ETHNIC AND CULTURAL CHALLENGES AT THE END OF LIFE: SETTING THE SCENE

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SUMMARY
Patients with advanced kidney disease come from diverse ethnic, cultural and religious backgrounds. This potentially causes conflict when considering end-of-life management for patients from minority ethnic groups in a Western healthcare system that is dominated by the principles of patient autonomy, beneficence, non-maleficence and avoiding futile care. This article explores the impact of religion and culture on truth telling and futile care at end of life.

KEY WORDS Palliative care • Psychosocial • Withdrawal

INTRODUCTION
Increasing migration into Western countries such as the UK has greatly changed the ethnic and cultural patterns of patient populations. This is particularly true when considering advanced kidney disease, which is much more common in many ethnic groups compared to the white European population (Patzer & McLellan 2012). As an example, London, which is typified by its multicultural society and population, has a resident non-UK born population of approximately 40% (Greater London Authority, Data Management and Analysis Group 2001). Almost two-thirds (63%) of all migrant Londoners are from BAME (Black, Asian and Minority Ethnic) groups; they also comprise one-fifth (22%) of London’s UK-born population (Greater London Authority, Data Management and Analysis Group 2006). Around 50% of patients on renal replacement therapy in London are from ethnic minorities, predominantly South Asian (UK Renal Registry 16th Annual Report 2013). Both patients and physicians have their own languages, explanatory illness models, religious beliefs and ways of understanding the experience of suffering and dying (Kagawa-Singer 2001). This is particularly pertinent in the renal setting where the high mortality associated with ESRD demands nephrologists to frequently engage in end-of-life discussions with their patients and their families.

Case History
Mrs M is an 82-year-old Somali woman with diabetes on haemodialysis; she had a right below-knee amputation six months previously and has been in hospital for a week with an ischaemic left foot; she has evidence of sepsis with multiresistant organisms on blood culture. She is now hypotensive and confused.

Haemodialysis is complicated by the loss of upper central venous access and poor blood flow rates on repeated femoral lines. The vascular surgeons have stated that no procedure is possible to improve blood flow to the left leg and that she is too unwell even for an amputation. A discussion is held with her family about Mrs M’s poor prognosis and inevitable death. The family state that they want full treatment as demanded by their religion and that ‘Allah decides when death happens’. Two days later, the femoral line clots. A further meeting is held with the family; it is explained that it would be futile to attempt another femoral line insertion, and that attempting to do so could be very uncomfortable and distressing for Mrs M. Subsequently, a family member phones the hospital patient affairs department and states that if their mother is not put back on to dialysis, they will contact Somali radio and accuse the hospital of racism. Following this, the renal...
team elects to maintain Mrs M on dialysis after further femoral line insertion. Over the next two weeks, Mrs M is maintained on haemodialysis, intravenous antibiotics and inotropes. She eventually has a cardiac arrest during dialysis and dies after an extended attempt of resuscitation.

The case history above illustrates many of the issues and potential conflicts that emerge when considering end-of-life management for patients from minority ethnic groups in a Western healthcare system that is dominated by the principles of patient autonomy, beneficence, non-maleficence and avoiding futile care. The outcome of this case history was far from ideal from the viewpoint of both the patient (inappropriate prolongation of dying, pain and discomfort from repeated femoral line insertions and dialysis attempts) and society (inappropriate use of limited healthcare resources). These potential dangers from too readily adapting to differing cultural values in an attempt to avoid conflict were discussed in a recent review article (De Pentheny O’Kelly et al. 2011). Proceeding with futile treatment is neither in the best interests of the patient nor of the healthcare system. To understand why this conflict can arise, it is important to consider the impact of religion and culture on attitudes at end of life towards intensity of treatment and potential withdrawal of life-sustaining treatment, and on the ethics of truth telling to patients and families.

**RELIGION AND END-OF-LIFE MANAGEMENT**

Beliefs and attitudes towards end-of-life care depend on religion as well as the culture of an ethnic community. It is, however, exceedingly difficult to summarise the impact of religion as there

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<th>Religion</th>
<th>Beliefs</th>
<th>Impact on EOL management</th>
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<tr>
<td>Christianity</td>
<td>Variation between Orthodox, Roman Catholic and Protestant beliefs. Key belief is repentance and life after death</td>
<td>If wanting to confess, strong religious justification for high-technology medicine to maintain consciousness until final anointing Those who have repented may recognise no need for aggressive interventions to postpone death and could even regard them as unjustified spiritual burden and distraction</td>
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<td>Buddhism</td>
<td>Inevitability of death is a central element of Buddhist teachings, which emphasise importance of death with an unclouded mind as this can lead to a better rebirth</td>
<td>There is no need to go to extreme lengths to provide treatment if little or no prospect of recovery. Some may be unwilling to take strong analgesics or sedatives. All people, regardless of their physical condition or whether conscious or not, are worthy of compassion</td>
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<td>Hinduism</td>
<td>Life is a transition between previous one and next. Beliefs about the next life (rebirth, heaven and liberation) vary. A good death is timely, in the right place, conscious and prepared, with the mind on God; a bad death is untimely, violent and unprepared. The family have a sacred duty to assist the dying before and after death</td>
<td>Fact that not all deaths are those of elderly people who have fulfilled life ambitions results in problems of disclosure and withdrawal of care. This results in tradition of non-disclosure and relatives protecting individual from knowledge in case he/she gives up hope and dies prematurely. This is exacerbated by the belief that modern medicine often provides hope, however unrealistic, that a cure is possible</td>
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<td>Islam</td>
<td>The Qur’an states that death does not happen except by God’s permission. Life is a divine trust and cannot be terminated by any form of active or passive human intervention, as its term is fixed by an unalterable divine decree. The ethical rule ‘No harm shall be inflicted or reciprocated in Islam’ expounded by the Prophet Muhammad has been evoked by Muslim jurists to allow withdrawal of futile treatment after consultation with patient, family and others involved</td>
<td>Decisions about aggressive invasive treatment to extend life are jointly made by all associated with the patient—including religious leaders. Withdrawal of life-sustaining treatments, when considered futile, is seen as allowing death to take its natural course; delaying the inevitable death is neither in the patient’s nor in the public’s best interests because of distribution of healthcare and financial resources</td>
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<td>Judaism</td>
<td>Man is created in the ‘Image of God’ and all human life is sacred. Ethical decisions are to be made within the axioms of divinely revealed biblical law and its rabbinical interpretation</td>
<td>In the presence of terminal illness causing ongoing suffering, treatments may, in exceptional circumstances, be withdrawn or withheld, but Rabbinic guidance may be desirable for such decisions</td>
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*Table 1: Impact of religion on end-of-life management.*
Adapted from Engelhardt (2005), Keown (2005), Firth (2005) and Sachedina (2005).
are often many variants of practice and beliefs within a single religion as well as the impact of the culture of ethnic groups or country of origin or residence. Furthermore, it cannot be assumed that an individual follows or believes all the practices of their given religion. A summary of the impact of religion on end-of-life management is given in Table 1; it is a simplified view and is based mostly on a series of papers published in the Lancet in 2005 (Engelhardt 2005; Keown 2005; Firth 2005; Sachedina 2005). It does not attempt to cover all religions but does illustrate how religious beliefs can impact on delivery of care at end of life both for the individual and the cultural group.

ETHICAL ISSUES OF TRUTH TELLING AT END OF LIFE RELATED TO ETHNICITY

Truth telling about prognosis and efficacy of potential treatments is required to avoid unrealistic expectations of patients and their families (De Pentheny O’Kelly et al. 2011). Attitudes towards communicating a poor prognosis to patients and/or families depend on religious and cultural factors and therefore vary between countries and between ethnic groups within a country. Ethics of minority groups usually follow their religion and country of origin (Johnson 2009). In many countries, including most Asian countries and some in southern Europe, decisions about what is told to a patient and the care received is made by the family. This inevitably causes conflict when these values are challenged by the principles of patient-centred care and patient autonomy that are the dominant culture of care in many Western countries—particularly in the English-speaking world of the UK, USA, Canada, Australia and some countries in Europe. Table 2 summarises attitudes towards truth telling in different countries and cultures; it is not comprehensive but does demonstrate that these differences exist.

DIALYSIS WITHDRAWAL AND ETHNICITY

There are no published data relevant to the UK. Recent studies in both US and Australia (Chan et al. 2012; Thomas et al. 2013) both show lower rates of dialysis withdrawal in minority ethnic groups compared to the white Caucasian population. Similar data have recently been reported from Canada (Ellwood et al. 2013). The reasons underlying the observed racial differences of dialysis withdrawal rates and end-of-life care are complex and include cultural and religious differences, differences in hospitals where patients are treated, differential access to care, differences in education and health literacy and mistrust of the medical system (Thomas et al. 2013). These relate to socioeconomic factors as well as cultural influences and are equally applicable to the wider population and non-renal disease as discussed by Jonathan Koffman in this Supplement.

NEED TO IMPROVE COMMUNICATION

One of the principal reasons for conflict between nephrologists and patients at the end of life is failure of communication. This is true for patients of all ethnicities and cultures including the predominant indigenous white population. In a Canadian study, less than 10% of patients reported having had a discussion about end-of-life care issues with their nephrologist in the last 12 months, while 83% thought that it was important to be prepared and plan ahead in case of death (Davison 2010).

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<th>Country/cultural group</th>
<th>Attitudes towards truth-telling</th>
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<td>China (Fan 2004)</td>
<td>When fatal diagnosis or prognosis, physician informs family and hides it from patient—up to family to decide whether, when and how to disclose truth to patient. Families usually decide to conceal such information—and physicians are willing to follow such decisions and cooperate with families in deceiving patients</td>
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<td>African American (Kagawa-Singer 2001)</td>
<td>Only God has knowledge and power over life and death and physicians cannot have access to this type of knowledge. Christian religious view held by many in African American community holds that suffering is redemptive—it is to be endured rather than avoided. Forgoing life support to avoid pain and suffering therefore might be seen as failing test of faith</td>
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<td>Italy (Gysels et al. 2012)</td>
<td>Trend of partial and non-disclosure persists. This arises within families independently of patient requests—though some evidence that physician preferences are moving towards full disclosure</td>
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<td>Spain (Gysels et al. 2012)</td>
<td>Tradition of partial and non-disclosure. Majority of doctors state that they would inform patient only in certain circumstances or if requested by patient</td>
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<td>Turkey (Atesci et al. 2004)</td>
<td>Tradition of non-disclosure. Over half of cancer patients interviewed were unaware of their diagnosis. Psychiatric morbidity higher in those who knew diagnosis. Data interpreted as understanding of diagnosis indirectly may be stressful (and better therefore to tell patients)</td>
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Table 2: Ethics of truth-telling related to culture and country.
Interviews of seriously ill haemodialysis patients have shown that they were significantly more optimistic than their nephrologists about their prognosis and transplant candidacy (Wachterman et al. 2013). Remarkably, only 6% of patients thought they had less than a 50% chance of being alive in five years, whereas actual survival at just less than two years of follow-up was only 56%. This discrepancy was hardly surprising as not a single patient reported receiving an estimate of life expectancy from a nephrologist in this study.

**CONCLUSION**

Quality of care at end of life for patients with advanced kidney disease will improve with the increasing awareness of the palliative care needs of this group of patients and the need to discuss prognosis and develop realistic planning for future care by patients and their families. It is important that all patients benefit and this will entail education of and awareness by the nephrology healthcare team about the cultural beliefs of the patients under their care. This will enable the barriers created by distrust and lack of knowledge of likely outcomes of care to be minimised.

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None.

**CONFLICT OF INTEREST**

No conflict of interest has been declared by the author(s).

**AUTHOR CONTRIBUTIONS**

EB is the sole author.

**REFERENCES**


