

Culturally competent care at the end of life: a Hindu perspective

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The word 'culture' is used in many different contexts. Culture generally refers to characteristics such as non-physical traits, e.g. values, beliefs, attitudes and customs, that are shared by a group of people and passed from one generation to the next (Spector, 2000). Culture is shared by members of the same cultural group. It is learned from birth through the processes of language acquisition and socialization. It is dynamic and keeps changing throughout a person's life and is adapted to specific conditions relating to the environment. With these characteristics, culture also influences an individual's health and illness experiences (Webb and Sergison, 2003).

As a result of the centrality of rituals surrounding the end of life in most cultures, palliative care is one area in which healthcare professionals need to practice culturally competent care (Webb and Sergison, 2003). Many of those who receive palliative care express concern that the service is not culturally appropriate for them and their family (Field et al, 2002). Little research has been undertaken in palliative care regarding the cultural issues associated with caregiving (Pasacreta and McCorkle, 2000). However, evidence from caregivers of other patient populations suggests that cultural background may play an important role in family stress and coping processes (Kinsella et al, 2000).

'Cultural competence' is the phrase used to describe the knowledge and interpersonal skills that allow others to understand, appreciate and work with individuals from cultures other than their own (Bouton, 2004). It involves an awareness and acceptance of cultural differences, self-awareness, and knowledge of the other person's culture and adaptation skills (McLaurin, 2002). Nurses are required to become sensitive to, and knowledgeable about, cultural differences and similarities in people's care requirements (Leininger, 2002). They must recognise the values of all cultures, races and ethnic groups and respond to these differences (Galanti, 2000). Increasing diversity and mobility of world populations accentuates the need for health professionals to render culturally competent nursing care (Ryan et al, 2000). To be culturally competent, nurses must first be culturally aware and sensitive and utilize knowledge gained from theoretical and conceptual learning (Tortumluoglu, 2006). Providing culturally competent care is a continuous and changing process whereby an individual system or healthcare agency develops meaningful and useful strategies based on knowledge of the cultural heritage, beliefs, attitudes and behaviours of those for whom care is provided (Bouton, 2004). This cultural awareness allows staff to see the entire picture and leads to improvements in quality of care and health outcomes. Developing culturally competent staff is an ongoing process.

This article addresses specific issues that healthcare professionals might encounter when looking after Indian patients receiving palliative and end-of-life care. It will first describe basic philosophies of Hinduism so that nurses can better understand the views associated with death and dying in Hindu culture. Practical aspects relating to death will also be discussed. Death and dying issues of diverse cultural groups in Western countries continue to be a major factor in end-

of-life care settings. This article is drawn from a study carried out with Indian migrants to Australia, exploring the experiences of family members of terminally ill Indian patients (Shanmugasundaram and O'Connor, 2009). Particular emphasis is given to end-of-life care issues for Hindus, as Hinduism is the predominant religion in India and the religion of most of the study's participants.

Hinduism and implications for practice

Hinduism is a strictly personal religion and, unlike other religious traditions, has no standard form of worship (Johnsen, 2009). For example, some Hindus meditate, others pray and some combine meditation and prayer with physical exercises as in some forms of yoga. Most Hindus have a small wooden shrine or an alcove in their homes set aside for offering devotional worship (Bhaskarananda, 2002). Daily worship, to receive blessings from specific gods, is performed by the woman of the house. The Hindu religious year abounds with festivals and these are frequently linked to a calendar based on the lunar cycle (Spector, 2000). Hindus have many holy places such as Badrinath, Puri, Dwarka and Rameswaram. Some rivers are also holy to them. Among these are the Godavari, Yamuna and Ganges (Sheikh and Gatrad, 2000).

There are various gods and goddesses in the Hindu religion (Johnsen, 2009). According to Hinduism, three lords rule the world: Brahma: the creator; Vishnu: the preserver; and Shiva: the destroyer (Gatrad et al, 2003). Lord Vishnu helped preserve the world by incarnating himself in different forms at times of crisis (Brodbeck, 2003). Hinduism's theological rationale is based on a body of sacred literature known as the *Vedas* (meaning knowledge), which was composed between 1200 and 600 BC (Johnsen, 2009). Besides the *Vedas*, other texts are recognized as having great authority: the Upanishads, Puranas, Ramayana and Mahabharata (Wright et al, 2004). The holiest book of Hindus is the Bhagavad-Gita (Radhakrishnan, 2001). It comprises three parts: karma-kanda, upasana-kanda and gnana-kanda (Walters and Portmess, 2001). The Bhagavad-Gita teaches various spiritual practices, such as bhakti (devotion), gnana (knowledge) and yoga (meditation). However, the key essence of the Bhagavad-Gita is the great saying: 'Tat-Tvam-Asi' (That Thou Art') which means that God is in every person (Brodbeck, 2003). The Bhagavad-Gita teaches that, 'for the soul there is never birth or death' and 'as the embodied soul continuously passes in the body, from boyhood to youth to old age, the soul similarly passes into another body at death. A sober person is not bewildered by such a change' (Radhakrishnan, 2001).

Karma

The law of karma (the moral law of cause and effect) determines life cycles through birth and rebirth (Firth, 2005). Karma is the spiritual merit or demerit that individuals acquire during their lives. Life forms pass through a chain of incarnations, thus assuming various positions in a hierarchy during their different lives (Radhakrishnan, 2001). The order of the lives in the hierarchy depends on that life form's moral behaviour in a previous life, spiritual advancement or purity (Bhungaliala and Kemp, 2002). It is believed that the divine spirit permeates the universe and people perceive the divine in accordance with their spiritual level. Perfection of karma leads to emancipation from the burdens of birth and rebirth (Thomas, 2001). This doctrine of karma strongly influences a Hindu's attitude to life, because they see life events as being the result of

one's karma (Warrier and Walshe, 2001). The idea that suffering is inevitable and the result of karma may cause people of Indian origins to refuse symptom control and offers of comfort.

If this situation occurs, nurses need to consult with the family members to arrange a Hindu priest to visit the patient. The priest will perform rituals or prayers and offer the patient 'prashad' (a sacred pudding). After this action, some patients may accept treatment. People with a strong belief in karma should be provided with the Bhagavad-Gita and religious music. Ultimately, nurses need to respect the act of karma and leave decisions to the patient and the family.

Diet

According to Hindu philosophy, all souls, including humans and animals, are respected. Arising out of this philosophy is the principle of ahimsa, which means to do no harm or to avoid violence to animals and humans (Walters and Portmess, 2001). It is this principle that underpins the practice of vegetarianism (Walsh et al, 2002). Hindus worship and respect some birds and animals such as the cobra, ape, peacock and cow. That is why most Hindus are vegetarian and will not eat beef, white meats, eggs and indeed anything that is produced from animals (Walters and Portmess, 2001). The cow is considered sacred and it is forbidden to eat anything derived from it (Gatrad et al, 2003). The further south in India the family's origin, the more likely it is that they will be vegetarian and be strict about the consumption of food that has touched beef. Some people, however, may eat cottage cheese, yoghurt, eggs and milk (Firth, 2001).

Beliefs about diet are not universal for all Hindus and depend on family beliefs or the individual. Therefore, nurses need to be sensitive to dietary needs and discuss with family members their beliefs. If hospital policies permit, the family members should be allowed to bring in foods such as idli (steamed rice cake) with dhal, rice or sooji congee (semi-solid porridge), which are common foods for sick people. Otherwise, health organizations need to ensure that vegetarian foods and vegetables are available. If the patients are terminally ill and unable to swallow normal foods, liquid diets such as rice porridge, thick soup and fruit puree can be given. The practice of fasting, particularly amongst elderly and widowed women, may impact on palliative and end-of-life care. (Elderly women will have practiced traditional rituals for a long time. Widowed women may be spiritual by nature because they are isolated from social functions and tend to follow rituals in their daily life.) Generally, it is believed that fasting cleanses the physiological system of the human body. This can lead to unwillingness, at the end of life, to take drugs of any kind on a fasting day, or for longer periods. This is relatively common amongst some Hindu groups and can have a considerable effect on hydration, nutrition and drug administration (Bigby, 2003). In this situation, nurses can administer morphine via injection, intravenous infusion or patches. These may be acceptable to the fasting person. Again, it depends on the family beliefs and practices and so nurses need to discuss these issues with the patient and family.

Decision making in palliative and end-of-life care

For Hindus, care of the dying and related decisions are the family member's responsibility (Worth et al, 2009). Truth-telling and informed consent are key components in palliative and end-of-life care, especially in decisions relating to cardiopulmonary resuscitation, artificial hydration and nutrition, intravenous infusion and oxygen administration (Doorenbos, 2003). In Western

cultures and religions, when mentally capable, it is the individual who gives their informed consent and makes decisions on their own behalf. In Hinduism, however, family members make the decisions, particularly the elder members of the family. In addition, the husband will make decisions for his wife (Thomas, 2001). In an Indian context, elders are greatly respected and given much importance in society. Most Hindus live within an extended family with as many as three generations in the same house. In the family, whatever the elders say, the younger ones listen and obey. Likewise, the son (preferably the elder son) in the family is highly recognized and valued, because he is responsible for taking care of his parents when they become old and sick. This son has all the rights for decision making (Doorenbos, 2003).

In some families, when elders are diagnosed with any life-threatening illness, they talk to the son in advance about their wishes and the formalities that need to be followed during the dying phase and after death. This may have legal implications in relation to informed consent. At times there may be a fine balancing line between local legislation and family culture. Every effort should be made to lessen the chance for conflict among families, between the families and clinicians and between the patients and clinicians. Many families trust doctors and believe they are god-like and so let the doctors make decisions for them (Bhungalia and Kemp, 2002). When decisions need to be made in palliative and end-of-life care settings, healthcare professionals need to solicit which person represents the family. Family meetings may be the appropriate decision-making forum for many families (Kinsella et al, 2000). Such meetings should include significant others in the family, e.g. son, daughter, husband, son-in-law, daughter-in-law and grandchildren above 18 years. These significant others will better understand the best time to disclose information to the patient, if indeed the patient actually wants any information. The patient will trust these people to make the most appropriate decisions. However, ultimately, the older son is the decision maker. Many elderly Hindu people have language difficulties and thus problems understanding medical terms. Ready access to interpreters may be problematic. This is another reason for family members to be consulted on all aspects of care.

Modesty and hygiene

People in the terminal stages of their conditions inevitably become more dependent on nurses and other members of the healthcare team for all their care needs. Nurses must be aware that, in Hinduism, as with other religions of the Indian subcontinent, there are particular requirements relating to modesty. Hindus need total privacy when it comes to bed baths, physical examinations and almost any other procedure. In addition to standard privacy norms practiced by nurses, privacy aspects relating to culture include limiting the number of nurses in the room, only exposing the body part which needs to be washed instead of exposing the whole body, and not allowing males in the room of a female until the person is dressed completely (Galanti, 2008). If patients are unable to wash themselves, nurses can organize the washing utensils and then go back once the person has finished. For Indian women, the person providing health care needs to be female. If a female nurse is not available, the care can be given by a female member of the family. Gender restrictions do not apply if the patient is male (Galanti, 2008).

Physical cleansing is associated with spiritual cleansing; hence, it is important to the Hindu to wash before they pray. As with most people of Asian origins, there will be the need for comprehensive washing after their use of the toilet, so a container of water should be made

available (Worth et al, 2009). Physical purity is valued. Therefore, Hindus try to shower daily in running water (as opposed to taking a bath) and require help to do this when they are ill. They prefer to bathe before saying their prayers and prayers are traditionally offered at sunrise. Hindus believe that bathing renders one both physically and spiritually clean, so the desire to bathe can be very strong amongst the terminally ill and they must be assured that help is available when required (Firth, 2005). Hindus have a strict ritual of defecation, bathing, the wearing of clean clothes and fasting, before they pray. This enables them to communicate with god in a purer form and the dying person may require assistance with these rituals (Gatrad et al, 2003).

A further problem relating to modesty is an unwillingness to discuss any problem relating to the genitourinary area. Therefore, constipation can be a major, undeclared problem. This can present considerable difficulty, particularly at the end of life. Many patients with advanced disease experience pain and are often on opioids, which can exacerbate constipation problems in terminally ill patients (Sykes, 1998; Lawrie, 2007). Therefore, nurses should be aware of the importance of assessing a patient's constipation status, observe for signs of abdominal discomfort and, where possible, enquire about the person's bowel movements, in a sensitive fashion (Lawrie, 2007; Payne, 2009).

Spiritual care

As is the case with other religions, Hindus have sacraments (samskara) that play a large part in their spiritual care and give expression to their aspirations and ideals (Wright et al, 2004). The sacraments aim to secure the welfare of the person performing the sacrament and advance his/her spirituality. These customs, rituals, rites and ceremonies give a deeper meaning and purpose to living and dying. The sacraments have a practical utility and form an integral part of the care associated with dying people and the bereaved. The samskara relating to the time after death is very important because, for a Hindu, the value of the next world is higher than that of the present (Haridharma dasa and Henry, 2004). The pandit (the Brahmin priest) can be very helpful in terms of carrying out spiritual care. For example, he may talk with the dying person about the philosophical attitudes to death in Hinduism and read from Hindu texts. He may also be able to help with the puja, the act of worship. He can also bring water from the Ganges as a comfort for the dying person.

Rituals and ceremonies during the dying phase and at the time of death

The dying person may wish to have a small statue or picture of the family god brought in and placed at the bedside. Older people are usually religious and they start the day with prayer; this practice will increase when they are sick and as they near death. Thus, nurses need to facilitate this task as much as possible and allow the family to use religious videos or music. Nursing homes in Australia are already doing this by providing melodious music for the dying (Taylor and Box, 1999). As noted above, Hindus consider the Ganges a holy river and its water sacred. The family may place a few drops of this water and a tulsi (basil leaf) into the mouth of the person who is dying. This action will purify the person. Their soul will rest in peace and they will attain the 'moksha'. This means 'release'. It is the liberation from samsara (the cycle of birth, death and rebirth), the final stage of life and the suffering and limitation of worldly existence (Ayer, 2008).

Families may wish to light small oil lamps and burn incense in the person's room. The basic principle of this ritual is aromatherapy. Such practice is carried out in many nursing homes in Australia (Taylor and Box, 1999). If oil lamps and incense sticks cannot be used, electric aromatherapy burners or a small, scented candle may be placed in the corner of the room. The light symbolizes bringing god closer and incense sticks are used for the purpose of aroma. This will enhance the ability of the dying person's soul to rest in peace. If relatives are prevented from performing these sacred rights it is believed that the dying person's soul will be impeded on its next journey. Some patients require prayer beads, which may be placed in their hands to provide comfort (Thomas, 2003). Many Hindus prefer to die at home (Warrier and Walshe, 2001). However, this is not always possible. Therefore, nurses must be aware of the rituals and ceremonies associated with Hinduism during the dying phase and at the time of death. They must aim, as much as possible, to ensure that the family is able to carry out their rituals and ceremonies with as much privacy as possible. If the patient has died in hospital and there is no privacy these rituals may need to be performed at home, i.e. the deceased person should be released to the family as soon as possible.

If health organizations are truly to provide culturally competent care these issues should be taken seriously. If a separate room or side-room is not available, measures need to be taken to release the deceased from the hospital as quickly as possible. Families can then perform all the required ceremonies and the body can be handed over to the funeral directors.

As death nears, family members and friends are likely to be present in large numbers. Chanting and various rituals are part of the process. As a person approaches death, the family will chant 'ram ram' or 'om' and recite from the Bhagavad-Gita (Radhakrishnan, 2001). Religious words or a mantra are whispered into the ears of the dying person. A thread with religious significance may be tied around the wrist or neck by a priest. The person may choose to lie on the floor in order to be close to Mother Earth when they die (Walton, 2009). Usually, family members like to stay with the patient when they are dying. Nurses need to be sensitive to their needs and feelings and allow at least one female relative to stay with them. Family members will not be happy if the patient dies without them. As discussed above, they need to do the last rites when the person is dying.

After death

If relatives are not present at the time of death they should be notified immediately in order to make necessary arrangements for death rituals and ceremonies, which are performed by the Hindu Brahmin priest. An ordinary Hindu man cannot perform them. Once the patient has died, if a large number of family members arrive to view the body, if possible they and the deceased person should be moved to a private area of the ward. This will require forward planning before the death occurs. After death, health professionals should touch the body as little as possible. Ideally, the family should be the only ones to touch the deceased. It is good practice for nurses to check with the family what they can or cannot do before the person has died. For example, if a person dies when no family member is present the nurses need to find out if they can touch the body before a member of the family arrives.

Soon after death, the deceased needs to be placed on the floor, preferably with the head facing the north (Gatrad et al, 2003). This may not be possible in the hospital setting but is practiced if the person dies at home. Only people of the same gender should handle the body after death, particularly for cleaning and dressing purposes, as it is culturally inappropriate to touch the opposite sex whether they are alive or dead. Non-faith members are permitted to handle the body as long as they are of the same sex. A family member of the same sex as the deceased should clean the body. Initial cleaning can be carried out by a nurse of the same sex in the hospital or nursing home. However, the final cleaning and washing are undertaken by family members, as requested by the patient before death. Once the body has been cleaned, family members apply sandal paste, turmeric and decorate it with jewels. Some families cover the body in a red cloth, although others prefer the body to be dressed with new clothes. Some patients wish to wear their wedding saris or wedding dhotis (Searight and Gafford, 2005).

If possible, a health professional skilled in bereavement work, who can communicate in the appropriate language, should be available (Gatrad et al, 2003; Firth, 2005; Galanti, 2008). The death certificate should be issued on the same day, together with appropriate paperwork, to ensure cremation can occur within 24–48 hours of death. There are no religious objections to autopsy; however, Hindus are happier if this can be avoided. Some Hindus object strongly to a postmortem and organ donation, desiring the body to remain intact (Firth, 2005). This area will need careful and sensitive handling because some jurisdictions require the involvement of the coroner.

Hindus are always cremated and where possible the ashes should be scattered on the River Ganges at Varanasi in India. Even in faraway places, water from the Ganges is usually used in death ceremonies, conducted by the pandit. This is often at the express wish of the deceased, who may have made stringent requirements about the kind of funeral they wanted (Sheikh and Gatrad, 2000). The collection of the ashes, which occurs the day after cremation of the body, is a ceremony known as Asthi-Sanchayana. The ashes are either dispersed in waters of sacred rivers or buried in the ground (Ayer, 2008).

Bereavement and its effect on the family

The quality of the dying process and the death has an impact on the bereavement and mourning of those who witness it (Koffman, 2001). Hindus who have witnessed what they perceive as a bad experience may be very anxious about the ghost of the deceased (Firth, 2001). Attention to spiritual beliefs in palliative care may therefore provide an existential framework in which grief is resolved more readily (Walsh et al, 2002). After death, family members follow a formal mourning period of between 10 and 16 days. Bereaved families are traditionally regarded as tainted after death and are avoided by others. Therefore, friends and relatives will not eat or drink at their house (Taschen, 2008). During the mourning period relatives eat simple food and dress without adornment. In some Hindu homes the head is shaved of the male whose near relation has died. The mourning family wear all white (Firth, 2005). During the mourning period there is a ceremony known as Sreda. This is when food is brought for the Brahmins and rites are performed for the dead. The chief mourners often go into retirement, but grief is expressed openly and warmly (Gatrad et al, 2003).

The period of impurity or pollution or defilement is generally for 10 days (from the day of last rites or cremation) for near relations. The rules to be observed during the period of impurity are of two kinds: negative (passive) and positive. The negative rules require the mourners to forego many pleasures and comforts and even the routine business of daily life, thus exhibiting grief and sorrow. These rules forbid activities such as cutting the hair and beard, the study of the Vedas (sacred texts of Hinduism) and the making of offerings. Positive rules that have their origin in the aggrieved feelings of the survivors include no sexual relations, sleeping on the ground, living on begged or purchased food and eating only in the day time. The days will be spent reading the Bhagavad-Gita and other religious books. On the 12th day the soul of the deceased is said to be recreated. On the same day nails and hair may be cut and the men can shave their beards and heads (Radhakrishnan, 2001; Brodbeck, 2003; Johnsen, 2009).

Hindu family members' lack of uptake of bereavement services, offered by specialist palliative care services, may suggest lack of suitability for their needs (Sheikh and Gatrad, 2000). Hindus tend to seek informal bereavement support from relatives and friends. Extended family members are often able to provide support if they themselves have experienced bereavement and understand what the bereaved are going through (Sheikh and Gatrad, 2000).

Conclusion

Culture and religion have a significant impact on people's perception of health and illness, especially towards the end of life (Corless et al, 2006). Times of distress such as serious illness and bereavement cause a community to lean towards their own culture (Kissane, 2004). Within a dominant culture, alleviating all distress resulting from cultural difference may not always be possible. Nurses need to be sensitive to particularities that will improve culturally competent end-of-life care. Cultural competence is an evolving process that depends on self-reflection, self-awareness and acceptance of differences. It is based on improving understanding of each individual situation, as opposed to just increasing theoretical, cultural knowledge (Webb and Sergison, 2003). Understanding different cultures and religious traditions will assist in the provision of culturally appropriate care in palliative care settings.

Recommendations for practice

Health organizations, particularly hospices, hospitals and nursing homes, need to provide education and training for nurses in multicultural issues in order for them to deliver care that is culturally congruent. Knowledge of family beliefs and practices, particularly about death and dying, will improve quality of life in end-of-life care.

Nurses need to identify language problems and, if possible, an interpreter should be arranged. Good communication skills and establishing interpersonal relationships will help to bridge the cultural gap between the patients, families and health professionals.

Healthcare organizations should have a separate prayer room or chapel where end-of-life rites and rituals can be performed. This will support family members and relatives to carry out their traditional practices and will avoid unnecessary tension when the patient is at the last stage of their life.

Multicultural guidelines should be provided to assist nurses and other members of the health team to gain knowledge, and thus provide culturally appropriate care.

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