

Is There a Case for British Muslims to be Exempted from the New Opt-Out Organ Donation Law?

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Abstract

Organ donation and transplantation medicine has posed challenging ethical problems ever since the first successful human to human heart transplant was performed in December 1967. In an effort to solve the conundrum of obtaining healthy living organs from dead bodies, the medical profession introduced a new understanding of death in 1968, then in the 1990s a new protocol for declaring death in dying patients was introduced and more recently an opt-out system for end-of-life organ donation has been enacted into law in Great Britain. Under this new opt-out system¹, informed consent is not required, consent for organ donation is presumed (deemed) for adults unless belonging to an exempted group.

This paper challenges the morality of presumed (deemed) consent imposed on British Muslims, the majority of whom do not support deceased organ donation². The author puts forward an argument that British Muslims should be exempted from the new organ donation opt-out law on religious grounds and puts forward some ideas which could be used to accommodate Islamic beliefs in end-of-life organ donation amongst British Muslims.

Introduction

Organ transplantation has been a real success story of modern medicine. It undoubtedly improves and saves the lives of thousands of people every year. But there is a worldwide shortage of organ donors. No religion formally forbids organ donation or receipt of organs from the living. However, deceased organ donation is discouraged or even forbidden by some religious authorities. And some ethicists consider the practice to be morally flawed^{3,4} on three main accounts: the organ donors are not truly dead, the potential organ donors are not told the whole truth, and the organs are removed without an informed consent in place.

These ethical objections have been raised since the world's first successful human to human heart transplant was performed on 3rd December, 1967, in South Africa. As the heart transplant surgeon Christiaan Bernard came out of the operating theatre after having performed the

operation he was met by the local media who asked him if the donor was dead when he removed her heart⁵.

In the first heart transplant performed in Israel at the Beilinson Medical Center in 1968, no consent was obtained and the donor's family was not even informed⁶. The source of the donor heart was hidden by the hospital. Only after applying to the health minister, demanding full disclosure, did the family discover the truth.

Only months after the first successful heart transplant the concept of brain death was introduced, and this facilitated the availability of suitable organs for transplantation. The brain death concept redefines what it means to be dead by declaring individuals with irreversible coma and loss of capacity to breathe as dead even though they may not have a single organ in their bodies which is dead. Brain death is a condition *sine qua non* for the transplantation

of viable organs such as the heart. Indeed, the main reason for introducing the concept of brain death was to increase the number of organs available for transplantation⁷. The brain death concept has undergone several ad hoc revisions designed to protect it from empirical falsification, but it still remains controversial^{8,9}. In the 1990s, a new protocol was introduced to increase the supply of organs for transplantation to meet the high demand.¹⁰ This new protocol is called donation after controlled circulatory (or cardiac) death, DCD for short¹¹. The guidelines for DCD were published in 2008 in the UK¹². Even this did not solve the shortage of organ for transplantation so further intervention was needed.

The latest intervention in Great Britain (England, Scotland and Wales) involves switching from an opt-in system to an opt-out system for deceased organ donation, thereby removing the need for expressed consent. The next step to increase organ donation numbers may be legalisation of organ donation euthanasia^{13,14} as its social and ethical acceptance increases.

What is Consent?

In a free, democratic society, an individual has the right of self-determination, the freedom to do with their body as he or she wishes. From a religious perspective, there are obviously some limitations to this freedom. This right that an individual has over his or her body prohibits others from interfering with the body without the individual's consent. So this right is by default negative; it is like a barrier which protects the right to a private domain. This barrier can only be legitimately crossed by a positive authorisation which we call consent. This consent then allows access to the private domain for a specific purpose only, such as a particular specified surgical procedure or medical examination.

The need for consent before any medical intervention is firmly embedded in modern healthcare. Doctors have an ethical obligation to respect patients' autonomy – that is, their right to be involved in decisions that affect them. Consent must be given voluntarily by an appropriately informed patient who has the capacity to exercise a choice.

Consent is not an intention in the mind or the heart but a public declaration of intention, either verbal or in writing. Consent is a voluntary declaration. So, can consent be presumed?

What is Presumed (Deemed) Consent?

Consent is a legal requirement for removal of organs or tissues under the Human Tissue Act 2004 (HTA)¹⁵.

Under the new Deemed Consent Act (2019)^{1,16} every adult is deemed to have consented to have their organ removed for transplantation unless the individual has registered to opt-out or a person who stood in a qualifying relationship to the person concerned immediately before death provides information that would lead a reasonable person to conclude that the person concerned would not have consented.

A presumed (deemed) consent policy denies organ donors the same ethical safeguards of informed consent that define advance decision making in other areas of medicine¹⁷.

Presumed Consent is Not Informed Consent

The UK General Medical Council's guidelines on consent¹⁸ state that there should be exchange of relevant information specific to the individual patient and that all patients have the right to be given the information they need to make a decision and the time and support they need to understand it.

To "presume" by default that we (doctors) have "consent" to remove organs from a deceased person because there is no prior statement from him/her against such an action cannot be said to meet the universal criteria for a valid consent as understood by the medical profession nor the HTA's own definition of a valid consent¹⁵ (page 48). Presumed consent is not actual informed consent¹⁹.

Furthermore, removing organs from someone who has not given expressed consent is more akin to taking organs rather than donating organs.

Justifying Presumed Consent for Organ Donation

Presumed (deemed) consent can be morally justified in a secular society²⁰. An argument can be made that it should be the duty of every citizen to donate his or her organs on death. Not doing so is morally wrong because the lack of organ availability leads to unnecessary deaths. Furthermore, surveys have shown that the majority of the UK public support organ donation²¹. From a utilitarian perspective, the adoption of presumed consent makes considerable sense. People hold their organs in stewardship for society, and when they have had their full benefit from the organs, it is time to pass the organs onto other individuals in society who can continue to benefit. In this way, presumed consent provides the greatest good for the greatest number of people by supposedly harming no one and benefiting many.

While presumed consent for organ donation can be justified in Western bioethics based largely on human reasoning, the same does not apply to Islamic bioethics which are based on Islamic law.

Are Organ Donors Actually Dead?

“Are organ donors actually dead?” Simply put, “No!”²²

The criterion of brain death does not meet any acceptable concept of death²³. There have been several cases reported of some reversible brainstem function in patients declared brain dead^{24,25,26,27,28}.

In the UK, there are just over 6,000 individuals waiting for an organ transplantation and about 600,000 people die every year. Based on these figures there should be no shortage of deceased organs. The reality is that solid organs from truly dead people are not suitable for transplantation, because their organs are dead. Only organs from living individuals are suitable. This is sufficient evidence that organ donors are not actually dead.

In current medical practice in the UK, organ donation is of two types: organ donation after brain death (DBD) and organ donation after controlled circulatory death (DCD)²⁹. Declaration of death, both for DBD and DCD, takes place in an intensive care unit setting. In both DBD and DCD, the donors are not truly dead^{30,31,32,33,34}.

Some ICU clinicians and peri-operative nurses have objected to participating in organ procurement because it is against their conscience.^{35,36}

Mufti Butt, a UK based Islamic scholar, in his detailed fatwa³⁷ commissioned by the NHS (UK), concurs that from an Islamic perspective neither DBD nor DCD fulfil the criteria of death³⁸. The fatwa was released a year before the new opt-out law was introduced in England in 2020. Unfortunately, the crucial message was not clearly communicated in the fatwa (which is 111 pages long) nor in the fatwa summary. Much of the media along with some individuals and organisations involved with promoting organ donation completely misunderstood the fatwa³⁹, thinking the fatwa gave the UK Muslims the green light for deceased organ donation. In reality, the fatwa approved deceased organ donation in principle only. The fatwa did not consider organ donation as currently practiced in the UK to be permissible because Butt does not consider the donors to be Islamically dead.

Does the Public Have the Right to the Whole Truth?

Telling the truth in a transparent manner is an established principle of good ethics⁴⁰ and is particularly important where information is communicated by Muslims in a mosque. Disclosure of all facts is essential for informed consent¹⁷. However, the whole truth about what organ donation entails is often kept from the public^{4,40,41} because of the possible consequences, on the assumption that revealing the whole truth may lead to refusal to donate organs. The public is provided with educational material that encourages donor registration without mentioning the possible negative consequences of organ donation³⁵.

The priority of the organ donation education programs aimed at the UK Muslim population has been to change negative views towards organ donation with the objective of improving organ donation rates by increasing awareness of the societal needs and religious permissibility. Initial data suggests that some of these programs achieved their desired objective⁴². Although in the past such unidirectional religiously-oriented interventions in Muslim communities have proven to be ineffective⁴³.

Maintaining public trust requires not only that doctors are loyal to their patients, but that their actions be entirely above suspicion in this regard⁴⁴. Public mistrust plays a significant role in limiting the number of organ donations.

If the whole truth is not revealed then presumed (deemed) consent is not only morally objectionable, it is not a valid informed consent.

A Moral Dilemma for Muslims

On the principle of reciprocity if a Muslim is willing to receive an organ he should be willing to donate his organs.

However, if one does not accept brain death and controlled circulatory death as actual death then “deceased” organ donors are not actually dead; it is the removal of essential organs which is the cause of their death. This poses a huge dilemma for Muslims, and other religions⁴⁵ which share the same beliefs about death and the taking of human life.

The purpose of Islamic law is to preserve life and mind (intellect). Unfortunately, current deceased organ donation practice challenges both of these purposes. The concept of brain death as actual death makes no logical sense while the process itself involves the taking of human life. God Almighty says in the Qur'an: “And that ye slay not the life which Allah hath made sacred, save in the course of justice,”⁴⁶ and “whosoever kill a human

being for other than manslaughter or corruption in the earth, it shall be as if he had killed all mankind,”⁴⁷.

A Muslim is also strictly forbidden to take his own life: “And do not kill yourselves,”⁴⁸.

By giving consent for “deceased” organ donation one is also giving consent to have one’s life ended in the operating theatre by the removal of one’s organs.

Organ Donation and Your Will

If you make a decision to donate your organs after death then that is a bequest (gift after death) which effectively becomes part of your Will from an Islamic perspective.

Muslim scholars have debated whether or not it is permissible for a Muslim to bequeath his organs⁴⁹ on the assumption that the organ donor is dead.

But in reality, because the donor is not actually dead, the donor is gifting his life rather than just gifting his organs. While the transfer of property after death requires written consent in the presence of two adult witnesses in English law, the transfer of body organs requires no written consent and no witnesses.

A New Protocol for End-of-Life Organ Donation

Current clinical practice of organ donation already violates the dead donor rule^{34,50,51}. So some medical doctors and ethicists have advocated abandoning the dead donor rule^{52,53,54}.

The dead donor rule is a deontic constraint that categorically prohibits causing death by organ removal. Abandoning the dead donor rule would require informed consent and it has the potential to increase the donor pool. However, abandoning the dead donor rule is unlikely to find much support amongst Muslim scholars and the Muslim public. The autonomy of the individual in Islam is not unrestricted as it may be in some Western societies, it is restricted by Islamic law⁵⁵ and, as such, a Muslim cannot choose to end his life.

The key question is: “How can organs be removed from brain dead and other Muslim patients close to end-of-life without ending their life in the process?”

Muslim patients on intensive care in whom a decision has been made to withdraw life support treatment could potentially donate one kidney and a lobe of liver^{56, 57} without losing their life in the process. Such patients would be given a full general anaesthetic for the

procedure, so the question of feeling pain or awareness is removed, and after the surgery the patient would be brought back from the operating theatre to the intensive care unit and, later on, life support treatment could be removed as already planned, allowing the patient to die naturally.

Advantages and Disadvantages of the New Proposed Protocol for End-of-Life Organ Donation

The perceived advantages of the new protocol include:

1. Potential donors can be informed of the whole truth about the organ donation procedure.
2. As it is a living organ donation it is likely to be acceptable to all Muslim scholars.
3. Donors would be given a full general anaesthetic as for an operation on a living person, so there is no issue of perception of pain or awareness.
4. The protocol does not rely on declaration of death so the issue of whether the donor is dead or not is no longer relevant.
5. There is potential to increase organ donation rates.
6. The quality of the organs should be better than in DCD protocol and as good as DBD protocol.

The perceived disadvantages of the new protocol include:

1. Essential organs cannot be removed.
2. Details need to be worked out to see if it is feasible and if it could be implemented in practice.
3. As the patients are likely to be seriously ill there is a risk of death during organ retrieval.
4. It is likely to be more complicated and costly.

Discussion and Conclusion

Under the new organ donation opt-out law, the UK government deems every Muslim adult living in Britain to have consented to donate his or her organs for transplantation after being declared brain dead. However, survey² carried out in 2019 by Agroni Research Ltd on behalf of NHS BT showed that only 31% of adult Muslims surveyed said that they support organ donation. In 2020, over 50 Muslim scholars⁵⁸ based in Britain signed a statement opposing deceased organ donation. The NHS commissioned fatwa by Butt released a year before the opt-out law was rolled out did not yield the

ruling hoped for. To presume (deem) consent in British Muslims is baseless and to impose it is morally objectionable.

Since it is clear that brain dead individuals are not actually dead^{22,24,59}, removing essential organs from such individuals is akin to active euthanasia⁶⁰, which is explicitly forbidden in the Islamic Faith^{61,62}. Removal of essential organs from a brain-dead Muslim could be seen as a violation of religious beliefs. When family members later find out the whole truth about deceased organ donation, it could lead to a feeling of lifelong guilt and resentment.

Under the European Convention on Human Rights (ECHR), Article 8⁶³-the right to respect private and family life- would be violated where a person's organs are removed, after death, without consent having been obtained during their lifetime⁶⁴.

For all these reasons I believe that Muslims should be exempted from the new opt-out organ donation law and organ donation should only be undertaken with prior expressed informed consent in place.

It is important that Muslim doctors and Muslim scholars^{65,66} discuss the subject openly with the aim of providing the Muslim public sufficient information to formulate an informed consent and ideally put forward unified guidance on the issue.

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