



What Intensivists Say About an Opt-Out System for Organ Donation

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ABSTRACT

Background. Singapore has had an opt-out organ donation system since the inception of the Human Organ Transplant Act in 2009. This law allows all Singapore citizens and permanent residents to donate their organs after confirmation of brain death, usually in the setting of devastating brain injury or stroke in an intensive care unit (ICU) setting, and such cases are referred to the National Organ Transplant Unit team by intensivists after the presumed clinical brain stem death testing. The further confirmatory tests, coordination with surgeons to find suitable recipients, and communication with family members is then carried out by the transplant coordinators from the National Organ Transplant Unit and not the clinicians. Despite a decade of the institution of the Act, the rates of organ donation remain low. This survey is the first aimed to assess the concerns and recommendations of the intensivists in Singapore.

Methods. This was an anonymous survey sent to 120 intensivists registered in Singapore with a 58% response rate. The survey included 14 open-ended questions. The respondents included both private and public sector intensivists. A qualitative analysis was carried out to analyze the emergent themes from the survey.

Results. A total of 79% of the respondents mentioned raising awareness through publicity, education, and advertising; 34% mentioned educating physicians and engaging ICU physicians in further planning of the organ transplant program in Singapore; 35% felt that publicizing more real stories of recipients would help. Generally, there was unease at the opt-out system infringing basic rights.

Conclusion. This is the first survey to elicit the responses of the referring physicians for organ transplant. Their opinions suggest that a wider awareness and buy-in is needed both by the public and the ICU physicians, and addressing their valid moral concerns is essential in bridging this gap.

THE SCARCITY of organs has dire consequences. As in other countries, the demand for organs in Singapore has far exceeded supply [1].

The Human Organ Transplant Act allows for the kidneys, heart, liver and corneas to be removed in the event of death from any cause for the purpose of transplantation. From 1 November 2009, HOTA covers all Singapore Citizens and Permanent Residents 21 years old and above, who are not mentally disordered, unless they have opted out. The upper age limit of 60 years has been removed [2].

According to the National Organ Transplant Unit today, more than 500 patients wait for a suitable organ match [3]. Because of the sensitivity of the topic, public engagement has been delicately performed by National Organ

Transplant Unit [4]. Cultural, religious, and ethnic factors have not been explored in finding reasons for the low rate of organ referrals. While there may not be data about the views of intensivists from other countries with an opt-out system, there is some published literature of views of other health care workers, intensivists' views on organ donation, and the challenges faced [5]. Some authors believe that a presumed consent system denies the autonomy of the donors and undermines varied end-of-life beliefs in society [6]. In other

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literature, intensivists believe that moral neutrality allows them freedom to practice professionally and allows for patient autonomy, rather than focusing on the organ donation numbers [7].

In all cases, patients who are brain-dead will receive intensive care and mechanical ventilation for at least 48 hours before a preliminary diagnosis is made [8]. Hence, intensivists (who take care of such patients in the intensive care unit [ICU]) lead in the preliminary brain death certification and referral to the transplant unit and therefore play a key role in the process [9]. Although they are obliged to refer the presumed brain-dead patient for further assessment by 2 independent clinicians, intensivists still are the primary physicians for the patients and their loved ones. Their duty of care extends until the end-of-life decision-making process has reached a conclusion and includes providing support to both the patient and the family [10]. Brain death certification is a set of 7 bedside clinical steps to look for cranial nerve responses arising from the brain stem. If absent, the patient is most likely brain-dead if all the prerequisites are met. This is followed by a more rigorous confirmation by 2 independent physicians or supplementary tests.

We aimed to survey intensivists in Singapore by means of this candid anonymous online survey. The aim of the study was to elicit the opinions about the hurdles facing organ donation referrals in Singapore under the opt-out system from the point of view of intensivists and also to obtain suggestions for improvement from intensivists.

METHODS

The study commenced after internal review board approval and project registration (Table 1). This was an anonymous online survey of all intensivists (consultants and above in Singapore who are practicing in the ICU and may or may not have been intensive care management registered in the Singapore Medical Council). The participants were approached via the Singapore Society of Intensive care medicine whose members are practicing intensivists. The survey comprised a yes/ no answer as well as open-ended questions. A 58% response rate (70 responses) was obtained in the period from January to July 2015 as shown in Table 2. The survey included 14 open-ended questions.

RESULTS

When asked about why the public had reservations about the opt-out Human Organ Transplant Act law the responses were varied: (“Do you feel the public are ready to accept Human Organ Transplant Act law?”) There were 4 main themes to this answer:

Table 1. KTPH Anesthesia Clinical Audit Project Registration Form

Project	Date of Registration
What Intensivists Say About an Opt-Out System for Organ Donation	Dec 2014

Table 2. Responses by Participants

Type of intensivist	40% Private 60% Public sector
Type of ICU	40% MICU 45% SICU 10% Mixed ICU 5% CCU
Prior knowledge of HOTA law	Yes 63%
Has it been successful	Yes 51%
Is it a practical law	Yes 78%
Is the public ready to accept it	Yes 51%
Felt confident in making a preliminary brain death certification on a patient	Yes 57%
Did not feel confident in managing extracranial organ preservation for potential organ donation after brain death testing	Yes 64%
Felt uncomfortable in referring risky organs for procurement	Yes 83%
Felt comfortable in communicating to families about referral for organ donation	Yes 52% (73% felt there were societal or cultural barriers for them, 18% felt it was time consuming, and 9% felt it was ethically or morally wrong to do so).
Felt uneasy about end-of-life conversations with families	Yes 40%
Felt it was their duty to discuss end-of-life care and it was part of effective communication	Yes 84%
Would donate their own organs to loved ones	Yes 99%
Would donate their own organs to strangers	Yes 81%

Abbreviations: HOTA, Human Organ Transplant Act; ICU, intensive care unit; KTPH, Khoo Teck Puat Hospital; MICU, medical intensive care unit; SICU, surgical intensive care unit.

1. A total of 90% felt that there were cultural, societal, and religious barriers to acceptance or organ donation in Singapore. The concept of body preservation after death is an important element. Some stated that there is a barrier to end-of-life conversations in our society that makes organ donation difficult to broach. Families may feel guilt and filial piety that can preclude consenting to donation.
2. In addition, 25% felt there was poor publicity of the opt-out system and most relatives were unaware of the law. This lack of awareness of the law and the aims of it made acceptance difficult especially at stressful times in the ICU. One respondent felt that the public “may accept the law but they might not be prepared to deal with it when their loved ones are certified brain dead.”
3. A third feature was the perceived lack of patient autonomy in a presumed consent system where the opportunity to refuse may be less advertised.

4. A total of 65% of the physicians felt a conflict of interest in raising this topic. This was primarily because physicians saw themselves as advocates of the patient and their families and hence felt uncomfortable in broaching a topic they knew would be perceived as harmful to the patient; 20% of the physicians feared repercussions, including media involvement and physical threats from the public.

The following varied responses were obtained when asked regarding who should be referring potential donors for transplant:

1. A total of 67% felt that transplant coordinators (or trained staff) and social workers or even a separate team of physicians who are not directly managing the patient should refer the patient for organ donation.
2. Some (57%) felt a strong conflict of interest in referring the patient. One said that "The primary care provider must be seen to be acting in the best interest of his patient without conflict of interest and therefore he cannot be the referral activator." As an additional suggestion, 1 respondent added that this conversation should be discussed before the patient becomes too ill, alluding to advance care planning.

The next question dealt with "What are the reasons, in the respondents' minds, for the low rates of referrals of organ donation in Singapore?"

1. Most of the answers (89%) mention a low rate of awareness and acceptance among the family members. The majority of the intensivists (79%) felt that the public was not accepting of organ donation and an opt-out system further places duress on them at a time of grief. One respondent indicated "The legal system being 'co-opted' without intrinsic proactive desire to donate organs shows its counter-productive effect for people who have not given thought to this issue or are adverse to thinking about such issues."
2. Another reason could be the difficulty in broaching this topic in the difficult end-of-life conversation where the ICU team is trying to convince families of the inevitability of brain death. Respondents felt that it is an emotional upheaval for the family and organ donation is a further burden on them.
3. Procedural difficulties including strict criteria and cumbersome logistics could also be a reason why some physicians prefer to offer with 1. A total of 90% felt that there were cultural, societal, and religious barriers to acceptance or organ donation in Singapore. The concept of body preservation after death is an important element. Some stated that there is a barrier to end-of-life conversations in our society that makes organ donation difficult to broach. Families may feel guilt and filial piety that can preclude consenting to donation. drawal of support rather than deal with the tedious and long drawn out process. "1. Too strict a criteria for the confirmatory testing of brainstem death. 2. Inadequate information for the public 3.

Poor communication 4. Traditional beliefs and stigmata about death" was the response from 1 intensivist.

4. Personal belief systems also are a reason. Low desire on the part of the physician may also preclude referrals.

Finally, as part of the second objective of the study, when asked their opinion on how to improve these rates many answers were elicited.

1. Most (79%) mentioned raising awareness through publicity, education, and advertising. One respondent indicated "Create a societal culture of willingness to donate organs, through gradual nurturing of future generations."
2. Others (34%) mentioned educating physicians and engaging ICU physicians in further planning.
3. Some (35%) felt that publicizing more real stories of recipients would help.
4. Generally, there was unease at the opt-out system infringing basic rights. As one respondent said, "We need to influence how the public perceives organ donation. Until there is data to assure us that when a person does not opt-out, they are actually opting in, we run the risk of going against the wishes of the majority of our patients."

DISCUSSION

The aims were to elicit the opinions of intensivists regarding the hurdles faced in organ donation referrals under the opt-out system. Our survey taps into some of the problems faced by referring physicians and their suggestions for improvement. The physicians feel that it is important to obtain family approval for donation to help them overcome the moral apprehension. A broader ethical debate with all stakeholders to answer the qualms of intensivists is required. In conclusion, a wider awareness and buy-in is needed both by the public and the ICU physicians, and addressing their valid moral concerns is essential in bridging this gap. Presumed consent is, as such, not the main reason for the low rates of referrals, as acceptance could potentially improve if interventions for raising awareness, referral training, and transplant organization are implemented [11].

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