Minors as Living Solid-Organ Donors

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ABSTRACT

In the past half-century, solid-organ transplantation has become standard treatment for a variety of diseases in children and adults. The major limitation for all transplantation is the availability of donors, and the gap between demand and supply continues to grow despite the increase in living donors. Although rare, children do serve as living donors, and these donations raise serious ethical issues. This clinical report includes a discussion of the ethical considerations regarding minors serving as living donors, using the traditional benefit/burden calculus from the perspectives of both the donor and the recipient. The report also includes an examination of the circumstances under which a minor may morally participate as a living donor, how to minimize risks, and what the informed-consent process should entail. The American Academy of Pediatrics holds that minors can morally serve as living organ donors but only in exceptional circumstances when specific criteria are fulfilled. Pediatrics 2008;122:454–461

INTRODUCTION

In the past half-century, solid-organ transplantation has become standard treatment for a variety of diseases in children and adults. The major limitation for all transplantation is the availability of donors. The gap between demand and supply is attributable to a multitude of factors including failure to procure consent for many potential deceased donors, the growing number of indications for transplantation, and the realization that transplantation can benefit an increasing number of individuals with end-stage organ failure, including those with significant comorbidities. Despite numerous policy attempts to increase the number of deceased donor organs and the acceptance of “expanded-criteria donors,” the deceased donor supply is inadequate to meet the growing demand. Instead, living donors constitute an ever-growing proportion of organ donors. Initially restricted to first-degree genetic relatives, living donation then expanded to include more distant genetically related relatives (eg, cousins), emotionally related relatives (eg, spouses), and friends (those with whom the recipient had a strong personal bond) and more recently has expanded to include altruistic strangers. Liberalization of medical criteria and upper age criteria also has permitted more people to qualify as living donors. In 2001, for the first time, more kidney donors were living than deceased, and the trend persists. Living donors have also provided segments of livers and, less frequently, lungs, pancreases, intestines, and skin for transplantation.

Although minors are more likely to be organ recipients than living donors, minors have served as living donors. The American Academy of Pediatrics (AAP) believes that minors may ethically serve as living donors but only in specific, limited circumstances. A minor will most likely be considered to serve as a living organ donor for a minor sibling, although there may be rare cases in which it is morally appropriate for a donation to be considered from a minor donor to an adult family member.

Participation of minors as living organ donors raises serious ethical issues. This report includes a discussion of the ethical considerations regarding minors serving as living donors, using the traditional benefit/burden calculus from the perspectives of both the donor and the recipient. The report also includes an examination of the circumstances under which a minor may morally participate as a living donor, how to minimize risks, and what the informed-consent process should entail.

HISTORY

The first successful kidney transplant between identical twins occurred in 1954. Three years later, judicial rulings permitted renal transplants between 3 sets of identical-twin minors (aged 14, 14, and 19 years, because at that time, the age of majority was 21 years). Although live children continue to be a rare source of solid organs in the United States, data from the United Network for Organ Sharing (UNOS) reveal that at least 60 children younger than 18 years served as living kidney donors between 1987 and 2000, during which time approximately 40 000 live kidney
RISK/BENEFIT RATIO

To determine if a living organ donation is ethically permissible, one must examine the risks and benefits to the donor and the recipient. Although ethically the risk/benefit calculation focuses mainly on the risks and benefits to the donor, it also considers the risks and benefits to the recipient and his or her family. The focus on the donor is to ensure that the donation promotes the donor's interests and respects the donor as an end in himself or herself and not merely as a utilitarian organ source. Consider, for example, a donation by someone with cognitive disabilities. There have been several court cases that have prohibited such donations on the grounds that the potential psychological and emotional benefit may be minimal or nonexistent if the individual does not currently understand why he or she is being asked to undergo the donor operation, particularly if that individual is not expected ever to understand the purpose.

Risks and Benefits to the Donor

Although serving as an organ donor is not in the donor's medical best interest, it may be in the donor's best interest, all things considered. For example, there are potential psychological and emotional benefits that a minor donor may experience. The child may develop greater self-esteem and be seen as a hero by his or her family, friends, classmates, and larger community. There are also the potential benefits that a child accrues when his or her family is relieved of the burden of caring for a seriously ill family member. For example, the donor may now receive more parental time and energy and more intrafamilial companionship and may benefit from improved financial resources. The psychological benefits may even accrue if the transplant fails, because the donor and his or her family can take solace in the fact that everything possible was done.

However, there are also psychological risks of serving as a living donor, although the data in children are limited. Although some adults experience greater self-esteem after donating, others feel lower self-esteem, a sense of neglect, and lack of appreciation after the donation as the attention refocuses on the recipient. Psychological risks may be greater in younger children, who may not understand the meaning of the lost body part or the reason for any scars.

The donor may experience guilt and blame if the transplant fails and/or the recipient dies. Several cases of adult donor suicides after failed transplants have been reported in the literature. Still, the vast majority of donors understand this risk and do not regret their decision.

Another risk is the potential coercive nature of the request: how can children refuse when their parents are asking them to donate? And, if a child does refuse, additional guilt may result. On the other hand, there are potential psychological and emotional risks from not being allowed to serve as a donor and the possibility of blame, by self or others, for the death of the family member if the child does not donate. These and other psychological risks and benefits need to be studied longitudinally.

There are some significant medical risks to the organ donor. First, there are the risks of surgery and anesthesia themselves. The calculated risk of mortality from kidney donation is approximately 2 in 10,000 and is up to 10-fold greater for a left lateral segment living liver donation (with the right-lobe having a greater risk than left-lobe). There are also risks of significant morbidity, including postoperative bleeding and infections. All donors experience acute pain, and some develop chronic pain. The risks of serious or significant morbidity to kidney donors are often quoted at less than 5% regardless of the surgical method of procurement (eg, laparoscopic versus open), although there is minimal experience with laparoscopic kidney procurement in children. The risks of serious or significant morbidity to liver donors cited in the literature are quite variable. One review described the range of serious morbidity for living liver donors between 0% and 69%, acknowledging that the discrepancies were attributable, in part, to individual center definition and recognition of morbidity as well as which liver lobe was being donated and the experience of the center. Other reviews have described the risk of morbidity as ranging from 0% to 100%. The true rate of morbidity and mortality for other solid-organ donations is difficult to establish (eg, lung, pancreas, and small bowel) because of the small numbers of reported cases in the literature and the lack of living-donor registries.

Long-term risks for the potential child donor need to be considered as well, especially because there have been no long-term data on the safety of pediatric donation. One study followed 111 minors younger than 16 years who underwent unilateral nephrectomy for unilateral renal disease. The study participants were re-evaluated 7.1 to 51.9 years after surgery (average: 26.0 years). The researchers found that renal function was maintained at approximately 75% of the reported normal 2-kidney value. Although adult data suggest that kidney donors are not at increased risk of chronic renal disease, it was reported recently that 56 previous adult living donors were later placed on waiting lists for deceased kidney transplantation. The contribution of the nephrectomy to the subsequent cause and timing of renal failure in these donors is unknown. Long-term follow-up is necessary to determine the risks to pediatric donors, because children, by the nature of their young age, will have a longer at-risk period of decreased renal reserve than will their adult counterparts. If the need for
the transplant is related to a genetic condition in the recipient, there is a risk that a genetically related donor may develop the same health problem and need a transplant at some time in the future; this may be particularly true of identical twins.

Although the worldwide experience of living pediatric liver donors is too small and too recent to allow statements about the actual long-term risks, these donors theoretically should suffer no long-term risks of liver failure, because the liver is a regenerative organ.

An additional risk to the donor is the restrictions in activities because of the donation. Frequently, organ donors are counseled to refrain from certain activities, especially those perceived as physically hazardous, despite the fact that guidelines have become less restrictive. The AAP now gives a “qualified yes” to participation in contact sports for children with only 1 kidney.34 The US military will not enlist a person with 1 kidney,35,36 although they may not necessarily discharge a serviceman who loses a kidney. No recommendations exist for donors of organs other than kidneys, although there should be no long-term restriction of activity for donors of partial organs, such as liver, intestine, and lung.

Benefits and Risks to the Child Recipient and the Family
The main benefit to the recipient is a healthy living graft. For kidney transplantation, if the donor and recipient are siblings, there is a 25% chance that they are HLA identical, which increases mean graft survival on a statistical basis. Ten-year graft survival for HLA-identical siblings is 75% (vs 56% for unrelated HLA-mismatched living donors and 44% for cadaveric donors).37 If they are identical twins, the graft can survive even without the need for immunosuppression. The recipient’s improved medical well-being benefits the recipient as well as the family and the donor. For other transplanted organs, there is no demonstrated benefit of HLA matching except that no organ transplants between identical twins require immunosuppression.

Risks to the child recipient are the medical risks of the transplantation procedure and the psychological and emotional risk of feeling indebted. There is also the potential risk of guilt should the donor sibling develop a significant chronic morbidity or die. Unless the children are identical twins, there are also the risks and adverse effects of immunosuppression, which include increased risk of infection and malignancies.

CONDITIONS UNDER WHICH A MINOR MAY PARTICIPATE AS A LIVING ORGAN DONOR
UNOS data regarding the participation of minors as donors10 suggest a lack of stringent criteria. In response, the Amsterdam Consensus Panel, an international panel of experts in transplantation, accepted a proposal that minors younger than 18 years should never be allowed to donate.34 The US Live Organ Donor Consensus Group, a national panel of experts in transplantation, however, argued that minors younger than 18 years could ethically serve but only in rare and exceptional circumstances.36 The AAP concurs that it may be permissible for a minor to participate as a living organ donor provided that stringent criteria are met. The US consensus group offered 4 conditions, all of which must be satisfied for a minor to ethically serve as an organ donor. The following is a review and modification of these 4 criteria with a fifth criterion added to ensure that minors only serve in very rare and exceptional circumstances.

Condition 1
The first condition requires both the potential donor and recipient to be highly likely to benefit.38 Condition 1 will most likely occur if donations by minors are restricted to donations within an intimate family setting in cases in which the psychological benefit to the potential donor is likely to be significant.19 Moreover, minors should never be considered as potential donors for strangers40 or people they only know through the Internet.

Condition 1 also implies that minors should not be asked to serve as living donors in cases in which the likelihood of success is low. The justification for this restriction is to reduce the psychological burden that the child donor may experience if the donation fails. Although all living donors may experience psychological distress (from either a successful or failed donation), competent adult donors should be allowed to accept lower benefit-to-risk opportunities, because they can give their own informed consent (see “Informed Consent”).

Condition 2
The second condition is a requirement that “the surgical risk for the donor [be] extremely low.”37 Although this is not quantified, the risks of certain solid-organ donations such as that of a kidney are known to be smaller than others, such as that of the liver. This would suggest that minors should be restricted to serve as living kidney donors. One could envision the rare situation in which the older adolescent might be permitted to donate a left lateral segment of the liver on the basis of his or her ability to make an informed decision,41 but the data to support the long-term safety of donation of lung, small bowel, and right liver lobes are currently insufficient to permit individuals younger than 18 years to donate these organs. Again, competent adults should have the right to take greater risks, although the transplant team, as moral agents, can decide that the risks are too great for any living donor.42

Condition 3
The third condition mandates that “all other opportunities for transplantation have been exhausted, no potential adult living donor is available, and timely and/or effective transplantation from a cadaver donor is unlikely.”38 To ensure that the child is truly a donor of last resort, children should not undergo donor evaluation until other potential living donors have been evaluated and found to be unable to donate. Children should also not be considered as living donors if deceased donors are likely to become available for their intended recipients.
The current kidney allocation system of the UNOS gives children special priority to receive a deceased donor kidney quickly, so unless there are extenuating circumstances (eg, the recipient is highly sensitized), the need to donate to a sibling should be rare. The practice of splitting livers from deceased donors increases availability of deceased donor livers for young children. These practices should eliminate the need for children to donate to their siblings in all but the rarest circumstances.

Condition 3 merits further clarification. For a child to serve as a donor of last resort, the recipient should be likely not to survive the wait to receive a deceased donor organ, despite being an excellent candidate for transplantation. Examples of such situations include cases in which the potential kidney recipient has exhausted dialysis access or is highly sensitized to most potential donors but not the identified child donor.

Some have argued to bypass condition 3 when the donor and recipient are identical twins because of the additional benefit provided to the potential recipient, who will not require immunosuppression. Although such a transplant provides great benefit to the recipient and, by extension, to the family, the benefit does not significantly alter the risks to the donor. If it is ethically impermissible for a minor to serve as living donor to a sibling because of the risks or because the child cannot make a voluntary and informed decision, the same standards should hold if the potential child donor is an identical twin.

Condition 4

The fourth condition requires “the minor [to] freely [agree] to donate without coercion (established by the independent donor advocate).” The Advisory Committee on Organ Transplantation of the US Department of Health and Human Services recommends that all living donors have a donor advocate. The donor advocate’s primary obligation is to help donors understand the process and procedures and to protect and promote the interests and well-being of the donor. If the donor is a minor, the donor advocate should have (1) training and education in child development and child psychology, (2) skills in communicating with children and understanding children’s verbal and nonverbal communication, and (3) working knowledge of transplantation and organ donation. Thus, donor advocacy will usually require partnering of professional colleagues to provide all these skills (an “advocacy team”). Even with an advocacy team, one must realize that the parental request for a child to serve as a donor for a family member may be perceived by the child as a request that cannot be refused. Minors who are evaluated to be donors must be evaluated for maturity and cognitive ability. Before they are allowed to give assent; they must be educated about living donation and counseled at various junctures that it is permissible to say no or to withdraw at any time before the procedure.

No minor should begin the consent process without the support of his or her parents and/or guardians. This decision is too momentous to be left to minors alone but should reflect a shared decision between minor and parent(s). That said, it is important to acknowledge that parents who give permission for their minor to donate have a potential conflict of interest by the nature of their relationship with both the donor and recipient, and because of the recipient’s illness, the parents may be prone to focus more heavily on the effect of their decision on the health of the recipient. Parents must have some insight into their own conflicts of interest, and the donor advocacy team should help them analyze their own decision-making processes.

In addition, minors should only be allowed to donate within intimate families and only as a last resort. The child advocacy team should ensure that the degree of emotional intimacy can justify the risks from the perspective of the minor donor, that there are no alternative donors who are adults, and that dialysis is not a realistic possibility for the recipient as a bridge to deceased donor transplantation. Although the US Living Organ Donor Consensus Group did not provide a lower age limit, younger children clearly are less able to make an informed and voluntary decision. Using a Piagetian conception of development, a firm lower age limit of 11 years can be set on the basis of the developmental stage of achieving abstract thought. Institutions that are uncomfortable with donation by preadolescents could alternatively choose a higher age cutoff (eg, 14 years). Nonetheless, recognizing that the cognitive and mental abilities of preadolescents and adolescents can vary greatly, an individual review of each prospective pediatric donor should be undertaken by the advocacy team to establish a child’s maturity and understanding irrespective of his or her chronological age.

Condition 5

In addition to the 4 criteria enumerated by the US Live Organ Donor Consensus Group, the AAP would add a fifth criterion. Condition 5 would require the emotional and psychological risks to child donors to be minimized. Data in the bone marrow transplantation literature suggest that the risks can be minimized by preparing future donors through medical role-playing, allowing them to ask questions, and including them in the decision-making process. Families need to be educated about the psychological risks that the donor may feel, particularly if most of the family’s resources remain focused on the ill recipient. Families must also be educated about the importance of affirming the donor’s role and the discomfort that some of the procedures may cause. These 5 criteria are summarized in Table 1.

TABLE 1 When Children May Ethically Serve as Solid-Organ Donors

<table>
<thead>
<tr>
<th>Children may serve as solid-organ donors if:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donor and recipient are both highly likely to benefit;</td>
</tr>
<tr>
<td>Surgical risk for the donor is extremely low;</td>
</tr>
<tr>
<td>All other deceased and living donor options have been exhausted;</td>
</tr>
<tr>
<td>The minor freely assents to donate without coercion (established by an independent advocacy team); and</td>
</tr>
<tr>
<td>Emotional and psychological risks to the donor are minimized</td>
</tr>
</tbody>
</table>

The first 4 criteria were adopted from the Live Organ Donor Consensus Group's consensus statement on the live organ donor and modified.
DOMINO DONORS

In rare cases, an organ recipient may serve as a living donor in what is known as a “domino” donation. For example, if an individual with cystic fibrosis undergoes a heart-lung transplant because of end-stage pulmonary disease, the removed heart may be “healthy” enough to be used for a solitary heart transplant. In that case, the recipient may simultaneously serve as a donor. This opportunity, although rare, may occur for both pediatric and adult patients, including pediatric patients who cannot understand what is occurring. In such cases, the procurement of the organ poses no additional medical risk to the donor and the use of organs ought to be permissible on the basis of normal standards of parental consent. The potential psychological risks and benefits to minors whose organs are used as domino donations have not been studied, but parents and physicians should consider the potential impact when deciding how much to explain to such minors.

INFORMED CONSENT

Legally, in pediatrics, parental permission is all that is required for consent to clinical treatment (with a few exceptions), whereas parental permission and the child’s assent is necessary for research purposes. Ethically, there are guidelines that promote obtaining both parental permission and the child’s assent for both clinical and research purposes. The term “assent” is used to signal that the child’s decision itself is not sufficient. It is understood to be an active agreement to participate and not a mere failure to object. Because serving as a solid-organ donor is not in a child’s medical best interest, although for some children it may be in their overall best interest, the AAP believes that serving as a solid-organ donor should require, at minimum, both parental permission and the child’s assent. This would disqualify all younger children and cognitively disabled children who are not able to give meaningful assent.

In seeking parental permission, it is important for the transplant team to acknowledge the tension that parents experience when 1 of their children is ill and the conflict of interest created if they ask 1 of their healthy children to serve as a potential donor. The transplant team must emphasize that minors should only serve as donors of last resort, and the team should help the family consider whether there are other potential healthy adults and/or whether the ill child can wait for a deceased donor organ. When a minor is a potential donor, the transplant team must help the parents weigh the risks and benefits for the healthy child to serve as an organ donor for an ill family member and not just weigh the risks and benefits from the perspective of the family as a unit.

Discussions between the transplant team and the minor must be developmentally appropriate. The psychological and medical aspects of the donation should be explored in language that is understandable to the potential donor. The donor must be informed that the donation may have some acute and long-term health risks. Although there have been few studies that explored the minor’s psychological response to serving as an organ donor, the adult literature shows that individuals may have unexpected reactions to donation. The minor needs to understand that the donated organ may fail or may be rejected by the recipient or that the original cause of the organ failure may recur and that the outcome is beyond his or her control. The literature shows that many donors feel neglected after donation as the focus returns to the ill recipient. Family members should be reminded that they need to be attentive to the needs of both the donor and the recipient.

Given the potential serious risks of living organ donation without concomitant medical benefit to the donor, minors should not be allowed to serve as solid-organ donors unless they can show some understanding of the risks and benefits of the donation and the procedures to be performed and affirm that their assent is voluntary. Although what is required for a minor’s assent to be adequate is not specified in any clinical or research guidelines, the ability to understand the risks and benefits of donation and to make an informed decision improves with the developmental maturity of the minor. There exist some data to suggest, at least in hypothetical cases, that older adolescents make decisions as well as their adult counterparts, but there is not a specific age at which these capacities uniformly exist. Case-by-case review by the transplant team and an independent donor advocacy team is necessary. Additional consultations by a psychiatrist and/or an ethics committee are recommended for younger minors. If there are doubts that the minor can provide voluntary assent or if there is concern about the minor’s comprehension of the risks, benefits, or procedures involved, the presumption should be to recommend against the child serving as an organ donor.

Although all children are vulnerable, children with disabilities are even more vulnerable than are healthy children. In the early court cases regarding kidney donation by incompetent individuals, some courts expressed concern about individuals with cognitive disabilities serving as organ donors, because the potential psychological and emotional benefit may be minimal or nonexistent if that individual does not understand why he or she is being asked to undergo the procurement. There is also concern that families may be more willing to expose these individuals to risks than they would be with other family members. To alleviate this concern, additional consultations by a psychiatrist and an ethics committee are recommended when a minor with cognitive disabilities is being considered as a potential living donor.

FOLLOW-UP

All children who serve as living solid-organ donors need long-term follow-up. Ideally, national donor registries should be established to collect short-term and long-term medical and psychological data that would allow for more accurate assessment of the risks, benefits, and outcomes of solid-organ donations. All minor donors and their guardians should be asked to authorize the long-term collection and storage of their health data. Parents should be responsible for authorizing the child’s registration, but the child should be asked to re-consent...
when he or she reaches the age of majority. Costs associated with maintaining living-donor registries should be estimated and included on a prorated basis in the reimbursement for the living-donor procedure. Currently, no such registries exist. Until national registries exist, the burden of collecting long-term follow-up data on pediatric donors must be assumed by transplant programs that perform such transplants.

ROLE OF THE COURTS

In the early years of transplantation (1950s to 1970s), judicial review was often sought when children were considered for organ donation. These cases raised the issue of whether parents can authorize an invasive medical procedure on a healthy child that does not promote the child’s medical well-being. The courts affirmed parental authority to authorize such procedures but required that the family demonstrate that the donation was in the donor’s best interest, which frequently entailed the family demonstrating that the donor would experience psychological benefit from helping his or her sibling and psychological harm if not allowed to help. Numerous cases affirmed the guardian or parent’s authority to authorize a donation from an incompetent adult (defined as a person who has reached the age of majority but lacks decision-making capacity) or child. The courts prohibited some donations by minors and other incompetent individuals, particularly when (1) the donor had severe cognitive disabilities and would not benefit from the recipient’s survival and (2) the donor was institutionalized and not an intimate member of the family. The AAP holds that parental authority is necessary but not sufficient and that the minor’s assent also is necessary.

Given that legal precedent for living organ donations by incompetent adults and children is firmly established, the AAP does not believe that every donation by a minor should require court approval. The real value of the judicial review process was historical in that it provided an independent advocate for the potential incompetent donor, a role that should now be fulfilled by donor advocacy teams. A donor advocacy team with special pediatric expertise should be appointed for all individuals younger than 18 years who are being considered as living solid-organ donors. The donor advocacy team should ensure that (1) the minor understands the risks and benefits of the procedure, (2) the minor has the developmental maturity to understand that participation is voluntary, and (3) the minor’s decision is voluntary. At least some of the conversations between the potential minor donor and the independent advocacy team should be held in the absence of other family members. If the minor is unwilling to serve or is emotionally or cognitively unable to appreciate, at some level, the risks and benefits or the procedures involved, the donor advocacy team should recommend against the donation. The donor advocacy team should also assess whether the recipient to whom the minor is being asked to donate is an appropriate candidate (eg, a child sibling with a high likelihood of doing well with the graft), that no adult living donors are available, and that waiting for a deceased donor transplant is not clinically appropriate. The donor advocacy team should help ensure that the parents are assessing the risks and benefits of a sibling donation from the independent perspectives of the recipient and of the donor. The donor advocacy team should affirm in writing that it has determined that the minor is operationally capable of understanding the donation procedures and that the minor actively assents to his or her participation. This process, then, should obviate the need for routine court review. Additional consultations (eg, with a psychiatrist and an ethics committee) are recommended for more complex cases such as those involving younger minors (eg, minors between 11 and 14 years old) or minors with cognitive disabilities, with court review as a last resort (eg, if a hospital lacks an ethics committee with sufficient expertise).

CONCLUSIONS

The AAP believes that it is morally permissible for minors to serve as living donors in exceptional circumstances only when the aforementioned 5 criteria are met (see Table 1). A donor advocacy team with training in child development and child psychology, with experience in communication and role-playing with children and with understanding of transplantation and organ donation, should be required for all transplants that involve living minor donors. Hospital ethics committee and psychiatric consultations should be considered for more complex cases, such as when (1) the minor donor has cognitive disabilities or (2) there are procedural questions given the child’s age (eg, when younger minors are being considered as kidney donors or when adolescents are being considered for donating a left lateral segment of the liver). Court review of pediatric donations should be rare (eg, if there is a question about whether the 5 criteria in Table 1 are met and the hospital lacks an ethics committee with sufficient expertise).

Parental permission is sufficient for domino donations by children. All other donations by minors should require both parental permission and the child’s assent. Although identical twins offer an immunologic benefit as living donors, the best interest of the donor child still requires that they serve as donors of last resort and only if all 5 criteria listed in Table 1 are met.

Finally, long-term follow-up data should be collected to help determine the actual benefits and risks of donation, both medically and psychologically, for children. These data should then be used to modify future recommendations for the permissibility of minors to serve as living solid-organ donors.

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