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Pediatric Organ Donation and Transplantation
Committee on Hospital Care and Section on Surgery
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American Academy of Pediatrics

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AMERICAN ACADEMY OF PEDIATRICS

POLICY STATEMENT

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

Committee on Hospital Care and Section on Surgery

Pediatric Organ Donation and Transplantation

ABSTRACT. Pediatric organ donation and organ transplantation can have a significant life-extending benefit to the young recipients of these organs and a high emotional impact on donor and recipient families. Pediatricians should become better acquainted with evolving national strategies involving organ procurement and organ transplantation to help acquaint families with the benefits of organ donation and to help shape public policies that will aid in efforts to provide a system of procurement, distribution, and finance that is fair and equitable to children and adults. Major issues of concern are availability and access; oversight and control; pediatric medical and surgical consultation throughout the organ donation and transplantation process; ethical, social, financial, and follow-up issues; insurance coverage issues; and public awareness of the need for organ donors of all ages.

ABBREVIATIONS. OPO, organ procurement organization; AAP, American Academy of Pediatrics.

BACKGROUND

The Omnibus Reconciliation Act of 1986¹ requires that all hospitals participating in Medicare and Medicaid programs refer all potential organ donors to their local organ procurement organization (OPO). It further mandates that all families of potential organ donors become aware of their option to donate. In addition, legislation further requires all hospitals to discuss organ donation with families of deceased patients. Even with these mandates, organ availability remains limited. The number of individuals who are on the national transplant waiting list remains far in excess of the number of organs procured.² Children from birth to 17 years of age account for approximately 3% of the waiting list. Debates are ongoing as to the best ways to manage the existing supply of organs and how to improve organ procurement in general.³ Kidney allocation policies of the United Network for Organ Sharing give additional points to children on the kidney transplant waiting list. Furthermore, the Children's Health Act,⁴ which was passed in October 2000, called on the Organ Procurement and Transplant Network to address the different needs of children and adults by developing specific criteria, policies,

and procedures to address each group's unique needs.

Organ transplantation is one of the most resource-intensive and expensive therapies available to children. For children, the costs are higher because of a longer expected lifespan after transplantation and loss of work for parents or guardians. Despite these increased costs, the significant benefits of organ and tissue transplantation should outweigh financial concerns.

ORGAN DONATION AND TRANSPLANTATION

The American Academy of Pediatrics (AAP) supports the role of OPOs by recommending that all potential donor families be approached in a systematic method by individuals trained in the psychological, social, and medical aspects of organ donation. It has been shown that the rate of families consenting to donate can be increased from the past national average of 40% to approximately 70% by using hospital or OPO staff who are specifically trained in organ procurement and by decoupling the death notification and organ consent processes.⁵ These processes should be handled in consultation with the child's physician. In addition, an aggressive approach to the medical management of the potential donor will help limit the number of medical failures of potentially procured organs.⁵

The medical and forensic investigation of the death of a child attributable to trauma (unintentional or resulting from abuse), sudden infant death syndrome, poisonings, etc, presents unique issues related to organ procurement. Close cooperation between the forensic system, transplant team, treating physicians, and OPO allows cooperative evaluation and guidance and successful organ procurement in most cases. Cooperation ensures that evidence will not be destroyed and that any injuries noted during the organ harvest procedure will be documented and reported. Some medical examiners believe that individuals who died as a result of abuse should not be organ donors. However, if protocols are developed through which the historical data, surgical and autopsy findings, and laboratory studies are cooperatively examined, most individuals whose death requires investigation can be donors.⁶⁻⁸

The AAP supports the key role of OPO professionals to provide family support during the donation

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process and in long-term follow-up of the donor family. The local success of these efforts is an integral part of increasing organ donation within the local community. In addition to OPOs, the broader medical community must also provide support to the donor family. This includes nurses, clergy, pediatricians and family physicians, child life specialists, and social workers. Involvement of the child's primary care physician and treating subspecialist during organ procurement and transplantation can be very beneficial in bedside management, discussion of complex or unusual diseases, and interaction with the donor family. Education of the primary care pediatrician and other health care providers about approaching the emotional and physical health of the donor's family can be provided by the OPOs. Each local medical community must evaluate its resources and have procedures in place to support the family after the death of a loved one and specifically after the death of a child. The primary care physician is an integral part of the care of the family and should be involved in support and follow-up of the donor family. In addition to family support, the staff at the local medical center should also receive training in dealing with the death of a child, including confidentiality and religious, cultural, and ethical issues. An ethics committee can also be useful in the development of staff support and for discussion of difficult individual cases.^{9,10}

Some unique considerations for the medical team caring for the pediatric organ recipient include support (emotional and spiritual) for the recipient, other siblings (eg, social aspects relating to their care), and parents or guardians (eg, maintaining employment status); and the availability of pediatric subspecialty support (critical care, dialysis, anesthesia, interventional radiology, etc). Pediatric transplant programs are smaller than adult programs, because fewer children require transplantation, yet they offer special expertise in children's health care (eg, critical care, dialysis, and interventional radiology). Children are much harder to relocate for medical care, because their families must accompany them and siblings must be cared for at the same time. Involvement of the child's primary care physician and local subspecialist can be beneficial in providing the more routine follow-up visits and laboratory monitoring. This decreases transportation costs and improves patient access to medical intervention. The impact on the entire family must be taken into account, because the outcome for the child will be maximized if the family unit remains intact.

FINANCIAL ISSUES

The cost of organ donation is born entirely by the recipient. Payment for an organ transplantation and subsequent follow-up care may be covered by employer and individual insurance policies.¹¹ However, the coverage of types of transplants, second transplants, and long-term care is variable, and most policies have a lifetime maximum amount or "cap."¹¹ Once this amount has been reached, the insurance company has no obligation to pay any additional benefits. The amount of the cap varies greatly and

may apply to just one procedure or to all procedures and treatments combined. The ongoing cost of transplantation plus ongoing long-term care may exceed the cap. Improved long-term survival in younger transplant recipients places them at high risk for reaching this cap. Medicaid rules vary from state to state, but most transplant procedures are now included. Because publicly funded programs such as Medicaid, the State Children's Health Insurance Program, TRICARE (formerly the Civilian Health Medical Program of the Uniformed Services), and others are insurers of a large segment of the pediatric population, transplantation financial issues must be addressed by state and federally funded health care programs.

PUBLIC AWARENESS

Because the death of a child is often not foreseen, many families have not considered the possibility of organ donation. Pediatricians, children's advocacy groups, and institutions that care for children need to increase awareness of the need for organs with the same zeal with which blood donations and immunization programs are promoted, through the use of posters in waiting rooms, handouts, and other public campaigns. Options also exist for the promotion of living donation and bone marrow transplantation. An opportunity to discuss these options within the context of anticipatory guidance during adolescent visits might arise when reviewing the risks of driving.¹² This interaction would better prepare the adolescent for future decisions that he or she may have to make regarding family members and serve to educate the parents of their own organ donation options at the same time.

RECOMMENDATIONS

1. Awareness of the need for increased organ donation and support for regional transplant programs should be promoted by the AAP at the local, regional, and national level and by pediatricians.
2. The treating physician should continue to be involved in cooperative medical decision-making and support of the family after the determination of brain death in the patient who had been awaiting organ donation.
3. The procedure for consent for organ donation should be handled by a trained professional, and the death notification and consent for organ donation processes should be decoupled.
4. Protocols should be developed that allow cooperative examination of evidence and injuries so that organ donation can successfully proceed in cases in which forensic investigation is required.
5. The US Department of Health and Human Services and the medical community must look closely at all transplant and organ donation regulations and work to ensure that children are fairly served by their policies.
6. An organ distribution system should recognize the following:
 - a. Health care for children needing transplantation is best provided by a health care system that provides specialized children's medical

care delivered by pediatricians, pediatric subspecialists, and surgical specialists with pediatric expertise.

- b. Issues related to relocation of the child and family for care, transportation, and family support must be addressed at all centers providing transplantations for children.
7. Education of staff should include medical, ethical, social, cultural, and religious issues related to the potential donor and recipient families.
8. Programs for support of donor families should be in place and should be coordinated with the child's primary care physician.
9. Adequate financial resources and payment for pediatric organ transplantation and lifetime follow-up care must be available.

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