

**End-of-life Care:
Culture/Faith perspectives
(Organ-failure case study)**

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Setting the UK Context (1)

Although over 3,000 people in the UK received an organ transplant in 2007/08, another 1,000 died after having waited in vain on the waiting list, which currently numbers over 8,000 people.

Data relating to organ donor waiting lists and organ donors highlights significant disparities between ethnic groups. For instance, UK data shows that people of South Asian (Indian, Pakistani, Bangladeshi or Sri Lankan origin) or African-Caribbean descent are three to four times more likely than white people to develop end-stage renal disease, largely because of the higher prevalence of type 2 diabetes

UK data shows them to make up 23% of the kidney waiting list but 8% of the population. A further concern is that only 3% of donors are from these communities.

UK Potential Donor Audit shows a 32% family refusal rate for White families and 74% refusal rate among non-White families

UK data:

Table 1 Ethnicity of cadaveric kidney donors and recipients, 1 January 2000 - 27 August 2001 and active waiting list patients, 27 August 2001						
Ethnic origin	Donors		Recipients		Waiting list patients	
	No.	%	No.	%	No.	%
Caucasian	1169	98	1863	88	3727	78
South Asian	18	1	170	8	652	14
African-Caribbean	7	< 1	68	3	299	6
Other	4	< 1	30	1	77	2
Total	1198	100	2131	100	4755	100

Time actively registered on list for kidney transplant, UK (1998-2000)

<i>Ethnic origin</i>	<i>Average wait median (days)</i>
White	722
South Asian	1496
Black	1389
Other	948

Setting the UK Context (2)

Empirical studies have shown that cultural issues are important influencing factors when making a decision about organ donation. The influence of belief and faith systems is less clear.

Recommendation 13: ‘There is an urgent requirement to identify and implement the most effective methods through which organ donation and the “gift of life” can be promoted to the general public and specifically to the BME population....’ (Organs for Transplants, Organ Donation Taskforce, 2008)

The Organ Donation Taskforce (Presumed Consent) therefore commissioned one-to-one interviews with senior representatives of faith and belief groups.

A total of 17 interviews were conducted by Professor Randhawa

What does the research say?

“I would not donate my eyes, ever, because of the ceremony prior to cremation when people come to the funeral to see the body. I don’t want to not have any eyes.”

“If the religious leaders gives us a clear cut opinion on this matter then we have less confusion. Religion is for people to live well; it shouldn’t be an obstacle to something positive like organ donation. More discussion and information will help us to proceed in this direction.”

“I don’t like the idea of my relatives having to see my body been carved up.”

“I’m not sure about life after death, but if there is life I want to go complete.”

“They (South Asian families) look after their own don’t they.”

Barriers to organ donation among minority ethnic communities

- Confusion about who can donate and receive organs and the organ donation and transplantation 'process'
- Mistrust/Lack of confidence in medical profession
- Fatalistic view - 'God has willed it'
- Reluctance to discuss death
- Little awareness of why South Asian & African-Caribbean people are more likely to need a transplant
- Assumed cultural and religious objections to organ donation

- Despite these barriers, communities agree that it is important to help their community and 'put something back'

Alkhawari et al (2005); Davis & Randhawa (2004); Morgan et al (2006); Randhawa (1998)

The future

Long-term

- How do we make the “gifting of organs” relevant and meaningful to a multi-ethnic and multi-faith society? – ‘Gift’ study; role models; religious leaders
- We cannot assume that all communities have the same opportunity to become organ donors – Referral rates to ICU; Organ requesting
- Should we engage the public with discourse of “disease prevention” as well as “organ donation” ?

Short-term

End of life care for renal failure patients – is it culturally competent?

End-of-life care - Evidence to date (1):

Current provision of end-of-life care services to minority ethnic groups may be regarded as 'culturally insensitive' for the following reasons:

- History and perception of palliative care services as only being available to white, middle-class patients
- Reluctance of GPs and other health care professionals to refer patients to palliative care services.
- Lack of information provided to minority ethnic groups about the availability of palliative care services.
- Poor communication between service providers and service users exacerbated by a lack of appropriate translation facilities.

End-of-life care - Evidence to date (2):

Current provision of end-of-life care services to minority ethnic groups may be regarded as 'culturally insensitive' for the following reasons:

- Services are not always attuned to the dietary needs of minority ethnic groups
- Services are not always attuned to the spiritual needs of minority ethnic groups
- Problems are compounded by other socio-economic factors (e.g. low income and debt)
- Lack of monitoring of the use of palliative care services by minority ethnic groups
- Lack of organisational policy on issues, such as Single Equality schemes

End-of-life care – a way forward ?:

Culturally-competent services:

- be aware of taboos and discrimination
- be aware of relevant legislation
- be aware and careful about making assumptions
- get to know the patient and the family
- discover the patient's situation within their own culture
- communication skills are invaluable
- do not use relatives as interpreters
- be sensitive but not over sensitive

End-of-life care – a way forward ?

Culturally competent services:

- recognise that attitudes to illness vary from culture to culture
- recognise that grief varies from culture to culture
- do not stereotype
- balance equality with difference
- recognise complexity and multiple causation of cultural patterns
- keep good records
- have an ethnically diverse staff
- provide a suitable environment/hospitality for all ethnic and faith groups

End-of-life care – a way forward ?

Culturally competent services:

- provide appropriate literature
- have a knowledge of different faiths and religious practices
- get to know local religious leaders of different faiths
- provide regular staff training
- meet with ethnic groups
- be aware of national organisations related to different ethnic and faith groups
- keep a multi-faith calendar
- train bereavement counsellors in non-western models

Further reading:

- Randhawa G (2008) Organ donation and transplantation – The realities for minority ethnic groups in the UK. In: W. Weimar, M.A. Bos, J.J. van Busschbach (Eds): Organ Transplantation: Ethical, Legal and Psychosocial Aspects. Towards a Common European Policy. Pabst Publishers.
- Owens A. & Randhawa G (2004) “It’s different from my culture; they’re very different”: providing community based ‘culturally competent’ palliative care for South Asian people in the UK. *Journal of Health and Social Care in the Community*, **12**, 414-421.
- Randhawa G. & Owens A. (2004) Palliative care for minority ethnic groups. *European Journal of Palliative Care*. **11**, 19-22.
- Randhawa G, Owens A, Fitches R, and Khan Z. (2003) The role of communication In developing culturally competent palliative care services In the UK: a Luton case study. *International Journal of Palliative Nursing*. **9**, 24-31.