British Journal of Anaesthesia **108** (S1): i88–i91 (2012)
doi:10.1093/bja/aer385

BJA

Death and organ donation: meeting the needs of multiethnic and multifaith populations

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Editor's key points

- Brain-stem death as currently defined remains incompatible with the beliefs of some orthodox Catholics and Jews.
- No religious faiths object completely to the principle of organ donation, although there is a divergence of opinion within Islam.
- Staff requesting organ donation must be familiar with different religious and cultural views regarding death and burial or cremation.

Summary. Deceased donation in the UK relies upon family consent. Approaching a family at the tragic time of a loved one's death requires significant emotional resilience from staff. The UK is comprised of individuals who have a number of life and death values which are, to some extent, based upon their faith, culture, and ethnicity. This paper seeks to provide an overview of some of key issues relating to death, death rituals, faith, and how these may impact upon organ donation. This should be of benefit to staff dealing closely with recently bereaved families and who will be requesting organ donation from them.

Keywords: death; organ donation; religion; medicine and religion; Christianity; Judaism; Islam; Buddhism; Hinduism; ethnic groups

At present, there are over 8000 people waiting for a suitable organ for transplantation throughout the UK. As the demand continues to grow for transplant organs, the pressure to procure organs from deceased donors is increasing. Empirical studies have shown that cultural issues are important influencing factors when making a decision about organ donation,[1 2] although the influence of belief and faith systems is less clear.[3–7] There are significant disparities between ethnic groups which are reflected in the organ waiting lists. For instance, research shows that people of Asian 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[8 9] and that while such groups represent only 8% of the population, they form 24% of the waiting list for kidneys.[10] A further concern is that only 3% of donors are from these communities.[11]

The Potential Donor Audit in the UK showed that there is variation in the refusal rate between white families and non-white families, at 35% and 69%, respectively.[12] Clearly, it is important to examine the reasons for all family refusals, but specifically, it is essential to develop a detailed understanding for the variation in refusal rate between families of different ethnic origins. To begin this process, it is important to appreciate that the diverse population within the UK comprises individuals who have a number of life and death values which are, to some extent, based upon their faith, culture, and ethnicity. This paper seeks to provide an overview of some of key issues relating to death, death rituals, faith, and how these may impact upon organ donation. It is hoped that this review will be of relevance to readers from all countries as we all strive to ensure that the possibility of organ donation is available to all. Most importantly, it is hoped that the review will be of benefit to those staff at the forefront of dealing with families who are experiencing the tragic loss of a loved one and will be making a request for organs from them.

Dealing with death

The first requirement for anyone caring for a family and the dying patient, who has the potential to become an organ donor, is to recognize their spiritual and cultural needs. It needs to be acknowledged that each prospective donor family will be different and the way in which they define their faith will be personal to them. However, health professionals will be in a far more informed position to support a family dealing with death, grief, and potential organ donation, if they have some basic knowledge of the beliefs of the religion concerned. To support this process, hospital staff should be offered regular training equipping them with the communication skills and knowledge base to ensure a family-centred approach to organ requesting. Staff involved with organ donation should also be encouraged to establish links with the hospital chaplains and faith leaders, who serve their local communities.

Religion and organ donation

There is an emerging evidence base relating to how religious viewpoints may influence organ donation.[3 4 13–16] We need

to acknowledge that most religious scriptures were written hundreds, if not thousands of years ago, before any consideration of organ transplantation. Consequently, any religious position on organ donation is subject to a religious scholar's interpretation of the scriptures and the values espoused by the faith. A number of families, who refuse organ donation, cite 'religion' as being a barrier to organ donation. What is less well understood is whether the families have an informed view of their faith's position regarding organ donation based upon extensive debate and thought with their faith mentor, or whether they are expressing an intuitive view based upon their personal interpretation. Both positions are legitimate. However, they do highlight the need to ensure that faith leaders and the public alike should be encouraged to discuss and debate organ donation within the context of their faith.

Within the UK, the main faiths are Christianity (Church of England, Scotland, and Wales, respectively; and Roman Catholics), Judaism, Sikhism, Islam, Buddhism, Zoroastrianism, and Humanism. The beliefs of the major faiths have been scrutinized in the literature. In addition, the UK's Organ Donation Taskforce recently commissioned a series of meetings with national representatives from these faith groups to discuss organ donation, and some of the quotes from these meetings are cited within this article.[17] It is very important to recognize that none of the faiths object to organ donation in principle, although within Islam, there is a divergence of opinion—either supporting or objecting to organ donation.[13]

The issue of a faith potentially objecting to organ donation raises an interesting dilemma, as it would be worth examining whether there is a similar objection to accepting an organ transplant. This highlights the need for ongoing dialogue between transplant professionals and policy makers with faith leaders to ensure that such dilemmas can be resolved. For some orthodox Catholics and Jews, the definition of brain-stem death remains incompatible with their faith, although they would support donation from a non-heart beating donor.[14 18]

Defining death

Empirical research has shown that the most common concern held by families regarding the definition of death in relation to organ donation is: 'Is my loved one really dead?' All main UK faiths, with Christian–Jewish routes, and those from the Indian subcontinent consider the human heart beat, or lack of, as clear signs of life and death. While some faiths will accept additional definitions used to define a person has died, others are uncertain. Therefore, defining death with a definition of brain-stem death has, in some faith groups, led to considerable debate and remains contested by faith leaders.[14 15 17 18]

> '*The issue of brain stem death is still highly controversial amongst those who interpret Jewish law*' (David Katz, Board of Deputies of British Jews).

> '*There is an anxiety in some quarters that hasn't surfaced, but is bubbling under the surface, and that is about the definition of death*' (David Jones, Catholic Bishops' Conference of England and Wales).

> '*One particular Tibetan group had great unease about the disturbing of the body in the hours after death (or what in Western medicine would be recognised as death) and would dispute the definition of brain stem death*' (Sally Masheder, Network of Buddhist Organisations).

Staff involved with organ donation should ensure that they are able to explain the definition of death in 'layman's' terms and be prepared to answer questions of clarification. Concomitantly, there should be a process through which policy makers and clinicians, who develop guidelines in relation to definitions of death, remain in regular contact with faith leaders to ensure that viewpoints are exchanged. Most importantly, any concerns expressed by faith leaders need to be acknowledged. Donor families deserve the right to know that their loved one is really dead, and any ambiguity relating to this matter is an unreasonable demand to place upon a family and will not assist the organ donation request process.

Death and the soul

For many families, once death has been confirmed, their focus will be on grieving for their loved one and protecting their body. Specifically, in relation to organ donation, issues related to afterlife and the immortality of the soul may arise for some families. Families may feel that removal of organs may be contradictory to these beliefs. It would be important for staff to stress that in all faiths, it is believed that the soul leaves the body after death, and therefore, there is no attachment of the soul to organs being removed for organ donation. Clearly, this issue needs to be dealt with with great sensitivity and the families' views must always take precedence.

> '*By passing your organs on and prolonging another life and therefore interrupting the cycle (of reincarnation) that Hindus believe in, there could be some issues for some people. The religion would not tell people that it is against organ donation, but it would say that there may be implications for the person living or dying*' (Raj Bharkhada, Hindu Forum of Britain).

Death rituals

Understandably, for many families, there are a range of rituals that are carried out at the time of death. It is important that staff pay due attention to these and ensure that these can be accommodated within the context of organ donation. There is evidence to suggest that many members of the public are unenthusiastic about organ donation because of fears and concerns about being dissected after death and the body being potentially disfigured. Issues around the time frame in which a death ceremony must be held, or the body disposed of, are also important to many families based upon their faith beliefs.[3 5 19]

> '*Burial/disposal should take place as quickly as possible. The norm for the Jewish Burial Societies is to bury on the day of death or if that is not practicable, on the following day*' (Draft Legislative Programme about Death Certification: Jewish Community Response, David Katz, Eleanor Platt QC and David Frei).

Buddhists and Christians bury or cremate their loved ones. The body is sometimes viewed in an open casket coffin by the family and close friends, either at home or at the cemetery or at the crematorium. The vast majority of Jews and Muslims bury their loved ones within 24 h of death. There is a tendency for some British Muslims who were born overseas to return the body of their loved one to the country of origin to be viewed by relatives and buried at a graveyard where other members of the family are buried. Hindus and Sikhs cremate their loved ones as soon as possible after death. In both groups, the body is washed and dressed in normal clothes by close family members. The body is then viewed by close friends and relatives before being taken to the crematorium.[3 6 7 14 15 18 19]

It is incumbent upon staff to allow families to observe these rituals as far as practicable within the parameters of organ donation. The family's priority will be to ensure a 'good death' for their loved one and this should not be perceived as being in conflict with organ donation.

Grief and bereavement

Individuals, families, cultures, and faiths deal with grief and bereavement in a wide range of ways. It must be stressed that although there is no right or wrong way of dealing with a family's needs, an understanding of the type of reaction to expect from recently bereaved relatives will help the transplant professional to manage the situation. The major challenge for the hospital staff is to initiate a dialogue concerning the possibility of organ donation. This is a very difficult task requiring immense emotional resilience on the part of both the family and the staff since it involves facing a family who has very recently been informed of the death of a loved one. The family may have large numbers present as they wish to ensure as many relatives as possible can pay their respects in the last few moments of a patient's life. Identifying the next-of-kin can prove a challenge in such cases and requires careful approach and negotiation by staff. In many cultures, grieving openly and crying loudly is the norm, whereas in other cultures, it is not. Staff need to consider the way they approach families on a case-by-case basis, ensuring that the family have an opportunity to consider organ donation.

Conclusion

Transplant waiting lists continue to rise in the UK and in most other countries. Family consent is integral to the success of organ donation programmes. The definition of death will always be an issue of debate. What is important is that this debate in relation to organ donation takes place in an informed environment whereby there is regular information exchange and discussion between faith leaders with transplant clinicians and policy makers. The family refusal rate in the UK shows that there is scope to make substantial improvements, specifically with non-white families. It is vital that religious and cultural views relating to death and burial/cremation practices are incorporated into the curriculum for those staff undertaking training on organ requesting from families.

Declaration of interests

G.R. was a member of the UK Organ Donation Taskforce. He is currently a Member of the UK Donation Ethics Committee and the Human Tissue Authority. The views expressed in this article are his own.

Funding

The Faith Leaders fieldwork was funded by the Department of Health.

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