

**Editorial**

## The Gift of Life – Social and Cultural Perspectives on Organ Donation in 2020

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**Background**

There are over 6000 patients waiting for a life-saving organ donation in the UK from figures published by the UK NHS Blood and Transplant agency in April 2019. The top 4 organs required amongst these are kidney (>4k), liver (407), lungs (338) and heart (290). In the same year, around 4k organ transplants were carried out from 2.5k donors. The number of patients dying while waiting on the active transplant register were approximately 6% for kidneys and up to 22% waiting for heart and lungs. We as a society have a significant mismatch.

While around 31% of people on transplant waiting lists are from black, Asian and minority ethnic (BAME) backgrounds, amongst the 1,600 total deceased organ donors in the UK, only 7.5% were from BAME communities. In addition there were 149 people from BAME communities who became living donors, donating a kidney or part of their liver. In the UK there is a high proportion of people from these ethnic backgrounds developing high blood pressure, diabetes and certain forms of hepatitis making them more likely to need a transplant at some point in their lives. Blood and tissue types need to be a match for the transplant to be a success and people from the same ethnic group are more likely to be that match.

Analysis of ethnicity data given when people register their decision to opt out suggests that those who make that choice, are much more likely to be from a BAME background (46% vs 77% choose to give consent). The main reasons BAME families gave for declining consent/authorisation for organ donation was that they felt it was against their religious/cultural beliefs or they were unsure whether the patient would have agreed to donation.



BAME families are less likely to discuss organ donation and are much more likely to decline to donate. There are indications that many people are making their decisions based on misinformation, because they are worried about the donation process itself or don't think that their faith or beliefs will be respected. Not knowing what their relative wanted is one of the biggest reasons given by BAME families for saying no to donation when approached by specialist nurses.

With the law changing in England and Scotland in 2020, it is really important that people have the information they need to make the decision that's right for them and their family. This article will explore the religious, social and cultural factors that may be influencing decisions in participating in the 'gift of life' initiative.

### Ethical, Religious, Social & Cultural Determinants

There is a global shortage of organs for transplantation but the story is very different between developed and developing countries (45-50 vs <10 per million population). Within developing countries the other major difference is the unusually low numbers of cadaveric vs live donations (>85%). (1) Although there are no overt objections to cadaveric transplants among the major religions of Asia, misperceptions and mistrust with the ethics of procurement and misuse, largely seem to limit consent for organ donation from potential donor families. From an ethical front, more than 80% respondents in a Chinese survey believed that organ transplantation extended life but were reluctant because (74%) believed that "donated organs have not been fairly and appropriately used; the wealthy and celebrities may be favoured"; and 61% agreed that "organ donation laws and regulations were not well developed, and result in unnecessary difficulties." (2) Balwani et al in a survey in western India found that majority were (59%) aware of organ donation but believed there is a potential danger of donated organs being misused, abused or misappropriated. About 47% of aware people said they would consider donating organs, while only 16% said they would definitely donate irrespective of circumstances. (3)

Following reports of trafficking in human beings (who are used as sources of organs and of patient-tourists from rich countries in 2004), the World Health Organization, called on member states "to take measures to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs, including attention to the wider problem of international trafficking in human tissues and organs". The Istanbul Declaration strived to achieve transparency and stricter control on the sale of organs. (4)

As far as is known no major religion formally forbids donation or receipt of organs or is against transplantation from living or deceased donors. There are rare examples of small cohorts/sections of religious groups where such dictats may have been given. Some orthodox Jews may have religious objections to "opting in." Transplantation from deceased donors may be discouraged by Native Americans, Roma Gypsies, Confucians, Shintoists, and some orthodox Rabbis. Some south Asian Muslim Ulemas (scholars) and Muftis (jurists) may oppose donation from human living and deceased donors because the human body is an "amanat" (trusteeship) from God and must not be desecrated following death, but they encourage



xenotransplantation. Data from a survey of muslims residing in western countries have shown that the interpretation of religious scriptures and advice of faith leaders were often major barriers to willingness for organ donation. (5) Others encourage living donation over cadaveric donation. The Catholic Church is against donation from anencephalic donors or after active euthanasia. (6) Yet there is a faith based non-profit organization, Matnat Chaim ("Gift of Life" in Hebrew), emerging as a major force for arranging living donor kidney transplantation mainly by facilitating altruistic living unrelated donor transplantation. (7)

### Cultural Challenges

Inadequate cultural competence and sensitivity when communicating with potential donor families by healthcare professionals may be an important determinant in refusals. Clinicians may not have an understanding of the cultural and religious perspectives of some muslim families of critically ill patients who may be approached about brain death and organ donation.(8)

### Misinformation

Where religious misinterpretation hurdles are crossed, misinformation may pose new challenges. While majority of respondents in an orthodox muslim country, (69%) considered organ donation and transplantation acceptable from a religious point of view, many were reluctant because they believed that one kidney was not enough to survive (50%) or that the remaining kidney may be affected (26%), whereas 15% expressed fear of the operation. (9)

### Policy

Over fifty years ago, in the United States of America, the Uniform Anatomical Gift Act (UAGA) was approved by the American Bar Association.(10) The UAGA provided a legal framework on which to base a nationwide organ donation system on the principles of altruism, autonomy, and public trust. The 2006 UAGA amendment reflected the public policy goal of making more organs available for transplantation. However, it transferred the authority over end of life decisions from patients or surrogates to organ procurement organisations, which may be inconsistent with common law and the ethical and legal standards that govern medicine. (11)

Such a concept of 'presumed consent' is a legislative framework in which citizens must place their name on a national opt-out register, otherwise their consent for donating their organs will be presumed. Changing legislation to a system of presumed consent in order to address the organ shortage has raised ethical concerns. (12) The Welsh Assembly passed legislation to enable the introduction of presumed consent in 2015. However, there is scant evidence that presumed consent will be effective. (13) Presumed consent alone is unlikely to explain the variation in organ donation rates between different countries, nor offer a panacea to address the significant mismatch in availability of organs.

### Infrastructure

Improvements in transplantation infrastructure in the UK have resulted in a 63% increase in deceased donation since 2007. If, family consent rates could be improved from the current



57% to Spanish levels of 85%, the UK's donation rate could be one of the best in the world.(13) Lack of adequate infrastructure and resources in developing countries pose a major roadblock for the retrieval and matching of organs, even if consent was available. Huge governmental investment in retrieval hardware and logistics would be necessary. (14) In cash-strapped societies, where minimum standards of health and hygiene are not universally available, there is little appetite for the incredible expenditure required for little gain from a public health perspective. Therefore the only progress is likely in living donors from near relatives or around metropolitan urban localities with private- public partnerships. A metropolis in eastern India, Kolkata, reported its first heart transplants almost simultaneously in public and private facilities in 2018, 24 years after India's first heart transplant was successfully conducted in New Delhi. (15) (16)

### The Spanish Plan

Organ transplantation has improved the lives of hundreds of thousands of patients all the world. While progress has been made to increase organ registration and the number of organs transplanted, much more must be done to realize the potential of life-saving therapy without jeopardizing ethical principles. The total organ donation shortage can be met with increase in the conversion rate from eligible deaths, which remain hugely variable across the world. (17) Challenges include an interplay of sociocultural factors, religious beliefs, misinformation, lack of culturally sensitive communication, infrastructure and organisational support. (18)

With 40 donors and more than 100 transplant procedures per million population in 2015, Spain holds a privileged position worldwide in providing transplant services to its patient population. The Spanish success derives from a specific organisational approach to ensure the systematic identification of opportunities for organ donation and their transition to actual donation and to promote public support for the donation of organs after death.

The Spanish plan had three specific objectives:

- (i) promoting the identification and early referral of possible organ donors from outside of the intensive care unit to consider elective non-therapeutic intensive care and incorporate the option of organ donation into end-of-life care;
- (ii) facilitating the use of organs from expanded criteria and non-standard risk donors; and
- (iii) developing the framework for the practice of donation after circulatory death. (19)

### Future

A combination of legislation, availability of donors, transplantation system organisation and infrastructure, wealth and investment in health care, as well as underlying public attitudes to and awareness of organ donation and transplantation, may all play a role, although the relative importance of each is not clear. (20) Further reviews could investigate the factors likely to modify donor rates but awareness and motivation from all healthcare professionals reaching out to their local community while demonstrating empathy and ethical organ donation is likely to have far-reaching benefits than legislation such as presumed consent which may propagate mistrust in certain societies. BAME leaders have a particularly



important role to play in redressing the imbalance in organ donations from their own communities, encouraging open discussions on the benefits within families reducing the proportion of relatives who decline consent on such grounds. The BAPIO seminar on Organ donation in Coventry in February is one of such initiatives to encourage open discussions of religious and cultural determinants.

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