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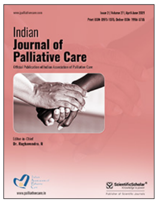

Review Article

Improving Access and Health Outcomes in Palliative Care through Cultural Competence: An exploration of opportunities and challenges in India

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ABSTRACT

People who belong to ethnic, racial and cultural minorities often have less access to healthcare and have poorer health outcomes when compared to the majority population. In the COVID pandemic, too, health disparities have been observed. Similar disparities have been noted in patients with advanced disease and suffering from pain, with minority patients having less access to or making less use of palliative care. In the US, a range of solutions has been proposed to address the issue of inequality in access to healthcare, with cultural competence figuring prominently among them. This study explores whether and how cultural competence may be applied to palliative care in India to improve access and health outcomes. In the literature, it is argued that, in diverse societies, cultural competence is an essential part of the solution towards equitable healthcare systems. Solutions to problems of healthcare disparities must go beyond an increase in financial resources as more financial resources will not necessarily make the healthcare system more equitable. A culturally competent system recognises and integrates at all levels the culture as a significant component of care, which is particularly relevant at the end of life. If efficiently implemented, cultural competence will lead to higher patient satisfaction, better follow-up and patient compliance and an improved reputation of palliative care among minorities. This may help to reduce inequalities in access and health outcomes in palliative care.

Keywords: Healthcare disparity, Health disparity, Cultural competence, Palliative care

INEQUALITIES IN ACCESS TO PALLIATIVE CARE

In July 1946, the representatives of 61 countries signed the Constitution of the World Health Organization. One of the first sentences of this constitution states, 'The enjoyment of 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] Although most people may find it obvious nowadays to agree with this statement in principle, the reality is that tremendous disparities in health and healthcare exist not just across the globe, but even within countries and societies. The problems related to disparities in health and healthcare have been elaborately studied in the US and studies continue to show ethnic, racial and cultural disparities in both health outcomes and access to healthcare. People belonging to ethnic, racial and cultural minorities have regularly been shown to have less access to healthcare and suffer from poorer health outcomes when compared to the majority population.[2-5]

Disparities in healthcare have to do with quality of healthcare and access to healthcare. The evidence of healthcare disparities in the US is massive, in particular for African or Black Americans. For instance, African-Americans in the US are less likely than White persons to receive adequate care in mental health.[6] There is disparity in diabetes care between White and African-Americans.[3] African-Americans use neurologic care substantially less than Whites.[5] These are just a few examples. Similar disparities can be found in all areas of healthcare in the US and among different minorities, such as Hispanics.[5,7]

Disparities in healthcare relate to health outcomes. The most obvious health disparity is life expectancy. African-Americans in the US have a lower life expectancy than their White fellow citizens. In 2015, African-Americans had a life expectancy of 75.5 years, while the life expectancy for White persons was 78.9.[8] Health disparities are not restricted to life expectancy and have been observed in all areas of health even oral health.[4] In the COVID-19 pandemic, too, health

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disparities have been observed. Early on in the pandemic, African-Americans were found to be more likely to test positive for the virus than White Americans.[9] These health disparities have a wide range of causes, such as lower health literacy, lower quality of living conditions and environment, increased likelihood of holding jobs that expose employees to health risks and that are less likely to provide them with health benefits such as health insurance.[10-12]

The mention of health insurance illustrates that disparities in health are often caused by disparities in healthcare. People who do not have health insurance have to pay out of pocket for all health expenditures. As a consequence, they will only have access to the healthcare that their budget gives them access to. This healthcare may be limited or of subpar quality. People who have less access to healthcare or who receive substandard care are more likely to have poorer health outcomes.

The disparities in healthcare persist even when patients have been diagnosed with advanced disease, are suffering from pain and other symptoms and would benefit from palliative care. As a holistic approach, palliative care is an essential component in strategies that attempt to address pain as a public health issue. Although pain is often considered as mainly a medical issue, it does need to be studied as a global public health problem. This is not only because of the massive occurrence of pain, with estimates indicating that around 20% of adults suffer from pain. Pain is, also, a public health issue because of the burden it puts on society, its costs to nations, the broader social impact of pain and, last but not least, disparities in pain and pain management across population subsections.[13,14]

Unfortunately, disparities have, also, been observed in access to palliative care. Studies in the US have observed that minorities are less likely to have access to palliative care in comparison to people belonging to the majority White population and minorities more often prefer aggressive care at the end of life.[15-17] Studies have, also, shown that when people belonging to minorities do receive palliative care, they are less likely to be satisfied with quality of care, communication and pain management.[16] A recent scoping review of literature identified various factors that contribute to this disparity. The review summarised the main factors as 'economic insecurity and lack of adequate insurance, cultural and spiritual values about health and medicine and geographic location'. There are also barriers to palliative care from the medical provider side, such as difficulties in communication and discrimination.[18] In these findings, the attention to 'cultural and spiritual values' as well as 'difficulties in communication' is important because it shows that barriers to palliative care are not only caused by economic factors but also have cultural and social causes, as well.

In India, too, disparities in health and healthcare persist. These disparities have been associated with poverty, rural residence and social class or caste with people belonging to scheduled castes, scheduled tribes or other backward castes more likely to have worse health outcomes and lower access to care.[19,20] As a consequence, subsections of the Indian population may not have equal access to palliative care. Although there is a need for more data on this issue, such disparities are a public health concern.

Palliative care in India has gone through tremendous development since the first palliative care programmes were established in the country in the 1980s. Unfortunately, due to limited resources, the existing programmes are unable to provide palliative care to all patients who may benefit from it.[21,22] Given the limited resources of palliative care in India, the issue of fair and equitable access to palliative care is all the more pertinent. The question that needs to be addressed is, 'what can be done to make sure that the limited available palliative care resources are distributed equitably across the population?'

Although poverty is a main driver of disparities in healthcare in India,[20] providing palliative care free of cost along with expansion of palliative care services may not be enough to end the disparities. As has been shown above, disparities in health and healthcare are not just an issue of money. In the US, a range of solutions has been proposed to address the issue of inequality in access to healthcare. The development of cultural competence figures prominently in these solutions.

Since palliative care offers a holistic approach to pain and suffering caused by life-threatening illness, it is natural to palliative care programmes to integrate some attention to cultural issues in their services. The WHO description of palliative care integrates attention to 'psychosocial or spiritual problems'.[23] These problems have cultural components. For instance, research in India has shown that many palliative care patients in India experience spirituality through religion, which closely interacts with culture.[24] Communication patterns, too, are guided by culture and palliative care providers in India need to be mindful of these patterns and communication customs while communicating with patients.[25-27] Palliative care organisations and researchers in India have been aware of the importance of culture to care and have designed studies, training programmes and models of palliative care provision that are mindful of the local culture. A highly relevant example is IAPC's Certificate Course in Essentials of Palliative Care, which includes the development of communication skills and pays attention to issues related to spirituality.[28] As will be explained below, striving towards cultural competence represents a comprehensive approach to dealing with patients in multi-cultural contexts so that palliative care providers and organisations develop relevant knowledge, skills and attitudes. This approach could further enhance and inspire the integration of attention to culture in palliative care provision, training and research in India. Systematic reviews showing the relevance and efficacy of cultural competence outside India,[29-36] constitute a reasonable base of evidence to argue in favour of its application to palliative care in India.

A literature search completed on 27 July 2021 showed, however, that cultural competence as a distinct concept and approach has not received significant attention in the literature on palliative care in India. The search was conducted in PubMed and EMBASE. To complement the search, the following journals were searched using the search function on the journals' websites: Indian Journal of Palliative Care (https://jpalliativecare.com/), Indian Journal of Medical Ethics (https://ijme.in/) and Indian Journal of Cancer (https://www.indianjcancer.com/). Following the published systematic reviews on cultural competence, search strings including terms derived from 'cultural competence' and 'cultural competency' were used. The search strings in PubMed and EMBASE included 'India'. Table 1 gives an overview of the searched databases and journals, used search strings and results before screening.

Titles and abstracts of retrieved studies were screened to determine whether the article studied cultural competence within the context of palliative care in India. While some of the retrieved studies paid attention to cultural aspects of care in India, none of the studies provided significant analysis of cultural competence within palliative care in India. Since no studies on cultural competence within palliative care in India were found, this article intends to explore the potential significance of cultural competence to palliative care in India. From an Indian palliative care perspective, it is important to consider how cultural competence may be applied to palliative care, because it could help to improve satisfaction with care and even enhance access and health outcomes.

CULTURAL COMPETENCE

The available literature clearly indicates that solutions to problems of healthcare disparities must go beyond an increase in financial resources. An increase in financial resources will not necessarily make the healthcare system more equitable. The US is a relevant example. The US has the most expensive healthcare system in the world. Yet, the system is rife with inequality.[2] Healthcare systems become more equitable when they strive towards equal healthcare access and health outcomes across populations served by that system. In the literature, it is argued that, in ethnically, racially and culturally diverse societies, cultural competence is an essential part of the solution towards equitable healthcare systems.[37]

The US is a prime example of such a diverse society. This ethnic, racial and cultural diversity has long historical roots, while, just like many other contemporary societies, the US society continuous to become more diverse. Driven by economic or educational opportunities or fleeing war or political oppression, people keep on leaving their countries of birth in search of a better life elsewhere on the planet. This has resulted in an ever larger proportion of the world's population living in cultural contexts that markedly differ from those they have been born into. The outcome of this migration is cultural diversity.[38] However, such a migration that leads to cultural diversity does not only take place across countries. It happens within countries, too. India has historically been a melting pot of cultures and religions. Driven by job opportunities people continue to migrate within India, including important migration patterns from rural to metropolitan areas.[39,40] People from rural communities who have been accustomed to more traditional forms of living are confronted with modern life in cities where Western values and lifestyles have mixed up with more traditional Indian ones. People may, also, end up in places where they do not understand the local language. This contemporary migration adds to the diversity that has characterised India for millennia. There is a tremendous religious diversity in India. Hinduism is a very diverse religion in itself in the context of which other religions, most notably Buddhism, Jainism and Sikhism have sprouted. Due to migration and conversion, there are substantial Islamic and Christian minorities too.[41]

Table 1: Literature search.

Database or journal	Search String	Number of results (before screening)
PubMed	([Cultural competence (MeSH Terms)] OR [cultural competencies (MeSH Terms)] OR [cultural competency (MeSH Terms)] or [competence, cultural (MeSH Terms)]) AND (India)	72
EMBASE	('Cultural competence' OR 'cultural competency' OR 'cultural competencies') AND India	151
Indian Journal of Palliative Care	Cultural competence	4
	Cultural competency	10
	Cultural competencies	10
Indian Journal of Medical Ethics	'Cultural competence'	4
	'Cultural competency'	0
	'Cultural competencies'	0
Indian Journal of Cancer	Cultural	122

Although all people in India share common cultural traits, cultural differences between religions and regions in India as well as between village and city may create feelings of estrangement. Such estrangement can have a profound impact when people need pain management and palliative care. There may be a disconnect between how cultural minorities experience and express their pain and how people belonging to the surrounding cultural majority do this. Pain responses vary across cultures because depending on cultural background people will attribute different meanings to pain, leading to different reactions to pain. When pain is experienced, culture will, also, inform the patient's decision whether or not to talk about pain including in a healthcare context.[42] For instance, among more traditional groups in Indian society, patriarchal dynamics that place higher value on men may make women less likely to express pain openly until it becomes intolerable. This may lead to substantial delays in care.[43] Culture may, also, determine the kind of treatment people search for pain. In India, Western-style biomedicine exists side by side with other medical systems, such as Ayurveda, Siddha, Unani (or *yūnānī*) and homeopathy. The kind of medical system patients choose will to a large extent depend on cultural preferences and identity, besides others factors, such as cost and availability.[44,45] Research has shown that there is an association between use of traditional medicine and delay in seeking care of biomedicine.[46] While culturally determined healthcare attitudes like a reluctance to discuss pain or a preference of traditional medicines can be observed across cultural groups in India, they may be more outspoken among particular groups such as the rural population, whose traditional attitudes and behaviours have been less influenced by global culture. Research indeed points towards differences in attitudes and practices regarding health and healthcare between people from rural areas and the city. For instance, a study conducted in Uttar Pradesh in 2014 showed that people from rural areas were more likely to take analgesics without prescription and expert medical advice than people living in cities.[47] Such attitudes and behaviours may persist when people from rural areas migrate to the city or even when they seek medical attention in hospitals in the city. The implementation of cultural competence at the level of individual healthcare providers as well as healthcare organisations is one factor that can support patients to gain access to the care they need in a timely manner.

To understand cultural competence, we first need to understand the word 'culture'. One influential definition of culture describes it as 'a complex whole which includes knowledge, belief, art, law, morals, custom and any other capabilities and habits acquired by man as a member of society'.[48] Consequently, people who have grown up in different societies may have different cultural beliefs, customs and assumptions, and not all people can be expected to have a spontaneous understanding of other cultures. Therefore, people, organisations and systems who interact with people from different cultures need cultural competence.

Cultural competence can be understood as the capacity of a person, organisation or system to be able to (inter)act and assess situations with knowledge and understanding of multiple cultures. Cultural competence enables healthcare providers to interact with persons from different cultural backgrounds in an effective way that integrates appropriate self-awareness, knowledge and skill.[15,49] The word 'competence' refers to 'the capacity to function effectively'.[50] A culturally competent healthcare system, therefore, recognises and integrates the significance of culture throughout the system so that it and all entities and persons working within it can function effectively when responding to the needs of patients from various cultural backgrounds.[50]

All this becomes particularly relevant at the end of life. For every living being, death is the common and consistent reality which everyone will eventually face. However, the experience and meaning of death are different for each individual and strongly determined by culture. The final stages of life are stressful. Providing culturally competent healthcare at this stage is, therefore, crucial.[51] Patients and their relatives may have culturally determined expectations about healthcare. When these expectations are not met, there is a potential for conflict, misunderstanding, poor compliance and worse health outcomes.[52] Conflict can appear in the form of disagreement between physicians and patients or can appear as decisions by patients which the physician does not understand or agree to, such as declining palliative care or not adhering to the proposed pain management therapy. Here, cultural differences are often the key source of conflict. Challenges result from cultural differences between the patient's background and medical practice. Physicians and the clinical team should explore beliefs and culturally determined values because these may often be relevant to understand preferences for care when the patient nears death. A healthcare organisation as a whole can only provide adequate palliative care if it acknowledges the patient's cultural background and integrates cultural competence.[53]

If palliative care providers know and accept the cultural background of a patient and integrate that knowledge in a patient-centred approach, care decisions will be better aligned with patient preferences and the patient and his or her near and dear ones will more often experience meaning and peace in the dying process.[54] On the other hand, care decisions that do not consider the patient's cultural values, which may include religious and spiritual values, may lead to care that is misaligned with the patient's goals. A study showed, for instance, that patients whose spiritual needs were supported by the medical team experienced better quality of life at the end of life and utilised hospice more often than patients who had not.[55]

In the literature, there is general agreement on the potential of cultural competence to improve access and outcomes in end-of-life care. As per the theoretical model, integration of cultural competence will lead to improved communication and patient satisfaction among cultural minorities. This, in turn, will make it more likely that the patient will start and/or continue palliative care, adhere to the proposed treatment and, thus, experience improved health outcomes.[37,56] In palliative care, these health outcomes would be improved pain and symptom management. Moreover, if patients and their relatives are satisfied with the services they have received, they are, also, more likely to recommend the service to other people within their cultural group. Nevertheless, although cultural competence has a strong theoretical foundation, more research is still needed in this area. For instance, the Oncology Nursing Society noted a 'significant gap in knowledge […] with respect to the provision of culturally sensitive palliative care' in its 2019–2022 research agenda and concluded that '[g]iven the importance of acknowledging and incorporating sociocultural norms into care, additional research in this area is needed'.[57] One area in particular where more research is warranted is the evidence base of cultural competence. While there is significant evidence that cultural competence improves patient satisfaction,[29,31] there are not a lot of data as to whether cultural competence effectively reduces inequality in health and healthcare.[34,58] Much is not known either about the applicability of cultural competence to healthcare in the developing countries such as India.[59] It is not that there are many negative findings. The issue has not been studied elaborately.[60,61] Trials in the area of cultural competence are hard to set up and blinding is in fact impossible. The few available studies, however, show encouraging results.[33]

DEVELOPING CULTURAL COMPETENCE IN PALLIATIVE CARE IN INDIA

Since cultural competence has been shown to improve patient satisfaction and there are good reasons to assume that it will improve access to palliative care as well as palliative care outcomes, it is important that palliative care programmes in India consider incorporating cultural competence in their services, training and research initiatives. Research is important because it will increase the evidence base of cultural competence and show the efficacy of approaches to cultural competence that has been specifically designed for palliative care in India. It is indeed important to realise that the idea of cultural competence has been developed in the US and not all aspects of the ways in which it has been implemented in the US may be applicable or realistic in developing countries such as India. For instance, to improve communication with patients whose mother tongue is not English, cultural competency literature from the US suggests not only the use of multilingual staff but also of 'foreign language interpretation services including distance technologies'.[62] Professional translators may not be available or affordable for palliative care programmes in India. This concretely means that, while the overall concept of cultural competence may be useful to palliative care in India, palliative care programmes need to be aware that models and approaches to cultural competence developed in countries such as the US may not be directly transferable to India. The programmes will need to research and evaluate to what extent these models and approaches can be integrated within their palliative care initiatives.

Palliative care programmes will need to implement cultural competence by focusing on three essential areas – knowledge, attitudes and skills[7,63] – and apply these to their own context while considering the cultural backgrounds of the patient population they are targeting. Knowledge refers to the socioeconomic and cultural characteristics of the groups that the palliative care programme treats. Palliative care programmes and their clinicians, counsellors and volunteers need to know and understand these. For instance, people working in programmes that treat patients in tribal areas need to know about how these people communicate about diagnosis. Clinicians who treat Muslim patients need knowledge about Islamic end-of-life beliefs and practices. They, also, need to be aware of specific socioeconomic factors that may make it harder for Muslim patients to access palliative care services. Muslims in India are proportionally more likely to be less educated and less likely to have a job than people belonging to the Hindu majority.[64] This impedes healthcare access.

Attitude implies the need to be sensitive to the cultural needs of patients and awareness of the own cultural limitations. People working in palliative care need cultural humility.[65] They need to be aware that their knowledge about the cultures of the patients they are treating may have important gaps. Such gaps are not a major problem on their own if the palliative care providers are willing to listen to and learn from their patients. What is needed is an attitude of humility, empathy, curiosity and respect. These attitudes need to be made operational in patient care, which requires skill. Without cultural skill, palliative care providers cannot learn from patients. Palliative care providers need skill to uncover what illness and disease mean to patients, how patients relate to the world and how they want to be treated. Through the application of cultural humility and skill, patients will be empowered to engage more fully in the decision-making process regarding their treatment. In India, patients are often left out of the decision-making process due to the generally accepted cultural assumption that they need to be protected from harm caused by bad news. Healthcare providers in India often acquiesce to requests from the family not to share diagnosis and prognosis with the patient.[25,66,67] The attitude of cultural humility will make palliative care providers aware of the limitations of such cultural practices and notions and may make them realise that they may not apply to all patients. Research among cancer patients in India has repeatedly shown that many of them want to receive more information regarding their illness and be involved in the decision-making regarding their treatment but do not get the opportunity.[67-69] Through cultural competence, healthcare providers learn to deal in an ethical manner with situations in which the information needs of the patient may not align with the family's wish to protect the patient from harm that, in their assumption, will be caused by that very same information.

When palliative care programmes integrate cultural competence through cultural knowledge, attitudes and skills, patients from different cultural backgrounds will more easily find their way to the palliative care service. The patients, as well as their relatives, will, also, be more satisfied and return for treatment and adhere to treatment recommendations, thus increasing patient compliance. In this way, cultural competence will contribute to improving access and health outcomes in palliative care in India.

CONCLUSION

Cultural competence is a very important tool in the development of palliative care, particularly when palliative care services are operating in a multi-cultural context, such as India. If efficiently implemented and adjusted to the Indian palliative care context, cultural competence will lead to higher patient satisfaction and likely and more importantly to reduce inequality in access and health outcomes in palliative care. The most significant advantage of cultural competence is that it has the potential of considerable benefit to patients without necessarily substantially adding to the operational costs of palliative care programmes. Cultural competence needs to be integrated in education and day-to-day operations but doing so does not require a substantial investment. Palliative care programmes need to start reflecting about how they can creatively incorporate cultural competence in their operations.

Declaration of patient consent

Patients' consent not required as there are no patients in this study.

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Conflicts of interest

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