

2020- THE ROLE OF FAMILIES IN SUSTAINING SOLUTIONS TO ORGAN SHORTAGE IN MALAYSIA

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ABSTRACT

Organ donation is a miracle in the modern medical world. Though it brings with it so many advantages, and is proven to have saved thousands of lives, however, it is not that easy to have it done. Organ shortage is one of the greatest challenges faced. It has become a global problem, particularly when the demand for organs is higher than the number of organs that could be supplied and benefitted by the patients in need. Through doctrinal research, this paper will highlight how families can play a big role in promoting plenty more organ donation procedures to be carried out while indirectly reducing the number of organ shortage too. Undeniably the family plays an extremely important role throughout the whole process of organ donation, The privileges spelt out towards family members, which allows them to decline any such intended donations to take place will be addressed in the light of the Human Tissues Act 1970.

Keywords: Organ donation, organ shortage, organs, family, supply.

INTRODUCTION

Donating organs is a noble act and considered as a miracle in the modern medical world. It saves people's lives, while bringing hope and happiness to many. In Malaysia, if one wishes to donate his organs, he himself must come forward and declare his intentions. Only by doing so, his organs could be taken and benefitted by others when the time comes.

Malaysia adopts the 'opting in system' which requires potential donors themselves to voluntarily come forward and register as organ donors. This is known as the "Contracting-In System". By virtue of this system, human tissues and organs are posthumously removed for organ donation, once informed consent has been obtained. The normal practice allows the donors to specify which part of their body that they wish to donate, and these wishes shall be carried out immediately, upon their death.

THE OPTING-IN SYSTEM

Every opting in system, requires persons to voluntarily come forward and register themselves as potential organ donors. This choice is never made compulsory. So, we can assume that these potential donors are those who are willing to donate their organs and would definitely want their wishes to be carried out immediately when the time comes. The nature of the opting in system emphasizes on volunteerism, so it is a must for all those who plan to register as potential donors to express and make known this noble intention of theirs to others. Remaining silent, or by just keeping this dream in one's heart alone, cannot become sufficient evidence that one has agreed to become a potential organ donor. Therefore, once one has decided to become a potential donor, one must come forward and express this intention by registering either manually or online. In simple words, the steps are to firstly come forward, express and communicate your intention, then register yourself.

THE HUMAN TISSUES ACT 1974

Malaysia does have an Act that exclusively pertaining to organ donation. Section 2(1) of the Human Tissues Act 1974 clearly specifies that every consent to donate organs must be expressed either in writing or if done orally, must be made in the presence of two or more witnesses present during his final illness. The donor must also express his request to have his whole body or any specified part of the body to be used after his death. The purpose and usage of the donated body or body part must also be specified, either for therapeutic, medical education or research purposes. This clearly signifies that communication is important at this stage, to officially declare yourself as a registered potential organ donor. Without registering, never can your organs be donated to others.

This practice also reflects the ethical concept of autonomy, where the patient has full power to decide and give consent regarding his treatment, including donating organs. Moreover, it is upon the potential organ donor to come forward and pledge his willingness to become an organ donor. He too shall be the one deciding what organs to be donated including the purpose for such donation. All this reflects autonomy and self-determination, where everything must be done with the consent and willingness of the donor himself, without being forced or by anybody or any other reason.

SHARING NEWS WITH FAMILY

Once a person has officially registered as a potential organ donor, the next step is to further share and communicate this important decision to their family members including their spouse, children, parents, and other close family members. The organ donor must not keep this important decision a secret to themselves, instead they should share the news with as many people as possible. This is to ensure that our close ones are aware and could give the support and assistance that we need later. Although to become an organ donor is a decision that the potential donor makes voluntarily, however, when it comes to implementing this wish, approval from others, especially from close family members is a must. Surprisingly, this wish may not automatically come true. There is a legal provision in our Human Tissues Act 1970 that can impede it from coming true. Therefore, there is no guarantee for these potential, registered organ donors to become actual donors as pledged earlier, especially if their close family members are not aware of this decision. Moreover the Act is very much consent-based and recognizes family rejection as valid and authoritative

Referring further to section 2(2)(a) of the Human Tissues Act 1974, the person lawfully in possession of the deceased body, after making reasonable and practicable enquiry, may permit donation where he believes;

- a) That the deceased had not expressed an objection to his body being dealt with after his death; or
- b) That the surviving spouse or any surviving next of kin of the deceased has not objected to the body being used for the donation.

Section 2(2) (b) of the 1974 Act above, clearly provides optional power to the surviving spouse or next of kin to authorize removal of any part of the deceased body, though it is still subject to any express objections by the deceased himself during his lifetime or any family objections brought forward. This provision allows organ donors to have their wishes being overridden by their own families. Therefore, immediate action must be taken to stop families from using their conclusive authority by rejecting and opposing organ donation intended by

their loved ones. Research found out that, almost half of the families of potential donors do refuse consent (Mark et al, 2001). Only if there is no objection from the surviving spouse or any surviving next of kin, the organ donation procedure suggested may proceed. In other words, even if the potential organ donor had already made a pledge and signed up to become an organ donor, but once there is objection from the deceased's spouse or next of kin, therefore, the organ donation procedure cannot take place. This requirement reveals how the Human Tissues Act 1974 is very particular pertaining to consent matters and does take family approval seriously.

In our opinion, when such situations take place, indirectly human autonomy is infringed and denied. For instance, if the deceased party had previously not consented to any organ removal to take place, we should respect his decision and allow him to rest in peace. Therefore, the body should be prepared for burial or disposal immediately. The deceased's organs must be left untouched and originally intact inside the body. Moreover, in a system where individual consent is considered pre-eminent, should we not also respect and uphold the human autonomy principles here? I strongly contend that in this situation, consideration must also be made on the possibility that the deceased had never intended to become an organ donor due to his own personal reasons, and therefore this fact must be respected too. So, no matter how desperate we are for donated organs, when a person does not register himself as one during his lifetime, his family members should not be given the authority to decide on his behalf. Coincidentally, this is in line with the Scottish Council on Human Bioethics which believes that organs and tissues of the deceased person should only be removed if this person had given his consent earlier. Any next of kin should not authorize the retrieval of organs when the individual had left no wishes, especially in an opting-in system applicable (House of Lords European Union Committee 17th.Report)

Similarly, if the deceased had already pledged to donate his organs, surely we must respect and honour his wishes. Therefore, in order to maintain and uphold the ethical principle of autonomy, their spouse, or next of kin, or anyone else, must never be allowed to interfere and stop the donation from taking place. The deceased's wish must be respected and carried out without delay. Indeed, potential donors would definitely want their decisions to be respected, regardless of whatever reason.

The fact seems unfair because, why should we allow others to override a decision that we had already soundly made when we were still alive. The decision itself was not easily made and would obviously have been made with care and caution. Allowing others, though only those close to us, to override it, is still an act of encroaching one's right to autonomy. All registered organ donors must be rest assured that his wishes to contribute his organs shall be honoured and carried out upon his death, without any fear of being overruled by his family later on. A patient's decision must be respected and given effect to. Not adhering to this, would be equivalent to robbing the patient of his right to own personality, which is serious and destructive.

So, improvements have to be made on the current practice. Families should no longer be approached for their consent to organ donation of the deceased, but it would be sufficient to approach them shortly before the organ procurement procedure taking place only as a sign of respect and to keep them abreast with the procedure taking place on the deceased party (Farah Salwani, 2014). By doing this, we are honouring the deceased's wish to become actual donors, which is part of upholding the principles of autonomy, while at the same time, showing respect to the grieving family. Similarly, for those who never pledged to donate

organs, we can never assume that they actually wanted to do so, but never had the chance. Their organs must remain untouched. Above all, sufficient communication among the parties could also help clarify the situation. If from the very beginning, the family members were aware of the donor's intention to donate his organs, perhaps it would be easier for them to agree as they have understood it.

INITIATING CHANGES

One of the most effective ways to solve this is by legally amending the Human Tissues Act 1974, particularly by removing the section contained therein which permits such occurrence to take place. So, section 2(2) (b) of the Act, which clearly acknowledges family objections particularly from the deceased's spouse and next of kin, must be removed. Hopefully, by implementing this change, we will be able to see more actual organ donations taking place as intended.

However, before such drastic measures are taken, we must encourage potential donors to express, discuss and communicate their intention with their close family members. Breaking the news earlier to families would give them a chance to understand and accept the decision better. Avoiding shocks and surprises on the day the donation is about to take place is a bit too hard, particularly when they are still grieving their loss.

CONCLUSION

Organ shortage is indeed a worrying problem that we face. Nevertheless, if proper action is taken in dealing with the potential donors and their family members, a lot of positive impact could surely be seen. Until changes can be legally made to our Human Tissues Act 1974, potential donors must be required to express and communicate their intention with their family. Families should support and honour the wishes of their deceased loved ones to help them save others in need too.

REFERENCES

Books

Cuzin, B. & J.M, Dubernard. 1995. *Organ Shortage: The Solutions*. Dordrecht: Kluwer
Farah Salwani Muda@Ismail. 2014. *The Organ Shortage Crisis in Malaysia*. Universiti Salns Islam Malaysia Publisher. Negeri Sembilan

Articles

Christmas, Ashley Britton, Mallico, Eric J. Burris, Gary W. Tyson, A, Bogurt, R.N., Norton, Harry James & Sing, Ronald F., 2008. "A Paradigm Shift in The Approach to Families for Organ Donation: Honouring Patients' Wishes Versus Request For Permission in Patients With Department of Motor Vehicles Donor Designations", *The Journal of TRAUMA Injury, Infection, and Critical Care*. Volume 65. Number 5, 1507-1510
Etzioni, Amitai. 2003. "Organ Donation: A Communitarian Approach". *Kennedy Institute of Ethics Journal*. Vol.13. No.1. 1-18
Kececiloglu, N, M.Tuncer, L.Yucetin, M. Akaydin, & G.Yakupoglu. 2000." Attitudes of Religious People in Turkey Regarding Organ Donation and Transplantation in "Organ Donation in Oman: Preliminary Report". 1998. *Transplantation Proceedings*. Volume 30. Issue 7. November 1998. 3624-3625
Marks,W.H, D. Wagner, T.C.Pearson. et al, 2006. "Organ Donation and Utilization in the United States". *American Journal of Transplantation*. 6. 1101

Tymstra, T. J, J.W. Heyink, J.Pruim & M.J.H. Sloof. 1992. “Experience of Bereaved Relatives Who Granted or Refused Permission for Organ Donation”. Family Practice. Vol.9. No.2. 141-144

Acts

National Organ, Tissue and Cell Transplantation Policy. 2007. Ministry of Health Malaysia.
Human Tissues Act 1974