Special Section: Children as Organ Donors

Cognitive Development and Pediatric Consent to Organ Donation

SUSAN ZINNER

Attempting to balance the needs and interests of minors with the obligation to protect them from their own potentially harmful decisions poses an ethical challenge for the physician. This problem is further exacerbated when the context is not medical treatment but organ donation. That is, medical treatment scenarios generally involve decisions likely to result in objective improvements to the minor's health status. Consent to organ donation, however, raises several vexing problems. First, how should the provider measure both the cognitive ability and competence to consent of the minor to ensure that the minor comprehends the risks and benefits of donation and that no coercion is involved? Second, given that improvement of one's health is an unlikely scenario, is there a way to measure subjective determinations of satisfaction and altruism enjoyed by a minor following organ donation? If so, should the physician regard these values in a manner analogous to physical improvement? Finally, are parents the appropriate decisionmakers for their children when a sibling-to-sibling donation occurs? Is it possible for parents to always act in the best interests of both children in this event?

The American Medical Association (AMA) has established the best-interest approach to guide physicians working with children and adolescents considering organ donation. The AMA Code of Ethics report notes that:

> The merits of a best-interest standard include its ability to incorporate the preferences of children as evidence of what is in their best interests without relying solely on a fictional determination of what they would want were their values more mature. Best interest also allows for the consideration of potential psychological benefits, when they exist, and weighs the medical risks of transplantation, rejecting transplantations which pose an unacceptably high risk to the minor source . . . [E]vidence of future benefit to the minor source should be clear and convincing. Possible benefits to a child include the following: Continued emotional bonds between the minor and the recipient; increased self-esteem; and prevention of adverse reaction to the death of a sibling. Whether a child will capture these benefits depends on the child's separate circumstances.[1]

Similarly, a number of state courts have justified sibling-to-sibling organ donation based on a determination that donation results in a number of benefits to the donor child.[2] Benefits include the potential harm likely to result if the minor is not allowed to donate the organ, and the psychological benefits associated with donation such as increased self-esteem and a higher family

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status.[3] Some have argued, however, that donation is seldom in a child's best interests.

> They are saying that it is in the child's best interests to: (1) be exposed to the unfamiliar and frightening environment of a hospital; (2) be exposed to the risks attending the use of general anaesthetics; (3) be exposed to the potentially serious peri- and post-operative risks associated with surgical removal of a healthy kidney; (4) be exposed to the potentially serious long-term risks associated with extended hyperperfusion of the remaining kidney, including known risks; (5) potentially experience the psychological trauma following a failed transplantation attempt; and finally, (6) potentially experience the "psychological benefits" following a successful transplantation attempt.[4]

Rozovsky notes that the Kentucky and Connecticut courts appear to rely on the substituted judgment theory as well.[5] Using substituted judgment, parents may consent for their minor children if their decision appears to be consistent with the values and actions of the child. Parents place themselves in the position of their child and make the decision the child would have made were he or she legally competent. Some legal scholars find this subjective test so fraught with potential abuses that they deem the best-interest test the better alternative.[6]

The first issue to explore is that of the cognitive abilities and limitations of the child and ensuring that the child is providing an acceptable consent or assent to the procedure. As Crouch and Elliott note,

> one of the necessary preconditions of receiving what the court calls psychological benefits is that the donor have sufficient cognitive development to recognize the social aspect of donation; that is, the donor must be aware not merely that his or her kidney has been removed, but rather that he or she has helped the sibling by donating in a way that few (perhaps no) others could ever do.[7]

The crucial question, then, becomes whether the child has the cognitive capacity to appreciate the quality of his or her action and the fact that this act is likely to result in a positive self-image. Given that younger children tend to be self-focused, this capacity is likely to be present primarily in older children and adolescents.

Classic Piagetian theory of child cognitive development holds that children ages 2–6 years old are in the preoperational stage and tend to be unable to generalize, lack the ability to think into the future, and need concrete examples.[8] Children 7–12 years old are capable of abstract thought yet may still need some previous experience with an idea to understand it.[9] Those at the formal operations stage, which begins at around age 13, possess the capacity for abstract thought and can use logical thinking to weigh risks and benefits of current and future actions.[10] Minors at the formal operations stage exhibit an adult ability to address a problem and may be capable of providing informed consent despite their chronological age. At this mature stage of cognition, individuals are able to "conceptualize where each of several courses of action may lead, and to choose between those options in a manner which considers the various possibilities inherent in each option."[11] As many states recognize the legal exception of mature minors (where children are allowed to consent to

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their own treatment if they can convince their provider they possess the requisite maturity level) and many states also allow minors as young as 12 years to consent for treatment of substance abuse and sexually transmitted diseases,[12] allowing mentally sophisticated minors to consent to organ donation appears to be a logical step. "It is arguable that if a minor could consent to intrusions of his body for treatment and blood donation, the right should include the opportunity to donate body parts."[13] Further, many 13-year-olds routinely make decisions about drug use or sexual activity in their daily lives that also require a fairly sophisticated ability to weigh risks and benefits.[14]

Interestingly, the question of whether a child possesses the necessary skills to render such a decision has been explored most often in the context of research. Research, especially research with no possibility of providing a direct benefit to the minor subject, closely mirrors issues involved in organ donation, where direct benefit is unlikely. Both provide the minor with the opportunity to demonstrate affection (for a sibling in the context of organ donation, and for future unknown children in the context of research) and are likely to result in enhanced self-image as a result of this altruistic gift.

Federal regulations governing the use of children in research have established some important criteria that may be analogous to organ-donation situations. Previous federal policies used a proxy consent model where parents or guardians made all decisions concerning their child's participation in research.[15] These guidelines were changed in 1983, however, when the Department of Health and Human Services (DHHS) determined that consent was only appropriate in situations where one had reached the age of majority and cannot be delegated to others.[16] Therefore, permission (and not consent) is now obtained from parents and assent (i.e., affirmative agreement that does not rise to the level of informed consent) is generally obtained from the child.[17]

The American Academy of Pediatrics (AAP) Committee on Bioethics addressed the issue of assent in pediatric medical treatment.[18] The group notes that assent should include:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
2. Telling the patient what he or she can expect with tests and treatment(s).
3. Making a clinical assessment of the patient's understanding of the situation and factors influencing how he or she is responding (including whether there is appropriate pressure to accept testing or therapy).
4. Soliciting an expression of the patient's willingness to accept the proposed care. Regarding this final point, we note that no one should solicit a patient's views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived.[19]

In her classic study designed to explore when children are able to make adultlike medical treatment decisions, Weithorn found that subjects as young as 9 years did not differ significantly from subjects ages 14, 18, and 21 when presented with complex scenarios.[20] Further, the 9-year-olds reached the same decision as the other groups in three of the four scenarios.[21] For our purposes, the most significant finding was that the reasoning process employed by 14-year-olds did not differ in any significant way from that of adults.

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Developing cognitive skills and associated limitations may affect the informational component of the system but not the value system enunciated.[22] Learning to reason and exercise these skills is an important step toward maturity. Choices made by children are "not necessarily inferior to those of adults simply because they have not had as much experience in determining how to go about putting their values into practice and attaining their goals."[23] If we grant minors demonstrating competence and maturity the right to make decisions about organ donation and other medical options, they are likely to become increasingly proficient.[24]

In the case of organ donation, minors deemed capable of providing consent and adults must be able to demonstrate sophisticated weighing of information prior to making a decision to donate. Information generally provided to potential organ donors includes:

1. the diagnosis and its degree of certainty;
2. the nature and purpose of the proposed transplant;
3. treatment alternatives that may exist, even though for lifesaving organs the possibilities may be few;
4. the prognosis without a transplant; and
5. the known risks and complications associated with transplantation, including those specific to the organ being transplanted as well as general risks of infection, rejection, and neoplasia.[25]

Research indicates that even some adults have difficulty demonstrating knowledge sufficient to provide informed consent.[26] Expecting younger minors to meet this standard may be unrealistic. Older children, such as those 13 or 14 years and older (i.e., at the formal operations stage on the Piaget cognitive developmental scale), appear to be adequately equipped to make these decisions, however.

The issue of parental coercion is more likely at the preoperational stage for minors 7–12 years old. This becomes less of an issue as the child matures. Indeed, one of the qualities of the formal operations stage is that adolescents are able to judge the merits of an act such as donation on its ability to help others and can make decisions about research not designed to have any direct, therapeutic benefit.[27] Analogously, research designed to produce no direct benefit to a minor is closely related to organ donation that provides no direct therapeutic benefit to a donor. Therefore, these minors may be able to render a mature decision in which parental coercion does not play a major role.

In response to the question of how the provider may ensure that the child's interests are being protected prior to organ donation and that no coercion is involved, physicians should use adult standards of competence when older adolescents are involved. If a minor of 13 or 14 years or older wishes to donate an organ to a sibling, providers should ascertain the maturity level of the minor. Many minors may be capable of providing an effective informed consent, especially in states recognizing the mature minor legal exception. Alderson cited attorney Sheila McLean, who affirmed this notion that "the competence of the decision made should be the issue rather than the age of the person making that decision. This would mean that the onus would be on the adults to justify non-involvement of the child in consent and decision making."[28]

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The second issue to examine is how to measure the likelihood of emotional satisfaction resulting from organ donation to an ill sibling. Further, are these inherently subjective emotions sufficient justification for donation when no direct benefit will result? This issue is closely related to the previous question, as only a truly informed consent will indicate whether altruistic feelings and self-esteem are likely to be high following donation.

One of the relevant ethical principles is that of respect for the child's limited autonomy. There is no moral duty to donate even when the anticipated benefits to the sibling are high.[29] Requiring a reluctant child to donate an organ may be viewed as sacrificing that child "in the name of a utilitarian calculation which betrays the loyalty we owe to their sacred, individual personhood."[30]

Jeffrey Spike addressed the issue of accrual of benefit to the donor when he asked, "But should we set the standard higher for altruistic gifts, in order to protect patients from harming themselves without a full understanding of the consequences?"[31] His proposal would create a two-tiered informed consent requirement—a lower standard to be used on occasions when the recipient will receive therapeutic benefit, and a higher standard when no therapeutic benefit is expected. This notion, which is similar to the DHHS federal regulations governing the use of minors as research subjects, may be appealing on its face but could further burden the provider who would then be responsible for ascertaining multiple levels of maturity. Also, such an approach is inherently subjective and creates the risk that, depending on one's provider, a competent child may be permitted to donate using one provider's standards and may not be permitted to donate using a second provider's standards. This also raises the ethically risky proposition that parents might be tempted to "forum shop" for a doctor likely to permit their child to donate.

In determining the benefits likely to accrue to the donor child, both long-term and short-term benefits should be considered. Sells has found that adult donors seldom regret the donation and score higher in self-esteem and lower in depression, regardless of the success of the transplantation 5–9 years later.[32] At least two writers, however, have questioned whether children are likely to experience any benefits, because of their youth and immaturity.[33] Literature concerning child donors and their feelings after donation is virtually nonexistent.

Present and future benefits, including the improved health of a sibling, increased feelings of self-esteem and self-worth, the concept of oneself as altruistic giver, and enhanced feelings of autonomy and control may encourage us to allow providers and parents to allow a child to donate to a sibling regardless of lack of direct benefit. Although subjective, these psychological benefits may be just as valuable to mental health as therapeutic benefits are to physical health. Also, as noted previously, experience making these weighty decisions allows adolescents to exercise and develop decisionmaking skills. As Purssell noted,

> We need to learn to respect children just as we do adults, both in regard to medical care and generally. Crompton (1992) suggests that we need to consider children as complete entities rather than simply immature adults. She also advocates a movement for "childism," just as some people advocate feminism, so that we can learn to value children for what they are and not just what they will become.[34]

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Finally, the third issue to explore is whether parents are the appropriate decisionmakers for both the donor child and the child who will receive the organ. Is it possible for parents to act in the interests of both children in this case? How can we resolve the conflicts of interest inherent in these situations? If we accept the dubious premise that parents are not the best surrogates in these instances, who should make these decisions?

The primary objection of allowing parents to make decisions for their child in these circumstances occurs "when the recipient is another family member [and] parents are in a conflict of interest as protectors of their infant's welfare. Their love and desperate hope for their other child might blind them to the real magnitude of harms their donor child would suffer."[35]

Further complicating this issue is the problem of using the best-interest standard within a family.

> The interests of more than one person are at stake. To attempt to cram a formal relation into an intimate context does violence to the morally significant aspects of the family relationship. . . . What is morally important and problematic about organ transplantation is precisely that it may *not* be in the best interests of the donor.[36]

The best-interest framework is most effective, the authors suggest, in situations where competing values are not involved, and families simply do not fall into that category. Individual interests are intertwined with family interests,[37] and it is often impossible to separate the two.

We assume that parents are the best decisionmakers not only because they generally act in their children's best interests but also because they are in the best position to know the values and goals of both the organ donor and organ recipient. As Tomlinson notes, "consent for treatment of a never-competent child is loyal to them only when it is based on reasonable presumptions about what the child's values and goals would be relative to the risks of harm and promises of benefit of the treatment."[38] Although the literature is sparse, several studies indicate, however, that parents may not always know their child's values and goals. For instance, one study found "very low agreement between parents' and child patients' views of psychiatric treatment, with parents underestimating the child's feelings of distress, anxiety, and negative reactions."[39] A second study found that the correlation between parent and child in measuring pain associated with venipunctures was low, whereas the correlation between pediatric nurse and child was better.[40]

Although not conclusive, these findings raise the issue of how well parents know the values espoused by the potential donor and recipient and, in turn, how well parental decisions reflect the interests of both children. Confirming this notion is research indicating that proxy decisions for (incompetent adult) patients tend to reflect the choice the proxy would make and not the choice that is in the best interest of the patient.[41]

Given that the possibility of parental coercion exists, should the provider seek input from others? For example, the provider may seek input from an independent individual or group, such as the hospital ethics committee.[42] Some European countries have also adopted this approach.[43]

Friedman Ross, among others, has argued strongly that parents remain the best decisionmaker in these cases: "parents are the better judge as they have a more vested interest in their child's well-being and are responsible for the

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day-to-day decisions of child-rearing."[44] Similarly, Kuczewski has noted that "if we assume that values do not simply emanate from some ineffable core within us but take shape through interaction with the environment, the family is a natural part of this process."[45]

Parents are often the best decisionmakers for their children because they are generally in the best position to know the unique values and goals of both children in a sibling-to-sibling donation. Participation in these decisions by independent third parties such as ethics committees or consultants may be advisable, however, in situations involving disagreement between parents or other family members and the potential donor child.

Once these hurdles are surmounted, sibling-to-sibling organ donation offers the opportunity of continued good health and a longer life for the organ recipient. Subtle pressure (such as newspaper articles referring to donation as "the gift of life") and not-so-subtle pressure (from parents or providers) should not transform what must remain a freely given gift into a mandated donation.

In conclusion, many adolescents of 13 or 14 years or older are able to make their own decisions. If a minor can clearly enunciate his or her values, wishes for donation, and appears to comprehend the attendant risks and benefits, a rebuttable presumption of competence may be appropriate. Similarly, the satisfaction that a minor feels from donation may be just as valuable as physical improvement following medical treatment. Finally, the presence of an independent third party may occasionally be necessary to protect the interests of the donor child.

Notes

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3. See note 2, Rozovsky 1990:622, citing *Little v. Little*.
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7. See note 4, Crouch, Elliott 1999:282.
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20. See note 11, Weithorn 1983:3.
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24. See note 23, Dickenson 1994:206.
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26. See, e.g.: Howard JM, DeMets D, BHAT Research Group. How informed is informed consent? the BHAT experience. *Controlled Clinical Trials* 1981;2:187–303, where 8% of the sample questioned appeared to believe that they were receiving therapeutic care instead of participating in research.
27. See note 8, Broome, Stieglitz 1992:151.
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30. See note 29, Tomlinson 1993:42.
31. See note 22, Spike 1997:168.
32. Sells RA. Consent for organ donation: what are the ethical principles? *Transplantation Proceedings* 1993;25(1):39.
33. See note 4, Crouch, Elliott 1999:282.
34. See note 28, Purssell 1995:624.
35. See note 29, Tomlinson 1993:43.
36. See note 4, Crouch, Elliott 1999:285.
37. See note 4, Crouch, Elliott 1999:285.
38. See note 29, Tomlinson 1993:42.
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