

THEME:ETHICAL CHALLENGES IN THE DECEASED ORGAN DONATION PROGRAMME:
ASIAN PERSPECTIVES

After presumed consent: a review of organ donation in Singapore

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Introduction: three schemes of organ donation

Singapore was the first Commonwealth country to enact, in 1987, a presumed consent law for organ donation (1). Referred to as the Human Organ Transplant Act (HOTA), it applied only to persons between the ages of 21 and 60 years who had suffered accidental deaths certified by the criteria of brain death or cardiac death; who were non-Muslims; and who had not formally dissented from ("opted out of") organ donation. The actual policy was implemented in 1988, after a six-month period to allow objectors to register their dissent, and applied only to donation of kidneys. The new law at that time came into existence alongside the older Medical (Therapy, Education and Research) Act (MTERA) of 1972, an "opt-in" scheme of voluntary donation, where persons could pledge to donate their organs and tissues (eg kidney, liver, heart, cornea, lung, bone, skin, heart valves, etc) for the purposes of transplantation, education or research upon death. An amendment to the HOTA in 2004 also permitted living organ donation, and permitted retrieval of other types of organs besides kidneys (livers, hearts, and corneas). The 2004 amendment further included all causes of death rather than solely death by accidental causes. Hence, in effect, three schemes of organ donation were set in place in Singapore by 2004, and further legislative amendments (2007, 2009 to HOTA) were made with the firm intent of expanding the supply of transplantable organs, and ensuring that organ donors are not exploited, unlawfully induced, or forced into organ retrieval by others (see Table 1).

The current provisions for organ donation by voluntary donation, presumed consent and living donation in Singapore are explained in Table 2, based on current information on the Ministry of Health's website (2).

The current situation

Organ donation rates under Singapore's older opt-in law (the MTERA, enacted in 1972) have been poor despite door-to-door canvassing and media publicity throughout the 1970s and 1980s, and continuing transplant awareness education through information booklets posted to citizens and permanent residents six months before the age of 21. Even after 35 years of canvassing donors for pledges, only 1.3% of citizens and permanent residents pledged their organs in 2007 (3).

These low take-up rates had prompted the introduction of the presumed consent/opt-out system under the HOTA in 1987. Opt-outs are rare, and this observation is consistent with research conducted regarding defaults and organ donations. Results of the survey revealed donation rates to be double in an opt-out system as opposed to an opt-in system (4). Between 2004 and 2009, only 2%–3% of Singaporeans opted out of donating organs after death (3). Hence, the presumed consent law had effectively increased the donor pool by more than 95% of the Singapore population. Yet, donor actualisation rates continue to fall. The introduction of the HOTA increased the rate of deceased donor kidney transplants from 4.7 per year during 1970–1988 to 41.4 per year during 1988–2004 (5). But early expectations of increased organ retrieval over time through the presumed consent to donation scheme enacted in the HOTA have not materialised (5–6, 8). For example, in spite of legislative efforts, the number of renal failure patients getting transplants through cadaveric and living donors has fallen over the years from a peak of 124 in 2004 to 62 in 2012;¹ this has been attributed to a dearth of deceased donor pledges and willing living donors (9).

With the initial enthusiasm about the presumed consent system, some members of the transplant community claimed that, while Singapore's religious and cultural pluralism might present many obstacles to deceased organ donation, social changes were afoot that would render obsolete, or at least ameliorate the effects of, belief systems that opposed the retrieval of bodily organs after death (10). However, while social change may be the reason that recent findings regarding the positive attitudes towards living organ donation of Singaporeans who are younger, more educated, have higher incomes, are single (never married, divorced or widowed), and hold professional jobs (11), this change alone has not reversed organ procurement rates in Singapore over time.

There have been repeated calls by transplant physicians in Singapore for better public education on ethical, cultural, and religious aspects of organ donation (1), improving physician training in the logistics of actualising donor referrals (3), in tandem with preventive measures to stem the tide of organ failure from rising rates of diabetes in Singapore's ageing population (12). In the case of kidneys, the donation rate has

Table 1
Legal provisions to expand organ supply and curb donor exploitation in Singapore

Legislation and year	Provision	Remarks
MTERA (1972)	Persons have the legal right to donate parts of their body to approved hospitals, medical or dental schools, colleges or universities for “medical or dental education, research, advancement of medical or dental science, therapy or transplantation” or to “any specified individual for therapy or transplantation needed by him”.	These legislative changes were undertaken gradually over time with intent to both expand the supply of transplantable organs, and to ensure that organ donors are not exploited, unlawfully induced or forced into organ retrieval by others.
HOTA (1987)	Under a new opt-out system, individuals are presumed to have consented to organ donation upon death. Family members have no legal right of objection, although in practice, organ retrieval is carried out with due regard to families. Excluded Muslims, who were automatically considered objectors because under the Muslim Council’s interpretation, removal of organs at death constitutes desecration of the deceased, and the consent of <i>waris</i> (paternal next-of-kin) was necessary for organ donation. Muslims in Singapore could opt-in to organ donation under HOTA, or pledge their organs under MTERA. Muslim exemption from presumed consent was removed in 2007, following a religious ruling by the Islamic Religious Council of Singapore permitting Muslims to come under the HOTA.	
HOTA Amendment (2004)	The Act was amended to permit retrieval of other types of organs besides kidneys (livers, hearts, and corneas), and all causes of death rather than only death by accidental causes. Living donor transplants were legalised, but written authorisation by a hospital ethics committee was required and applicants had to be screened for eligibility.	
HOTA Amendment (2009)	The Act was amended to remove the upper age limit of 60 years for deceased donations to allow transplantable organs to be assessed for medical suitability. Paired exchanges permitted. Reimbursement of donors for documentable or reasonable costs allowed. Under Section 14 (3)(c) of the HOTA, costs that may be reimbursed include expenses incurred for medical procedures, childcare, loss of earnings, short- or long-term medical care as a consequence of organ donation. Regulatory oversight of all living organ donations was established under Section 15A (3) through appointment of doctors and laypersons to a National Panel of Transplant Ethics Committees (hereafter TECs). Organ commercialism outlawed, with heavy penalties instituted including hefty fines (up to SG\$100,000) or a jail term (up to 10 years), or both.	

Table 2
Legislative provisions for organ donation in Singapore

Act	HOTA		MTERA
Source	Living	Cadaveric	
Consent	Voluntary	Presumed consent	Voluntary
Age			Age limit for organ pledging: 18 years and above The adult next-of-kin can also pledge the organs of deceased patients of any age for donation.
Organs included	Kidney Liver	Heart Cornea	All organs and tissues
Purpose(s)	Transplant		Transplant and treatment Education Research
Nationality	Singapore citizens and permanent residents		Any nationality
Religion	Any religion (Muslims included under HOTA from 1 August 2008)		Any religion (For Muslims, MUIS has issued <i>fatwas</i> stating that the donation of kidney, liver, heart and cornea is permissible.)

been consistently low by international standards. In 2004, although the number of kidneys transplanted through retrieval from deceased and living donors reached a peak, the donation rate for cadaver kidneys remained low in Singapore at 8 donors per million population (pmp) compared to between 13 and 34 pmp in Europe (13).

Reasons for low organ procurement rates

The reasons for low organ procurement rates from cadaveric and living sources in Singapore are also well-documented. Transplant teams report several clinical and ethical challenges in donor identification, donor referrals, and donor actualisation (3).

1. Organ pledges are rare due to many personal factors including, according to physician reports, apathy and inertia, fear of death and reluctance to discuss death, belief that medical decisions to withhold or withdraw life-sustaining treatments would be influenced by one's donor status, and feelings of personal uncertainty about transferring organs into the bodies of strangers (10).
2. The concept of brain death remains an ethically ambivalent issue, and closely tied to the need to clarify the conditions under which organs may be legitimately retrieved from the deceased for transplantation (13). The 'dead donor rule' which has fuelled widespread professional discomfiture in modern healthcare is no less controversial in Singapore (14).
3. Continued reliance on identifying potential donors from brain dead heart-beating patients only, and leaving out the much larger numbers who could be identified for donation after cardiac death on the presumption that the organs retrieved from this source are of poorer quality (3). At the same time, protocols for instituting organ preservation techniques and controlled cardiac death are still regarded as controversial (15).
4. Continued reluctance to deploy extended criteria for donation, such as organs from deceased donors with clinical risk factors, on the assumption of poorer outcomes compared to transplantation using organs that meet the standard criteria (16).
5. When grieving family members object to organ retrieval by presumed consent to donation, in the face of uncertainty about the wishes of the deceased, doctors have been reluctant to press the issue (12).

This consideration of familial bereavement, however, differs from the process of informed consent, which, as part of HOTA, happens at the age of 21 when the person receives a packet with information on the Act and necessary forms for opting-out. Persons who do not register an objection to removal of organs under the HOTA are presumed to have consented to organ donation on an informed basis. Families although lacking a legal right to stop the retrieval of organs, are appropriately given due concern for their bereavement. The doctor's reluctance to press the issue can be better managed as mentioned in point 7 under proposals in Table 3.

6. Some insight into the dearth of living donors has been provided by researchers who have investigated family members' reasons for not donating. Besides the fear of the risks of surgery, risks to health and other individual factors (11), family pressures weigh on the organ donation decision for both potential donor and potential recipient. Such decisions can be so pressurising on families as to sever long-standing ties when potential donors keep silent or disappear, and potential recipients feel abandoned or betrayed (10). Sometimes, objections are raised by in-laws and other relatives (1).
7. A report on Chinese traditional cultural beliefs surrounding organ donation predicts that family consent to donation of a loved one's organs after death would be rare among the Chinese, who constitute 74.2% of Singapore citizens and permanent residents (17). Proper disposition of corpses in accordance with Confucian beliefs about filial piety, popular beliefs about spiritual presence in bodies for several hours post-death, fears about angering the ghost of someone whose body is subjected to organ donation or autopsy, fears of offending the "angry ghosts" of persons whose lives were ended in an untimely manner by accidents, homicides, suicides, executions, etc (18).

Table 3 summarises the reasons for low organ procurement rates in Singapore, as reported in the literature, and ethical and practical issues to be addressed among stakeholders in future efforts to improve donation rates.

Conclusion

The history of organ transplantation in Singapore and the procurement of organs for transplantation are ethically sensitive issues. This review has focused on low organ procurement rates in Singapore over the years, and on the analysis of reasons that has become available in the literature on this subject. Writers have been equally prolific in recommending strategies for improving the organ donation record in Singapore, and expressing perspectives on the ethics of different approaches (1,3,16).

While the enactment of a presumed consent law in 1987 was momentous and led many in the transplant community to think that progress in transplantation was inevitable, the reality as we now know has been less encouraging. The present consensus appears to be that legislation alone is not enough to raise organ donation to higher levels to meet the needs of patients with end-stage organ failure, a problem that has reached unprecedented levels in Singapore. Transplant professionals have pressed for better practical strategies to address the areas of personal motivation of donors, eg the willingness of younger Singaporeans to make living donations to intimates but not strangers, and the willingness of the elderly to donate to strangers (11); the changes in cultural and religious beliefs in an increasingly literate population; investing in physician training to improve donor identification, referral, and actualisation rates in all hospitals (3); improving the organ donation experience for patients by enhancing trust in medical professionals and addressing misplaced fears concerning the medical risks of donation.

Table 3

Improving the organ donation experience: proposals from the literature

Reasons for low procurement among stakeholders	Proposals
<p><i>Individuals</i></p> <ol style="list-style-type: none"> 1. Fear of death or apathy lead to individual failure to pledge organs, or express preferences about organ donation 2. Fear of surgical risks and risks to health and employment 3. Mistrust of medical professionals 	<ol style="list-style-type: none"> 1. A presumed consent system addresses this preference for silence; but the voluntary communitarian basis of this system must be well-publicised and accepted within society. 2. Investments in trained transplant coordinators, and dissemination of trustworthy information on organ donation risks should be undertaken by hospitals providing transplant services. 3. Transparent guidelines and protocols for hospital intensivists regarding withholding/ withdrawing mechanical supports, evaluation of brain death, and donor identification should be developed.
<p><i>Professionals</i></p> <ol style="list-style-type: none"> 4. Uncertainty about the ethics of, and protocols for, determining brain death 5. Uncertainty about the ethics of, and protocols for, communication with families about organ donation after brain death 6. Uncertainty about the ethics of, and protocols for, donation after cardiac death 	<ol style="list-style-type: none"> 4. Intensive care protocols should be independently carried out regardless of a patient’s organ donor status or suitability. 5. Organ donor suitability should be evaluated by transplant coordinators, and discussed with the patient’s family, only after decisions to limit life-sustaining treatment have been independently taken, or a determination of brain death has been independently carried out. 6. Once decisions to limit life-sustaining treatment have been independently taken, transparent and well-validated protocols for commencing organ preservation procedures and treatments should be explained to families. The ethical basis of donation after cardiac death is the presumed consent of patients who have not opted out of organ donation. The ethical basis of commencing organ preservation procedures and treatments must lie in reasonable professional certainty that these are not harmful to the patient. Its legal basis is provided under the HOTA.
<p><i>Families</i></p> <ol style="list-style-type: none"> 7. Bereavement 8. Cultural and religious beliefs 9. Uncertainty about the patient’s wishes 10. Family conflict (living donation) 	<ol style="list-style-type: none"> 7. Transplant teams should be sensitive to the needs of family members in bereavement, and should develop protocols (such as time-limited stays on organ retrieval) that reflect consideration towards families. Skilled counsellors should help families to potentially seek solace in the beneficent act of organ donation. 8. Transplant coordinators should be careful not to rely on stereotypes and assumptions about religious and cultural traditions, and how individuals bring such considerations into organ donation and other decisions. 9. Transplant coordinators should be mindful that family members who have no prior knowledge of a deceased loved one’s wishes may also rely unduly on stereotypes and assumptions, and should be prepared to engage in more considered discussions about known aspects of the patient’s character and general values and preferences. 10. Family relations can be disrupted by an organ donor’s decisions; but families can sometimes also exert undue pressure on donors. Transplant teams should deal carefully with such situations, and in helping donors to come to an informed choice, consider the extent to which an organ donation decision strengthens or harms a patient’s critical interests.

After presumed consent, the next era of transplant services in Singapore is likely to focus on ethically informed transplant practices that emphasise motivational factors in voluntary deceased and living organ donation; strengthening understanding of the present communitarian basis of the organ donation system under the HOTA; professional training, independence and integrity in the clinical and administrative setting in light of ethical objections to the “dead donor rule”, and the application of difficult-to-accept neurological criteria for the determination of death; judicious extension of donor criteria (donation after cardiac death, deceased donors with clinical risk factors) without compromising fair outcomes for all recipients.

Note

¹ Another source places the figure at an even lower number of 51 kidney transplants in 2012. Available from: http://www.straitstimes.com/sites/straitstimes.com/files/20130811/ST_20130811_RBLIVER11A_3786808.pdf

References

1. Prabhakar KS. Cadaveric and living organ donation. Natural limitations. Possible solutions. Singapore experience. *Ann Transplant.* 2004;9(1):31–3.
2. Ministry of Health, Singapore. The Medical (*Therapy, Education and Research*) Act (MTERA). Singapore: MoH; 1987, updated 2010 Nov [cited 2014 Jun 2]. Available from: http://www.moh.gov.sg/content/moh_web/home/legislation/legislation_and_guidelines/the_medical_therapyeducationandresearchactmtera.html

3. Kwek TK, Lew TW, Tan HL, Kong S. The transplantable organ shortage in Singapore: has implementation of presumed consent to organ donation made a difference? *Ann Acad Med Singapore*. 2009 Apr;38(4):346–8.
4. Johnson EJ, Goldstein D. Medicine. Do defaults save lives? *Science*. 2003 Nov 21;302(5649):1338–9.
5. Vathsala A. Twenty-five facts about kidney disease in Singapore: in remembrance of World Kidney Day. *Ann Acad Med Singapore*. 2007 Mar;36(3):157–60.
6. Soh P, Lim SM. Impact of the opting-out system on kidney procurement in Singapore. *Transplant Proc*. 1991 Oct;23(5):2523.
7. Soh P, Lim SM, Tan EC. Organ procurement in Singapore. *Ann Acad Med Singapore*. 1991 Jul;20(4):439–42.
8. Seah S, Emmanuel S, Vathsala A, Tan S, Woo KT. The potential for cadaver organ retrieval in Singapore. *Transplant Proc*. 1992 Oct;24(5):2073.
9. Khalik S. Number of kidney failure cases in Singapore on the rise. *The Straits Times* [Internet]. 2013 Nov 3 [cited 2014 Jun 2]. Available from: <http://www.straitstimes.com/breaking-news/singapore/story/number-new-kidney-failure-patients-singapore-the-rise-20131103>
10. Woo KT. Social and cultural aspects of organ donation in Asia. *Ann Acad Med Singapore*. 1992 May;21(3):421–7.
11. Owyong LM, Lim C, Leng CW, van der Erf S, Joshi VD, Sin ST, Hong ST, Chye PG, Seng GT, Yi-Shern TK. Factors influencing living kidney donation in Singapore. *Prog Transplant*. 2012 Mar;22(1):95–101.
12. Tan J. S'pore organ donation rate still low despite law. *The Straits Times* [Internet]. 2010 Nov 26 [cited 2014 Jun 2]. Available from: <http://www.healthxchange.com.sg/News/Pages/Singapore-organ-donation-rate-still-low-despite-law.aspx>
13. Schmidt VH, Lim CH. Organ transplantation in Singapore: history, problems, and policies. *Soc Sci Med*. 2004 Nov;59(10):2173–82.
14. Truog RD, Miller FG. The dead donor rule and organ transplantation. *N Engl J Med*. 2008 Aug 14;359(7):674–5. doi: 10.1056/NEJMp0804474.
15. Phua J, Lim TK, Zygun DA, Doig CJ. Pro/con debate: in patients who are potential candidates for organ donation after cardiac death, starting medications and/or interventions for the sole purpose of making the organs more viable is an acceptable practice. *Crit Care*. 2007;11(2):211.
16. Voo TC, Campbell AV, de Castro LD. The ethics of organ transplantation: shortages and strategies. *Ann Acad Med Singapore*. 2009 Apr;38(4):359–6.
17. Department of Statistics, Singapore. Population trends 2013. Singapore: Department of Statistics, Ministry of Trade & Industry; 2013 [cited 2014 Jun 4]. Available from: http://www.singstat.gov.sg/publications/publications_and_papers/population_and_population_structure/population2013.pdf
18. Ikels C. Ethical issues in organ procurement in Chinese societies. *China J*. 1997 Jul; No. 38:95–119.

Organ donation in the Philippines: should the dead do more?

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Abstract

This paper asks whether the Philippines should focus on ways of dealing with end-stage renal disease by getting more transplantable kidneys from the dead. Would it be more ethical to put the burden to donate on the dead (who have already lost their chance to consent) than on the living (who can consent)? Given the risks involved in undergoing nephrectomy and the lack of benefits arising from the procedure to donors, the dead should be the first to put their kidneys on the line. In the Philippines, unfortunately, living donors have had to bear the greater burden in this regard. Starting with a brief account of developments surrounding the impact of the Declaration of Istanbul on the situation in the Philippines as well as in other countries, the paper examines what the living have been expected to do, what they have actually done, and what lessons the experience with living donors offers for the understanding of cadaver transplants. The paper then looks at possible ways of increasing the sources of kidneys for transplantation and asks if these ways could be implemented successfully and ethically in the Philippines.

Introduction

Organ transplantation is a medical intervention whose success for a patient is primarily dependent on what another person, living or dead, and who is not part of the medical team, can contribute. A number of organs can be transplanted but for the purposes of this paper, the focus is on kidneys – for transplantation in the context of the Philippines. This paper asks whether the dead should do more. Should the Philippines

focus on ways of dealing with end-stage renal disease by getting more transplantable kidneys from the dead? Would it be more ethical to put the burden to donate on the dead (who have already lost their chance to consent) than on the living (who can consent)? Given the risks involved in undergoing nephrectomy and the lack of benefits arising from the procedure to donors, the dead should be the first to put their kidneys on the line. Unfortunately, that does not seem to be the way things have happened in the Philippines. For a long time, living donors have put their kidneys – and health and safety – on the line for renal patients.

By way of a background, this paper starts with a brief account of developments surrounding the impact of the Declaration of Istanbul (DoI) on the situation in the Philippines as well as in other countries. It is pertinent to ask what the living have been expected to do, what they have actually done, and what lessons the experience with living donors offers for the understanding of cadaver transplants. The paper then proceeds to examine the situation as regards dead organ donation by looking at possible ways of increasing the sources of kidneys for transplantation. We ask if these ways could be implemented successfully and ethically in the Philippines.

Impact of the DoI

As a guidance document, the DoI on Organ Trafficking and Transplant Tourism has had a remarkable impact on the improvement of ethical organ transplantation throughout