

End-of-Life Care for Ethnic Minority Groups

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Death and dying are profound events that bring into focus important ethical and medical questions for all patients, whatever their cultural background. For ethnic minority groups and their families, specific issues or barriers may arise related to culturally appropriate health care practices, cultural or religious differences, diverse health beliefs, and access to services for care and support during end-of-life conditions. National policy and local initiatives in both the United States and the United Kingdom support the development of services that address the care of ethnic minorities. This article examines end-of-life care for ethnic minority groups. (*Clinical Cornerstone*[®]. 2004;6[1]:43–49) Copyright © 2004 Excerpta Medica, Inc.

BARRIERS TO PALLIATIVE CARE IN ETHNIC MINORITY GROUPS

Inequalities in access to health care are well documented for ethnic minority patients.¹ A number of studies have shown that ethnic minority patients have reduced access to palliative care, appropriate pain and symptom relief, or the opportunity to die at home or in a hospice,^{2–6} which has led to poorer symptom control⁷ and lower satisfaction among caring relatives of dying patients in these groups.⁸ The reasons for these inequalities are complex and partly the result of a preference for more aggressive care; low interest in hospice care; and cultural differences among minority patients, eg, a family-oriented style of decision making, mistrust of the medical profession, language and communication barriers, financial constraints, transportation difficulties, and perception of racial bias.⁹ Language difficulties may not be overcome

and even worsened by selective translation when using relatives as interpreters.¹⁰ In the United States, African Americans are less likely to appoint a durable power of attorney for health care, write an advance directive, or discuss treatment preferences,¹¹ and they are more likely to opt for lifesaving and life-prolonging treatments compared with palliative care.

KEY POINT

Ethnic minority patients have reduced access to palliative care, appropriate pain and symptom relief, or the opportunity to die at home or in a hospice compared with nonethnic patients.

National policy and local initiatives in both the United States and the United Kingdom support the development of services that will address the care of ethnic minorities,¹²⁻¹⁴ which also lies within the context of European law.

IMPROVING END-OF-LIFE CARE FOR ETHNIC MINORITY GROUPS

Barriers to end-of-life care can be overcome using various means, including the recruitment of health care personnel from ethnic minority groups and the greater involvement of individuals from such groups in planning and delivering care, eg, interpreters, bilingual health care assistants, and liaison workers^{15,16}; encouraging freedom to celebrate religious ceremonies; improving access to health information in different languages¹⁷; and developing what may be termed a “culturally sensitive” approach to health care through training and medical education.^{18,19} A consistent finding in many studies is the significance of poor communication as a barrier to health care. Access may be improved by good information communicated in a culturally sensitive manner, underpinned by an appropriate health strategy and good system of community palliative care.^{20,21}

Many hospitals in the United Kingdom now employ chaplains representing the major faiths, so that, for example, Hindu, Muslim, and Sikh patients may have appropriate spiritual support as well as a sympathetic ear when due respect is not given to religious customs. Faith-specific prayer rooms are also available in areas with high concentrations of religious minorities.

KEY POINT

A consistent finding in many studies is that poor communication is a barrier to health care access.

CULTURAL DIFFERENCES IN DEATH AND DYING

Important differences exist in the needs of various cultural groups for palliative care, terminal care, han-

dling of the body immediately after death, funeral arrangements, and other religious or spiritual needs. The following brief descriptions are intended to enhance awareness of cultural and religious diversity, but should not prevent physicians and health care workers from engaging in a sensitive discussion of individual needs.

Palliative Care

A number of possible barriers exist to the provision of palliative care for ethnic minorities, including institutional discrimination, a lack of education and training in transcultural issues relating to health care, and a failure to appreciate the complexity of beliefs and needs in a protocol-driven health care system.^{22,23} The risk of communication failure grows as communities become increasingly multicultural.²⁴ Recommendations made by researchers to improve the care of ethnic minority patients at the end of life include providing information through appropriate literature, interpretation, and liaison services; equal opportunity strategies; staff training; systematic referral arrangements with general practitioners; improved ethnic monitoring; and cultural sensitivity in service provision in palliative care.^{25,26}

The Last Hours or Days of Life

It is essential that spiritual aspects of end-of-life care be considered and that health care is sensitive to the cultural and religious beliefs of patients and their relatives.²⁷ Although many dying patients and their families believe that spiritual issues are as important as physical symptoms in the process of care,²⁸ consensus varies as to how this is discussed with the physician or clergy. Physicians also have attributed less importance to these spiritual issues,²⁹ highlighting the necessity of greater awareness among health care professionals. Several studies show that when such spiritual needs are addressed, the morale and confidence of patients are markedly improved.³⁰ Addressing these needs may require considerable preparation to gain a greater understanding of beliefs and potential issues and becomes even more relevant as a patient nears death.³¹ Despite cogent arguments, death is inextricably medicalized within Western society.^{32,33} Medical teams have an important but not exclusive role in caring for the dying.³⁴ Poor outcomes, such as inadequate symptom control and com-

plicated grief, may arise when dying patients or their relatives are not allowed to follow their religious customs or rituals.³⁵ Whatever an individual's religious background, each has his or her unique spirituality.³⁶ As death nears, spiritual issues become even more prominent, which may make it easier for sensitive issues to be broached.³⁷ It is important to recognize that the great world faiths have been mentally and spiritually preparing people for death—much longer than the modern scientific establishment.

Christians believe in life after death but not as reincarnation. Christian patients or their relatives may request a chaplain or priest attend them prior to death to say prayers. It may be important to Roman Catholic or Anglican (Episcopalian) patients or their families that they be anointed by a priest prior to death. The wishes of the patient and family should be ascertained in time to allow a priest, either from the chaplaincy or the patient's own priest, to be called. This practice is sometimes referred to as last rites or extreme unction but is usually called the sacrament of the sick and does not presuppose imminent death. It symbolizes forgiveness, healing, and reconciliation. If an infant is in danger of death, many Christian parents may wish for the baby to be baptized. This option should be offered sensitively. Some Christians (eg, Baptists) may prefer a prayer of blessing instead. In an emergency any Christian may perform the baptism if a chaplain or priest is not available simply by sprinkling water on the baby's forehead, and saying "NAME (can be omitted), I baptize you in the name of the Father, the Son, and the Holy Spirit. Amen."

Although Judaism emphasizes this life, an afterlife where the soul lives on is professed. A Jewish patient's own rabbi should be contacted if the patient or family makes such a request. At the point of death, those present may make a small tear in their clothing as a mark of grief. According to Jewish law, a dying person should not be left alone; families may wish to stay with the dying for their last days or hours. It is traditional for Jews to have the chance to say a special prayer or confession.

Hindus consider death a part of the ongoing process of reincarnation and they believe their past actions will influence their next life. Hindus prefer to die at home, and every effort should be made to accommodate this. Some believe that there is a right and auspicious time for death.³⁸ Hindus who are

dying may request a priest or family member to pray, read chapters from holy books, or sing hymns by their bedside. Before a death, Hindus may offer food and other articles to the needy, to religious persons, or to the temple. In India, water from the Ganges is given to the patient just before death, usually by the eldest son. This water is believed to be holy, providing salvation for the departing soul.

Muslims regard death as inevitable and as a door to the afterlife of eternity and death is considered a gift that enables them to be with God. Muslims believe that the process of dying can sometimes be very painful and hence always ask God to make their death pain free.

In Buddhism, dying is considered a part of life. Full and frank discussion of death with the patient and relatives is usually appreciated. Buddhists believe in reincarnation, and a fundamental element of Buddhism is the knowledge that this life is one of an endless succession of lives. Because their actions in this life will affect the quality of the next, Buddhists therefore accept all responsibility for their actions. Many Buddhists wish to remain alert in preparation for death and thus may refuse drug therapy. The family may seek to notify other Buddhist relatives or friends to meditate with and for the dying person.

If a Christian Scientist patient has not been admitted voluntarily, eg, after an accident, it is likely that the patient might prefer to be transferred to a Christian Scientist nursing home to be treated in accordance with Christian Science belief.

Rastafarian families will usually want to be involved at all stages of care. The family and friends of Rastafarian patients may pray at the bedside, but no particular rituals are involved.

For pagans, it is important to have information that will enable them to prepare for death. Pagans may wish to have a religious rite, conducted by a pagan priest/priestess, following their death. Unless asked for, a visit from the hospital chaplain would not be appropriate.

Owing to their belief in reincarnation, Sikhs see death as another step in life and not necessarily a sad occasion. The family generally stays with the dying person and recites from the Sikh holy book, the *Guru Granth Sahib*, particularly if the patient is near death and cannot recite from the book himself or herself.

KEY POINT

Death is inextricably medicalized within Western society; however, medical teams do have an important but not exclusive role in caring for the dying.

Immediately After Death

All faiths and cultures afford respect to the dead and to the body after death. Different faiths have different ways of dealing with the dead that have religious and cultural significance to followers. Some faiths have simple processes, whereas others have more complex rituals.

In Judaism, a family member in attendance may wish to carry out the last offices or rites. Traditionally a son or the closest relative present will close the eyes. If no relative is present, a non-Jewish person cannot touch the body; therefore, gloves must be worn, the patient straightened, and the eyes closed. Clothing should be left on and the body wrapped in a clean sheet. Some Orthodox Jews may wish the body to remain where it is until the funeral directors can collect it. Whenever possible the hospital mortuary should be avoided; however, if the death occurs on the Sabbath, the mortuary will have to be used. If the body must remain in the hospital, the relatives may wish to stay with it. After death, the family or rabbi may say a prayer.

The body of a dead Muslim remains as sacred as the body of a living Muslim. Referral should be made if possible to the Muslim burial council to ensure that arrangements accord with belief and custom. After death it is crucial that unless absolutely necessary for medical reasons a non-Muslim does not touch the body. If it is necessary, gloves should always be worn, and the attendant should be a person of the same sex. Whenever possible, it is preferable for close family members to be present to close the eyes and position the hands. Although it has left the body, the soul is believed to be watching over and will be hurt if the body is not treated properly. Any tubes, false teeth, contact lenses, jewelry, or artificial limbs should be removed. The jaw should be bound to hold

the mouth closed. The ankles must be fastened together with a bandage to avoid opening of the legs. The arms must be placed straight down the side of the body with straightened fingers. The body must not be washed or the nails or hair cut and the clothed body should be wrapped in a white sheet. Sometimes close relatives will wash and wrap the body themselves. The body can then go to a mortuary, where it will remain untouched pending the arrival of a Muslim representative for collection.

In the Sikh culture, although the family may wish to perform last offices or rites, it is acceptable for health staff to do so in their absence. However, it is essential that the 5 k's not be disturbed or removed: the kangha (comb), kesh (uncut hair), kirpan (dagger), kara (iron or steel bracelet), and kachhera (shorts). These are signs of obedience to the will of God and have a deep moral, practical, and spiritual significance. If it is necessary to remove the kachhera, they must be replaced. The hair and beard must not be trimmed. The limbs should be straightened and the jaw supported as the person's face will be shown. If there is a viewing in the chapel of rest, the Christian cross should be removed.

The Baha'i, founded c.1835 in Iran, now total >7 million followers worldwide. Their main temples are located in Haifa and New Delhi. The Baha'i prefer that the body be washed immediately and wrapped in a plain cloth. Embalming is not allowed. In contrast, Buddhists leave the body undisturbed for as long as possible so that family members can observe in silence or chant quietly.

Burial or Cremation

Both burial and cremation may be performed by Christians. Roman Catholics may prefer burial. Eastern Orthodox prohibit cremation. No religious objections are made to postmortems in the Christian faith. Some denominations, such as the Church of the Latter-Day Saints (Mormons), will dress the body for burial after death once it is released from the hospital. Burial is usual, although cremation is not prohibited for this latter group.

When a Jewish person dies, burial must take place as soon as possible after death; however, Jews cannot be buried on the Sabbath or on major religious holidays. Cremation is not allowed within the faith. The burial service can be held at the graveside or in a syn-

agogue. The body may be washed after death by holy Jewish attendants and dressed in burial shrouds. As a rule the Jewish religion does not permit postmortems unless required by law, in which case the local rabbi should be consulted.

In the Hindu culture following a death, men and women from the family may wash the body. The body is wrapped in a white cotton shroud, and it is the sacred duty of the eldest son in a Hindu family to light the funeral pyre. Family members may wear white clothes as a sign of mourning for 10 days after the funeral ceremony and eat only simple foods during this time. The priest may also sprinkle blessed water that has been drawn from the Ganges over the body or place a sacred tulsī leaf in the mouth. A thread may be placed around the neck or wrist, which must not be removed. Hindus are usually cremated, but children may be buried. Following cremation the ashes may be dispersed, preferably in flowing waters, or may be sent to India to be spread in the Ganges.

An early burial (as soon as possible after death) is a requirement in Islam. Family and community members will be grateful for the rapid release of the body from medical supervision. Burials are often in a shallow unmarked grave with a mound of earth above; although in Western societies, to some extent this has been replaced by more conventional graves and stones. Burial is followed by 40 days of mourning of which the third, seventh, and 40th day after the burial are especially significant.³⁹

In the Baha'i faith, cremation is not permitted and burial close to the place of death (usually within 1 hour transport) is preferred.

Buddhists celebrate few life events; however, funerals are the exception. In Buddhism, blessings and counseling are offered to the bereaved or sick.

In Rastafarian culture, burial is preferred but cremation is allowed, and there are no special rituals. The funeral is not elaborate, and the body may be flown back to the country of origin.

Routine last offices and rites are fitting, and both cremation and burial are acceptable for humanists. In the United Kingdom the family may wish someone from the Humanist Association to carry out a nonreligious funeral.

All Sikhs are cremated. After the cremation, the family return to the temple where they are told which charities should be contributed to. A year later they

return for hymns and prayers and to make further charitable donations. It is customary after a death for friends to bring food to the family, and the family provides food for all visitors in the prescribed 10- to 13-day period of mourning.

SUMMARY

Primary care physicians and health care teams have important lessons to learn about caring for dying patients from ethnic minority groups. Cultural awareness is part of a wider awareness of the diverse beliefs and needs of these patients. The variations within an ethnic minority group are as wide as the variations among the different groups. It is important to avoid a "cookbook" approach to the process of end-of-life care and to respect the rights of individuals, families, and groups to their cultural belief systems. The descriptions provided here of faith-specific requirements are general guidelines only and should not take the place of sensitive inquiry of the patient or relatives.

Recommendations made by researchers to improve the care of ethnic minority patients at the end of life include information provided through appropriate literature, language interpretation, liaison services, equal opportunity strategies, staff training, systematic referral arrangements with health care practitioners, improved ethnic monitoring, and cultural sensitivity in service provision in palliative care. Attention to such details may well ameliorate the bereavement agencies.

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Dialogue Box

EDITORIAL BOARD

How do hospitals in the United Kingdom individualize terminal care to patients of different faiths?

SIRIWARDENA

Many hospitals in the United Kingdom are able to call on religious leaders or practitioners of different faiths, for example, a Christian chaplain, Jewish rabbi, Hindu priest, or Muslim imam, who can come to the institution and provide advice and support in terminal care situations.

EDITORIAL BOARD

Are you aware of any religious groups who might find it offensive to remove intravenous lines and other medical devices following the death of the patient?

SIRIWARDENA

I am unaware of any; in general, it is correct to remove devices. For people of the Islamic faith, for example, it is particularly important to remove anything artificial.

EDITORIAL BOARD

For which religious faiths should every effort be made to allow the patient to die at home?

SIRIWARDENA

Buddhists as well as Hindus prefer to die at home with their families. Having said that, based on surveys conducted in the United Kingdom, many patients, regardless of their religion, would prefer to die at home with their families. That often doesn't happen at the moment because of lack of primary

care resources, family support, or crises in care; this leads to the situation being reversed in practice.

EDITORIAL BOARD

How significant is the problem of selective translation when using family members as interpreters? Should family members not be used as translators when discussing terminal care?

SIRIWARDENA

The practitioner should be aware of the problem, but it should not prevent the use of a family member as a translator. If possible, it may be very helpful to have another person assist in translation, such as a religious leader, in addition to the family member. Although the views of the dying individual are important, it may also be culturally important for some of the decisions to be made by the family rather than by the individual.

EDITORIAL BOARD

What would you regard as the most important "take-home" lessons about providing culturally aware terminal care?

SIRIWARDENA

First, how people wish to be treated at the end of life varies significantly between cultures. Second, not only do differences exist among religious and cultural groups, individual variations occur as well within these same groups. Lastly and most importantly, avoid making assumptions about how people want to be treated, and openly ask patients and their relatives what their preferences are regarding terminal care.