

Cultural Sensitivity in Palliative Care: A Bridge to Holistic Patient-Centeredness in India

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Abstract

This article explores the pivotal role of cultural competence in shaping the landscape of palliative care, particularly within the intricate weave of a culturally diverse environment such as India. Cultural competence, encompassing knowledge, attitudes, and skills, emerges as a transformative tool that holds the promise of not only enhancing patient satisfaction but also addressing existing inequalities in access and health outcomes within the realm of palliative care. By adeptly tailoring cultural competence to the Indian palliative care context, providers can effectively bridge the gap between diverse cultural backgrounds and patient care. A distinctive advantage lies in the potential of cultural competence to bring about significant benefits for patients without substantially elevating operational costs. The integration of cultural competence into education and daily operations stands as a potent strategy for harmonizing the diverse tapestry of palliative care in India, fostering inclusivity, and steering the pathway towards more equitable outcomes.

Keywords: Cultural competence; Palliative care; Multi-cultural context; Patient satisfaction; Health outcomes; Cultural diversity; Patient-centered care; Healthcare disparities

Introduction

Individuals belonging to ethnic, racial, and cultural minorities often face limited healthcare access and encounter inferior health outcomes in comparison to the majority population. These disparities have also become evident during the COVID-19 pandemic. Similarly, discrepancies have been identified among patients with advanced illnesses and experiencing pain, wherein minority patients encounter reduced availability or utilization of palliative care services. In the United States, a variety of strategies have been suggested to tackle healthcare access disparities, with a significant emphasis on cultural competence. This research delves into the potential application of cultural competence to palliative care in India, aiming to enhance accessibility and health outcomes. Existing literature argues that in diverse societies, cultural competence plays a pivotal role in establishing equitable healthcare systems. Addressing healthcare disparity issues necessitates solutions that extend beyond mere financial augmentation, as increased financial resources alone may not inherently foster a more equitable healthcare system. A culturally competent system acknowledges and integrates cultural considerations across all levels of care, particularly pertinent during end-of-life scenarios. When effectively implemented, cultural competence can result in heightened patient satisfaction, improved compliance, follow-up, and an enhanced reputation of palliative care, particularly within minority communities. This approach holds promise for mitigating inequalities in access and health outcomes within the realm of palliative care.

Disparities in access to palliative care: In July of 1946, delegates from 61 nations endorsed the World Health Organization's Constitution. Among the initial declarations in this constitution is the assertion that "The right to enjoy the highest attainable standard of health is one of the fundamental rights of every human being, without distinction of race, religion, political belief, economic or social condition [1]." While most individuals today might readily agree with this principle, the reality is that significant inequalities in health and healthcare persist not only on a global scale but also within individual countries and communities. Extensive research has addressed the issues tied to healthcare disparities, particularly well-studied in the

United States, where ongoing investigations reveal ethnic, racial, and cultural discrepancies both in health outcomes and healthcare accessibility. Individuals from ethnic, racial, and cultural minorities consistently demonstrate reduced access to healthcare and confront inferior health outcomes when contrasted with the majority population [2-5]. Disparities within the realm of healthcare encompass both the quality and accessibility of medical services. The United States provides ample evidence of these healthcare disparities, with a notable focus on African or Black Americans. For instance, African-Americans in the US encounter a lower likelihood of receiving adequate mental health care compared to their White counterparts. Disparities are also evident in diabetes care, where discrepancies exist between White and African-American populations. Moreover, African-Americans underutilize neurologic care in comparison to Whites. These instances merely scratch the surface, as similar imbalances extend across all healthcare domains in the US, affecting various minority groups, such as Hispanics. These disparities extend to health outcomes, with life expectancy being a particularly salient indicator. In the US, African-Americans exhibit a lower life expectancy than their White counterparts, with data from 2015 revealing a gap of 75.5 years for African-Americans versus 78.9 years for White individuals. Health disparities pervade every facet of well-being, including oral health [3-5]. The COVID-19 pandemic has further highlighted these disparities, with African-Americans initially testing positive for the virus at a higher rate than White Americans [6,7]. These healthcare inequalities stem from a myriad of factors, including lower health literacy, substandard living conditions, occupational hazards, and limited access to health insurance. The availability of health insurance underscores the link between healthcare and health disparities. Individuals without insurance must bear the brunt of

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Received: 01-Aug-2023, Manuscript No. jpcm-23-110312; **Editor assigned:** 03-Aug-2023, PreQC No. jpcm-23-110312(PQ); **Reviewed:** 17-Aug-2023, QC No. jpcm-23-110312; **Revised:** 23-Aug-2023, Manuscript No. jpcm-23-110312(R); **Published:** 30-Aug-2023, DOI: 10.4172/2165-7386.1000561

Citation: Jain A (2023) Cultural Sensitivity in Palliative Care: A Bridge to Holistic Patient-Centeredness in India. J Palliat Care Med 13: 561.

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healthcare costs, leading to constrained access and potentially inferior care. Consequently, reduced healthcare access or subpar care correlate with poorer health outcomes. Even in cases where patients are grappling with advanced diseases, pain, and related symptoms, disparities persist in accessing palliative care. As an integral part of a comprehensive approach, palliative care plays a crucial role in addressing pain as a public health concern. While pain is often viewed primarily through a medical lens, it warrants a global public health perspective due to its widespread prevalence and societal impact. Moreover, disparities in pain and its management persist across diverse population segments. Regrettably, these disparities extend to palliative care access as well. Studies conducted in the US indicate that minorities are less likely to access palliative care compared to their White counterparts, with minorities also displaying a preference for aggressive end-of-life care. Furthermore, when minorities do receive palliative care, they express lower satisfaction with aspects such as quality of care, communication, and pain management. A recent review highlights a range of factors contributing to this disparity, encompassing economic insecurity, insurance limitations, cultural and spiritual beliefs, geographic location, communication challenges, and discrimination.

In India, similar disparities persist in health and healthcare, often linked to poverty, rural residence, and social class or caste. Marginalized groups, including scheduled castes, scheduled tribes, and other backward castes, experience inferior health outcomes and restricted access to care. Consequently, specific sections of the Indian population encounter unequal access to palliative care. While further data is necessary to fully elucidate the extent of these disparities, their existence raises significant public health concerns. The evolution of palliative care in India has been remarkable since the inception of its initial programs in the 1980s. Nonetheless, the existing palliative care initiatives are constrained by limited resources, rendering them incapable of extending their services to all eligible patients [8]. Given these resource constraints, the issue of fair and equitable access to palliative care becomes even more pertinent. The fundamental question that demands attention is: How can the available palliative care resources be equitably distributed across the population? While poverty undoubtedly contributes to healthcare disparities in India, offering cost-free palliative care and expanding its services might not suffice to eliminate these inequalities. As demonstrated earlier, health disparities transcend mere financial considerations [9,10]. In the United States, various solutions have been proposed to address healthcare access disparities, with a particular emphasis on developing cultural competence.

Given its comprehensive approach to alleviating pain and suffering caused by life-threatening illnesses, palliative care programs are naturally positioned to incorporate cultural considerations into their services. The World Health Organization's description of palliative care underscores attention to "psychosocial or spiritual problems," which inherently contain cultural elements. Research conducted in India reveals that spirituality, often intertwined with religion and culture, is experienced by many palliative care patients. Communication norms are similarly shaped by culture, prompting palliative care providers in India to be attuned to these patterns and customs when interacting with patients [11]. Within India, palliative care organizations and researchers have recognized the significance of cultural factors in caregiving. They have devised studies, training initiatives, and care models that conscientiously account for local cultural nuances. A notable example is the Indian Association of Palliative Care's (IAPC) Certificate Course in Essentials of Palliative Care, which encompasses communication skills development and addresses spirituality-related

issues [12]. As elaborated below, the pursuit of cultural competence presents a comprehensive strategy for engaging with patients within multicultural contexts, equipping palliative care providers and organizations with pertinent knowledge, skills, and attitudes. This approach holds the potential to enrich and stimulate the integration of cultural awareness into palliative care delivery, training, and research across India. The existence of systematic reviews illustrating the relevance and effectiveness of cultural competence beyond India furnishes a sound foundation of evidence to advocate for its application in the realm of Indian palliative care. The existing body of literature undeniably underscores that addressing healthcare disparities mandates a broader approach than solely augmenting financial resources. A mere infusion of funds may not inherently render the healthcare system more equitable, as exemplified by the case of the United States. Despite having the world's most costly healthcare system, the US continues to grapple with glaring inequalities. The pursuit of equity in healthcare systems necessitates a commitment to ensuring uniform healthcare access and comparable health outcomes across the diverse populations they serve. Within scholarly discourse, it is posited that, especially within societies characterized by ethnic, racial, and cultural diversity, cultural competence stands as a pivotal component in fostering genuinely equitable healthcare systems [13]. The United States stands as a compelling illustration of such a multifaceted society. This rich tapestry of ethnic, racial, and cultural diversity has deep historical roots, and in parallel with numerous contemporary societies, the United States continues to experience ongoing diversification. Motivated by economic prospects, educational avenues, or the need to escape conflict and political persecution, individuals persistently depart from their countries of origin, seeking improved prospects elsewhere on the global stage. This phenomenon has led to an expanding segment of the global populace residing within cultural contexts that diverge significantly from their native backgrounds, resulting in a heightened prevalence of cultural diversity. However, the emergence of cultural diversity through migration is not solely confined to international boundaries; it also unfolds within the confines of individual nations. India, for instance, has historically epitomized a melting pot of cultures and religious beliefs. The dynamics of job opportunities perpetuate ongoing migration within India, including notable patterns from rural to urban centers [14,15]. Individuals hailing from rural communities, accustomed to more traditional ways of life, find themselves navigating modern urban environments where Western values intermingle with traditional Indian norms. This juxtaposition may extend to linguistic challenges, as people find themselves in locales where the local language remains unfamiliar. This contemporary internal migration adds another layer to the diversity that has characterized India for millennia. Religious diversity is a paramount feature of India's cultural landscape. Hinduism, as a multifaceted faith, has given rise to other religions within its context, most notably Buddhism, Jainism, and Sikhism. As a result of migration and conversions, substantial Islamic and Christian minority communities have also emerged. While common cultural threads bind people across India, variations in culture stemming from religious affiliations, regional disparities, and the urban-rural divide can engender sentiments of alienation. This sense of detachment becomes particularly poignant when individuals require pain management and palliative care. Notably, a divergence often exists between how cultural minorities express and experience pain and the corresponding norms prevalent in the cultural majority. Cultural backgrounds fundamentally shape how pain is perceived, leading to distinct responses to pain stimuli. When pain arises, an individual's culture also influences their decision to vocalize their discomfort, a facet that extends into healthcare contexts. For instance, within more traditional sectors

of Indian society, patriarchal dynamics that prioritize male figures might inhibit women from openly expressing pain until it reaches an unbearable threshold. Such dynamics can significantly impede prompt access to care [16]. Additionally, cultural factors can steer the choice of pain treatment. In India, Western biomedical practices coexist with other medical systems, including Ayurveda, Siddha, Unani, and homeopathy. Patients' selection of a medical approach is often guided by cultural proclivities and identity, alongside considerations like cost and availability. Research underscores a correlation between the utilization of traditional medicine and delays in seeking biomedical care. While these culturally molded attitudes toward healthcare, such as reluctance to discuss pain or a preference for traditional remedies, cut across diverse cultural groups in India, they may be more pronounced within specific segments, such as the rural populace, whose traditional convictions and behaviors exhibit less influence from globalized culture. Indeed, studies reveal disparities in health-related attitudes and practices between rural and urban populations. A 2014 study conducted in Uttar Pradesh demonstrated that rural residents were more inclined to use analgesics without formal prescriptions and expert medical guidance compared to their urban counterparts [17]. Such attitudes and behaviors often persist even when rural individuals migrate to urban centers or seek medical assistance within urban hospitals. The integration of cultural competence at both individual healthcare provider and institutional levels emerges as a pivotal factor in ensuring timely access to necessary care for patients.

To grasp the concept of cultural competence, it is paramount to first comprehend the term 'culture.' A notable definition of culture describes it as a multifaceted entity encompassing knowledge, beliefs, art, laws, morals, customs, and a range of capabilities and habits acquired by individuals as members of a society. Consequently, individuals hailing from diverse societies often possess dissimilar cultural beliefs, customs, and assumptions. Not everyone can be presumed to inherently possess an intuitive grasp of other cultures. Thus, individuals, organizations, and systems that engage with people from various cultural backgrounds necessitate the application of cultural competence [18]. Cultural competence can be construed as the ability of an individual, organization, or system to interact and navigate situations while possessing comprehensive knowledge and understanding of multiple cultures. This competence empowers healthcare providers to effectively engage with individuals from diverse cultural contexts, incorporating appropriate self-awareness, knowledge, and skill into their interactions. The term 'competence' denotes the aptitude to function effectively. A healthcare system that embodies cultural competence comprehends and incorporates the significance of culture across its entirety. This ensures that all constituents within the system can function adeptly when addressing the needs of patients from diverse cultural backgrounds. This becomes especially salient in the context of end-of-life care. For every living being, death is an inevitable and shared reality [19]. However, the perception and significance of death vary markedly for each person, significantly influenced by cultural factors. The concluding phases of life are fraught with stress. Consequently, the provision of culturally competent healthcare at this juncture assumes paramount importance. Patients and their families may harbor expectations of healthcare influenced by their cultural norms. When these expectations are not met, the potential for conflict, misunderstandings, non-compliance, and adverse health outcomes arises. Such conflict might manifest as disagreements between physicians and patients or in patients making decisions that physicians do not comprehend or endorse examples include rejecting palliative care or deviating from proposed pain management strategies. In many

instances, these conflicts stem from cultural disparities between the patient's cultural background and medical practices. Physicians and clinical teams should explore these beliefs and culturally ingrained values, as they often hold relevance in comprehending care preferences as a patient approaches the end of life. To ensure the provision of adequate palliative care, healthcare organizations must acknowledge and integrate the patient's cultural context, thus embracing cultural competence. When palliative care providers possess awareness and acceptance of a patient's cultural background, infusing this knowledge into a patient-centric approach facilitates care decisions that closely align with patient preferences. Consequently, patients and their loved ones are more likely to derive meaning and tranquility from the dying process. Conversely, care decisions that disregard a patient's cultural values, which may encompass spiritual and religious elements, can lead to care that diverges from the patient's intended goals. A study, for instance, revealed that patients whose spiritual needs were supported by the medical team reported a higher quality of life during their final moments and opted for hospice care more frequently than those whose spiritual needs were not addressed.

Within existing literature, a consensus exists regarding the potential of cultural competence to enhance both access and outcomes within end-of-life care. According to the theoretical framework, the incorporation of cultural competence is projected to yield improved communication and heightened patient satisfaction among cultural minorities. Consequently, this augmentation is expected to heighten the likelihood of patients initiating and/or continuing palliative care, adhering to prescribed treatments, and ultimately experiencing enhanced health outcomes. Specifically within palliative care, these improved health outcomes would encompass more effective pain and symptom management. Furthermore, contented patients and their families are more inclined to endorse the services they have received, thus increasing the likelihood of recommendations within their cultural group. Nonetheless, while cultural competence boasts a robust theoretical underpinning, further research in this domain remains essential. An illustrative example is provided by the Oncology Nursing Society, which acknowledged a "significant gap in knowledge pertaining to the provision of culturally sensitive palliative care" in its research agenda for 2019-2022. The society concluded that additional research is imperative, emphasizing the necessity of incorporating sociocultural norms into care. An area warranting particular attention is the evidentiary basis for cultural competence. While substantial evidence supports the correlation between cultural competence and enhanced patient satisfaction, the available data regarding whether cultural competence effectively mitigates healthcare inequalities remain somewhat limited. Furthermore, the applicability of cultural competence within healthcare systems of developing countries, such as India, remains a relatively unexplored terrain. It's worth noting that the paucity of findings is not indicative of negative results; rather, the issue has not been comprehensively investigated. Notably, trials involving cultural competence are complex to establish, with blinding proving impractical. However, the scant available studies do present encouraging outcomes [20].

Fostering cultural competence in Indian palliative care: Given the demonstrated enhancement of patient satisfaction through cultural competence, and the plausible link to improved access and outcomes in palliative care, it becomes imperative for palliative care initiatives in India to contemplate the integration of cultural competence into their services, training, and research endeavors. The role of research in this pursuit is pivotal, as it contributes to building a more robust evidence base for cultural competence while highlighting the effectiveness of

culturally tailored approaches designed specifically for palliative care in India. Nonetheless, it is essential to recognize that the concept of cultural competence primarily emerged within the US context. Notably, not all facets of its implementation in the US may seamlessly translate or align with the realities of developing countries such as India. A pertinent example pertains to the recommendation from US cultural competency literature for improving communication with patients who do not speak English as their primary language. While the US model suggests employing multilingual staff and utilizing foreign language interpretation services, including remote technologies, the feasibility and availability of professional translators might pose challenges for palliative care programs in India. In essence, while the overarching framework of cultural competence holds relevance for palliative care in India, it is imperative for these programs to be cognizant that certain models and approaches of cultural competence developed in countries like the US might necessitate adaptation before being practically applicable in the Indian context. To this end, palliative care programs must undertake diligent research and evaluation to ascertain the extent to which these models and approaches can be effectively assimilated within their specific palliative care initiatives in India. This conscientious approach ensures that the principles of cultural competence are harmonized with the unique cultural dynamics and practicalities of the Indian healthcare landscape.

Discussion

Palliative care programs are tasked with the imperative of embedding cultural competence across three foundational domains: knowledge, attitudes, and skills, all uniquely tailored to the specific cultural landscapes of the patient populations they serve. Knowledge encompasses an understanding of the socioeconomic and cultural intricacies characterizing the groups under the care of the palliative program. This entails that clinicians, counselors, and volunteers possess insights into the cultural nuances of the patients they interact with. For example, practitioners engaged in programs catering to tribal communities should familiarize themselves with the distinctive ways these individuals communicate about diagnoses. Similarly, clinicians attending to Muslim patients must be well-versed in Islamic beliefs and practices surrounding end-of-life matters. Additionally, an awareness of specific socioeconomic challenges hindering Muslim patients' access to palliative care is essential, as Muslims in India often contend with lower education levels and reduced employment opportunities compared to the Hindu majority. The aspect of attitude underscores the importance of sensitivity toward patients' cultural needs and an acknowledgement of one's own cultural boundaries. Cultural humility is a requisite attribute for those engaged in palliative care. Recognizing that gaps may exist in their understanding of the cultures they serve, care providers must exhibit a willingness to listen to and learn from their patients. This necessitates an attitude characterized by humility, empathy, curiosity, and respect. The operationalization of such attitudes within patient care, in turn, demands skill. Cultural skill empowers palliative care providers to unravel the significance of illness and disease to patients, understand their worldview, and ascertain their treatment preferences. Through the application of cultural humility and skill, patients are empowered to actively participate in decisions related to their treatment. In India, the prevailing cultural notion that patients need to be shielded from distressing news often leads to their exclusion from the decision-making process. Healthcare providers in India commonly comply with family requests to withhold diagnosis and prognosis from patients. The adoption of a culturally humble perspective enables palliative care providers to recognize the constraints inherent in certain cultural practices and beliefs, prompting them to acknowledge that

these might not universally apply to all patients. Research within the realm of cancer patients in India consistently underscores the desire of many patients to receive comprehensive information about their illness and actively engage in treatment decision-making, a desire that often goes unmet. Through the lens of cultural competence, healthcare providers become adept at navigating ethically complex scenarios where a patient's informational needs diverge from the family's intent to safeguard the patient from perceived harm linked to that very information. As palliative care programs incorporate cultural competence encompassing cultural knowledge, attitudes, and skills, patients from diverse cultural backgrounds will encounter a smoother pathway to accessing palliative care services. Patients and their families will likely experience heightened satisfaction and exhibit increased commitment to seeking and adhering to recommended treatments, thereby bolstering patient compliance. This comprehensive approach effectively contributes to the enhancement of both access and health outcomes within the realm of palliative care in India.

Conclusion

Cultural competence emerges as a pivotal tool in advancing the field of palliative care, particularly within the intricate tapestry of a multi-cultural environment like India. When adeptly implemented and thoughtfully tailored to the unique contours of Indian palliative care, cultural competence possesses the capacity to elevate patient satisfaction and, notably, to ameliorate disparities in both access and health outcomes within the domain of palliative care. Notably, the paramount advantage of cultural competence lies in its potential to yield substantial benefits to patients without imposing an undue burden on the operational expenses of palliative care programs. The integration of cultural competence, while essential in education and day-to-day operations, need not necessitate a significant fiscal investment. This heralds a call for palliative care initiatives to embark on inventive contemplation, envisioning innovative ways to seamlessly weave cultural competence into their modus operandi.

Acknowledgement

Not applicable.

Conflict of Interest

Author declares no conflict of interest.

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