

"Epidemiology of paediatric intensive care unit admissions, deaths and organ donation candidacy: A single-centre audit": Correspondence

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Dear Editor,

Cardiac transplantation is an option for children with end-stage heart failure, but around the world there has been an issue with inadequate organ availability. Effective donor management is crucial to the successful recovery of organs for cardiac transplantation. The recent paper by Low et al.¹ demonstrates that while there are potential donors (who may be identified during admission to the intensive care unit), there remains a gap between the number of potential donors and the actual number of organs donated. The authors, and indeed also the authors of the corresponding editorial,² call for an independent group of medical professionals to support end-of-life decision-making for children with terminal disease. We agree with this recommendation. Here, we articulate the practical ethics underpinning donor stewardship and consider how families with a child close to death may be better supported in the grieving process while given the opportunity to consider donating their child's organs (specifically the heart) to save another child's life.

While there are many ethical issues that have been considered at the end-of-life, 2 principles are fundamental to the care of the potential donor: the principles of autonomy and justice.

The principle of respect for a person's autonomy remains a central principle in medical ethics.³ Parents of a child should be allowed a choice in each important aspect of their child's care. Indeed, the preferences and choices of older children should also be considered. Therefore, it remains important to respect the care preferences of the family and the child as the child reaches his or her end-of-life. In medically appropriate cases, the family should be given the choice of whether they would like to consider organ donation.

Justice is the principle that promotes the fair and equitable use of resources.⁴ Organs are a scarce resource. Each year, it is expected that 1 child (less than 16 years of age) would require a ventricular assist device or cardiac transplantation at our centre as a life-extending procedure. While there are important

considerations and requirements to be fulfilled for each heart transplant recipient, given that there are potential donors, it would be an opportunity lost should the family not be given the opportunity to decide on whether they wish to donate their child's organs in the event of death.

Donation of organs from adult donors is legislated under the Human Organ Transplantation Act (HOTA).⁵ Through this Act, individuals above the age of 21 may actively refrain from organ donation as an "opt out" approach. Organ donation in children, in Singapore falls under the Medical (Therapy, Education and Research) Act, or MTERA. Under this Act, explicit informed consent is required from a child's parents or legal guardians for organ donation upon the death of a child. The question is therefore, how can parents be presented a choice for or against organ donation upon the impending death of their child? A careful and sensitive approach is required, particularly in paediatrics.

The encouragement to donate may come from another person. Building on the work of Thaler and Sundstein, Wilkins et al. have termed this as "interpersonal nudging."⁶ While at face value, the term "nudge" carries a connotation of a manipulation of an individual's choice, Thaler and Sundstein define a "nudge" in a more neutral way, as "any aspect of the choice architecture that alters people's behaviour in a predictable way without forbidding any options or significantly changing their... incentives."⁷

It can be argued that the intentional identification of potential donors and the subsequent organ donation are right actions because they lead to an outcome of goodness—a life saved. This is the utilitarian approach. Some good can therefore be derived from an otherwise heartbreaking experience. However, if such actions were to result in significantly unbearable pain for the bereaved family, it would be necessary to reweigh the scales, as this approach would no longer maximise total net happiness. Overall, interpersonal nudging would be a simple articulation of the possibility of organ donation.

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Table 1. Four-box toolkit in the donation of the heart for transplantation in paediatric patients.

Medical indications • Are there medically good reasons for withdrawal of care? • Are there other reasonable options of care that the patient/family would like to explore?	Patient preferences • Has the patient indicated his or her preference towards organ donation? • Does the family/legal guardian have a preference towards or is against organ donation?
Quality of life • Does the family have adequate support in the grieving process? • Is the family able to make meaning of the impending death and potential organ donation?	Contextual issues • Legal issues in different jurisdictions. Are there legal constraints to organ donation/organ harvesting? • Religious values of the patient and the family.

There is a narrow window of opportunity of approximately 6 hours for the donor heart to be transplanted⁸; and donor parents would expectedly be under tremendous stress during this period. Every cardiac transplantation as an event is an intersection of 2 crises, one involving the donor (and family)—the “donor crisis”; and another involving the recipient (and family)—the “recipient crisis.” It would be prudent to develop a robust system to care for both these aspects of the event but here we will consider primarily the “donor crisis”.

A simple “nudge” during the “donor crisis” as part of end-of-life care would be to have an independent medical professional team articulate the possibility of organ donation in a suitable case.⁹ This team would act apart from the intensive care team and may then broach the subject from a more impartial perspective. In our view, ideally palliative care specialists may fulfil the leadership role, working together with a transplant coordinator from the National Organ Transplant Unit (NOTU), as part of their holistic end-of-life care for these children (considering that the act of organ donation is a part of the grieving process). Alternatively, medical doctors with adequate training in intensive care, palliative care and bioethics may also be suitable. Social workers and clinical psychologists would also be expected to be important members of this interdisciplinary team. We have included the four-box toolkit¹⁰ (Table 1) to clarify the practical ethical framework of approaching potential donor families.

Ethical donor stewardship is an important aspect of managing the crisis of a paediatric cardiac transplant. In the Singapore context, an interdisciplinary team led by a paediatrician or palliative care specialist independent of the intensive care team would be well-placed to broach the subject of organ donation to the family, allowing the expression of parental autonomy, yet ensuring that the opportunity for the recovery of the organ is not lost, such that suitable children with end-stage cardiac failure may receive the heart they need.

Ethics statement

Not applicable.

Declaration

All the authors have no affiliations or financial involvement with any commercial organisation with a direct financial interest in the subject or materials discussed in the manuscript.

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Authors’ reply

Dear Editor,

We appreciate the opportunity to respond to the letter titled “Epidemiology of paediatric intensive care unit admissions, deaths and organ donation candidacy: A single-centre audit”: Correspondence, which highlights the ethical dilemma for healthcare teams caring for a potential paediatric organ donor—the duality of autonomy (for the donor family) versus (vs) justice (for the potential recipients of organs). Here, we further elaborate on sociocultural and logistical challenges faced by the medical teams when raising the topic of organ donation, discuss the role of a neutral third-party and emphasise the need to better understand families’ attitudes towards organ donation to guide future advocacy work.

Emerging social science research highlights how decision-making differs when one decides for another person as compared with himself or herself.¹ In relation to paediatric organ donation, risks may be assessed differently because parents feel a greater weight of responsibility for the outcomes for their child.² This is evidenced by a local study on organ donation decisions for next-of-kin vs self, which showed that survey participants were less willing to donate their relatives’ organs than their own, highlighting 2 key factors—fears about organ donation and religion—predicting congruency between decisions for family vs self.³ In addition, the effect of culture on organ donation has been extensively discussed by various groups over the years (albeit mainly in the adult population) and remains one of the barriers to increasing organ transplant uptake in Singapore.^{4,5} In our audit, 8 paediatric aged patients were identified who met the criteria for organ

donation (Table 1).⁶ Of these, 2 organ donors make up the 6 paediatric deceased organ donations that occurred in our hospital over the past 10 years. By extrapolating the findings on attitudes of organ donation in Singapore,⁵ we postulate that parents struggle with the guilt of not only having failed to protect their child, but also not allowing their child the dignity of dying whole, on top of making complex medical decisions. We suggest that a study assessing current attitudes towards paediatric organ donation among parents may guide future advocacy work.

We identified logistical challenges towards holistic discussions on organ donation in our cohort. Based on our data, time was often short, with potential organ donors having a median length of intensive care unit stay of 4 (4, 8.5) days.⁶ In addition, majority of patients in our cohort who qualified as potential organ donors were admitted for unexpected/accidental causes such as drowning and traumatic brain injury (Table 1). As such, raising the topic of organ donation in such high stress, emotionally charged environment may be perceived as insensitive and refusal of the medical team to enact further life saving measures. Physicians may thus find themselves straining to practice the principles of autonomy and justice as raised by the authors of the letter.

As discussed in the original publication, a neutral third-party who is well versed in end-of-life care and organ donation would be best to identify the candidate donor and to facilitate the conversation on organ donation.⁶ We agree that it may be during these discussions, that interpersonal nudging may be used. Interpersonal nudging uses social and psychological insights to subtly influence another person’s behaviour by creating an environment or situation where a desired choice is more likely.⁷ However, contrary to

Table 1. Characteristics of potential organ donors in the cohort.

Patient	Age (year)	Sex	Race	Comorbidity	Cause of death	Organ/tissue donated
1	15	Female	Chinese	None	Hypoxic ischaemic encephalopathy	No
2	11	Male	Malay	None	Drowning	No
3	4	Female	Chinese	None	Viral encephalitis	No
4	<1	Female	Chinese	Global developmental delay	Hypoxic ischaemic encephalopathy	No
5	11	Male	Chinese	None	Intracranial haemorrhage	No
6	5	Female	Chinese	None	Drowning	No
7	6	Male	Japanese	None	Traumatic brain injury	Yes
8	2	Female	Malay	None	Drowning	Yes

the letter, we disagree that this needs to necessarily be led by a medical specialist (e.g. palliative care specialist). Indeed, involvement of a palliative care provider can positively contribute to the care of these patients and families by supporting families through their grief, navigating difficult or sensitive communications, and assisting with end-of-life decision-making that is congruent with the patient/families' goals of care.⁸⁻¹⁰ However, the role of a neutral third party may be fulfilled just as well by a trained nurse or medical social worker. In Singapore, the donor coordinator (DC) from NOTU serves this role well. Their early involvement in end-of-life conversations with families, even before the diagnosis of brain death is confirmed, can help prepare families for the possible discussion on organ donation. It is found that familiarity with the professional who formally asked for donation consent was important in achieving a favourable donation decision.² Hence, early involvement by the DC is vital. In further discussions, the DC takes the role of helping families to navigate the medical and non-medical nuances of organ donation, thereby giving the managing physician space to focus on their primary responsibilities of care to the patient. This also enables organ donation to be conducted in a timely, appropriate and dignified manner, with family members informed and supported.

Despite the enactment of MTERA and HOTA in 1972 and 1987 respectively, Singapore has one of the lowest organ donation rates in developed nations, with many groups calling for further advocacy and community engagement.⁵ In response, the NOTU embarks on efforts to promote greater awareness of organ donation and transplantation. For example, the Live On Festival encourages youths to explore and express their perspectives on the topic through art and writing. This programme incorporates the values of responsibility, compassion and empathy by offering insights into the emotive and delicate aspects of organ donation and transplantation. In a survey from the US, education, donation attitudes and beliefs, and knowledge of brain death were significantly associated with donation decision.² The finding that parents who consented to organ donation were more likely to have received information about organ donation/transplantation within the last 6 months than were non-donors, makes a strong case to increase efforts in community awareness and education programmes.

In conclusion, attitudes towards paediatric organ donation remain relatively unexplored and are a key barrier to improving organ donation rates. Understanding how social and cultural factors influence parents' decisions on organ donation will help tailor future

advocacy work and guide policy changes. Establishing the role of a neutral, third-party interdisciplinary team who can, in the limited time, support and guide families through the patients' end-of-life journey will enable the primary physician to focus on medical issues while increasing the likelihood of a favourable organ donation decision.

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