

EMPIRICAL RESEARCH REPORT

Exploring Cultural Values that Underpin the Ethical and Legal Framework of End-of-Life Care: a Focus Group Study of South Asians

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Abstract

The central tenets of the legal and ethical framework that govern end-of-life care are dignity, equality, freedom of religion and respect for self-determined choice. These are variously protected by common law, statute and the European Convention of Human Rights. The interpretation and implementation of policies that govern end-of-life care depend upon the values that are attributed to these four principles. The cultural values that underpin these principles were explored in a focus group study of South Asians, the largest minority ethnic group in Britain. The findings revealed that the values attributed to dignity and equality were fundamental and humanitarian. Faith-based beliefs reflected values of expression and freedom of religion, legal protection of the same and culture-based spirituality. Traditional autonomous decision-making was considered to be less important than involvement of the family and the communitarian ethic. The social impact of values such as these will be directly significant when implementing policies and processes intended to ensure that minority ethnic groups enjoy equality in end-of-life care. The findings of the study are contextualised within a theoretical legal and ethical framework.

Introduction

The key principles that govern end-of-life care are dignity, equality, freedom of religion and self-determined choice. Legal protection is conferred by the European Convention of Human Rights and the Equality Act 2010. While the universality of these principles is unquestionable, their interpretation and how such rights are given effect by public healthcare providers is fundamentally important if they are to have real meaning. A range of customs, mores and cultural values specific to minority ethnic groups needs to be recognised and sensitively accommodated into end-of-life care. The need is urgent. Data from the most recent census reveals the increasing ethnic and religious diversity of British society. The proportion of White British has fallen from 87.5 per cent to 80.5 per cent of the population. Compared with the previous census

there are now 4,000,000 fewer Christians in England and Wales and a substantial increase in those who profess non-Christian faiths.¹

Recent policy initiatives and best practice guidance have focused on care of the dying. Specific examples include the End-of-life Care Strategy,² the Liverpool Care Pathway,³ the Gold Standards Framework,⁴ and the Preferred Priorities for Care tool,⁵ all of which have been endorsed by the National Institute for Health and Clinical Excellence. Most of these otherwise excellent initiatives have focused on physical and psychological aspects of care, while giving relatively little consideration to pervasive connotations of faith, dignity, equality or the cultural values and mores of minority ethnic groups.

The objective of this exploratory qualitative study was to determine the values considered significant by South Asian participants in the context of end-of-life care. Given the complexity of anthropological and sociological conceptions of ethnicity and culture, the study focused only on South Asians since they are the largest minority ethnic group in England and Wales.⁶

Methodology

Ethical approval was obtained prior to commencement. Two mixed gender focus group discussions were conducted with six volunteers in each. Each discussion lasted for two hours and was conducted between July and September 2011. Participants included highly respected members of the local South Asian community and comprised followers of Hindu and Islamic faiths. There was a 50:50 per cent ratio between faiths and also between those born abroad and those born in the United Kingdom. All were fluent in English and their ages ranged from 28 to 72 years.

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- ¹ Census 2011, 'Religion in England and Wales 2011' (Office for National Statistics, 2012), www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rpt-religion.html (accessed 10 January 2013).
- ² Department of Health, 'End-of-life Care Strategy. Promoting High Quality Care for All Adults at the End of Life', (London: Department of Health, 2008).
- ³ Liverpool Care Pathway, www.liv.ac.uk/mcpcil/liverpool-care-pathway.
- ⁴ Gold Standards Framework, www.goldstandardsframework.org.uk.
- ⁵ Preferred Priorities for Care, www.endoflifecareforadults.nhs.uk/assets/downloads/ppc_document_v22_rev_2011.pdf.
- ⁶ Census 2011, 'Ethnicity and National Identity in England and Wales 2011' (Office for National Statistics, 2012) www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rpt-ethnicity.html.

A focus group methodology was selected as the method of choice for exploring the values and views of participants.⁷ Prior to commencement a preliminary pilot study involving three volunteers was used to develop and refine two illustrative scenarios that were used as a preamble to the focus group discussions.

Consent was obtained at the start of the focus group discussions and the study aims and objectives were outlined. The focus groups were facilitated to explore perceptions of values in the context of care of the dying. Participants were encouraged to interact among themselves, although the facilitator intervened when necessary to clarify ambiguities and perceived inconsistencies. Discussions were digitally recorded and verbatim transcripts produced within a week. Following verification of the data against the recordings, subsequent analysis involved indexing (labelling) the data according to the four emergent principles of dignity, faith, decision-making and equality. Indices were then collated to form themes under each of four principle headings. These themes were determined by the frequency with which words and phrases occurred in the transcripts. In order to ensure rigour, comparisons were made by two researchers who collaborated after independently analysing the data to identify similarities and differences.⁸

Results

The results are displayed according to the four key tenets. The themes are illustrated by sample quotations from study participants who have been coded according to their faith (M = Muslim, H = Hindu) and gender (M = male, F = female).

(a) Dignity

1. A humanitarian value

'It is only natural that when you are dying you should be treated with dignity. All human beings deserve this.' (MF2)

2. An absolute expectation

'When a person is dying, he must be treated with respect. You cannot do anything else. It does not matter who he is or whatever religion or anything else.' (HM1)

⁷ M. Bloor et al., *Focus Groups in Social Research* (London: Sage, 2001).

⁸ J. Ritchie & J. Lewis, *Qualitative Research Practice. A Guide for Social Science Students and Researchers* (London: Sage, 2004).

(b) Faith

1 Right of expression

'[My GP] respected all our religious rights and catered for all our religious needs [when my father died] and ensured the best outcome. We were allowed to do everything according to our religion.' (MF2)

'[It is] important for doctors and nurses to [provide] the best medical care, but they must also understand and respect the religious feelings and beliefs of NHS [National Health Service] patients, particularly when that patient is dying.' (MF3).

2. Freedom of religion

'Our religious sensitivities need to be respected. We are entitled to this right.' (HM3)

3. Legal protection

'Of course I can openly show my religious beliefs, or anyone can when they are dying, and the law must protect this.' (HM2)

4. Spirituality

'The soul comes out when the heart stops beating. We, as Muslims, want to be alert for as long as possible in order to read our final prayers (...).' (MF2)

5. Tolerance and understanding

'I think that being accepting and tolerant would make sure that all of us at the time of death could be happy. It does not depend upon your colour or religion, and would apply to all of us.' (HM3)

'From the time of death the body needs to be buried on the same day. This may be difficult if death is in a hospital setting and people do not understand this need.' (MF2).

(c) Decision-making

1. Self-determined choice

'If I am dying, then it is not so important for me to make the decision about what will happen to me.' (HM3)

'A person I know from India refused to make any judgment or decision for himself and left it to others. The doctor and nobody [sic] could do anything about it.' (HM1)

2. Family involvement

‘In my case it is my family, including my sons and their wives, who can make the decision.’ (HM2)

‘I do not know about this. I thought if a person cannot make a decision, then the brother or sister can make a decision.’ (HM3)

‘Let me give you an example. I lost my father recently. When he was dying, as a family we made a collective decision as to what to do and what not to do. He was happy about it and we felt comfortable.’ (MF2).

3. A communitarian ethic

‘You can’t just be isolated and by yourself. A lot depends upon your network and family and community and what else everybody, then you get the best outcome.’ (MF1)

‘From a religious perspective we can do things to a certain extent. You also have to consider the community. Community is important.’ (HM1).

‘Yes, if the person cannot make a decision, then the next of kin makes a decision.’ (HM1).

4. Advance decisions

‘I don’t know about this and how this will help. I trust my family more than anyone else and they will do their best.’ (HM1)

(d) Equality

1. A core principle

‘We need to understand each other, um, because God has made us the same.’ (HM2)

2. Legal protection

‘Of course the law must respect all as being equal, not just sometimes but all the time.’ (MM1)

Discussion

The core values that emerged from data analysis are considered in the context of the contemporary legal and ethical framework that governs end-of-life care.

Dignity and equality

The concepts of dignity and equality were considered to be the pre-eminent guide for end-of-life care. The consensus perspective was that any interference with personal dignity at this time would be at odds with respect for humanity and tantamount to degradation. Although the term 'degradation' was not used specifically, this was the sense conveyed. Although Article 3 of the European Convention of Human Rights expressly prohibits degrading treatment and protects dignity of the person, 'dignity' remains an amorphous concept consisting of nuanced facets that lead collectively to empowerment. It is regarded as a virtue by which persons derive moral rights and standing which are inherent to being human. Thus, since dignity exists as a constituent aspect of human nature, to act contrary to human dignity would be to act contrary to human nature.⁹ Dignity comprises not only respect for the physical person but also for person-centred values.

The values attributed to equality were similarly considered relevant on humanitarian grounds. Safeguards are provided by the Equality Act 2010 which recognises a range of 'protected characteristics' and protect those to whom such characteristics apply. Of relevance to end-of-life care, Part III of the Act makes it unlawful for those providing a service or exercising a public function to discriminate, harass or victimise persons with a protected characteristic such as race, religion or belief.

From the perspective of social philosophy, the essential basis of moral equality can be incorporated into a utilitarian system of ethics in that each person counts for one, and none for more than one.¹⁰ In practical terms, the interests of any one individual will be ascribed the same worth as those of any other. In similar vein is the perspective that a moral imperative exists to give equal consideration to everyone's interests.¹¹ It is therefore implicit in the principle of equality that concern for individuals ought not to depend upon their abilities, nor their characteristics. This is the basis upon which minority ethnic values deserve to be upheld.¹²

Faith

In the context of end-of-life care, the values attributed by the participants to religion (and its practice) were the right to express faith-based belief, legal pro-

⁹ D. Beylveled & R. Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford: Oxford University Press, 2001).

¹⁰ J. Bentham, *An Introduction to the Principles of Morals and Legislation*: an authoritative edition by J.H. Burns and H.L.A. Hart (Oxford: OUP, 1996).

¹¹ R.M. Hare, 'Rules of War and Moral Reasoning', *Philosophy in Public Affairs* 1, no. 2 (1972).

¹² P. Singer, 'All Animals are Equal', in *Bioethics: An Anthology*, 2nd ed., ed. H. Kuhse & P. Singer (Wiley-Blackwell, 2006), 568-577.

tection of this freedom and culture-specific spirituality. Freedom to express faith-based beliefs and practice rites of religious significance by, and for, the dying individual was a shared expectation. Faith and the expression of belief form part of societal values and portray the universality of human rights.

One compelling reason for categorising faith-based beliefs as ‘a right’ would be on the collective interests of a minority group. Section 13(1) of the Human Rights Act 1998 provides that:

If a court’s determination of any question arising under this Act might affect the exercise by a religious organisation (itself or its members collectively) of the Convention right to freedom of thought, conscience and religion, it must have particular regard to the importance of that right.

This suggests that privileged attention ought to be given to freedom of collective aspects of faith-based worship.

Collective religious liberty operates to empower communities which share a common faith. Furthermore, these communities may at times carry out functions such as burial and care bestowed immediately prior to death, all of which can have implications for care that is given in a hospital setting. For followers of Islam, for example, the body must be buried on the same day. Although collective religious rights are recognised in law there is some debate as to whether these ought to have an independent existence. A fundamental reason for such protection is based upon the concept of dignity and respect for the individual. On this basis the collective dimension cannot be ignored as its value comes from a number of discrete interests. The absence of protection might result in subjugation of minority faith followers, or at least impart a sense that the minority religion is not accorded the same weight as that given to a majority faith.

The value of freedom of religion is expressed as an expectation and a right in itself. From a secular perspective, equality of religious and secular beliefs is based on an approach that removes religion from the equation. Thus religion or faith-based belief is prevented from being selected for either prejudice or partiality. The alternative is that respect for religion and faith-based belief is founded upon an irreducible core characteristic of inherent value.¹³ A potential problem with the latter approach is the wide variation of beliefs and practices, and the difficulty in distilling what could be recognised as a universal core. One way forward might be to base justification for protection of individual freedom

¹³ L.G. Sager, ‘The Moral Economy of Religious Freedom’, in *Law and Religion in Theoretical and Historical Context*, ed. P. Cane, C. Evans & Z. Robinson (New York: Cambridge University Press, 2008); J. Webber, ‘Understanding the Religion in Freedom of Religion’, in *Law and Religion*, ed. Cane et al.

of religion on the premise of liberalism and ‘justice as fairness’.¹⁴ The justification for liberal rights would depend upon reasonable people having respect for equality of citizenship and co-operation. This was the view of participants who felt that the state and the NHS would act to facilitate religiously motivated end-of-life needs.

All participants shared the expectation of the right to freedom of religion. In law, freedom of thought, conscience and religion are grounded in Article 9 of the European Convention of Human Rights. Article 9(1) protects the *forum internum* (the sphere of inner belief) as an unassailable right which includes freedom to choose (or change) one’s religious belief. Article 9(1) also protects the *forum externum*, or external aspects of worship, teaching, practice and observance. In determining whether a manifestation based on belief will qualify for protection, the court will scrutinise the narrow second order question as to whether the manifestation falls within any one of the four categories and whether protection would be necessary and proportionate in a democratic society.¹⁵ Several Muslim participants explained that wearing a *jilbab* (a full length loose body covering) would be the preferred attire of devout Muslims at the time of death, yet this may not always be available within hospitals. While the relevance of wearing a *jilbab*, or not, in employment contexts could be justified on the basis that people may have to accept (at times) a certain level of inconvenience,¹⁶ it seems difficult to reconcile this with the care of a dying Muslim in an NHS hospital. Although hospitals are obliged to have equality and diversity policies in place, it has been argued that this is an exercise in bureaucracy rather than an attempt to implement meaningful change.¹⁷ In order to achieve substantive enhancement of quality it is likely that in-depth consideration will be required of the *impact* of policies within hospital settings, as well as the development and dissemination of initiatives for staff training.

From a spiritual perspective all participants valued being alert just before death, since this would permit specific religious rituals to be carried out in order to allow the safe passage of the soul; this would not be achieved if a person’s conscious awareness was impaired through medication. The importance of the passage of the soul at this time is founded upon the orthodox principle commonly held in Eastern cultures of substance dualism, by which the immortal

¹⁴ J. Rawls, *Political Liberalism* (New York: Columbia University Press, 1993).

¹⁵ *Kosteski v. Former Yugoslav Republic of Macedonia* (App. No. 55170/00), 13 April 2006 (paras. 39 and 44).

¹⁶ *Begum v. Tenby High School* [2006] UKHL 15, Lord Hoffman at para. 50 and Lord Bingham at para. 23.

¹⁷ L. Vickers, ‘Promoting Equality or Fostering Resentment? The Public Sector Equality Duty and Religion and Belief’, *Legal Studies* 31 (2011): 135-158.

soul is regarded as a separate entity from the physical body. Post-Darwinian Christian theology has questioned the theory of substance dualism. The 'no soul' dictum operates as a holistic concept of mental, ethical and personal properties,¹⁸ and does not sit comfortably with the dualistic concept of the person as expressed by some minority faith groups. Thus, at the time of death (within hospital settings), failure to adhere to specific faith-based and spiritual rituals could have a distressing effect on the dying individual, as well as friends and relatives. Facilitating a framework of equality and diversity that permits such practices within mainstream health services may present a real challenge.

Decision-making

Participants gave relatively low weight to the need for autonomous self-determination or advance care planning. From their perspective, the preponderant values in decision-making at end-of-life were involvement of the family and decision-making through a communitarian ethic.

In English jurisdiction, autonomy is the bedrock of the traditional paradigm for self-determination at end-of-life and is the basis for treatment refusal. It encompasses concepts of privacy and freedom to choose, and is linked with notions of liberty, dignity and independence from obligation.¹⁹ The law robustly protects the competent adult's right to refuse even life-saving treatment.²⁰ From a Kantian perspective, autonomy emerges from transcendental freedom. This freedom represents the power of the will to choose an end for itself. One does not consult any other empirical conditions, as by doing so would diminish the action of free will.²¹ Yet for participants, the value of autonomous choice was marginal.

It was not therefore surprising that similar lack of interest extended to prospective decision-making by way of advance decisions. In fact, this topic generated relatively little discussion. The expectation was that a relative or family member would be able to decide for a person lacking capacity. In English law, respect for prospective autonomous choice is protected by the Mental Capacity Act 2005, which also provides for the ability to create an advance decision or a lasting power of attorney for healthcare decisions to apply in the event of future

¹⁸ H.M. Ducharme, 'The Image of God and the Moral Identity of Persons: An Evaluation of the Holistic Theology of Persons', in *Law and Religion*, ed. R. O'Dair & A. Lewis (Oxford: Oxford University Press, 2001) 1-25.

¹⁹ G. Dworkin, *The Theory and Practice of Autonomy* (Cambridge: Cambridge University Press, 1998).

²⁰ *Re B (Adult: refusal of treatment)* [2002] EWHC 429 Fam; *Re AK (Medical treatment: consent)* [2001] 1FLR 129.

²¹ H.E. Allison, *Kant's Theory of Freedom* (Cambridge: Cambridge University Press, 1990).

incapacity.²² The intrinsic value of advance care planning arises from the notion of rationality and prospective autonomy.²³ Yet such a paradigm may need to be re-evaluated within specific cultural contexts.

Family involvement in end-of-life decision-making was considered to be optimal. The moral responsibility that families often assume over their relatives will tend to sway healthcare deliberations. Family members might be expected to have valuable insight about an incompetent patient's conception of the 'good' as well as that person's values and preferences. The family might be expected to play an important and munificent role in decision-making. Failure to engage with the family at end-of-life could lead to breakdown of trust, particularly if there is an expectation that family members make decisions on behalf of sick relatives.²⁴ In Asian cultures, it is not uncommon to include sons and daughters in medical decision-making, and the moral basis for this rests on concepts of filial piety and family autonomy.²⁵

A recent study involving in-depth interviews of patients with long-term illnesses, and their relatives, was carried out within the NHS.²⁶ Relatives became active participants in discussions and patients often sought their relatives' endorsement for their decisions. In these situations the family is often conceptualised as an autonomous unit which has led to the concept of 'family autonomy'.²⁷ A competent patient may consider benefits to other family members who may expect their own interests to be taken into account. Thus benefit with a family unit as an entity may be achieved at some cost to the individual, who may decide that the family is a high priority.

At times this ethic may extend more widely than to members of the immediate family. In life, reliance on and support of others is inevitable and an individual might come to a conclusion that is influenced by the concept of *sensus communis*. Thus the value attributed to decision-making at end-of-life is a relativistic one and involves striking a balance between self-determination and giving effect to

²² J. Samanta, 'Lasting Powers of Attorney for Healthcare under the Mental Capacity Act 2005: Enhanced Prospective Self-determination for Future Incapacity or a Simulacrum?', *Medical Law Review* 17 (2009): 377-409.

²³ A. Hurka, 'Why Value Autonomy?', *Social Care in Practice* 13 (1987): 361.

²⁴ E. Hui, 'A Confucian Ethic of Medical Futility', in *Confucian Bioethics*, ed. R.P. Fan (Dordrecht: Kluwer Academic Publishers, 1999).

²⁵ H. Lindemann Nelson & J. Lindemann Nelson, *The Patient in the Family. An Ethics of Medicine and Families* (London: Routledge, 1995).

²⁶ R. Gilbar, 'Family Involvement, Independence in Patient Autonomy in Practice', *Medical Law Review* 19 (2011): 192-234.

²⁷ R.P. Fan, 'Self-determination versus Family Determination: Two Incommensurable Principles of Autonomy', *Bioethics* 11 (1997): 309-322.

essential extrinsic factors. The attitudes of others, and their interest in the individual, cannot be wholly ignored because of shared values. This could be linked to transmitting commonly held values at end-of-life. Modern versions of autonomy have therefore focused on the formulation of relational autonomy. While recognising individuals as free agents, relational autonomy nevertheless emphasises a reliance on others to support decision-making and is based upon a dynamic reciprocity between the individual and others who are closely involved. End-of-life decisions tend to be made within social contexts, at least to a degree. From the perspective of South Asian values, an individual has responsibility to respect and take into account the interests of the family and the community. Such a view might call for a reconfiguration of thinking in the minds of those more familiar with westernised models. Relational autonomy does not deny the importance of personal freedom. Instead it aims to promote decision-making within the context of shared interaction, experiences and values, all of which are fundamental to life.

Critical reflection on the study

The current qualitative study was designed to explore the values attributed by South Asians to the key principles that govern end-of-life care. Focus groups were used as a means of generating interaction between participants. The group process was harnessed to enrich the discussions, and diversity within the group provided added value. The main feature of this method is that it combines opportunity for accessing information with discussion and deliberation, thereby providing an enriched output of thoughts, views and ideas. Reflection and refinement of the views are used to reframe emergent issues to encourage a deeper consideration by the participants and to develop key themes.

As with all qualitative studies, some limitations remain. It cannot be assumed that the sample was wholly representative, but the authors aimed to describe a diverse range of experiences and views within this specific cultural group. However, only one cultural group was targeted and participants represented just two faiths, Hindu and Islam. Furthermore, the study did not canvass the views of persons actually at end-of-life.

Implications for practice and research

This study is unique and provides valuable insights into cultural values that could feed into a framework for end-of-life care. There are relevant implications for clinical care and the development of policy and processes within NHS organisations. Providing more detailed guidance in respect of end-of-life care for minority ethnic groups would enable harmonisation with human rights legislation and the Equality Act 2010.

There are also implications for legal doctrine. Consideration needs to be given as to how race, religion and culture intersect, and whether these characteristics

ought to be teased out, rather than being bundled together in order to categorise the identity of the claimant. A further area of enquiry might be that of discrimination at the intersection of race, religion and ethnicity. Relatively little attention has been given to culture and ethnicity compared with gender or sexual orientation. Given the increase in the minority ethnic populations within Britain, it seems likely that there will be development of jurisprudence in this area.

Conclusion

The cultural values that are attributed to end-of-life care were explored using focus groups of South Asian participants. There was a consensus that dignity and equality were fundamental concerns. With regard to faith, core values included the right to express faith, freedom of religion and culture-based spirituality. In respect of decision-making, autonomy (either contemporaneous or prospective) was accorded relatively low weight and emphasis was given to family involvement and a communitarian ethic. A number of these outcomes in respect of core values reflect a culturally specific mindset. Such values need to be recognised and incorporated into practice if real meaning is to be given to protection of human rights and equality at end-of-life.

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