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FOCUS ON: GAT & CONTROVERSIES IN ANAESTHESIA

Cultural issues surrounding end-of-life care

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Summary According to census data approximately 8% of the UK population is classified as an ethnic minority. This is greater in Britain's urban areas and given associations between inner-city living, low socio-economic status and ill-health it is inevitable that staff throughout the National Health Service will have to deal with critically ill patients from ethnic minorities. Invariably some of these contacts will involve the possibility of end-of-life care on an intensive care unit. Any ingrained values within western culture and medical practice have the potential to clash with the values of other cultures, at best through innocent misunderstandings and at worst through a conscious failure to engage. Such differences (real or perceived) can lead to open conflict and hostility, which if associated with end-of-life care can hinder the provision of effective palliative care and create lasting negative impressions for both staff and relatives. A need to understand cultural differences exists. Such a need is a two-way process and from the perspective of healthcare workers in the critical care unit faced with ''end-of-life'' decisions it encompasses consideration of factors such as ethnicity, religion and/or spirituality, age, socio-economic status and interpretations of autonomy.

Introduction

Britain is a multicultural society with ethnic minorities in the 2001 census accounting for 4.6 million people or 7.9% of the total population; a growth of 53% between 1991 and 2001. Half of the total minority ethnic population considered themselves as Asian of predominantly Indian, Pakistani or Bangladeshi origin. A quarter described themselves as being Black, 15% of Mixed Ethnicity, 5% Chinese and 5% Other Ethnicity.[1] Such diversity presents challenges to healthcare professionals because it is important that healthcare providers consider the cultural needs of a patient and learn how cultural factors influence their response to illness, suffering and death. Increased understanding allows clinicians to provide a framework for patients to cope with these experiences.[2] However, difficulties may arise where differences in beliefs and customs exist as these may appear contradictory to routine practice within Western Medicine. Physicians may have ingrained values that are

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alien to a patient of a different cultural background.[3] The potential for misunderstanding and conflict is great.

Such conflict can be further exaggerated by the current political climate in the UK that highlights cultural and ethnic variations between different groups. Whilst the long-term aims of democracy may be to peacefully merge different cultures creating a subsequent tolerant and multi-ethnic monoculture, the current day-today reality is that distinct differences exist between cultural groups and that many, if not all such groups require care within the National Health Service. Clinicians must therefore be aware of cultural diversity and develop skills relevant to providing culturally appropriate and effective care. Nowhere is this more important than in care of the dying patient on the intensive care unit.

Discussions on improving the quality of end-of-life care regularly occur on the intensive care unit owing to it being a place where the transition from potentially curative to palliative treatments occurs.[2] Many constituents of a good or bad death are based on the opinions of those involved and hence may be strongly influenced by ethnicity, culture and religion. There is evidence to suggest that patients do not always receive the care they perhaps desired and these deficiencies in end-of-life care tend to be more pronounced in ethnic minority populations.[4] This article therefore aims to highlight cultural and religious issues surrounding death in the intensive care unit.

Understanding cultural difference

Increased understanding of factors shaping cultural identity equips staff with the ability to deal with an individual's requirements. Culture can be described in general terms as "the predominating attitudes and behaviours that characterize the functioning of a group or individual." It is thus an important part of the context within which individuals, including healthcare professionals understand their environment and make decisions about how to act.[5] Culture encompasses influences from race, ethnicity, religion, age and socioeconomic status and is a therefore an ever changing variable. It becomes highly meaningful when interpreted within the context of a patient's life.[6] By ignoring the significance of another's culture, we presume a superiority of our own cultural beliefs potentially devaluing the beliefs of others.[5] Furthermore there is a risk of stereotyping that can lead to biased or discriminatory treatment.[3,5,6] Culturally effective care therefore relies upon sensitivity and competence on the part of the clinician.

Basic concepts of culturally effective care

Cultural sensitivity and *cultural competence* describe appropriate attitudes and skills in the delivery of culturally proficient care. A lack of *cultural sensitivity* can lead to undesirable or inappropriate clinical outcomes with misperceptions hindering effective interaction with patients and their families during the dying process.[5] Cultural sensitivity describes both an awareness of how culture shapes values, beliefs, world views, etc., and an acknowledgement of and respect for differences that exist. This allows maintenance of a non-judgemental attitude toward unfamiliar beliefs and practices plus a willingness to negotiate and compromise when conflicting views arise.[3] Acquisition of the knowledge and skills that enhance the management of cultural issues in the clinical environment is called *cultural competence*[7] and requires skilled verbal and nonverbal communication as a means of appreciating differences.[3] Addressing and respecting cultural differences increases trust leading to improved care.[5]

Further challenges arise from diversity within specific ethnic minority groups.[8] Patients are individuals and do not necessarily share exactly the same cultural traits as other members of a culturally similar group.[3] Generalizations regarding specific cultures can disguise important intracultural variations and if used to predict an individual's behaviour, may lead to stereotyping,[3,6] e.g. the designation "Black" could refer to West Indians, Africans and British-born blacks; "Asians" may include persons who have evolved from the Indian subcontinent or the Far East.[3] There are further variations within the major religious groups, e.g. Christianity encompasses the Roman Catholic, Protestant and Eastern Orthodox Churches; there are also two main branches of Islam in the UK, Sunni and Shia. The process of *acculturation* also impacts on an individual's belief systems, i.e. how ethnic origin is tempered by the host society (in this instance the UK or regions therein) and whether beliefs have altered as a consequence.[9]

Healthcare systems themselves can also create barriers to culturally effective care in that facilities are not generally designed for cultural diversity and instead favour a "one-size-fits-all" approach to care. Limitation in resources may thus hinder the ability to adjust care and accommodate certain needs or practices of a particular individual.[10] Once

again improved understanding can minimize such potential pitfalls and allow clinicians to provide culturally effective end-of-life care.

Culturally effective end-of-life-care

The Ethics Committee of the Society of Critical Care Medicine (USA) and the Intensive Care Society (UK) have published recommendations for end-of-life care in the intensive care unit that include the need for cultural awareness amongst clinicians involved in decision-making processes.[11] There are broadly two phases in the management of patients at the end of life. The first is concerned with shifting the focus of care from curing disease to maximizing comfort. The second phase implements such decisions whilst ensuring the needs of the patient and family. Cultural variations that can exist throughout such care processes are discussed below.

Decisions to limit care

It is frequently accepted that continued aggressive care in the intensive care can be detrimental. Life sustaining therapies may prolong the dying process rather than facilitate a recovery which is distressing to all involved in caring for the patient. Death in the intensive care unit therefore frequently follows the limitation of such therapies.[4] The decision to withhold or withdraw support is often a difficult decision influenced by various factors including the culture of the physician, attitude of the country and religious beliefs.[12] European studies have revealed that physicians' and patients' religion can cause significant differences in the use of end-of-life therapies with values and practices differing from country to country (probably through the diverse religion and cultures within Europe[13,14]).

Furthermore who decides on limiting life sustaining therapy is subject to international variation, e.g. in North America, patient autonomy is held with such regard that patient/family involvement is common in end-of-life decision making whereas in southern Europe, decisions tend to be physician-directed, often made without any family involvement.[9] Consensus regarding good practice at the end of life is however developing. The majority of deaths in the ICU are anticipated and preceded by decisions to limit or withdraw active treatment in order to focus on palliative care.[4] Such a process is often gradual, developing (as a minimum) over a period of hours and therefore the opportunity to consider and debate beliefs can occur, minimising misunderstanding (providing staff have prior knowledge and awareness of relevant issues.) Such issues include secular or religious concepts of autonomy and specific religious or spiritual beliefs/requirements.

Patient autonomy

In Western medicine patient autonomy is often the primary focus of decision making. It emphasises the rights of patients to be informed of their condition, treatments and the ability to choose or refuse care. However not all cultures place the same value on autonomy. In many non-western cultures, families prefer to initially receive information before they decide how much to disclose to the patient.[10] Reasons for nondisclosure include a view that such discussions are impolite or disrespectful or that open discussion may provoke unnecessary mental anguish eliminating hope.[8] When faced with such possibilities, we should acknowledge that in certain cultures information can be imparted indirectly through nonverbal communication.[5] Facial expressions, tone of voice and other nonverbal cues can convey the seriousness of a condition without the need for explicit statements. This can be particularly important in Far Eastern cultures but also has relevance in Western Society.[8]

Conflict in the sphere of autonomy occurs when the beliefs and wishes of the family differ from those of the patient, doctors or both, e.g. Islamic cultural edicts are against informing patients of a terminal diagnosis. This is contradictory to the concept of patient autonomy yet within the context of Muslim beliefs it would be unethical to inform the patient directly.[4] However if the patient desires and is capable of understanding the implications of their illness then their wishes should be respected and the matter discussed with family members who have differing views.[10]

With regard to decision making, cultures that place a high value on beneficence and non-maleficance have a tradition of family centred healthcare decisions, e.g. traditional Chinese society has much less emphasis on individual rights, self-expression and self-determination than Western Society and at times of severe illness, the family serves to protect the patient by not burdening them with truth about prognosis.[5,9] Among East Asian cultures from Korea, China and Japan, family-based decision-making is common as illness is considered a family rather than an individual event—a function of filial piety, the traditional ideal of parent care in these cultures.[8]

Respect and sensitivity are necessary for a patient refusing to make decisions about their care, who instead (voluntarily) prefers family or physician centred decision-making.[15]

At face value the above should make many end-of-life decisions clear however many intensive care patients lack decision-making capacity. The concept of patient autonomy thus becomes difficult to uphold with implications for determining the preferences of an individual. Advance Directives were developed to deal with this problem but many patients admitted to intensive care have not actually completed a "living will" and their influence on patient outcome including quality of life remains uncertain.[4] Furthermore, based on evidence from the USA, uptake and use of such directives by the "non-European" population is variable.[6,15] In such cases, the closest relative often provides a "substituted judgement" to serve the patients interests, but this also has limitations. Surrogates can provide useful information[16] but close relatives may fail to accurately represent the patient's wishes by experiencing high levels of anxiety and depression which compromise their decision-making ability. The burden of decision making may also be significant.[4] Further North American evidence shows that African and Hispanic Americans are more likely to demand aggressive life-supporting treatments relative to their European counterparts.[5,6] Adequate communication and understanding of another's value systems is therefore once again the keystone to reducing disagreements and providing a shared approach to decision making.[4]

Spirituality and end of life customs

Spirituality can be described as "matters concerned with or affecting the soul".[10] It is not necessarily synonymous with religion (often a more formalized concept defined by doctrines through which individuals' beliefs are externally expressed). More often it is concerned with the patients own consideration of meaning and purpose and their relationship with themselves and others. It is significant in end-of-life care but can often be neglected, possibly through appearing more nebulous relative to actual religious beliefs. Failing to address spiritual needs can cause concern, distress and potential conflict similar to that of failing to address religious beliefs. Conversely recognition and intervention can give strength, provide relief and build trusting relationships between all carers.[17] Spiritual need can manifest covertly as emotional distress, aloofness, or failure to make meaning of the situation or be explicit, e.g. desires to fulfil a religious ritual, make peace with the world, other people, God, etc.[17,18]

An assessment of spirituality in the intensive care unit can be initiated by any member of the healthcare team. This may begin with the family rather than the patient as their physical condition frequently leaves them unable to communicate preferences. Sensitivity is paramount if the relevance and influence of religion/spirituality specific to an individual is to be determined along with their need for any extra support that may give additional comfort at difficult times. At such junctures community faith leaders and spiritual advisors representing faith traditions can be invaluable by informing and guiding the healthcare team through cultural differences that may hinder their success in recognizing the spiritual needs of their patients.

Spiritual or religious practices also play an important role in preparing for death. Such rituals (performed at times of significant transition)[10] can provide meaning, security and solace.[19] They include prayer, chanting, sacred texts or sacraments.[5,17,20] Ceremonies can be performed at the bedside to ease the passage of dying and religious leaders may be present to pray with the family.[20] Whilst accommodating such needs is the ideal, doing so can be difficult on the intensive care unit with potential cultural and physical barriers, e.g. inclusion of large extended family networks and outward expression of grief. Nevertheless performance of rituals can be supported if they do not interfere with the care of other patients and their families.[17] Relaxation of policies such as visiting-times and number of visitors permitted may be required to adequately facilitate cultural practices.[21] The need for clear, empathic communication is thus self-evident if confrontations are to be avoided. Staff education and prior liaison with the afore-mentioned spiritual leaders can aid this process giving clinicians an understanding of cultural traditions incorporated in a population, affording the opportunity to deliver culturally effective end-of-life care.

In addition to a broad understanding of beliefs, views relating to handling the body, organ donation and autopsy should be considered. A comprehensive review of such issues within Britain is beyond the scope of this article however beliefs concerned with dying and death amongst the major religions are listed as a guide in Table 1.

Following death, continued support of the family is necessary[22] with specific needs depending on individual and cultural characteristics.[23] Expressions of grief are culturally patterned and can vary

Table 1 Religious beliefs and attitudes regarding death.

Faith	General beliefs	Beliefs regarding care of dying	Handling and preparation of the body	Attitudes towards organ donation/ autopsy
Buddhism	No one God but many Gods acknowledged although as lesser beings than Buddha. Believe in rebirth and that the present life influences the next. Following the teachings of Buddha brings them closer to Nirvana.	Time for meditation which brings enlightenment is important. Patient may be reluctant to take medication that clouds the mind and impairs meditation. May appreciate a visit from a Buddhist monk/ sister. Generally calm and accepting of death.	Incense may be lit in the room. The family may choose to wash the body. Cremation is usual.	Usually no objection to post mortem. No consensus regarding organ donation.
Hindu	Three supreme Gods worshipped along with numerous others. Belief in a soul that needs to be freed to join the supreme being. Believe in reincarnation. Different sects have different beliefs.	Ritual of washing gives physical and spiritual cleanliness but modesty should be preserved. Time for prayer and meditation important. Pictures, beads or charms may be kept close to the patient. Water from the River Ganges may be given. A Hindu priest may tie a thread around the wrist or neck which should not be removed.	Non-Hindus may touch the body if it is wrapped in a sheet or they wear gloves. The family may wish to wash the body and have it placed on the floor while incense burns. All are cremated as soon as possible.	No objection to organ donation. Post mortems generally objected to as considered disrespectful, unless legally necessary.
Islam	Believe in one God, Allah. Believe in life after death and resurrection of the body. Judgement by God according to a person's deeds delivers him to heaven or hell. Five religious duties are: faith, prayer, almsgiving, fasting and pilgrimage to Mecca.	Family and friends provide emotional support. Prayer is said five times daily facing Mecca. The face of a dying person should be turned towards Mecca. Readings from the Koran may de said close to death. The patient may wish a religious leader to visit. Modesty should be preserved.	Non-Muslims touching the body after death should wear gloves. The head is turned to the right towards Mecca. The family may wish to wash the body themselves. Muslims are buried as soon as possible.	Organ donation is acceptable. Autopsy only permissible for legal or medical reasons.
Judaism	Believe in one God, an afterlife and physical resurrection of the dead. Strong sense of the value of human life.	No last rites but a visit from a Rabbi may be requested. Psalms and prayers are recited by the patient and family.	Traditionally, the body is left for 8 min with a feather over the nose and mouth to confirm death. The jaw is then bound and the arms placed by the side. This may be done by the family. The body is placed on the floor, feet towards the door with a	Post Mortem resisted by Orthodox Jews unless ordered by civil authorities. Organ donation frowned on in most cases.

Table 1 (*continued*)

Faith	General beliefs	Beliefs regarding care of dying	Handling and preparation of the body	Attitudes towards organ donation/ autopsy
	Different groups: Orthodox—traditional, non-Orthodox—make religious observance fit into modern society.	Powerful grip on life can produce ambivalence to a dying person.	candle at the head. The body should not be moved on the Sabbath but this is rarely practicable. The body should not be left alone. Funeral occurs as soon as possible. Orthodox Jews are buried, non-orthodox Jews may be cremated.	Non-orthodox Jews have more relaxed attitudes.
Sikhism	Believe in one God. Individuals, by doing good find the route to salvation. Believe in reincarnation and a path towards perfection. Strong community aspect.	Near death, the family pray at the bedside and read from the holy book. Some may prefer to pray privately.	Non-Sikhs may touch the body but the family may wish to prepare the body themselves in which case the body should be wrapped in a plain sheet. The family will wash and dress the body. The 5 K's should be left intact.	No objections to organ donation.
	Wear 5 symbols of Sikhism: Kesh, uncut hair; Kangha, comb; Kara, steel bangle; Kirpan, symbolic dagger; Kaccha, long under-shorts.	Tend not to be very scared of death because of the doctrine of reincarnation.	Apart from neonates, all are cremated, and should be as soon as possible.	No objections to post mortem.

Devised from Chambers,[17] Neuberger,[18] and Intensive Care Society (UK) Guidelines for Bereavement Care in Intensive Care Units.[22]

widely.[6,24] Western hospital culture expects calm and controlled mourning that can conflict with the natural practice of grief expression in other cultures.[21] Many grieving practices can however be facilitated and serve to allow for the adjustment to the implications of the loss and ultimately closure. Once again prior knowledge on the part of carers allows for support in a manner fitting individual circumstances and the culture/expectations of a community.[21,23,24]

Attending the needs of the culturally diverse

Much of the above deals with collective cultural traits concerned with death and dying, however as with mortality predictors (e.g. APACHE scores) they apply to a population rather than an individual and whilst Western Culture perceives itself at being adept in dealing with individuals within its own social framework, end-of-life care also requires appreciation of individuals within ''non-Western'' cultures. A simple strategy for respecting cultural diversity has been created by the anthropologist Koenig, who researched multiculturalism and end of life care. Whilst advocating that staff have a general knowledge of different cultural groups, patients should be approached as individuals within the context of their surrounding support mechanisms (Table 2). The adage of ''treating each case on its merits'' applies.[6]

Conclusion

Attention to cultural differences has a large impact on the quality of end-of-life care. However, all too often, healthcare providers are poorly equipped with basic knowledge regarding patients' cultural and social background despite such characteristics influencing end-of-life preferences. Acknowledgement of cultural differences opens doors to effective communication and breeds trust between concerned parties. Understanding how a culture shapes attitudes, beliefs, emotions and behaviour

Table 2 Meeting an individual's cultural needs during end-of-life care.

Language
- Assess the language used to discuss illness and disease, and the extent to which they are prepared to discuss prognosis and death.

Decision making
- Determine whether the patient or their family are the main decision makers of important family matters.

Perceptions
- What is their perception of the present illness and the dying process?
- Are they fatalistic about the course of events?

Religion
- What is their religious background and how important is religion to them?
- Give consideration to their views on miracles and an afterlife
- Do they have any specific religious customs and rituals?
- Should the body be handled in a certain way after death?

Social support/resources
- What resources including community and religious leaders, translators are available to aid the interpreting and relevance of the cultural aspects of each case?

Koenig and Gates-Williams.[6]

regarding illness and death can facilitate the delivery of culturally appropriate care. It is arguably unrealistic to suggest that healthcare providers should learn all common beliefs surrounding critical illness and death; however it is reasonable for them to be informed of the needs of the populations encountered regularly in their practise. Cultural backgrounds and how individual patients relate/adhere to such matters should be determined. Inquiries about values are necessary and having a structured approach towards determining cultural identity assists. Staff are then better equipped to recommend and negotiate treatment, minimize misunderstanding and conflict and ultimately provide comprehensive and compassionate palliative care.

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