

# The state of paediatric deceased-organ donation at a South African tertiary public-sector hospital: A 14-year analysis

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**Background.** Solid-organ transplantation (SOT) has been proven to be a highly effective and life-saving treatment modality for adults and children suffering from end-stage organ failure. However, high paediatric waiting-list mortality has been reported, and children may suffer irreversible physical and deleterious psychological effects if not transplanted timeously.

**Objectives.** To identify in-hospital barriers to organ donation and gain a better understanding of the paediatric donor landscape.

**Methods.** A retrospective descriptive study of consecutive deceased-donor referrals at Red Cross War Memorial Children's Hospital over a 14-year period, from 1 January 2007 to 31 December 2020.

**Results.** During the study period, 156 in-hospital deaths were recorded in the trauma unit and 1 425 in the paediatric intensive care unit. Ninety-three of the 1 581 patients (5.9%) were referred to the on-call transplant co-ordinator as potential organ donors, of whom 69% had been involved in a traumatic accident, including 52% in road traffic collisions. The mean age of the potential donors was 7 years with 60.2% being boys.

On initial assessment, 67 of the 93 potential donors (72%) were assessed as eligible for donation of at least one solid organ. The transplant co-ordinator attempted to approach all families for consent; however, five families/next of kin could not be located despite multiple attempts. Among the remaining 62 eligible donors, 44 families/next-of-kin declined consent for solid-organ donation, resulting in a consent rate of 29% ( $n=18$ ). Several families refused consent for religious reasons. One of the consented donors did not proceed to procurement as there were no suitable recipients. Seventeen donors proceeded to theatre, the intention being solid-organ procurement, but in 2 donors the organs were assessed as being unsuitable for transplant. From the remaining 15 donors, a total of 46 organs were procured and successfully transplanted: 14 livers, 30 kidneys and 2 hearts.

**Conclusion.** During the 14-year study period, only 15 deceased donors could be utilised for SOT, as a result of low in-hospital referral (5.9%) and consent rates (29%). The reasons for low referral and consent rates are complex and often multifactorial, which the current study was not designed to investigate in sufficient detail. Future studies should be designed to further interrogate our findings, while accommodating for nuances specific to the paediatric deceased-donor population and their families.

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Solid-organ transplantation (SOT) has been proven to be a highly effective and life-saving treatment modality for selected adults and children suffering from end-stage organ failure.<sup>[1,2]</sup> However, reports from the USA have described a higher waiting-list mortality in paediatric patients (32.9%) compared with adults (16.5%).<sup>[3,4]</sup> In addition, waitlisted children may suffer irreversible physical (such as poor growth and brain development) and deleterious psychological effects if transplants are not done timeously, owing to the delay in reaching important developmental milestones.<sup>[1,3]</sup> Good quality, size-matched organs are often needed to ensure satisfactory post-transplant outcomes, further impacting waiting times because of the low number of paediatric deceased donors.

A decreasing trend in the availability of paediatric deceased-donor kidneys has been reported by investigators in Europe and the USA.<sup>[5]</sup> This phenomenon has largely been attributed to a decreasing number of childhood deaths as a result of healthcare system improvements such as better access to antibiotics and immunisations, the provision of

ever-safer paediatric anaesthesia and intensive care, and the adoption of more stringent road-traffic legislation including mandatory bicycle helmets and seatbelts.<sup>[3,5,6]</sup>

Reports have indicated that some healthcare workers may be hesitant to refer potential paediatric donors to transplant co-ordinators, for fear of worsening the family's distress and grief.<sup>[3,7-9]</sup> However, the parents or guardians that were willing to donate children's organs did not experience more psychological distress during the consent process than what has been described in adult-donor cohorts.<sup>[3,4]</sup> Notwithstanding, organ-donor consent rates have been reported to be lower in children than in adults.<sup>[1,10]</sup> Parents often have restricted knowledge about their child's wishes regarding organ donation, likely due to the child's limited exposure to the topic of donation and a lack of mental capacity to fully comprehend and communicate their wishes.<sup>[3,7-9]</sup>

According to a prospective descriptive study performed in Cape Town, South Africa (SA) over a 1-year period, a deceased-donor consent rate of 24.3% was achieved in the public sector with

two-thirds of the referrals emanating from emergency units.<sup>[11]</sup> In addition, a retrospective analysis performed at a tertiary public-sector hospital in Cape Town over a 10-year period (2007 - 2016) reported a consent rate of 32.7% in 514 adult eligible donors.<sup>[12]</sup> As there are currently no reports in the literature on paediatric organ donation in SA, our aim is to analyse local data to identify in-hospital barriers to organ donation, and to gain a better understanding of the paediatric donor landscape.

## Methods

This is a retrospective descriptive study of consecutive deceased-donor referrals at Red Cross War Memorial Children's Hospital (RCWMCH) over a 14-year period, from 1 January 2007 to 31 December 2020. The primary aim of the study was to identify and further define the key factors that prevented potential paediatric donors from being utilised as solid-organ donors. The secondary aims were to describe the evolution of donor referral patterns by observing trends in the number of referrals, eligibility for solid-organ donation and consent rate over the study period. In addition, we set out to describe the number of SOTs that resulted from deceased-organ donation. Lastly, we compared the number of referrals to the number of in-hospital deaths that occurred within a specific clinical area.

The number of in-hospital deaths that occurred in the trauma unit (TU) and paediatric intensive care unit (PICU) and the number of SOTs that were performed with organs retrieved from actual deceased donors were recorded. Institutional data were retrospectively obtained from deceased-donor, SOT and patient clinical records, and the hospital death register. Patients 18 years or older at the time of death were excluded from the study.

The following definitions were applied when categorising donors. A possible donor is a patient at the end of life that is supported in a manner that preserves the family's right to donate tissue and/or organs. A potential donor is a possible donor that has been identified and timeously referred by the treating team for a formal assessment of the donation potential. An eligible donor is a potential donor who has been assessed and meets the medical criteria for donation. An actual donor is defined as a consented eligible donor in whom an operative incision was made with the intent of organ recovery for the purpose of transplantation. A utilised donor is defined as an actual donor from whom at least one organ was transplanted.<sup>[13,14]</sup>

Descriptive statistics and temporal trends were used to summarise sample characteristics (including age, gender, cause of death, eligibility for donation and consent rates). Continuous variables were summarised by median with interquartile range (IQR), and frequencies with proportions for categorical variables. Analysis was performed in Stata 16 (StataCorp, USA).

Approval to conduct the research was obtained from the University of Cape Town Human Research Ethics Committee (HREC ref. no. 51/2022).

## Results

During the 14-year study period, 156 in-hospital deaths were recorded in the TU and 1 425 in the PICU. Ninety-three of the 1 581 patients (5.9%) were referred to the on-call transplant co-ordinator as potential organ donors. Of the 1 425 patients that died in the PICU, 71 (5%) were referred, while the TU referred 22 of the 156 deaths (14.1%) for assessment. The mean (standard deviation) age of the 93 potential donors was 7 (4) years. Twenty-eight (30.1%) were girls, 56 (60.2%) were boys, and 9 (9.7%) children did not have their sex documented. The cause of death is described in Fig. 1; motor vehicle collisions accounted for the majority of deaths (38.7%).

On initial assessment, 67 of the 93 potential donors (72%) were assessed as eligible for donation of at least one solid organ; families/next of kin were approached for consent by the transplant co-ordinator (Fig. 2). Nearly all potential donors were referred with the intention of donation after brain death (DBD), with only 1 potential donor referred for donation after circulatory death (DCD).

In 5 eligible donors, the families/next of kin could not be located despite multiple attempts. In the remaining 62 eligible donors, 44 (71%) families/next of kin declined consent for solid-organ donation, resulting in a consent rate of 29%. One of the consented donors did not proceed to procurement as there were no suitable recipients for the organs (Fig. 2).

Seventeen donors proceeded to theatre with the intention of solid-organ procurement, but in 2 donors the organs were assessed as not being suitable for transplant at procurement. In the remaining 15 donors, a total of 46 organs were procured and successfully transplanted, including 14 livers, 30 kidneys and 2 hearts (Fig. 2).

There has been an observed decrease in deaths over time (Fig. 3), while the number of potential donor referrals remained relatively constant (between 3 and 10 per year).

Fig. 4 shows trends in potential, eligible and consented donors. There was a decline in potential and eligible donors observed from 2007 to 2012, followed by an increase until 2017. There was a sharp decline in donor numbers in 2018 and 2019.

## Discussion

In SA, there is still a large gap between the supply and demand of organs for transplantation, resulting in prolonged waiting times. Despite well-established living-donor kidney and liver programmes, waiting lists continue to grow.<sup>[15]</sup> SA has a low deceased-donor rate compared with the rest of the world.<sup>[16]</sup> The annual number of deceased donors have been consistently below 2 per million population (pmp), compared with other low- to middle-income countries like Brazil where deceased-donor rates are around 14 pmp.<sup>[16]</sup>

While most studies investigating the factors which affect the decision-making around organ donation have been conducted in adult populations, some reports have suggested that these factors may be similar in children and adults.<sup>[1,9,17]</sup> The reasons why potential donors do not become utilised donors may be divided into systemic factors, organ/donor-related factors and permission. Systemic factors include failure to identify or refer donors, failure of timeous referral and lack of an appropriate recipient. Donor or organ factors such as medical unsuitability and anatomical abnormalities may result in a donor not being utilised. Permission which involves consent refusal and expressed intent not to donate may further impact potential donor utilisation.<sup>[13]</sup>

While it is unclear how many paediatric deceased donors were utilised nationally, the proportion of paediatric SOTs performed in SA in 2017 and 2018 was 10.9% (27/248) and 13.3% (36/271), respectively.<sup>[17]</sup> Despite growing in- and outpatient numbers, the number of in-hospital mortalities at our institution has continued to decrease over time, suggesting continuous improvements in the healthcare system. However, the number of potential donor referrals remained relatively constant (between 3 and 10 per year), possibly owing to increasing donor awareness established through regular educational engagement. The appointment of a transplant co-ordinator in 2017 corresponded with a temporary increase in the number of potential and eligible donors.

Alarming, only 5.9% of reported in-hospital deaths were referred to the transplant co-ordinator on call. Without a specifically designed, prospective study, the reasons for this remain speculative, but may

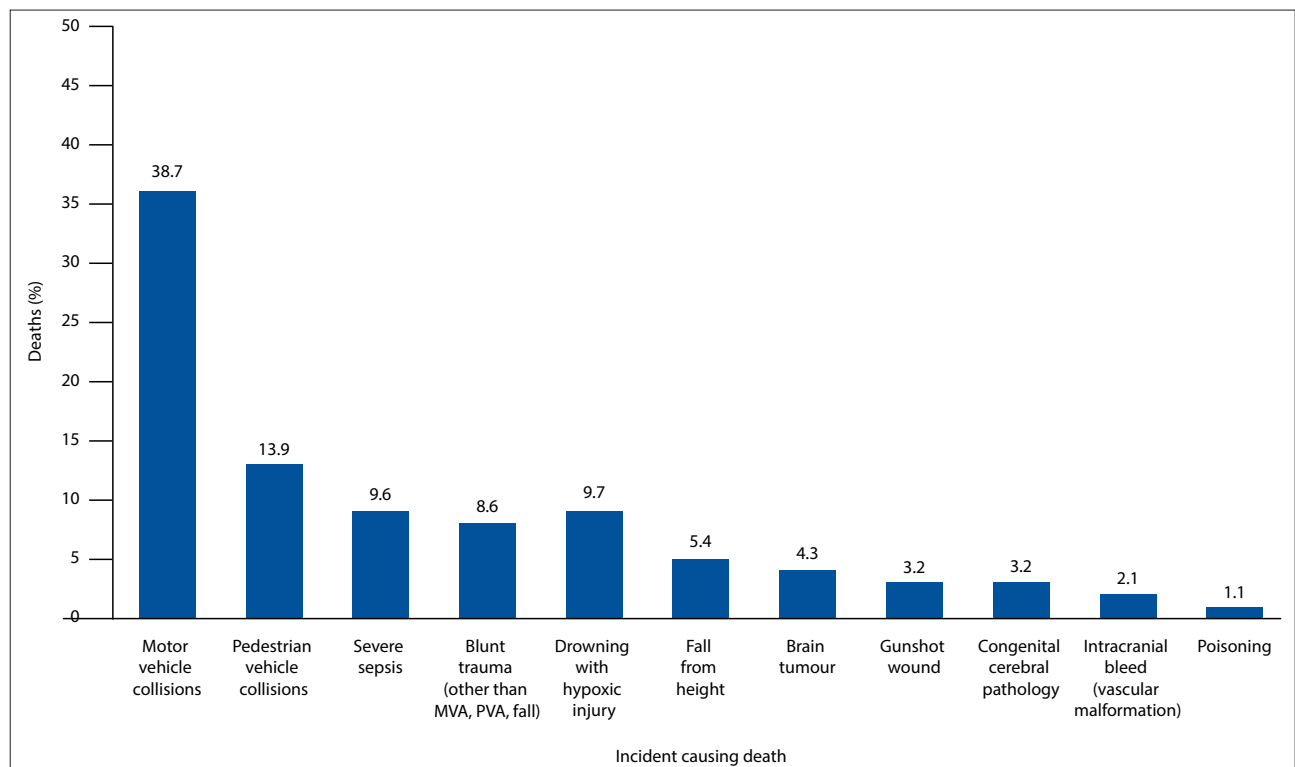


Fig. 1. Cause of death in 93 potential donors.

include a delay in referrals, decision by clinicians not to refer, limited resources to manage a donor, or a lack of awareness and knowledge on the donor-referral processes. Regardless, this finding highlights the need for further engagement with healthcare workers to establish routine referral to the transplant co-ordinator as part of good end-of-life care.

The TU referred proportionally more possible donors (14.1%) than the PICU (5%). Although the study was not designed to analyse this phenomenon, the following explanations could be considered. In an environment where access to PICU is limited, the TU may have had to offer mechanical ventilation and other supportive measures to critically ill children, especially when the prognosis was guarded. In addition, it may have been more likely for possible donors in PICU to have had a perceived negative attitude to donation, compared with possible donors in TU.

Despite having an active adult DCD programme at our institution, only 1 donor referral with the intention of DCD was received during the study period, highlighting the need for increased consideration, awareness, and training regarding this mode of donation. The DCD programme is implemented according to the SA guidelines on death determination, which offers clear, pragmatic evidence-based medical guidance in the SA context.<sup>[18]</sup> DCD has expanded considerably in Europe over the last 10 years. Equal DCD and DBD donors' rates are reported in the USA and Spain.<sup>[19,20]</sup> Obstacles to effective implementation include a lack of uptake and acceptance by both clinicians and the public, as well as the challenge of ensuring cultural and religious engagement and support for determination of death. DCD is a viable method to increase organ availability among the paediatric population, and organs from paediatric DCD have been shown to have similar outcomes as DBD.<sup>[19,20]</sup>

Sixty-seven of the 93 referrals (72%) were assessed to be medically suitable for donation of at least one solid organ. This compared favourably with a geographically similar adult cohort, where 59.7% of potential donors were assessed as being medically

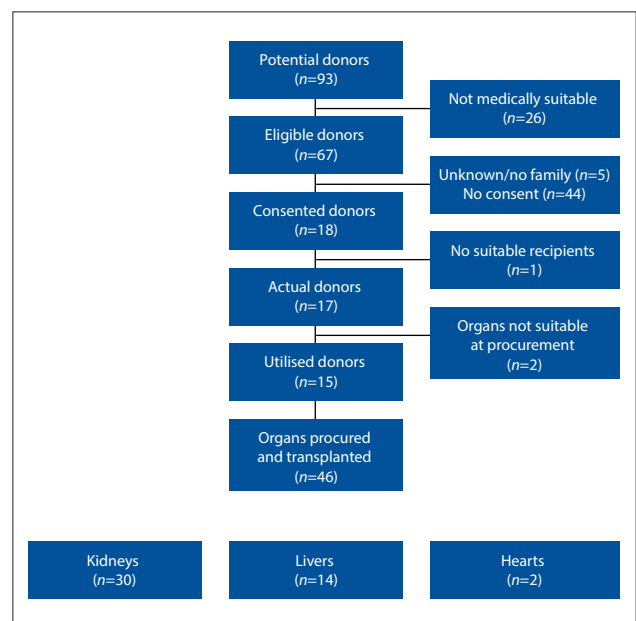


Fig. 2. Flow diagram highlighting the key factors that prevented potential donors from becoming utilised donors.

suitable for donation.<sup>[12]</sup> This finding may reflect a lower incidence of chronic comorbidities in the paediatric population compared with adults.<sup>[12]</sup> Potential donors were more likely to be assessed as medically suitable (or eligible) during the second half of the study (2013 - 2020). Unfortunately, the reasons for declining donation on the basis of medical ineligibility were not consistently documented. However, 7 of the 26 patients were assessed to have organs too small for transplantation based on their weight and age, with the youngest potential donor being 5 months old. All donors that were declined locally based on weight and/or age were referred nationally to other

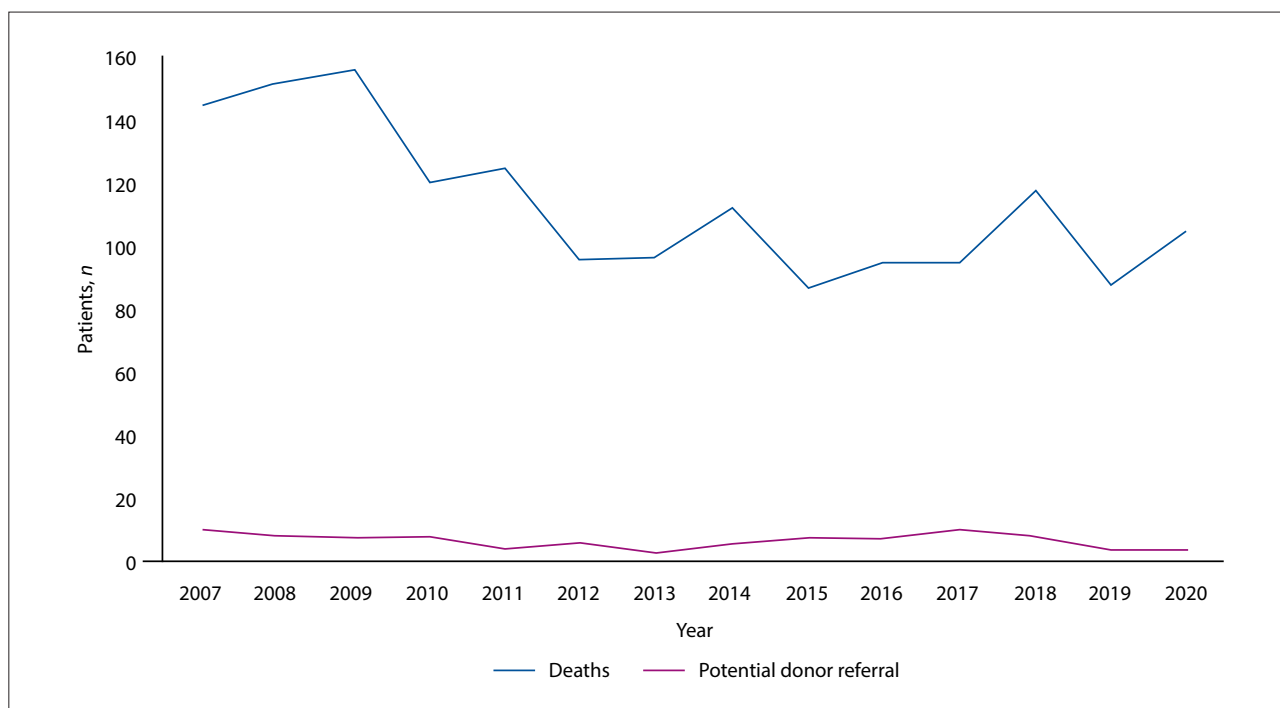


Fig. 3. Observed trends in the total number of PICU and TU deaths and referrals.

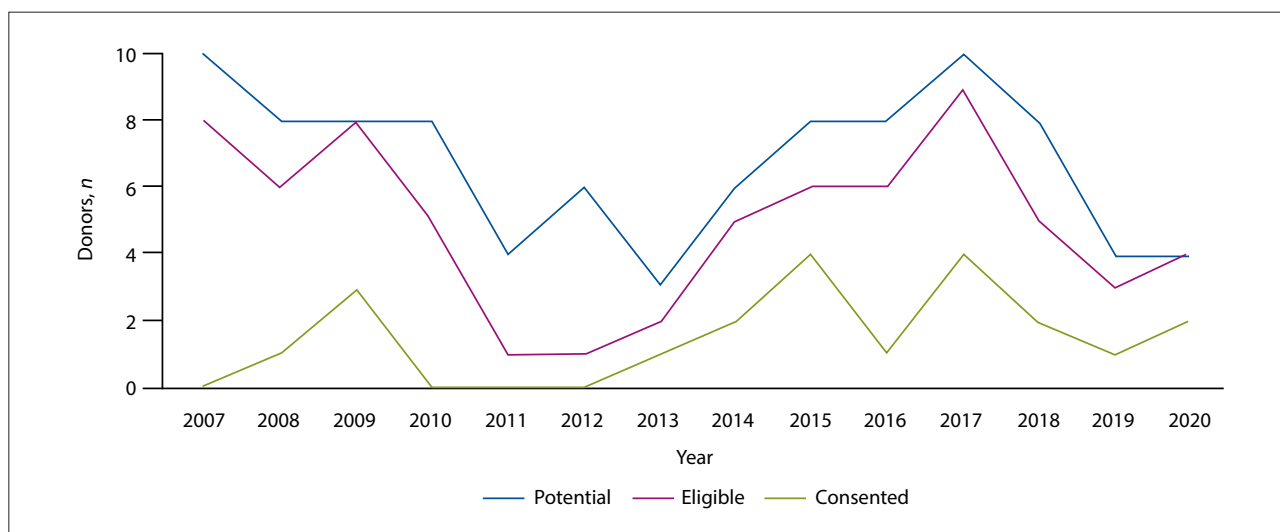


Fig. 4. Observed trends in the number of potential, eligible and consented donors.

transplant centres. The youngest utilised donor was 3 years old, donating kidneys and liver.

Similar to other countries, SA employs an opt-in system where consent is provided by family or guardians.<sup>[8,21]</sup> In the case of paediatric donors, the decision-making process is left in the hands of the parents or guardian to consent to organ and tissue donation. The consent rate achieved in our study was 29%, which is in keeping with most international reports on paediatric donors, but slightly lower than the 32.7% achieved in a corresponding SA adult population.<sup>[12]</sup> Studies have shown that a lower consent rate can be expected in younger age groups.<sup>[1,10]</sup> In Ireland consent for organ donation was obtained for only 33% of potential donors aged 15 years or younger, resulting in an annual paediatric deceased-donor rate of 5 pmp between 2004 and 2009.<sup>[1]</sup> The organ-donation consent refusal rate is 42% in the UK, making it one of the highest in Europe. This is still low in comparison with the 71% refusal

in our study. A multiple logistic regression study was done to identify modifiable factors associated with consent in the ICUs or emergency departments in the UK between 2012 and 2013.<sup>[22]</sup> Consent for DBD was 68.9%, and for DCD 56.5%, much higher than the 29% consent conversion in our study.

Patient ethnicity, knowledge of a patient's wishes and involvement of a specialist nurse in organ donation were previously reported to be strong indicators of consent conversion.<sup>[22]</sup> In our study we did not report ethnicity but observed cultural and religious background to be of importance when discussing organ donation. It is also important to note that parents of paediatric donors rarely have prior knowledge of their child's wishes regarding organ donation. As in our study, the addition of a nurse transplant co-ordinator improved the donation process; this is someone with special training into acquiring consent and donor management, among other things. The findings from our study are difficult to interpret in the context of international reports, as

most research in this field is from countries with developed economies, with well-established healthcare systems and consent policies.

In a country as culturally diverse as SA, it is important to be mindful of the complex dynamics that may present when the family of a potential donor is addressed. The requirement to consult with elders, particularly in the setting of the African culture, may further affect or delay the ability to attain consent. Another pertinent factor specific to paediatric organ donation is the lack of knowledge about the patient's wishes with regard to organ donation.<sup>[8,9,12,18,23]</sup> Parents often have very little, if any, prior knowledge or understanding about their child's wishes regarding organ donation because of the child's inability to comprehend all aspects of donation.<sup>[8,9,15,21,24]</sup> A study conducted in the Netherlands among 2 016 children aged 12 - 15 years, found that while 99% of children had heard about organ donation, only 43% had previously discussed organ donation at home. This number improved to 72% following school-based education on donation and transplantation.<sup>[3]</sup>

Religious objections to organ donation have frequently been reported in the literature.<sup>[23,25]</sup> Several patients from our study refused consent for religious reasons, from both the Christian and Muslim faiths. While most religions are not opposed to organ donation or transplantation, certain religions have specific objections related to the removal of organs and interference with burial rituals.<sup>[17]</sup> Additionally, there are many ethnic and cultural variations in which preservation of the integrity of the body holds some spiritual or religious significance.<sup>[6,7,18]</sup> It is important that requesting transplant coordinators can engage on these issues when approaching a family for consent.

To ensure clear and accurate communication with families, it is crucial to create an environment in which qualified transplant co-ordinators can reliably drive the process. Language is a key aspect of communication that has been shown to affect organ-donation consent rates.<sup>[21]</sup> Hospitals should take this into account, particularly for a nation like SA with 11 official languages, when employing transplant co-ordinators.

The socioeconomic status of a family may have an impact on decision-making, with studies showing that families of a higher socioeconomic background were more likely to have been informed about organ donation and healthcare issues than those of a lower socioeconomic status.<sup>[10,25]</sup> This can only be speculated on for our study population as the majority of our patients are not from affluent backgrounds. The study institution is a government hospital catering to patients with and without medical aid funds. Owing to the retrospective nature of the study, we cannot assume the socioeconomic status of the referred donors as it was not detailed in the report documentation. Prospective studies are needed to better support this statement.

Seventeen donors proceeded to theatre with the intention of organ donation. In 2 donors, absolute contraindications to donation were identified at organ retrieval, specifically very small kidneys which were not suitable for transplantation. On average, 3.1 solid organs were retrieved and transplanted per actual deceased donor. Ultimately, only 18.3% of potential donors proceeded to actual donation, compared with 20.3% in a corresponding adult cohort.<sup>[11]</sup> Paediatric donors are preferentially allocated to paediatric recipients whenever possible, which is also in line with paediatric allocation policies internationally, prioritising paediatric patients on the waiting list, protecting certain deceased.<sup>[26]</sup> It is the allocation policy of the Western Cape to allocate kidneys from donors <18 years to recipients <18 years of age, so these donors likely benefitted paediatric recipients.

A limitation of this study is that death status was evaluated only for PICU and TU. The numbers of the ward and medical emergency deaths statistics would be required to obtain a better idea of

improving the donor referral pathways for the hospital. There were missing data on gender, weight and reason for consent refusal in some cases. We recommend increasing brain-death testing in appropriate patients and referral of all brain-dead patients to the transplant co-ordinators within the hospital for organ procurement. We recommend implementation of the National Institute for Health and Care Excellence (NICE) guidelines,<sup>[27]</sup> which address identification and referral of potential organ donors (Box). There also needs to be prioritisation of identification of donors and development of paediatric donation guidelines. Furthermore, enhancing effective communication with the family is necessary to improve outcomes. Increasing the advocacy using public campaigns on donation could increase the donor pool and consent rates.

#### Referral triggers

National Institute for Health and Care Excellence (NICE) recommendations include timely identification and referral of potential organ donors. Hospital staff should initiate discussions with a specialist nurse co-ordinator for organ donation, when one of the following criteria exists:

- Defined clinical trigger factors in patients who have had a catastrophic brain injury:
  - Absence of  $\geq 1$  cranial nerve reflexes
  - Glasgow Coma Scale score of  $\leq 4$  that is not explained by sedation; and/or a decision has been made to perform brainstem-death tests, whichever occurs first.
- Intention to withdraw life-sustaining treatment in patients with a life-threatening or life-limiting condition, which will, or is expected to, result in circulatory death.

## Conclusion

The consent conversion rates, and number of paediatric organ donors are low. SA's low deceased-donation rate is multifactorial throughout the deceased-donor pathway; however, it can be largely attributed to consent refusal. Increasing the development of support structures for referral of patients for organ donation, quality assurance of the consent process and sustained information/education campaigns are needed. There is a need to improve organ donation activities in SA, especially in the paediatric population. Government support at provincial and national level is required and appropriate co-ordination and monitoring of organ donation and transplant programmes is also pivotal. Further research into the paediatric donation process and the specific factors influencing parental donation decisions is urgently needed as paediatric donors are preferentially allocated to paediatric recipients and there is an acute need for increased transplant access for paediatric patients.

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