslim focus on fulfilling Allah's will, underscoring the importance of culturally sensitive palliative care approaches.

Spiritual need for patients and family caregivers

Research underscores the critical importance of spiritual care and family support in palliative and end-of-life care. Chawak et al. (2020) observe that the emotional and physical well-being of patients heavily relies on family caregivers, with family presence during medical consultations playing a key role in patient care. Similarly, studies in Mumbai and South India reveal that family, faith, and community support serve as significant coping mechanisms and motivators for patients, highlighting the roles of family members, friends, and even other patients in providing emotional support and assisting with medical adherence.

Daniel et al. (2022) and (2021) further emphasize the strength that patients draw from their families and faith, with caregiving extending beyond physical support to include spiritual and emotional sustenance. The collective effort of family, friends, and the community not only aids in the patients' coping strategies but also enhances their quality of life, underscoring the intertwined nature of spiritual needs and social support networks.

Gardner et al. (2020) point out the importance of maintaining connections with family and friends for patients' self-perception, highlighting how such support systems are crucial for the patients' overall well-being and ability to face the challenges of their conditions.

In essence, the studies collectively underscore the profound impact of spiritual and family

support on palliative care patients, revealing how these elements significantly contribute to easing the journey through their illness, despite the incurability of their diseases. This spiritual and social support network not only helps patients manage pain and anxiety but also imbues their final days with meaning and dignity.

Challenges of spiritual aspect

Research highlights significant challenges caregivers face in providing spiritual care, from handling the physical and emotional demands of caregiving to navigating their own spiritual and emotional wellbeing. Bhasin and Bharadwaj (2021) note the exhaustion and disconnection caregivers often feel, compounded by their responsibilities and the relentless progression of the disease. Filipponi et al. (2023) emphasize the emotional toll on caregivers, including guilt and psychological distress, while Farhadi et al. (2022) point out the physical, financial, and emotional stresses that can overwhelm caregivers, leading to a perceived loss of self and deep sadness over the gradual loss of their loved ones.

Pinto et al. (2019) discusses how patients sometimes grapple with their spiritual beliefs, especially when facing end-of-life decisions, and how isolation or financial strain can exacerbate these challenges. Daniel et al. (2022) highlights the additional burdens placed on women who feel abandoned by their families due to their inability to fulfill traditional roles, further complicated by the stigma surrounding cancer.

Moreover, Najjar and Hauck (2020) identify language barriers as a significant challenge in providing spiritual care, emphasizing the need for effective communication strategies in multicultural care settings. Lloyd et al. (2019) underlines the social and financial hardships faced by families of stroke patients, emphasizing the extensive support needed for long-term care.

These studies collectively underscore the multifaceted challenges in delivering spiritual care in palliative settings, ranging from the personal struggles of caregivers to the broader societal and financial constraints that impact patient care. Addressing these challenges requires a holistic approach that supports both caregivers and patients, recognizing the vital role of spirituality in palliative care.

CONCLUSION

This scoping review not only highlights the critical role of Hindu family caregivers in providing spiritual care within palliative settings but also underscores the challenges they face, including emotional and financial strains. The depth of spiritual and religious practices in supporting terminally ill patients is evident, emphasizing the need for healthcare systems to adopt culturally sensitive approaches that respect Hindu spiritual beliefs. The findings advocate for an integrative palliative care model that acknowledges the significance of spirituality, thereby enhancing the quality of care and support for Hindu patients and their families during the end-of-life journey. Importantly, this knowledge holds particular relevance for Muslim nurses, who represent a significant portion of the profession. It encourages them to integrate transcultural care principles when attending to patients of diverse races and religions. By fostering an understanding of Hindu spiritual care needs, Muslim nurses can contribute to a more inclusive and respectful healthcare

environment, thus improving the palliative care experience for patients and families across different cultural and religious backgrounds. This approach not only bridges cultural divides but also enriches the nursing profession with a deeper level of empathy and compassion, essential qualities in the provision of end-of-life care.

Declaration of interests

We declare no competing interests.

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