Samanta, J., Samanta, A., & Madhloom, O. (2018). A rights-based proposal for managing faith-based values and expectations of migrants at end-of-life illustrated by an empirical study involving South Asians in the UK. *Bioethics*, *32*(6), 368-377. https://doi.org/10.1111/bioe.12447

Peer reviewed version

Link to published version (if available):
10.1111/bioe.12447

Link to publication record in Explore Bristol Research
PDF-document

University of Bristol - Explore Bristol Research
General rights

AUTHORS*

ABSTRACT

International migration is an important issue for many high-income countries and is a situation that is accompanied by opportunities, as well as challenges. South Asians are the largest minority ethnic group in the United Kingdom and this diaspora is reflective of the growing diversity of British society. An empirical study was performed to ascertain the faith based values, beliefs, views and attitudes of participants in relation to their perception of issues pertaining to end-of-life care. Empirical observations from this study, as well as the extant knowledge-base from the literature, are used to support and contextualise our reflections against a socio-legal backdrop. We argue for accommodation of faith based values of migrants at end-of-life within normative structures of receiving countries. We posit the ethically relevant principles of inclusiveness, integration and embedment, for an innovative bioethical framework as a vehicle for accommodating faith based values and needs of migrants at end-of-life. These tenets work conjunctively, as well as individually, in respect of individual care, enabling processes and procedures, and ultimately for formulating policy and strategy.

INTRODUCTION

The current scale of international migration is an important issue for many high-income countries, a situation accompanied by opportunities as well as challenges.[1] In Europe, Germany witnessed the largest increase in international migration and between 2014 and 2015 the United Kingdom (UK) saw an increase of twenty-four per-cent.[2] Data from the most recent UK census reveals significant changes in ethnic and religious diversity.[3] Since 2001 the proportion of White British dropped from 87.5% to 80.5% of the population. There were four million fewer Christians in England and Wales in 2011 compared with 10 years previously and there has been a substantial increase in the number of persons professing non-Christian faiths, or no religious belief. While the UK has accepted migrants for centuries, the last decade has been different particularly in respect of free movement of mainly younger, economically active, persons from Eastern Europe.

Despite recent demographic trends from Eastern Europe, South Asians (who began to arrive in the UK nearly seventy years ago) remain the largest minority ethnic group in the United Kingdom.[4] Many of these first generation migrants are now reaching the ends of their lives and the availability of responsive end of life care has become a new priority.

It has long been recognised that views and perceptions of end of life care are diverse and tend to be influenced by notions of culture, faith and belief. Although the population of Britain has traditionally been Christian a significant proportion is affiliated to other religions or to no religion at all.[5] Faith and religious belief can be expected to have particular significance at end of life where philosophical, moral and spiritual considerations are likely to engage.

---

[1] The Organisation for Economic Co-operation and Development (OECD). 2015. Comprehensive and co-ordinated international response needed to tackle refugee crisis.
Available at: http://www.oecd.org/migration/comprehensive-and-co-ordinated-international-response-needed-to-tackle-refugee-crisis.htm
(http://www.oecd.org/migration/comprehensive-and-co-ordinated-international-response-needed-to-tackle-refugee-crisis.htm) [Accessed 07 July 2017].
[2] D. Barrett. 2015. Migration to Britain Sees One of the Largest Shifts in the Developed World, Says OECD Report. *The Telegraph*.
Available at:
http://www.telegraph.co.uk/news/uknews/immigration/11881723/Migration-to-Britain-sees-one-of-the-largest-shifts-in-the-developed-world-says-OECD-report.html
(http://www.telegraph.co.uk/news/uknews/immigration/11881723/Migration-to-Britain-sees-one-of-the-largest-shifts-in-the-developed-world-says-OECD-report.html) [Accessed 07 July 2017].
[3] Office for National Statistics (ONS). 2011. Census 2011. Religion in England and Wales.
Available at: http://www.ons.gov.uk/
(http://www.ons.gov.uk/) [Accessed 07 July 2017].
[4] Ibid.
[5] Office for National Statistics. Census 2011. Religion in England and Wales 2011. Http://www.ons.gov.uk/ [Accessed 07 July 2017].

A liberal and economically developed society ostensibly respects and recognises the rights of persons and purports to uphold values such as tolerance, equality and diversity in the context of its trans-cultural socio-legal framework. These values are exemplified by initiatives such as reforms to the equality and diversity agenda, as well as the more established human rights jurisprudence which collectively proscribes discrimination by service providers on grounds that include religion and belief.

The right to freedom of religion or belief is enshrined in Article 9 of the European Convention on Human Rights. The scope of this freedom has broad application and confers absolute protection to the internal dimension of religious belief ('forum internum') and proscribes coercive interference with freedom to have, or adopt, a religion or belief of one's personal choice. In respect of freedom to express or manifest personal faith or belief ('forum externum') restrictions may be applied in order to pursue a legitimate aim. Nevertheless, any restriction must be a proportionate response.[6]

In Great Britain legal recognition of freedom of religion (or none) has become clear following implementation of the Equality Act 2010. Section 4 of the Act describes 'religion and belief' (or none) as being a protected characteristic where 'religion' means any religion and 'belief' means any religious or philosophical belief.[7] It is unlawful for service providers or those exercising a public function, to discriminate, harass or victimise those with a protected characteristic.[8] This duty is accompanied by positive obligations to have 'due regard' to equality of opportunity and the need to foster good relations.[9] In the UK it remains the case that most people die in public hospitals. All public bodies that provide end-of-life care therefore have a positive duty to promote equality of opportunity and good relations between people of different faiths as well as the secular. Service users are protected when requesting services as well as during service provision and provider organisations and those exercising public functions have a duty to make reasonable adjustments.[10]

In a previous paper we presented aspects of a focus group study that pertained specifically to perceptions of South Asians cultural values in respect of end-of-life care. [11] The key

---

[6] *P.M. Taylor. 2005. Freedom of Religion. UN and European Human Rights Law and Practice.*
[7] s.10 Equality Act 2010.
[8] Part 3 (including sch. 2 and 3) Equality Act 2010.
[9] s.149 Equality Act 2010.
[10] s.29(7) Equality Act 2010.
[11] *J. Samanta & A. Samanta. Exploring cultural values that underpin the ethical and legal framework of end-of-life care: a focus group study of South Asians. J Med Law and Ethics 2013; 1: 61-72.*

values that emerged were dignity, equality, religious beliefs and relational acceptance of decision making for themselves by others (with lesser reliance on self-determined choice).

In this paper we propose a bioethical framework that accommodates religious and faith-based values of migrants at end-of-life, within the normative canvas of receiving countries. We articulate this innovative framework on the basis of our personal reflections embedded within an ethical and socio-legal context, and illustrated by empirical observations obtained from a focus group study of South Asians living in the UK. Its message is relevant for all countries that are experiencing increased migration of diverse populations.

THE EMPIRICAL STUDY

For the purpose of this article 'South Asians' are persons who originate through their family line from the Indian sub-continent, and who self-identify themselves as such in respect of their ethnicity. In the main they comprise either first, or second, generation migrants to the UK. Although the focus of this article is "faith based", ethnicity (as opposed to "race") nevertheless remains a relevant category as values and attitudes of persons are linked to both culture and ethnicity. The categorisation of race and ethnicity has been helpfully clarified by a research project that was conducted at Ludwig Maximilians Universitat Munchen Institute for Sociology. [12] Racial categorization is based upon grouping by a commonality of physical, biological and genetic traits usually resulting from ancestry. Ethnic categorization is founded on a commonality of geographic origin, language and culture resulting in values that may be shared and held in high esteem by members of that group. Our study focuses on the latter. We therefore do not see the need for digression into race, but hold that ethnicity is relevant for our discourse.

The study took place in Leicester, a city in the Midlands, which has one of the largest Asian/Asian-British populations. Ethical approval was obtained from De Montfort University, Leicester. Prior to commencement outline details of the study aims and objectives were given to participants. Consent was obtained for the discussions to be digitally recorded. The participants were self-selected members of the South Asian community who responded to an advertised call (made on our behalf) by the Leicester Centre for Ethnic Health Research. The Centre has a public consultation panel and an established acumen for supporting research

---

[12] This was conducted under the lead of Prof. Dr. Hella von Unger: https://bibliothek.wzb.eu/pdf/2014/iii14-601.pdf [Accessed 07 July 2017]

projects that seek to recruit participants of black minority ethnic origin. Participants were of both genders, of Hindu and Islamic faiths, and were born abroad or in the United Kingdom. The age range was between 28 and 72 years. In total there were 12 participants, six males and six females, seven Hindu and five of Muslim faith.

A qualitative approach was chosen to ascertain the values, beliefs, views and attitudes of participants in relation to their perception of issues pertaining to end-of –life care. Two focus groups of two hours duration were facilitated during which participants were encouraged to interact among themselves rather than with the facilitator who intervened, at times, to clarify ambiguities and challenge apparent inconsistencies. Participants were asked to express their views in terms of what they would expect for someone of their faith or religion, in respect of end-of-life care provided within an institutional setting in the receiving country. They were to do so by reflecting (separately) upon two hypothetical scenarios: first, if the recipient was a known close family member, and second, if the recipient was a distant unknown person.

Verbatim transcripts were generated within a week of each session, verified for accuracy against the voice recordings, and then played back to ensure that the speech extractions were mapped appropriately to follow each individual's personal contribution. Unabridged transcripts were used to enhance the rigor of the strategy.[13] An open coding system was used followed by axial coding to identify generic categories themes and link these to their subcategories[14] using a variant of content analysis with words and phrases being assigned to the generic categories. In order to ensure verifiable results and to reduce the possibility of bias, two persons worked independently on the data. Collaborative discussion of the findings took place (between JS and AS) in order to avoid critical issues being overlooked.

EXPLICATION OF FINDINGS AND DISCUSSION
   a) Methodological challenges

Perhaps because of the nature of the subject, we received an outpouring of personal tales with emotive stories that contained sensitive information. As a result, after having analysed the transcripts, we determined that the usable data in terms of verbatim quotations would be

---

[13] *M. Bloor, J. Frankland & M. Thomas, K. Robson. 2001. Focus Groups in Social Research. London, Sage Publications Ltd; R. A. Krueger. 1998. Analysing and Reporting Focus Group Results. London; Sage Publishing: 128; V. Braun & V. Clarke. Using Thematic Analysis in Psychology. Qual Res Psychol 2006; 77: 77–101.*
[14] *A. Strauss & J. Corbin. 1998. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. London: Sage Publications.*

limited. However, there were a number of extractions that were potentially valuable from an ethical perspective.

We are mindful of the growing use of empirical research to inform debate in normative ethics. This has been deployed principally for gathering qualitatively rich data, and using the methods of research from the social sciences.[15] It is quite rightly urged that empirical data in the context of ethics should be used cautiously and responsibly so as not to distort results inadvertently and thereby generating misleading normative ethical conclusions. Marcel Mertz and colleagues have helpfully set out a "road map" with detailed criteria for conforming to empirical research in ethics.[16] Nonetheless we are equally mindful that in combining ethics with empirical data, a useful starting point is people's actual beliefs, intuitions and other attributes such as values and attitudes.[17]

With this in mind we recourse to a "hybrid methodology" which we believe is best suited to encompass the transdisciplinary arc of clinical practice and law within which our expertise lies. We present our findings and subsequent discussion in the light of a perspective that attempts to integrate socio-empirical and normative methods. In this paper we use extractions from the data sets to illustrate concepts of key relevance to the area of managing faith based values and expectations of South Asians (of Hindu and Muslim faith). Illustrative quotations have been infused within the discussion to maintain fluidity of discourse. The sources of contributions are indicated according to gender and religious denomination: Muslim male; Muslim female; Hindu male; and Hindu female.

The key concepts that we elaborate upon are (i) an intrinsic right to religious and faith based values at end-of-life; (ii) the right to respect for freedom of religion at end-of-life; and (iii) culture dependent spiritual beliefs pertaining to death. Our framing of these key concepts is reflective and dually founded upon several years of clinical experience (AS) of caring for patients from a migrant South Asian background,[18] as well as educed from academic

---

[15] See for example *Haimes E. What can the social sciences contribute to the study of ethics? Theoretical, empirical and substantive considerations. Bioethics 2002, 16(2):89-113*. See also *Borry p, Schotsmans P, Dierickx K. The birth of the empirical turn in bioethics. Bioethics 2005,19(1):49-71*

[16] *Mertz M, Inthorn J, Renz G, Rothenberger L G, Salloch S, Schildman J, Wohlke S, Schicktanz S. Research across the disciplines: a road map for quality criteria in empirical research. BMC Medical Ethics 2014,15:17*

[17] *Borry p, Schotsmans P,Dierickx K. Empirical Ethics: A Challenge to Bioethics. Medicine, Healthcare and Philosophy 2004,7:1-3*

[18] *Samanta A, Johnson M R D, Guo F, Adebajo A, Snails in Bottles and Language Cuckoos: An Evaluation of Patient Information Resources for South Asians With Osteomalacia Rheumatology 2009, 48 (3):299-303; Samanta A, Shaffu S, Panchal S et al., Tinkering at the edges or collaborative symbiosis? Ethnicity and*

literature, which can be an effective way of maximising the utility of the collective knowledge-base and is an important source of information.[19] We contextualise our discourse against a socio-legal background to enable us to articulate the principles for an innovative bioethical framework for accommodating minority faith based needs at healthcare organisational level. We hope that the proposed framework may have some impact upon informing policy-makers as to the management of minority faith-based values at end of life.

For a hybrid methodology it cannot be claimed that the conventions of any one of the disciplines (law, clinical practice and ethics) that perfuse this study must be followed strictly as there is no standardized way (as yet) of describing a process for epistemic integration across disciplines. However, we do not believe that the approach we have taken detracts from the usefulness of this study, because to the best of our knowledge, there is very little similar data from countries receiving South Asian diaspora. We believe that our observations will add value to the literature in these areas of academia and practice.

b) An intrinsic right of religious and faith based values at end-of-life

Freedom to practice rituals of religious significance at end of life was a shared expectation of participants. But the question remains as to why the beliefs of any minority group should merit special recognition in policy, as well as protection in law. Respect for faith and religious belief derives from the historic suppression of minority groups by dominant populations and is founded upon sociological arguments that minority interests and characteristics such as culture, ethnicity and religion are worthy of protection.[20] From the perspective of cultural anthropology the normative content of concepts such as race, rights and religious minorities has evolved from a shared origin and influenced by the development of minority rights that have ancestry in religious ideology. It is from here that respect for faith

---

rheumatology: a consensual review discussion. Diversity and Equality in Health and Care 2012, 9: 209-217; Samanta A, Shaffu S, Ethnicity and musculoskeletal health: Census and consensus. Diversity and Equality in Health and Care 2012, 9: 219-222.

[19] *See for example, Gleit BG, Graham B. Secondary data analysis: A valuable resource. Nursing Research 1989, 38(6);380-381. See also Hinds PS, Vogel RJ, Clarke-Stefan L. The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. Qualitative Health Research 1997, 7(3): 408-424*

[20] *N.M. Stolzenberg. Righting the Relationship Between Race and Religion and Law. Oxf J Leg Stud 2011; 31(3): 1-20.*

and belief have developed alongside ethnicity and culture to become major players on the contemporary legal and political scene.

Attempts to avoid religious conflict lie at the heart of policies of tolerance that have evolved subsequently into laws and policies to protect minority rights. Recognition of religion as a human right can be viewed as part of the wider notion of respect for 'peoplehood' in representing the depiction of the person as part of a unified collective, or else as a shared value belonging to a defined class of persons.[21] Nevertheless, these societal values that depict the universality of human rights have developed from the wellspring of Western thought and it is these same thoughts and values that have transmuted into ideals of almost global influence. The extent to which assumptions such as these can still be justified, or whether such ideals represent a form of cultural hegemony, is debatable.

An accepted formulation of the universal right to freedom of religion might be representation by its application in a way that reflected characteristics of identity including diversity, religion, or culture. One participant referred to the recent death of her father by explaining that the (White British) general practitioner had handled end-of-life care sensitively by respecting the family's religious rites and needs, and emphasised that "we were allowed to do everything according to our religion".[22] The real relevance of this universal right, particularly in the context of care of the dying, was to embed a genuine ethos of diversity based upon religious liberty as a collective interest for all, irrespective of race or religion. This was exemplified by a participant who said that if "a person is dying he must have respect – it does not matter who he is or what religion". [23]

One participant argued that the expression of faith and religious belief at end of life should be unrestrained on the basis that this was "a right since this is part of our society, our beliefs and our culture."[24] Section 13(1) of the Human Rights Act 1998[25] 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

---

[21] Ibid.
[22] Muslim female participant (DW)
[23] Hindu male participant (QJ)
[24] Muslim female participant (VE)
[25] *P. Cumper. 2000. Religious Organisations and the Human Rights Act 1998. In Law and Religion in Contemporary Society: Communities, Individualism and the State P. W. Edge & G. Harvey, eds. Aldershot: Ashgate: 17 – 30.*

right." In essence, this implies that the courts ought to give privileged attention to collective aspects of religious liberty. In protecting this right it is assumed that where there is conflict the concept of collective liberty ought to prevail justified on the basis of proportionality. Collective religious liberty operates to empower communities who share a common faith and who structure and organise their lives according to the principles of their religious ideals. While the effects will be felt principally on community life, which in turn impacts upon the lives of individuals, its scope is wider than Article 9 and extends to privileges that can incorporate (inter alia) hospital care.[26]

Religious communities can, at times, carry out functions similar to those of the state. These functions, for example, include marriage, education, burial and care given before, or at the time of, death. This was illustrated by one participant who stated that: 'In my religion [Islam] administering simple hygiene at the time of death should be left to the family and [my religious] community rather than non-Muslim doctors or nurses.' This was because care given by a person of a different gender to the patient could be detrimental spiritually.[27] For followers of Islam the need for expedited disposal of the body is imperative and a definitive timeframe exists. Lack of appreciation or facilitation, along with direct or indirect constraints, could lead to avoidable delays and the possibility of indirect discrimination. This was a major consideration for one participant because the body needs to be buried on the day of death.[28]

Recognition and facilitation of such aspects of religious liberty cannot be achieved without privileging religious perspectives, or practices, of minority groups. Whilst a liberal democracy might not wish to debate questions of religious truth, the state is nonetheless compelled to weigh the relative values of expression of religious belief. A commitment to religious rights and immunities represents a form of 'passive' protection in that it represents a refusal to use state force to modify behaviour based on a conviction of righteousness founded upon religious belief (subject to the derogations of Article 9(2). This compares with the granting of specific privileges, as a form of positive protection, based upon the assessment of specific religious rituals and needs at end of life in the context of the perceived value of that religion's impact upon society.

---

[26] *J. Rivers. 2000. From Toleration to Pluralism: Religious Liberty and Religious Establishment Under the United Kingdom's Human Rights Act. In Law and Religion. Rex J. Ahdar ed, Aldershot: Ahsgate: 133 – 162.*
[27] Muslim female participant (UF)
[28] Muslim female participant (VE)

Although collective religious rights are recognised in law it is debatable whether these rights have a separate and independent existence.[29] Collective rights derive from individual interests and gain validity and value from the constituents of that collective. Historically, protection of religious interests has been used to prevent conflict caused by religious diversity. From a utilitarian perspective this protection might seem to be a relatively weak interest and one to be prevailed upon readily if this is likely to conflict with the competing rights of others. Calls, for example, have been made to withdraw state funding from the Multi-faith Group for Healthcare Chaplaincy.[30]

A more fundamental reason for protection is based upon respect for dignity.[31] Although the individual is the primary right holder, the collective dimension cannot be ignored since its value derives from the multiplicity of discrete personal interests. The shared concern of several participants was that failure to recognise religious interests as a collective right at end of life would be stark evidence of subjugation of minority faith groups by secularism. If no protection was afforded then this meant that their religion and faith was unrecognised. The consensus was that 'There is a huge knowledge gap in hospitals between what is provided and what we want on the basis of our religious beliefs.'[32]

Whether the state should maintain impartial neutrality between the religious beliefs of people or whether these beliefs ought to be incorporated into the fabric of state policy, to facilitate manifestation of such beliefs through state emanations such as the National Health Service (as a government organisation), is moot. Rightly, or wrongly, in the UK there is no neutrality between the state and the Church which is part of the constitutional structure. Secularism, founded on the concept of a clear divide between the religious and non-religious, is unlikely to be perceived as neutral by the devout. The non-allowance, non-acceptance or even neutral stance taken by public organisations towards manifestation of religious beliefs may lead to alienation of followers and compel the faithful to behave contrary to their preferred ideal.[33]

---

[29] *J. Rivers. 2010. The Law of Organised Religions: Between Establishment and Secularism. Oxford: Oxford University Pres; B. Parekh. 2000. Rethinking Multiculturalism: Cultural Diversity and Political Theory. London: Palgrave.*

[30] National Secular Society (NSS). 2012. NSS Briefing: Hospital Chaplaincy. Available at: http://www.secularism.org.uk/uploads/nss-hospital-chaplaincy-campaign-briefing.pdf (http://www.secularism.org.uk/uploads/nss-hospital-chaplaincy-campaign-briefing.pdf) [Accessed 07 July 2017].

[31] *R. Dworkin. 1985. A Matter of Principle. Massachusetts: Harvard University Press; R. Dworkin. 1997. Taking Rights Seriously. London: Bloomsbury Academic.*

[32] Muslim male participant (ZA)

[33] *B. Parekh. 2000. Rethinking multiculturalism: Cultural Diversity in Political Theory. 2nd ed. London: Palgrave Macmillan.*

One narrow secularist view is that religion ought to be a matter confined to the private realm. This perspective, however, might not align with the ethos of a publicly funded national health service (as in Britain) and where the majority of deaths still occur in hospitals. Lack of policy in this area carries risk that health professional discretion might prevail over faith-based end of life preferences and all the more so given the imbalance in power between health professional and patient.

At end of life the notion of religion and its linked spirituality can be of crucial importance to the individual, the family and the wider community. A dichotomy between manifestation of religious belief and secular acceptance of the same could cause tension. If policymakers feel bound to prioritise the religious perspective (or none) of the majority then this could impact negatively upon minority groups. A middle path is needed that draws upon both reason and faith in decision making that can be expected to impinge upon personal choice about how to die in a hospital.[34] Participants felt that as members of minority faiths they had a right to a defined space for religious expression within this public domain. As an example, a comment was made emphasising that it was necessary to raise the 'religious rights of [minority group] patients and make them aware of these rights.'[35]

c) The right to respect for freedom of religion at end-of-life

Religious freedom at end of life was expressed strongly by one participant who felt that: 'Our religious sensitivities need to be respected. We are entitled to this right'[36] Debates about law and freedom of religion tend to be argued from two sides. One perspective, grounded in equality and parity of religious and secular belief argues against conferment of privilege upon religious perspectives and ideologies.[37] This approach, in effect, removes religion from the equation and in so doing prevents its selection for prejudice, or partiality. With regard to end of life care, the liberal humanitarian approach would be to flexibly consider the needs of each and every individual on an empathic and personalised basis as opposed to an application of rule-based process designed chiefly to mitigate against discrimination. Pro-forma based end of life care plans, for example, prevent religious belief from being selected for preferential

---

[34] *E. Wicks. Religion, Law and Medicine: Legislating on Birth and Death in a Christian State. Med Law Rev 2009; 17(3): 410 – 437.*
[35] Hindu male participant (SH)
[36] Hindu male participant (SH)
[37] *L.G. Sager. 2008. The Moral Economy of Religious Freedom. In Law and Religion in Theoretical and Historical Context. P. Cane, C. Evans & Z. Robinson, ed. Cambridge: Cambridge University Press: 16 – 25.*

recognition and favour with the touchstone as 'equality' rather than respect for religion or belief.

The alternative approach is that religion has an essential quality of inherent worth.[38] This calls for respect for religion and belief as a core characteristic, recognised as intrinsically valuable, which justifies rights to freedom of religion. A potential problem with this approach is the wide variation in beliefs and practices. Distillation of an irreducible core of divergent religions is not simple.[39] For one participant the principal need was for '... raising rights of patients and making them aware [as this] will allow translational conveyance of the message to the clinical staff.'[40] On probing the point it was apparent that the 'message' that participants wanted to convey consisted of two components: first, that minority non-Christian faiths (in common with Christianity) held a core element that was prized by the devout; second, that one's inner values were reflected in religious belief. At times these components tended to be conflated during cross-discussion within the group. There was an expectation that: 'People giving medical care at end of life should respect ethical and moral religious implications'[41] . This was supported by a comment 'I think that personal values should be taken into account like washing and hygiene [at end of life].'[42] Expressions such as these would suggest that consideration of one's own inner beliefs and attempts to define a synergy with these and other existing values might not wholly align in respect of migrant group expectations from the receiving country.

For participants the overarching expectation was that the NHS, as a public body, would facilitate religiously motivated end of life requirements deemed necessary by the faithful based on their religious beliefs. This would align with a liberal state which recognises and supports an equitable value system. Participants felt that 'There is a huge knowledge gap between what is provided [by the NHS] and what [followers of minority faiths] want,'[43] and that it was important for health professionals to understand and respect religious feelings. [44] This was particularly apparent at end of life when 'personal values should be taken into account' when religious and cultural 'sensitivities need to be respected.'[45] There are two

---

[38] *J. Webber. 2008. Understanding the Religion in Freedom of Feligion. In Law and Religion in Theoretical and Historical Context. P. Cane, C. Evans & Z. Robinson, ed. Cambridge: Cambridge University Press: 26 – 43.*
[39] *R (Hodkin & Anor) v Registrar General of Births, Deaths and Marriages* [2013] UKSC 77
[40] Hindu male participant (QJ)
[41] Muslim female participant (UF)
[42] Muslim female participant (DW)
[43] Muslim male participant (BY)
[44] Muslim female participant (VE)
[45] Muslim female participant(UF)

principal reasons for this. First, it is equitable and fair to all and yet compatible with the possibly strongly held beliefs of some individuals. Second, it avoids the need to justify (on grounds of political theory) the reasons why special recognition, or protection, on the basis of faith should extend to some, when those beliefs are not shared by all.[46]

d) Culture dependent spiritual beliefs pertaining to death

All participants held the view that a dignified death was paramount within their frames of reference. This was exemplified by reluctance to being just kept alive by artificial means: 'if there was) a high chance I would never regain consciousness, I would not want to be kept alive by machines,'[47] and that 'there is no point in being kept alive on machines if they do not wake you up.'[48] While conceptions of dignity were fundamental equally important was the support and presence of family and friends. There was a reluctance to accept medical treatment that preserved life in an impaired state of consciousness: "Look at the Liverpool Care Pathway. The main option is one of pain relief and you are dosed up. I do not believe in that. We, as Muslims, want to be alert for as long as possible in order to read our final prayers (Shahada) which is a declaration of faith".[49]

Similar views were held by others: 'That is a problem with Hindus as well. If you are dying you need to read Bhagavad Gita. You pass from one body to another. The person should be conscious for that.'[50] There was a clear expectation that a dignified death, on this interpretation, ought to be facilitated by public healthcare. The unanimous view was that if organisations could not provide the necessary environments for some aspects of spiritual beliefs as articulated as 'hospitals cannot help when the soul comes out of the body because you have to die' .[51] Participants were emphatic about the need to avoid treatments that could blunt conscious awareness at end of life. This need was founded upon belief of the need to allow passage of the immortal soul as a separate entity from the physical body.

From a Westernised perspective it might be difficult to appreciate why some minority faith groups consider that consequences could be devastating if specific spiritual rituals are not

---

[46] *D. Meyerson. Why Religion Belongs in the Private Sphere, not the Public Square. In Law and Religion in Theoretical and Historical Context. P. Cane, C. Evans & Z. Robinson, ed. Cambridge: Cambridge University Press: 44-71.*
[47] Muslim female participant (DW)
[48] Hindu female participant (RI)
[49] Muslim female participant(UF)
[50] Hindu male participant(LO)
[51] Hindu female participant(TG)

adhered to at end of life. Assumptions that modern Christian theological beliefs ought to prevail over non-Christian dualism that characterises the beliefs of some minority faith followers can cause tensions, particularly if the beliefs of the latter are injured in some way around the time of death. The concept of man as a unified being is a solipsistic conclusion that can be challenged on the basis that dualism has been the consensus for centuries. In fact, the pre-Darwinian traditional concept of the soul as the incorporeal entity of divine creativity derives from orthodox Western theology.[52] By comparison, the 'no soul' doctrine as typically employed in its modern (Western) formulation, has been dominant only for the last century or so.[53] Dualism, as a commonplace view in everyday life and morality (right versus wrong) might be expected to permeate circumstances normatively at end of life. Faith and religious belief are often governed by traditional customs and systems. Within the framework of law and jurisprudence in a multi-cultural society these customs and systems need explicit acknowledgement by the courts in the event of litigation that involves freedom of religion.

Faith based practices and rituals carried out at the time of death may have profound significance for the dying individual and their loved ones. Yet facilitating these practices within mainstream health services may present real challenges.[54] Empirical evidence suggests that at the time of death, and during bereavement, the prevailing characteristics are emotional intensity, existential anxiety and spiritual or religious concerns.[55] Minority ethnic faith groups may commemorate death from an explicit faith based perspective set in the nuanced context of belief in the divine and the afterlife which demands preparation, and never more so than at the time of death.[56]

While every religion incorporates a common, deeper strand that reflects a universal element of the psycho-spiritual experience, some attitudes to spirituality are faith specific. One study carried out in a non-European population revealed fundamental beliefs that gave comfort at

---

[52] *St Thomas Aquinas. Summa Theologiae, Ia, Q.90, art. 2, translated by E. Hill, (Vol. 13, 1964) 7-9; Augustine, The Trinity, Book 10, Chapter 10, Section 16, translated by E. Hill (1991).*

[53] *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: Current Legal Issue 2001; 4; Oxford: Oxford University Press 1 – 25. R. O'Dair & A. Lewis, eds.*

[54] *M. Lloyd. Embracing the Paradox: Pastoral Care with Dying and Bereaved People (Contact Pastoral Monographs No 5, Contact Pastoral Limited Trust, Edinburgh 1995); M. Lloyd. Philosophy and Religion in the Case of Death and Bereavement. J Relig Health 1996; 35: 295 – 3010. The long tradition of nurses recognising spiritual need in palliative care and at end of life is acknowledged in the literature and these professionals are likely to be most closely associated with the personal expression of belief at this time: see, M.O. Amante, Spiritual Care: The Heart of Palliative Nursing. Int J Palliat Nurs 1997; 3: 4; B.S. Barnum. 1996. Spirituality in Nursing: from Traditional to New Age. 2nd ed. London: Springer Publishing*

[55] *M. Holloway. Spiritual Need and the Core Business of Social Work. Br J Soc Work. 2007; 37(2): 265 – 280.*

[56] *S. Firth. 1999. Spirituality and Ageing in British Hindus, Sikhs and Muslims. In Spirituality and Ageing. A. Jewell, ed. London: Jessica Kingsley: 158 – 174.*

the time of death.[57] One of these was the importance of dying in a manner that ensures transmigration of the soul which characterises some faiths that are not practised by a substantial part of the European population. Family and friends are expected to facilitate the peaceful passing of the soul through the medium of religious and spiritual rituals in accordance with the inevitability of karma which resonates with conceptions of peaceful death for Hindus.[58]

Specific end of life rituals can be fundamentally important for the dying (and for their family and friends) in sustaining spiritual bonds and offering a sense of dignity and meaning during the transition from life. The adoption of a trans-cultural approach may well be a challenge for healthcare policy as well as the need to comply with equality and human rights.

    e) Limitations of the data

Due to resource constraints the data were derived from only two focus groups. Purposive sampling was used to invite 12 participants who were self-selected according to their interest in the research and on the basis of their self-identified religious affiliation. The study did not seek to draw a random sample and it cannot be inferred therefore that the results are representative, nor can they be presented as "scientific evidence". The focus of the empirical study was end of life care, and did not explore wider issues such as the attitudes of Hinduism and Islam to treatment decisions, palliative sedation or culturally related spiritual beliefs that favour consciousness thereby impacting upon pain and symptom management.

We do not aver that our data found normative recommendations. For the reasons above (as well as some already discussed as part of methodological challenges) we have used data to illustrate the themes of this paper. We offer our empirical observations in support of our reflective constructs within this area of humanitarian care at the time of death and align these with concepts arising from clinical experience as well as the literature.

A FRAMEWORK FOR ADDRESSING ETHICAL IMPLICATIONS FOR HEALTHCARE

---

[57] M. Holloway. Death the Great Leveller? Towards a Transcultural Spirituality of Dying and Bereavement. *J Clin Nurs* 2006; 15(7): 833 – 839.
[58] S. Firth, op. cit., note 53.

a) Faith based values and expectations as a moral right

In considering a rights-based approach to faith-based values at end of life Moskop argues: "Since the duty to provide adequate health care cannot be fulfilled by individuals, we will require a theory which posits important rights against society with corresponding social obligations and which seek to integrate such rights and obligations within a coherent and morally defensible social system".[59] Moskop applies Rawls' theory of justice as fairness to the distribution of healthcare,[60] which is built upon a theory of justice whereby all individuals matter equally and maximally[61].

For Rawls the question as to whether religious belief ought to be given special status and respect depends upon the interrelationship of the key concepts of 'comprehensive doctrine' and 'reasonable pluralism.'[62] A comprehensive doctrine combines value in human life and principles of personal character with ideals of friendship, family and associational relationships. Human reason is exercised within a framework of reasonable pluralism and represents plurality of reasonable (yet possibly incompatible) comprehensive doctrines. 'Comprehensive doctrines' may therefore be composed of a range of disparate values subsumed within reasonable pluralism and may encompass faith and religious belief. On this interpretation there should be nothing particularly distinctive about either faith or religion that would permit unusual privilege. Reasonable people should therefore be willing to set aside contested beliefs for the purpose of advancing the cause of justice as part of overall political ideology.

Rawls uses the 'justice as fairness' approach to justify protection of *individual* freedom of religion based upon liberalism as a political doctrine. Political liberalism is based upon social orders or a justified hierarchy of values. The tension that inevitably underpins this thesis relates to the validity that all reasonable people ascribe to purist principles of justice without recourse to *personal* privileges based on reasons of faith or belief. The reasonableness paradigm is wide and predicated on co-operation on even terms with all persons enjoying equal status.[63]

---

[59] *J. C. Moskop Rawlsian Justice And A Human Right To Health Care. J Med Philos 1983; 8(4): 329-38, 331.*
[60] *I. Kant. 1996. The Metaphysics of Morals. Cambridge: Cambridge University Press: 23.*
[61] *J. Rawls. 2000. A Theory of Justice. Oxford: Oxford University Press.*
[62] *J. Rawls. 1993. Political Liberalism. New York: Columbia University Press.*
[63] *J. Rawls. The Idea of Public Reason Revisited. Univ Chic Law Rev 1997; 64(3): 765 – 807.*

Rawls' justification for liberal rights (including freedom of religion) depends upon reasonable people's respect for equality of citizenship and co-operation on terms that are acceptable to all. This aligns with Kant's supreme principle of morality which requires us to: '[a]ct in such a way that you treat humanity, whether in your own person or in the person of another, always at the same time as an end and never simply as a means'.[64] A right, according to Kant, is '[a]ny action…if it can coexist with everyone's freedom in accordance with a universal law'.[65] Thus, a moral obligation must be capable of being applied universally, equally applicable to all individuals.[66] Consequently, the significance of a rights-based approach is that it recognises that each individual person is important. Individuals possess rights by virtue of the fact of being human.

b) A framework to accommodate faith based values and expectations

Based upon our personal and experiential reflections and our discourse supported by empirical observation we propose principles for a framework to accommodate faith based values and expectations of migrant groups at end of life, and suggest that this might assist receiving countries in providing ethnically and culturally sensitive care for this group of people. The ethically relevant principles that may have key implications for policy and healthcare derive are *inclusiveness, integration* and *embedment*. These tenets impact respectively on end of life care at individual, institutional and policy levels and are integral to the ethical values of virtue, tolerance and respect for the individual.

Inclusiveness

Globalisation, as well as international migration, has led to the mushrooming of cultural diversity in many receiving countries that were characterised previously by their long histories of monochromatic communities. It has long been recognised that lack of understanding of different cultures may lead to health disparities.[67] Racial stereotyping can also affect the ability of migrants to use public services.[68] These inequalities have predominantly been recognised in relation to physical diseases.[69] We have argued previously

---

[64] *I. Kant. 1969. The Moral Law. London: Hutchinson University Library: 91.*
[65] Kant, op. cit. note 60, p. 23.
[66] Ibid: 23.
[67] *A. Bischoff. Caring for Migrant and Minority Patients in European Hospitals: A Review of Effective Interventions. 2003. Basel: Swiss Forum for Migration and Populations Studies.*
[68] *N. A. Al Abed, P.M. Davidson & L. D. Hickman. Healthcare Needs of Older Arab Migrants: A Systematic Review. J Clin Nurs 2013; 23: 1770 – 1784.*
[69] *P. Rhodes & A. A. Nocon. A Problem of Communication? Diabetes Care Amongst Bangladeshi People in Bradford. Health Soc Care Community 2003; 11: 45 – 54.*

that healthcare providers have a duty to acknowledge the multiracial character of the populations they serve and be prepared to address these needs proactively.[70]

Recognition of diverse religious and faith-based values at end-of-life is essential for full inclusiveness of migrants within receiving societies and to provide needs responsive healthcare. We have already advanced rights based arguments in support which are buttressed by respect for the individual and protection of dignity. These values are of universal application premised on the basis of equality of persons. Although freedom of religion is enshrined in law, [71] meeting faith-based values at end of life is different and requires commitment to inclusion of people within the fabric of society, conceptually founded on moral, or humanitarian, rights.

The significance of this distinction relates to the subjective experience of the dying person, as opposed to an ideological commitment or preservation of an orthodox health professional rule or guideline. Pluralism of values at end-of-life implies that good care should properly be centred on the person's own conceptions on what is good. Unless there is true inclusiveness there will be a mismatch between expectations formed on diverse faith and religion-based values, and the experiences of the individual, as well as family members, at end-of-life.

Integration

In order to benefit the individual migrant, inclusiveness needs to be integrated into institutional processes. Integration requires acceptance and acknowledgement of inclusiveness and personal values. Participants in this study shared the expectation that those near to death had the right to manifest their religious beliefs openly in public and felt that there should be legal protection for the same.[72] Certain rituals motivated by religious belief may not align readily with normative Western values and therefore may be less likely to be acknowledged by healthcare professionals. By way of example, Hindu participants referred to the importance of bedside chanting by the extended family. Public expression of grief, such as weeping and wailing, were perceived as facilitative and a necessary requirement to ensure the safe onward passage of the soul. Furthermore, at end-of-life, certain religious rites demand that no foreign material is present in the body. A decision to follow this religious

---

[70] *A. Samanta, J. Samanta & M. R. D. Johnson MRD, et al. Rheumatoid Arthritis in Minority Ethnic Groups: Batons of Disease, Clinical and Social Cultural Features Amongst British South Asians. Divers Equal Health Care 2005; 2: 99 – 118.*
[71] Article 9 of the European Convention on Human Rights.
[72] Hindu male participant(KP)

ritual might conceivably conflict with medical advice. For integration, it is necessary to raise awareness and knowledge about minority faith-based and religious values at end-of-life. This requires education and training of staff at all levels so that health professionals are adequately equipped with the transactional skills for multi-cultural end-of life care. Such training needs to be disseminated widely and monitored, to ensure sustainable consistency for respect and empowerment of migrant values.

In addition to these educational imperatives, a further potential challenge is lack of resources. While undoubtedly important and a current priority, certain adaptations might be achieved relatively easily without incurring considerable expense. Muslim participants, for example, explained that wearing a *jilbab* a loose, full-length body covering, is required for devout persons at the time of death, and yet this option is not available routinely in hospital settings. The issue of wearing a *jilbab* (as part of school uniform) has been tested in the House of Lords.[73] Although the circumstances were different to those at end-of-life, the court was impressed by the 'immense pains' the school had taken to devise an inclusive policy to respect religious beliefs by engaging with local communities to ascertain real, as opposed to perceived, cultural and religious needs without detriment to the wider society and norms.

Integration at healthcare institutional level is based on an assessment of the needs of migrants, and addressed by raising awareness, providing training and developing services that are culturally compliant.

Embedment

For inclusiveness and integration to have real meaning, culture-specific values for end of life care need to be embedded in decision-making at all levels. Such embedment needs to be driven through strategy and policy in order to overcome obstructions to social cohesion within wider communitarian norms.

Within Europe, there is a large difference in health policy approaches that are directed at addressing migrant healthcare needs.[74] While some countries have tried to develop suitable initiatives, specific strategies are often lacking. This is despite recognising that over a decade ago the European Commission stressed the need to remove barriers of inequality, such as

---

[73] *Begum v Tenby High School* [2006] UKHL 15.
[74] *M. L. Vazquez, R. Terraza-Nunez & I. Vargas et al. Health Policies for Migrant Populations in Three European Countries: England; Italy & Spain. Health Policy 2011; 101: 70 – 78.*

health as well as the more general and universal needs of migrants, including end-of-life care, when vulnerabilities become more acute.[75] Although some focus has centred (over the last 40 years) on health needs,[76] less attention has been paid to health care needs more generally. The challenge for receiving nations will be to provide end of life and healthcare more generally for migrants with specific characteristics and requirements by translation into creative new models for the provision of such care.

The importance of early embedment cannot be overemphasised because any change from embedment takes time. England has a long history and experience in receiving migrants and having a National Health system that provides universal coverage and equal rights to access as for the native population. It promotes racial equality values[77] and supports the inclusion of minority groups in programmes that deal with health promotion.[78] Yet such initiatives [79] can be successful only if there is a clear recognition that embedment into health policy works most effectively in conjunction with integration into processes, along with inclusiveness of individual values.

Although hospitals must have an equality and diversity policy in place that is consistent with multi-faith perspectives, it is arguable that the public sector duty to advance the equality agenda could turn into a mere 'tick box' exercise that emphasises compliance with bureaucratic process rather than introducing positive change.[80] The achievement of real and substantive enhancement of quality and acceptance of the nuances of migrant faith-based values at end-of-life requires a new, proactive culture. A narrow approach based on policy objectives alone may have little effect other than perpetuating a restrictive regime for those of minority groups.

CONCLUSION

In this paper we argue that the faith-based and cultural values of migrants regarding end-of-life care expectations should be accepted and accommodated as part of the receiving

---

[75] Badilla B, Pereira M. Health and migration in the EU: building a shared vision for action. Challenges for health in the age of migration. *Lisboa: health and migration in the European Union*; 2007

[76] *L. A. Aday, R. M. Andersen. A Framework for The Study of Access to Medical Care. Health Services Research 1974; 9: 208 – 220.*

[77] *Department of Health, Race Equality Action Plan. London: Department of Health; 2004.*

[78] *Department of Health. Single equality scheme. 2007 – 2010. London: Department of Health; 2007.*

[79] *Department of Health. Religion or Belief: a practical guide for the NHS. London: Department of Health; 2009.*

[80] *L. Vickers. Promoting Equality or Fostering Resentment? The Public Sector Equality Duty, and Religion and Belief. Legal Studies 2011; 31: 135 – 158.*

country's societal norms. End of life care is a live theme at a time when increasing international migration is leading to new challenges for providers of public healthcare. We argue that an expectation for tolerance of these values is supported on the ethical basis of a moral right.

However, it would be jejune to merely acknowledge such an entitlement. Supportive healthcare systems are necessary for actual fulfilment of these values, by enabling care at end-of-life that is meaningful spiritually, as well as physically.

In order to achieve this, we have posited the ethically relevant principles of inclusiveness, integration and embedment, for a bioethical framework as a vehicle for translating a moral supposition into practice. These tenets work conjunctively, as well as individually, in respect of individual care, enabling processes and procedures, and ultimately for formulating policy and strategy.