

Pediatric Deceased Donation—A Report of the Transplantation Society Meeting in Geneva

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The Ethics Committee of The Transplantation Society convened a meeting on pediatric deceased donation of organs in Geneva, Switzerland, on March 21 to 22, 2014. Thirty-four participants from Africa, Asia, the Middle East, Oceania, Europe, and North and South America explored the practical and ethical issues pertaining to pediatric deceased donation and developed recommendations for policy and practice. Their expertise was inclusive of pediatric intensive care, internal medicine, and surgery, nursing, ethics, organ donation and procurement, psychology, law, and sociology. The report of the meeting advocates the routine provision of opportunities for deceased donation by pediatric patients and conveys an international call for the development of evidence-based resources needed to inform provision of best practice care in deceased donation for neonates and children.

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OVERVIEW OF THE MEETING

An international meeting was convened by the Ethics Committee of The Transplantation Society in Geneva, Switzerland, on March 21 and 22, 2014, to explore the practical and ethical issues pertaining to pediatric deceased donation of organs (hereafter, pediatric donation). There were 34 participants from Africa, Asia, the Middle East, Oceania, Europe, and North and South America, with expertise inclusive of pediatric intensive care, internal medicine, and surgery, nursing, ethics, organ donation and procurement,

psychology, law, and sociology (Table 1). Participants were selected by a multidisciplinary steering committee, and representation was sought from regional professional societies of transplantation.

The intent of the meeting was to provide ethically informed practical recommendations for health professionals and policy makers seeking to establish or improve existing pediatric organ donation programs globally, and to identify neglected opportunities for research in this field. Four work groups were electronically convened prior to the meeting, to address the following topics that were subsequently presented and reviewed in breakout and plenary sessions in Geneva:

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D.M. wrote the initial draft of this article, and was responsible for subsequent revisions, with substantial assistance from T.N. F.L.D. participated in the design and drafting of the article. T.N., M.S., K.B., J.B., F.D., J.R., M.S., R.S. also assisted with revisions to the article. B.D.G. contributed writing and assisted with important structural revisions. G.D., S.S., R.T., F.M., and M.B. contributed to the writing and content to revisions of the article.

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TABLE 1.
List of pediatric donor meeting participants

Barbari	Antoine	Representative MESOT, Lebanon
Bennett	Renee	Representative ITNS, United States
Bos	Michael	Chair, TTS Ethics Committee, the Netherlands
Bouësseau	Marie-Charlotte	WHO, Switzerland
Bramstedt	Katrina	Bond University, Australia
Brierley	Joe	Great Ormond Street Hospital for Sick Children, United Kingdom
Danovitch	Gabriel	UCLA, United States
Delmonico	Francis	President, TTS, Canada
Dhawan	Anil	Representative ILTS, United Kingdom
Dobbels	Fabienne	University of Leuven (KU Leuven), Belgium
Dominguez -Gil	Beatriz	Representative ONT, Spain
Ha	Jongwon	Representative AST, South Korea
Harmon	William	Children's Hospital Boston, United States
Joseph	Mathew ^a	Christian Medical College Vellore, India
Langer	Robert	Semmelweis Institute, Hungary
Lewis	Penney	King's College London, United Kingdom
Martin	Dominique	The University of Melbourne, Australia
McCulloch	Mignon	University of Cape Town, South Africa
McDiarmid	Sue ^a	UCLA, United States
Moazam	Farhat	Center for Biomedical Ethics and Culture, SIUT, Pakistan
Myrick	Craig	Representative NATCO, United States
Nakagawa	Thomas	Wake Forest School of Medicine, United States
Nino-Murcia	Alejandro	Representative STALYC, Colombia
Noël	Luc	WHO, Switzerland
O'Connell	Phillip	President-Elect TTS, Australia
Rodrigue	James	Beth Israel Deaconess Medical Centre, United States
Sarwal	Minnie	University of California San Francisco, United States
Schotsmans	Paul ^a	Representative ESOT, Belgium
Shapiro	Ron	Children's Hospital Pittsburgh, United States
Siebelink	Marion	University Medical Centre Groningen, the Netherlands
Siminoff	Laura	Temple University, United States
Sweet	Stuart	Representative ISHLT, United States
Trompeter	Richard	Representative IPTA, United Kingdom
Weimar	Willem	Representative ELPAT, the Netherlands

^a These individuals participated in preparatory work for the meeting but were unable to attend in person.

- Donor recognition and policy in the Pediatric Intensive Care Unit (PICU)
- Ethical Challenges in End-of-Life Care
- Family Decision Making
- Allocation of Pediatric Donor Organs

A further plenary session occurred to discuss the issue of death determination in children. In this report, we review the common themes of discussion and key recommendations that emerged from this meeting.

THE IMPORTANCE OF PEDIATRIC DONATION

Organizations, such as the American Academy of Pediatrics, encourage physician education and participation in pediatric donation, collaboration with organ procurement

organizations, and advocate equity in donation and transplantation.¹ Nevertheless, pediatric donation remains a neglected subject of research and public commentary internationally.² This contributes to a lack of awareness among policy makers, health professionals, and the public regarding opportunities to establish or improve donation programs.

Optimizing donation and utilization of pediatric organs and the experience of donor families and professional staff involved in their care are key components of efforts to meet increasing needs for transplantation. Thousands of children and adults benefit from transplants using deceased donor organs annually.³ However, limitations inherent in size-matching organs to pediatric recipients exacerbate difficulties in providing transplants for children. More than 150 children die annually while awaiting organ transplantation in the United States and Europe.^{2,4,5} Although deaths may be declining, more children are removed from waiting lists because their condition deteriorates, and they become ineligible for transplantation.⁴ In some countries, lack of pediatric deceased donation programs means that children in need of transplantation, especially hearts, lungs, and livers, will die unless they are able to travel abroad and receive compassionate access to foreign transplant programs.

Pediatric donation represents a small but invaluable portion of the deceased donor pool, comprising roughly 6% of deceased donors in the United States⁶ and 3% in Australia,⁷ the United Kingdom,⁸ Spain,⁹ and Eurotransplant countries. Conversely, children comprise approximately 1.5% of the waiting list for transplantation in the United States¹¹ and in Eurotransplant countries,¹⁰ 2% in the United Kingdom,¹² 3% in Australia,¹³ and 6% in Spain.⁹ (We note there is international variation in definition of pediatric donors according to age: in the United States and the United Kingdom, pediatric donors are those in the category of 0 to 17 years; in Australia and Spain, published data groups pediatric donors from 0 to 14 years, and in Eurotransplant from 0 to 15 years.¹⁰ For the purpose of organ allocation, definition of pediatric recipients according to age also varies between and within countries and according to organ type.¹⁰)

Studies evaluating the potential of neonatal and pediatric donation are scarce.¹⁴⁻¹⁸ Nevertheless, the proportion of PICU deaths potentially suitable for organ donation in countries such as Spain and the Netherlands is estimated at approximately 11%.^{9,14} The falling rates of donation after brain death and rising rates of donation after circulatory death (DCD) in the United States³ and some Western European countries^{9,14} indicate an evolving pattern of donor potential in general terms, and in pediatrics in particular. The incidence of brain death in the pediatric population is fortunately declining as a result of general safety measures and advancements in neurocritical care. This has been observed in a recent study in Spain (from 25 pediatric brain death cases per million population in 2000 to less than 10 in 2011).⁹

DONATION IN END-OF-LIFE CARE

Withdrawal of life-sustaining medical therapies should be viewed as a process, rather than an event. Opportunities for donation are often lost during end-of-life care, especially when withdrawal of medical therapies takes place without early notification of "key donation persons" (KDPs) to allow engagement with the family or health care team and to

enable timely evaluation of possible donors.¹⁸ Noting there is considerable international variation in terminology and role descriptions of professionals engaged in organ recovery activities, the term “key donation person” is used throughout this report to refer to an organ donation specialist or equivalent: the professional with primary responsibility for donation in a particular setting. The KDP should be included in discussions about end-of-life care and donation with other individuals responsible for provision of end-of-life care. An institutional culture where end-of-life care is inclusive of opportunities for donation supports early referral and preserves the option of donation for patients and families.

Forensic cases involving the medical examiner or coroner may also impair opportunities for donation when request for donation is denied by these authorities.¹⁸ Early involvement and education of the medical examiner or coroner is essential to ensure evidence is not altered or lost during the donation process.

Despite the well-recognized value of saving and improving lives through organ transplantation, families and health care professionals may perceive elements of the donation process as ethically challenging during end-of-life care. These ethical challenges can occur during patient management, and especially in the context of DCD.^{19,20} Unfounded parental hopes of recovery and survival, and fears that cessation of futile interventions may result in withdrawal of care for their child may underpin reluctance to consider donation.^{19,21} Concerns about harming potential donors or their families through discussion of donation, use of interventions to preserve donation opportunities, or recovery of organs after death is declared may discourage health professionals from enabling donation opportunities.²⁰ These apparent conflicts between the interests of a potential donor and their family and the benefits anticipated from donation may result from inadequate communication between staff and family. Furthermore, lack of appropriate education about donation and end-of-life care, and lack of experience among staff for whom pediatric donation is usually a rare event can result in poor understanding and implementation of donation protocols and procedures, ultimately affecting the donation process.

When providing end-of-life care, the child's best interests must be paramount, with due consideration of the principles of beneficence (promoting welfare) and nonmaleficence (minimizing harm). Such interests include previously expressed preferences of the child regarding donation when these are known.²² The interests of children, like those of adults, should be recognized as socially embedded, with consideration for the interests of families where relevant. Potential harms to the interests of the child and family may include prolongation of the dying process, use of futile interventions, and delayed decision making that may preclude the option for donation.

Provision of optimal care at the end of life is an ethical duty of health care professionals caring for dying patients. This encompasses a duty not to offer or implement futile interventions and to withdraw interventions when they become futile. Families should be assured that the cessation or withdrawal of interventions when deemed futile does not mean withdrawal of care for the child. End-of-life care must include the management of the child's symptoms, including pain and suffering, as well as provision of emotional and spiritual support to the child and family.^{19,23} It should be an expectation that parents and family are offered the option of being present

during end-of-life care and during the determination of death.^{19,23}

SYSTEMATIC IDENTIFICATION AND ROUTINE REFERRAL OF POTENTIAL DONORS

Organs transplanted from pediatric donors provide excellent outcomes for many recipients, yet multiple factors contribute to missed or neglected opportunities for pediatric donation.^{3,14-18} Evidence available indicates that rates of donor identification within PICUs vary considerably.^{14,18} In a national study conducted in the Netherlands, rates ranged from 60% to 95% across different PICUs.¹⁴ In a national U.S. study, hospitals with a level 1 trauma program and/or a pediatric critical care fellowship had higher donation rates.¹⁸ Early assessment and routine referral of possible donors to a KDP representing the relevant organ procurement organization or equivalent should help to prevent missed opportunities for donation, as evidenced in adult donation programs.^{24,25} Early referral increases parental authorization of donation by allowing greater time to consider this option.^{19,26}

All patients facing end-of-life issues should be considered possible donors, particularly those presenting with devastating brain injury. Assessment of donor potential should be determined using established guidelines²⁷⁻³⁰ and coordinated with a KDP, or an expert in the area of organ donation. The use of clinical triggers or other methods to facilitate prompt identification of all possible donors, in conjunction with a policy of required referral, will help to improve performance in the process of pediatric donation.²⁴ Systematic audit of all potential donors should occur to ensure accountability and responsibility for all providers involved in the donation process.²⁵

DETERMINATION OF DEATH

Deceased donation is conditional upon professional confidence and societal trust in the determination of death and must be supported by a legislative framework.³¹ Public and also professional discomfort or even distrust in the process of determining death in children may undermine support for deceased donation. Factors that may impair opportunities for donation within the hospital setting include: parents' and health professionals' lack of knowledge and understanding of death determination^{20,26}; poor communication, including the diversity of terminology used to describe death; and variations in practice for the determination of death.³²⁻³⁵

All processes for the determination of pediatric death, whether through neurological or circulatory criteria, should be governed by regional, national, or international guidelines (e.g.,³⁶⁻³⁸). Global standardization of practice is desirable; however, there may be variable local requirements for the process of death determination—such as use of specific diagnostic modalities and the timing of repeat evaluations. Policies governing determination of death should identify suitably qualified professionals to determine death and stipulate requirements for the documentation of death. Determination of death should occur in a timely manner, and the process should be carefully explained to parents so there is understanding and confidence in this determination.

ENGAGEMENT WITH FAMILIES

Parents and families are central to the process of pediatric donation. All families should be provided the opportunity to

make a decision regarding organ donation whenever this possibility exists. The option of donation should routinely be offered in the context of end-of-life care, with a personalized approach to each case taking into account cultural, religious, and other aspects related to the child and family, and the circumstances of death.^{19,26}

Understanding factors that influence parental decisions can increase consent rates for donation. Where decision-making occurs, many parents choose to authorize donation.^{14,18} However, research in this area of pediatric donation is limited. Available evidence about approaching parents for pediatric donation reveals differences from adult authorization from a spouse. Although approach for donation by a trained KDP is strongly recommended for adults, evidence suggests that authorization for pediatric donation increases when a competent and trusted person from the healthcare team and a KDP discuss donation opportunities.²⁶ An appropriate requestor need not be a clinician, provided they have received suitable training in this field. Preexisting positive attitudes toward organ donation, exposure to information about donation, family consensus, sensitivity of the requestor, sufficient time for decision making, and introduction of the topic of donation by a trusted member of the child's health care team are among the factors which positively influence consent for pediatric donation from families.^{19,26} Approaching families about pediatric donation should be planned with close collaboration between the KDP and the critical care team. Donation is a decision made by the family or surrogate, not the health care team. Medical staff should be prepared to support parents who may initiate conversations about donation.^{26,39}

The experience, expertise, and attitudes of health professionals in the PICU—and in the emergency department where dying children are more rarely situated²³—play a critical role in facilitating family decision making about donation and improving the overall experience of families during the death of their child. Effective and ongoing communication with parents must begin early in the process of caring for a critically ill or injured child. Families should be well informed by treating clinicians throughout their time in hospital, with regular, clear, consistent and sensitively conveyed communication, so as to assist in understanding and acceptance of a less than favourable outcome or impending death, futility of interventions where relevant, and the determination and declaration of death.^{19,23,26}

Donation discussions should assess and directly address concerns and barriers to donation, including consideration of the preferences of the child when known.²² Parents of potential pediatric donors should be informed of the possible allocation of pediatric organs to adult recipients, with reasons for such allocation explained and the overall benefits to children in need of transplantation detailed.³ Health care professionals providing end-of-life care should understand that allowing families to pursue donation opportunities may potentially provide solace as parents face the tragic loss of a child. Careful consideration of donation opportunities may minimize the risk of later regret from parents who decline donation.^{19,26}

MANAGEMENT OF DONORS

Where possible, pediatric donors are best managed collaborating with KDP in a pediatric facility by pediatric critical

care specialists who understand the unique needs of children and their families.^{18,40} Management of the potential donor should be viewed as a continuum of care. This includes family support throughout the donation process and appropriate comfort measures for potential DCD donors. Continuation of medical management after determination of death if donation is planned is essential to avoid loss of transplantable organs. Medical care after death should be directed toward sustaining organ viability. Specific protocols can preserve opportunities for donation and assist in standardizing donor management. Use of donor management goals increases available organs for transplantation.⁴⁰⁻⁴² Protocols and goals should be clearly established using existing national or international resources and guidelines and complemented by educational and training programs for relevant staff. When implemented, consent rates for donation and the number of organs recovered for transplantation increase.⁴³

Parental requests (e.g., regarding integration of cultural or religious rituals with organ recovery process) should be honored where possible, and parents should be allowed to be with their child until the time of organ recovery. Organ recovery should be coordinated with surgical recovery teams and operating room staff who participate in the continuum of care. Parental support is essential during and after organ recovery and support should also be available for medical staff after the emotionally taxing event of the death of a child. Donation may comfort not only families, but also the medical team,^{19,44} and donation outcomes should be shared with the family and staff.

ORGAN ALLOCATION

Allocation of pediatric donor organs is complicated by several factors. Size matching considerations, organ-specific issues, use of various prioritization schemes to optimize utilization of pediatric donor organs, and access to transplantation for pediatric recipients.⁴⁵⁻⁵⁰ Allocation decisions may influence public support and parental consent for pediatric donation.^{19,26,49} Accordingly, allocation systems should strive for transparency, so as to avoid for example parental disappointment where organs are unexpectedly allocated to adults, and ensure outcomes of allocation policies meet their underlying goals. Allocation systems, including those prioritizing pediatric recipients, should be carefully evaluated with respect to their impact on pediatric access to organ transplantation and optimal utilization of pediatric donor organs.^{1,45,49}

Use of neonatal and smaller pediatric donor organs is increasing.² Opportunities for transplantation of neonatal and pediatric DCD organs into adult or pediatric recipients as clinically appropriate should be maximized. Barriers to the recovery or use of neonatal and pediatric donor organs^{15,16} and transplantation to pediatric recipients (e.g., concerns about adherence, or lack of suitable recipients within national transplant programs) undermine the goals of allocation policies and should be addressed where possible. International collaboration and use of organ sharing agreements may increase the utilization of pediatric organs for transplantation by potentially reducing discard of organs due to the lack of suitable local recipients.⁴⁸ Ongoing research evaluating the use of vascularized composite grafts and downsizing of adult deceased donor organs for pediatric recipients should also continue. Allocation

TABLE 2.**Core recommendations of the expert working groups**

Priority interventions
<p>1. <i>Promote public and professional awareness of pediatric deceased donation</i></p> <ul style="list-style-type: none"> • Pediatric specific data to be henceforth included in the Global Observatory on Organ Donation and Transplantation,⁵² to provide a comprehensive account of activities internationally.
<p>2. <i>Improve public and professional understanding and support for donation through education</i></p> <ul style="list-style-type: none"> • Organizations responsible for the public education and promotion of donation are urged to develop and include information specific to pediatric donation; • The media should be encouraged and assisted to report accurately and sensitively on deceased donation and related events to address myths and misperceptions. • Professionals responsible for managing critically ill children should routinely receive training in provision of end-of-life care and organ donation (including DCD), as well as death determination; • Healthcare teams and the KDP or organ recovery specialist should work together to increase chances of successful donation and recovery of pediatric organs; • Health professionals from all specialties and disciplines (e.g. nurses, physicians, physician assistants and allied health workers including neonatology, palliative care, anaesthesia, emergency medicine) who may be involved with care of potential or actual donors should be encouraged and enabled to access donation education. Additionally, medical examiners and coroners should receive education about donation and work with healthcare teams to preserve the option of donation; • The Transplantation Society and other professional organizations should support educational and training opportunities at national and international professional meetings; • National and international professional organizations should assist in development and promotion of educational resources to meet local needs.
<p>3. <i>Expand research in pediatric donation</i></p> <ul style="list-style-type: none"> • Clinical, health policy and social science researchers should be encouraged and supported to undertake <ul style="list-style-type: none"> ◦ cross-cultural research investigating attitudes of healthcare providers toward pediatric donation and potential barriers to their participation in donation opportunities, and factors influencing family decision-making in pediatric donation; ◦ evaluation of the potential for pediatric donation in the context of different health systems, and of factors impeding or facilitating opportunities to establish donation programs; • For established programs, ongoing evaluation of donation processes, policies and guidelines, including those governing allocation of recovered organs should be performed and outcomes published.
<p>4. <i>Improve access to and implementation of policies and protocols</i></p> <ul style="list-style-type: none"> • Health authorities should strive to develop systems enabling potential pediatric donors to be cared for in pediatric institutions by individuals trained in the unique needs of children and their families; • Pediatric protocols should be routinely used where possible to standardize pediatric donation and management practices. Health authorities, professional organizations, and healthcare institutions providing care for pediatric patients should collaborate and promptly establish plans for development, introduction and implementation of standardized, best practice guidelines that can be adapted by local health systems. These should include guidelines for: <ul style="list-style-type: none"> ◦ recognition of potential donors; ◦ timely and accurate determination of death; ◦ provision of care to potential donors and their families; ◦ optimal management of the donor; ◦ recovery, allocation, and transplantation of donor organs; • All policies pertaining to pediatric donation and transplantation should be consistent with the WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation³¹ and the Declaration of Istanbul on Organ Trafficking and Transplant Tourism.⁵³

policies should be developed and appropriately revised as these practices evolve (e.g.,^{49,51}).

CORE RECOMMENDATIONS

The lack of research evaluating the international scope, quality, and impact of policy and strategic interventions in the field of pediatric donation provides a limited evidence base for recommendations for practice. The consensus of the expert working groups is that increased awareness, education, and development and use of guidelines are requirements for best practice in pediatric donation. Furthermore, research evaluating clinical practices and outcomes thereof, education interventions, and implementation of policy and guidelines will inform development of more specific evidence-based guidelines and recommendations for practice in the future. Table 2 summarizes the core recommendations for immediate intervention by governments, health

authorities, institutions and professional organizations seeking to improve pediatric donation. Although this meeting was concerned with pediatric donation of solid organs, we note that many of these recommendations are also applicable to donation of tissue for transplantation.

CONCLUSIONS

This report of the Transplantation Society Meeting on Pediatric Deceased Donation advocates the routine provision of opportunities for deceased donation by pediatric patients. Recommendations based on available evidence, expert opinion, and consensus highlight the need for multidisciplinary research and dedicated training and education in the field of pediatric deceased donation among the public and health care professionals to preserve and provide the opportunity for donation where possible for children and their families.

The importance of providing expert holistic care for children and their families throughout the end of life, including donation where relevant, consistent with ethically informed evidence-based and consensus-based guidelines and policies is noted. In particular, the need for consistency and confidence in the determination of death through standardized practice in accordance with regional, national, and international guidelines is noted. The Meeting thus conveys an international call for more clinical, social sciences and health policy research in order to develop and evaluate evidence-based resources needed to inform provision of best practice care in deceased donation for neonates and children.

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