Response to "Special Section on Children as Organ Donors" (CQ Vol 13, No 2)

A Critique

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I would have preferred that the Special Section on Children as Organ Donors had focused on the donation of a specific organ because morally relevant differences are obscured when the subject is discussed in general terms. The donation of a lobe of liver and peripheral blood or bone marrow stem cells does not result in the permanent loss of vital tissue because these organs regenerate; however, a kidney does not regenerate and its donor loses a vital organ permanently. Liver tissue and peripheral blood or bone marrow stem cells are typically required to save a life, but, because most patients with end-stage renal disease can be kept alive on dialysis, the donation of a kidney is rarely life saving. Also, donor risk is organ specific; for example, it is more dangerous to donate a lobe of liver than it is to donate peripheral blood or bone marrow stem cells.

The justifications for organ retrieval from children most commonly used in court decisions and by some of the Special Section authors include "increased self-esteem and a higher family status," "emotional satisfaction," and "a positive self image" for the donor. These arguments fail to adequately distinguish between a benefit to a donor and a donor's best interests. That organ donation confers a benefit does not necessarily mean the donation is in the child donor's best interest. If a child lacks self-esteem only a foolhardy therapist would recommend organ donation as appropriate treatment. If enhanced self-esteem is considered a desirable goal for all children, there are safer means to that end. A child can learn a second language, become an expert tennis player, or work in a charity food kitchen. Benefits must be weighed against risks. If parents want to give their children a "positive self-image," piano lessons may be more appropriate than excising one of their kidneys or a lobe of their liver.

A number of ethicists[1] have argued that obligations to donate an organ are inherent in familial relationships. Jansen would go beyond the bonds of family and advocates an "intimate attachment principle." Child organ donations are permissible when "there exists an attachment between the child donor and the recipient such that the well-being of the former depends, in part at least, on the well-being of the latter" (pp. 140–1). The notion that relationships provide justification to take an organ from a child is unfounded. Familial and other types of intimate relationships have existed for millennia, but human organ transplantation has been available for only 50 years. There can be no sociological or anthro-

Cambridge Quarterly of Healthcare Ethics (2005), **14**, 301–305. Printed in the USA.

pological data that support obligations to donate an organ as durably engrained in relationships. The law does not impose an obligation to donate an organ to a relative. It may be a "moral ideal" for a man to donate a kidney to his brother, but few people would consider such a donation a "moral obligation." Why should relationships impose on children a moral obligation most of us do not impose on adults?

Childhood relationships can be transient. What would Jansen say to a 30-year-old woman who lives with only one kidney because at age 11 she donated the other one to her best friend—a woman with whom she has lost contact and has not seen in 15 years! Relationships are important and can define the boundaries of permissible child organ donation; however, the existence of relationships does not in itself justify organ donation. To limit the potential for abuse, if a child is permitted to donate an organ, the recipient should be a first-order relative with whom there is a meaningful attachment. Jansen notes that the well-being of the donor is bound up with the well-being of the recipient; however, it doesn't necessarily follow that this well-being is of a sufficient magnitude to justify risking the child donor's life. Jansen states that when the risks to a child are more than minimal there should be routine judicial review, but she doesn't provide guidance for the courts to determine how strong the intimate attachment should be to justify risks such as serious injury or death. Child organ donation rooted in intimate attachments is a notion better suited to romantic literature than bioethics.

We should be wary of Zinner's contention that some children are able to give informed consent because they possess advanced cognitive functioning. A well-considered, mature decision to donate an organ requires, in addition to adequate cognition, a stable sense of personal values and a lack of impulsivity. It also requires sufficient inner strength to resist the potential coercion inherent in unbalanced power relationships such as that between parents and a child being asked to donate an organ to a sibling. Zinner notes that in many states children are classified as "mature minors," and in certain settings, such as sexually transmitted disease clinics and substance abuse programs, they are granted the prerogatives of adult decisionmaking. These facts have little bearing on whether children should be treated as adults with regard to organ donation. Typically, mature minors have earned that designation, not by passing a test of maturity but by making, for better or worse, certain decisions, such as to get married or to join the military, that makes treating them as adults a pragmatic decision. And I would hesitate to accept as sufficient evidence of maturity a child's ability to acquire gonorrhea or become a cocaine addict. Zinner notes that "the competence of the decision made should be the issue rather than the age of the person" (p. 128), but she does not precisely describe any method for determining whether a child can make a competent decision and she gives no data that any method trumps age as a surrogate marker for mature decisionmaking capacity. More substantial supporting data are needed before we accept her contention that a child may not, at least functionally, be a child. Zinner also notes a movement to respect children, analogous to feminism, called "childism"; we confront absurdity when a movement to value children is employed to justify removing their organs.

The authors do not appropriately confront risk because they never acknowledge that if a sufficient number of organs are retrieved, some

healthy children will die. Ladd makes the recklessly naïve statement that "liver donation is fairly safe, with donor survival 100% and complications rare" (p. 143). Her reference is the experience of one transplant center yet to experience its rendezvous with statistical inevitability. Because there is no mandatory reporting of deaths to any central repository, data on live donor deaths are incomplete. However, it is clear that live liver donation cannot be called safe. In a survey of transplant centers, one death was noted in 449 donors (0.22% mortality rate) and at least one transplant-related donor death was reported after the survey was completed; 14.5% of donors had one or more significant complication related to their donation.[2] In a three-year period from 1999 to 2001, of 15,782 kidney retrievals from live donors, seven deaths were reported for a rate of one death for every 2,255 donors (0.04%).[3] Arguments for using children as organ donors should be sufficiently compelling to justify the death or serious injury of a healthy child. Most of the justifications in the Special Section don't meet this standard.

It can reasonably be asked why I emphasize death as a possible donor outcome when it is an infrequent occurrence. Because it is impossible to predict which donors will die, a fatal outcome is a potential reality for every donor and cannot be dismissed as irrelevant. Any theory of justification that ignores donor injury or death is incomplete because those outcomes are part of the landscape of organ donation. Also, the enormity of a child donor's death makes this outcome impossible to ignore and mandates a high level justification for putting a child at risk. Imagine explaining to the parents of a child who died after donating an organ that the possibility of enhanced self-esteem or the benefits of a childhood relationship justified the death of their son or daughter! I doubt many parents would find satisfaction in such tepid rationalizations.

The reason we retrieve organs from children (and adults) has little to do with the justifications provided by the authors. We take organs because we perceive the medical benefits obtained as sufficient to justify any potential harms. If you retrieve enough kidneys and lobes of liver, and perhaps even peripheral blood or bone marrow stem cells, a healthy donor will die. We accept what is ultimately a form of human sacrifice[4] for its utilitarian benefits. We have tacitly allowed that alleviating the need for dialysis for about 2,300 patients is worth the death of one healthy donor and that the death of one healthy donor is worth the opportunity to save 500 patients dying of liver disease. Obligations inherent in relationships and the best interests of donors are obscuring smoke screens and, as suggested by some of the authors, rationalizations for those who find the utilitarian truth cold and disquieting.

A utilitarian basis for organ retrieval does not necessarily constitute moral impropriety. We should respect the principle of beneficence and not be ashamed of trying to save a life or heal the sick. What makes organ donation ethically complex is that it occurs in a swirl of conflicting principles. Beneficence toward the sick jousts with the injunction to avoid inflicting harm. When children are considered as organ donors then another principle, the obligation to protect the vulnerable, adds to the moral complexity. We should be extremely nervous about permitting violations of this principle because the monumental crimes of history have been attacks on people who were unable to protect themselves.[5]

Children are vulnerable and the authors would afford them insufficient protection. They would, with dubious

justification, declare some of them mature and capable of consenting to organ donation. They would allow intimate relationships and speculative, perhaps nonvital, benefits, such as enhanced self-esteem, to justify the surgical invasion of a defenseless child who can reap only medical harm from the intervention. Ethicists must acknowledge that the perpetration of this type of assault on children is not justifiable. There is, simply put, no intrinsic justification for removing all or part of a healthy organ from a healthy child! All attempts at justification are rationalizations or worse.

I will now make the admittedly questionable semantic distinction that if live organ donation by children is unjustifiable, it may, nonetheless, be permissible for utilitarian reasons. The statement that an unjustifiable act may be permissible could, in the context of ethical discourse, mean that in the end the unjustifiable act is in fact justifiable. The concept of an unjustifiable act that is permissible for utilitarian reasons serves two functions. It indicates the act should be permitted only for the most compelling utilitarian reasons. Also, to label an act unjustifiable but permissible would spare us a litany of rationalizations, such as those in the Special Section, masquerading as justifications. We should admit that we allow, with a measure of regret, an act we cannot morally justify because the utilitarian benefits are perceived sufficient to permit the moral transgression. Simply put, the ends justify the means.

And we are gamblers. Most organ donors will not die and will not suffer serious injury. Although we cannot justify the death of a child organ donor, we gamble that when the odds of death or serious injury are low we can behave as if these complications did not exist. We cannot justify the death of a child who donates a kidney, but we engage in a moral gamble and play the odds. We, like the authors, behave in each case as if death or serious injury was not a possible outcome. For 2,299 of 2,300 kidney retrievals, death is a reality we can ignore. We are utilitarian gamblers who bet that what makes taking an organ from a child unjustifiable will not happen. We blind ourselves to what is improbable, and using that psychological technique, what is unjustifiable becomes permissible.

The difficult art of moral judgment challenges us to define when an unjustifiable act is permissible because of its utilitarian value. In this setting clinical ethics must perform, in an organ-specific manner, a risk–benefit analysis. The relevant factors are the risk to the donor, the benefit to the recipient, and the therapeutic alternatives. For organ donation by children the risk to the donor should be extremely low, the therapeutic alternatives nonexistent, and the benefit to the recipient extremely high. The nature of the relationship between donor and recipient should only determine whether donation can be considered in the first place.[6]

I have attempted this type of moral calculus for the retrieval of kidneys from children (and the mentally retarded).[7] My position, which I consider protective of children, permits the retrieval of a kidney only when the donation is the only way to prevent imminent death. Recipients are limited to first-order relatives with whom the recipient has a meaningful relationship. Because most end-stage renal disease patients can be kept alive on dialysis, I would allow utilitarian considerations to permit the unjustified act of taking a kidney from a child only when the risk to the donor is extremely low and the death of another child is otherwise certain. This position proscribes kidney retrieval from children in almost all cases.

I have abandoned the quest to morally justify taking organs from children but would, with very restrictive conditions, permit the practice because of utilitarian considerations. Although I have presented these utilitarian considerations as a pragmatic calculation, my position is not entirely amoral because it is supported by the principle of beneficence.

A justification for retrieving organs from children based on reciprocal altruism is also theoretically possible. Species that provide each other mutual assistance have a survival advantage. Vampire bats who have obtained an adequate blood meal have been observed feeding vampire bats who have gone hungry. On other occasions, when the once hungry vampire bats have been the successful feeders, they have been observed feeding the vampire bats that fed them in the past. This mutual assistance is advantageous to vampire bats considered as a group and is sustained by emotions such as empathy, sympathy, and gratitude that have been conserved by evolution. In a similar fashion, giving a kidney from child A in a family to child B in the same family might be justified if there was a binding pact that had the tables been turned and child A needed the kidney, he or she would have gotten one from child B. A justification based on a commitment to mutual assistance would also have utilitarian roots, but they would be planted in both the principle of beneficence and the principle of justice. Although I suspect most families who would take a kidney from one child for the other would do the same were their children's positions reversed, in the absence of established commitments, justifications based on reciprocal altruism remain theoretical.

Notes

1. Crouch RA, Elliott C. Moral agency and the family: The case of living related organ transplantation. *Cambridge Quarterly of Healthcare Ethics* 1999;8:275–87; Howe EG. Allowing patients to find meaning where they can. *Journal of Clinical Ethics* 2003;13:179–87.
2. Brown RS Jr, Russo MW, Lai M, Shiffman ML, Richardson MC, Everhart JE, Hoofnagle, JH. A survey of liver transplantation from living adult donors in the United States. *New England Journal of Medicine* 2003;348:818–825.
3. Data as of April 19, 2002, reported to the Organ Procurement and Transplantation Network and provided by the United Network for Organ Sharing.
4. At Mount Sinai Hospital in New York City, Michael Hurewitz, a newspaper reporter, donated a lobe of liver to his brother Adam, a physician with liver disease. Michael died of postoperative complications and Adam recovered. It can in retrospect be said that Michael was sacrificed to save his brother. Of course, no one intends for any particular donor to die as a result of their donation. However, because it is known that the surgical mortality rate is not zero, some donors will inevitably die. The global enterprise of live liver transplantation accepts a willingness to sacrifice a healthy person to save a larger number of people with advanced liver disease. In that sense live liver transplantation entails human sacrifice.
5. Judge J.J. Steinfeld, who wrote the dissent in the seminal *Strunk v. Strunk* (445 S.W.2d 145;169Ky) case (closely decided by a 4 to 3 vote) that approved retrieval of a kidney from a severely retarded man succinctly stated the dilemma: "My sympathies and emotions are torn between a compassion to aid an ailing young man and a duty to fully protect unfortunate members of society" and worried "because of my indelible recollection of a government which, to the everlasting shame of its citizens, embarked on a program of genocide and experimentation with human bodies I have been more troubled in reaching a decision in this case than in any other."
6. The relationship does not justify the donation; it sets boundaries that limit the potential for abuse.
7. Steinberg D. Kidney transplants from young children and the mentally retarded. *Theoretical Medicine and Bioethics* 2004;25:229–41.