

*In the name of Allah, The Beneficent, The merciful*

**We have honoured the progeny of Adam; ... given for them sustenance things good and pure; and conferred on them special favours; above a great part of Our creation.**

[The Glorious Qur'ān, Al-Isrā', 17:70]

This submission should not be interpreted as a rejection of the practice of cadaveric organ donation which, itself, remains a point of contention amongst contemporary Muslim scholarship, but rather it is argued that the Human Transplantation (Wales) Bill does not give due regard to the universal principle of respect for personal autonomy, emaciates the very concept of donation, and assumes what cannot reasonably be assumed. It relegates any notion of donating or giving to simply salvaging and taking - taking without asking at that.

The Qur'ānic verse quoted above is self-evident and comprehensive in its recognition of dignity for all human being without limitations or qualifications. The superiority of mankind discussed here is due to the intellect which is the basis of obligation.<sup>i</sup> The principles of autonomy of the individual, beneficence, non-maleficence and justice are considered established principles of the medical field which govern the ethical practice of medicine and research. Islam too recognises these principles, although their application may differ from a western secular understanding. In the context of the current debate, Islam acknowledges the principle of autonomy conferred upon man as God's viceroy on earth.<sup>ii</sup> This latter principle recognises the rights of individuals to self-determination and is rooted in respect for the individuals' ability to make informed decisions about personal and other matters. However, this requires the full disclosure of information to the individual since one can validly make choices only if one is fully informed.

Informed consent can be described as “a voluntary and explicit agreement made by an individual who is sufficiently competent or autonomous, on the basis of adequate information in a comprehensible form and with adequate deliberation to make an intelligent choice about a proposed action.”<sup>iii</sup>

Thus, basic requirements of informed consent include a discussion and an enumeration of risks, benefits, and alternatives. This discussion should address either serious or frequent risks or both. The individual concerned should be encouraged to ask questions and express concerns. The process should be voluntary and without coercion. It is the existence of such discussion and the transfer of information and decision-making rights that empowers the patient and respects his or her autonomy.

The Human Transplantation (Wales) Bill not only does not meet the basic requirements of informed consent, it actually relies on the individual being either languid or not being informed at all.

Furthermore, the current debate has not taken into account accepted meanings of presumption in Law and science and the consequences for rights of ownership that would arise should the Bill become law. Any action or decision made on a presumption is accepted in Law and science as one based on judgment of a provisional situation. It should therefore allow the possibility of reversing the action or decision. The Bill will not permit such reversal. Once organs are mistakenly removed the deceased cannot be returned to his/original state.

The absence of a positive indication of an individual's wishes cannot be interpreted as a desire to donate organs – to do so would be quite presumptuous! Without express consent it is difficult to be sure that someone would have wanted to be an organ donor. At best, one can maintain a neutral assumption until the wishes of the individual are established one way or the other. Whilst an act to do something should come from an instruction, an omission should not require specific instruction. Under the Bill the burden of ensuring that the respect for the individual's preference has been upheld is shifted on to the individual rather than on to the state. The Bill stipulates that the law will "deem" that someone has consented, but if the only evidence of consent is a lack of evidence of objection then this "deeming" is a legal fiction. It is not real consent.

The Bill places the value of body organ function above the requirement for permission from the individual. It demands moral responsibility – organ donation is the proper thing to do in the case of one's death.

It would also be difficult to establish a system that records an individual's objection to donation and makes the record easily and immediately available to all doctors and health care providers involved in terminal or critical care.

The Bill, as it stands, does not require the state to accept the wishes of relatives should they object to their loved one's organs being removed. Rather, the state may take the organs without the prior free and express consent of the deceased, and without, or even against, the express wishes of relatives. Whilst this is a policy for organ transplantation it is not a policy for organ *donation*. Organ donation must remain a truly altruistic positive action by the individual. A gift – not routine salvage.

The Bill law must state in unambiguous terms that in the absence of an explicit statement of the wishes of the deceased, the relatives will be able to refuse permission for the removal of organs. The Bill lacks effective protection for conscientious objection based on faith or ethical or family reasons.

It is pertinent to note that Islamic bodies, such as the London based Islamic Shariah Council, that gave pioneering edicts in support of organ donation are opposed to the system of 'deemed consent'. It is quite likely that rather than increase the availability of organs from the Muslim community the Bill will reduce the number of organs being donated.

The Bill creates a moral dilemma for even those Muslims who support organ donation but consider the policy of 'deemed consent' to be at odds with their faith. Contemporary Muslim scholars who have decreed organ donation to be a permissible and praiseworthy act have also required the donation to be with the express permission of the deceased or of his/her relatives. Thus, even according to these scholars the Bill does not respect the requirements of donation as per the Muslim faith.

Finally, the above discussion exists in an environment wherein the actual point of death remains a point of contention amongst not only medical practitioners and specialists but also amongst Muslim scholarship. In 1987, the Islamic Fiqh Academy of the Muslim World League based in Mecca decreed that the irreversible cessation of all brain activity was sufficient to remove the life support systems but not to determine that death had indeed occurred. This, decree has found favour amongst the majority of Muslim scholars worldwide.

I would thus urge the political parties in Wales to reconsider their positions on a system of 'deemed consent' and instead increase their efforts to raise awareness under the current system.

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<sup>i</sup> Al-Qurṭubī M, Al-Jāmi' li Aḥkām al-Qur'ān, 10:190.

<sup>ii</sup> The Glorious Qur'ān, Al-Baqarah, 2:30.

<sup>iii</sup> Aveyard H. Implied consent prior to nursing care procedures. J Adv Nurs. 2002;39:201-7.