

## Practitioner's Blog

# Organ Donation: To ask or not to ask?

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Perhaps one of the most difficult and sensitive conversations that takes place in healthcare is about the subject of organ donation. Regrettably this conversation frequently takes place alongside or subsequent to the breaking of bad news of death or imminent death to relatives. In intensive care settings, discussion about organ donation is sometimes initiated by relatives when they have had time to come to terms with imminent death and are seeking some good in an otherwise hopeless situation, thus the discussion may not be so distressing. Unfortunately this is not the case in emergent situations. Death in the emergency department is almost always sudden, unexpected and invariably traumatic for relatives.

In this situation raising the subject of organ donation is daunting for even the most skilled clinicians. Responding appropriately and with compassion to a relative's desperation while at the same time remaining acutely aware of the benefits of organ donation and society's increasing need for donor organs calls for a very measured and timely response to avoid compounding distress and even provoking anger in an already anguished situation. Despite ongoing teaching of emergency staff about organ donation and support from specialist nurses, opportunities for organ donation are often lost in the urgency and fast pace of the emergency department. On occasions this may be due to logistical reasons but more worryingly it can be due to erroneous assumptions or lack of knowledge and cultural competence on issues pertaining to organ donation and transplantation.

This was the case recently when a young woman of Middle Eastern origin and Muslim background was brought to the emergency department having collapsed in the shower at her home. When she arrived in the department she was being artificially ventilated by the paramedical crew. A CT scan of her head showed she had suffered a massive cerebral haemorrhage. Following thorough examination and discussion between the specialist medical teams it was concluded that the injury to her brain was not compatible with life. The advice of the intensive care team was to stop active treatment in terms of artificial ventilation which would only prolong suffering and to allow the woman to die with comfort and dignity, in a separate room, with her family present. It was at this point that one of the nursing staff intervened and suggested the possibility of organ donation. His suggestion was initially discounted and there was a general disagreement among the specialty doctors about the appropriateness of the suggestion, their main rationale being that, because of her background and presumed religious beliefs, neither she nor her family would agree to organ donation. However after some discussion the intensive care doctors agreed to keep the patient supported whilst waiting for family in the Emergency Department.

The nurse contacted the Specialist Organ Donation Team

and requested them to attend the emergency department as a matter of urgency. This was to ensure the family could have a knowledgeable and skilled person approaching them in the first instance to introduce the organ donation process in a sensitive and compassionate way that would not in any way detract from their shock or grief but might offer some solace in the face of such tragedy. Once the family accepted that there was no hope of recovery they fully accepted the concept of organ donation and consented to the process. The patient was then transferred to Intensive Care overnight with surgery for retrieval planned the next day thus giving the family more time to come to terms with the decision they had made.

This case clearly demonstrated many of the difficulties, misconceptions and lack of cultural competence that continue to mitigate against a more successful and equitable transplant programme in the UK. There continues to be a significant gap between the availability of organs for donation and patients desperately in need of transplants. The situation is even more serious for members of Black, Asian and some other ethnic minority communities. Recent figures from the NHS Blood and Transplant service have shown a significant difference between consent/authorisation rates for eligible donor members of these groups and their white counterparts. According to the NHS Blood and Transplant (NHSBT) service (<http://www.nhsbt.nhs.uk/>) figures, 66% of Black, Asian and some Ethnic Minority (BAME) communities in the UK refuse to give permission for their loved ones' organs to be donated compared to 43% of the rest of the population. This lower donation rate is significant and serious given that patients from BAME are more susceptible to illnesses such as hypertension, diabetes and heart disease all of which may result in organ failure where transplant may be the only lifesaving treatment. Since blood and human leucocyte antigen types are among the most important factors when organs are matched, success of transplantation is likely to be greater when the ethnicity of the donor and recipient are the same. As a result of this ongoing shortage many BAME patients wait longer than white patients for a transplant or may die while waiting and this can be misconstrued as a bias towards white patients and an inequality in the transplant programme.

The reasons for a lower donation rate among ethnic minorities is complex and not simply down to culture and religion although this is often perceived by healthcare professionals as the main barrier as was demonstrated in this case. Randawa's (1998) findings suggested that culture and religion play a much less prohibitive part in determining organ donation than previously implied. A qualitative study by Al Khawari, Stimson and Warrens (2005) found that refusal was partly due to a lack of transplant awareness, but also a mistrust of health care professionals. Similarly Irving, Tong, Jan et al. (2012) found that factors, such as religion and culture, are often inextricably linked with

more complex issues such as a distrust of the medical system, misunderstandings about religious stances and ignorance about the donation process. Morgan, Kenten and Deedat (2013) studied attitudes among ethnic minorities to organ donation in America and the UK. They concurred with these views identifying a similar distrust of the healthcare system. Moreover another study in the America by Guadagnoli, McNamara, Evanisko et al. (1999) hypothesized that the behaviour of hospital staff may be related to the disparity in rates of organ donation by ethnic minorities. They found that hospital staff approached families of African-American patients less often and this was thought to be due to how hospital staff related to families and perceived their disposition towards donation. In some instances, as in this case, this perception prevails among some healthcare staff.

The donation or receipt of organs from living or deceased donors is not explicitly forbidden by any of the major religions. Indeed all the major religions in the UK support the principles of organ donation and transplantation (NHSBT 2015, Carlisle 1995, Gatrad and Sheikh 2001) Nonetheless religion can be a barrier if people believe their religion does not allow it and many are unsure of their religions stance on the issue (Al Khaweri et al, 2005). Also it must be recognised that there are different schools of thought and religious jurisprudence on the subject and there is striking variability in attitudes to organ donation throughout the Middle East and Asia which undoubtedly has some bearing on organ donation of BAME patients in the UK.

It is all too easy to attribute low rates of organ donation to culture and particularly religion and one could argue that it is much easier for BAME families to cite religious reasons for refusing rather than declare their mistrust and anxiety about the concept and process. What this case and the literature on organ donation has demonstrated is that we as healthcare professionals need to review our own prejudices and assumptions, become more informed and employ more effective strategies to engage our multicultural patient population as partners in care. It is clear that we underestimate our patients on occasions and that we have some way to go in building the trust and improving cross cultural communication that is essential to improving organ donation rates among our ethnic minority patients.

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