

A Minor Kidney Transplant Problem: Ethical Issues in Considering Living  
Kidney Donation from Child to Father

Case Summary:

The 14 year-old daughter of a 42 year old man with end stage renal failure wants to donate a kidney to her father. She appears to be making this decision independently with no evidence of coercion. What are the ethical considerations one needs to address in the decision-making process?

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St. Luke's Physician Guild Ethics Essay Competition

Dec 31, 2013

Organ transplantation has steadily increased as procedures and outcomes improve, but need has vastly outpaced sources of donors. Occasionally organs come from living donors, but usually only family members volunteer because of the risks for the donor. While adults can decide to donate, children typically cannot. Children are viewed as cognitively too immature to be competent decision-makers on that scale, and it is unethical to transplant from a child who is unable to participate in the decision. However, there is no clear cut off between an incompetent child and a competent child. It is unjust to dismiss a minor as unable to contribute to their own care or that of their family simply due to their age. Though ethically precarious, given sufficient necessity it may be reasonable for a minor to serve as an organ donor. The following is a discussion of the ethical considerations in a case involving a 14 year old girl wishing to donate a kidney to her father (see case above).

The United Network for Organ Sharing (UNOS) reported that between 1987 and 2000, at least 60 of 40 000 live kidney donations performed, were from donors younger than 18 (1). The issue has since been reviewed by a number of expert panels and in 2005 the Amsterdam Consensus Panel resolved that minors younger than 18 should never be organ donors (2,3). However, the US Live Organ Donor Consensus Group had previously argued that minors could ethically be organ donors in exceptional circumstances, a position which continues to be supported by the American Academy of Pediatrics (AAP) (2,4). The US Group suggested four necessary conditions for ethical organ transplantation from a living child donor, to which the AAP added a fifth (2,4). The first condition requires that both donor and recipient are highly likely to benefit (4). Generally this can only be in cases involving family members (2,4). The second is an

extremely low surgical risk for the donor (4). Third is 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” (4). The fourth condition requires voluntary consent, free from coercion, as established by the independent donor advocacy team (4). The advocacy team should include transplant specialists and counsellors acting on behalf of the donor (2). The fifth condition is to minimize emotional and psychological risks to the donor (2).

In addition to evaluating the case for adherence to these criteria, it may be evaluated for conflicts in the 4 prima facie moral principles of autonomy, beneficence, justice, and non-maleficence (5). There are two major moral conflicts. The first is between beneficence and non-maleficence. There are definite benefits and risks to both the daughter and the father which should be compared to alternative treatments. The second is between the moral duty to avoid harm and the potential capacity for an autonomous decision from the daughter in the care of her and her father (non-maleficence vs. autonomy). The case will be evaluated for adherence to the five conditions suggested by the AAP by presenting them within the context of these major moral conflicts, followed by a brief summary of suggestions regarding the case.

### **Beneficence versus Non-Maleficence**

The AAP requires a high benefit to risk ratio for both the donor and the recipient, and an extremely low surgical risk (2). Of the living solid-organ transplants, only kidney donations are low enough risk to be supported by the AAP in children (2) The risk of death in adults from kidney donation is 2 in 10 000, with morbidity less than 5% (2,6). Short term risks are typical of surgery, but in the longer term they include increased risk

of high blood pressure, incidence of kidney failure, and diseases of the remaining kidney (7). The full long term effects are still unclear in children, who are potentially at greater risk by virtue of living longer without the kidney.

In terms of medical benefits and risks, this scenario does not widely differ from other scenarios of living organ donations from family members. Organs from relatives have more similar HLA tissue typing, which is among the most important in determining relative tissue rejection. When compared to deceased donor kidneys, living donor kidneys have somewhat better outcomes when transplanted, with a success rate of 90-95% after one year (compared to 85-90%), and a lifespan of 15-20 years (compared to 10-15 years)(7). However, it is unclear if a child's kidney would function as well as a fully matured kidney as data is from child to child donations. Typically, kidneys accommodate substantial increases in demand, so it potentially could support the father for several years. In one study, a child recipient of a kidney maintained about 75% of normal two kidney renal function for 50 years (8).

The psychological impacts are also significant. The daughter may benefit from having a family which is no longer dealing with an illness, having her father in her life, and potentially being seen as a hero (2). Most adult donors remain satisfied with their decision and report increased self esteem (7,9,10). However, some are negatively affected; feeling lack of appreciation and lowered self esteem following donation (9,10). This is particularly worrisome for a young girl who might not fully understand the gravity of the decision and be affected by it much later. For this reason, it is particularly important that the psychological risks to the daughter be minimized, as suggested by the AAP (2).

Overall, a deceased organ is a better option when compared with the potential medical and psychological risks to the daughter, provided that the father can realistically wait. Although surgical risk is low, the benefits for the daughter are not great enough to outweigh the risks. As suggested by condition 3 from the AAP, this is likely to remain the case unless every other option for donation has been exhausted (2).

### **Non-Maleficence versus Autonomy**

Generally, only parental consent is required for decisions involving a minor, but there is clear conflict of interest in that the father is the recipient. It is reasonable that the AAP additionally requires minors to consent voluntarily to the transplant.

Her capacity to agree to the transplant must be assessed - that is, voluntary consent free from coercion, given full disclosure and comprehension of all relevant information, with discussion of reasonable alternatives. The AAP argues that all transplant alternatives be exhausted (2), however I would further argue for alternatives of not donating at all, perhaps through prolonged hemodialysis or compassionate care for the father.

Practically, she should be separated from her parents to ensure she can freely discuss and state her views. Although the parents may not be overtly persuading their daughter, for many children it is almost impossible to say no to their parents. The option to say no should be a real possibility to her. It may be difficult for 14 year old girl to comprehend life without her father, or the impacts that a decision not to donate could have on her family.

This case is unique in that the daughter appears to independently wish to donate her kidney. Although rare, if she were considered a mature minor, she should be

afforded the same right to that choice as any adult. Historically, autonomy has been determined by the age of majority, which is 18 in Alberta. However, the legal age of majority has become more and more irrelevant (11). The "mature minor doctrine" passed by the supreme court of Canada allows adolescents who have become cognitively mature enough to understand and participate in their own decision making to do so. While Quebec has established 14 to be the absolute fixed limit for considering a minor to be mature, in Alberta there is no fixed age (12). Generally, courts will not consider an adolescent to be mature until at least age 16, however there have been rare cases as young as 14 (12).

### **Conclusion and Summary Suggestions**

It is exceedingly rare that a 14 year old would be considered capable of offering true informed consent in this scenario. Nevertheless, it is essential to assess if she has a full and mature picture of the benefits and risks associated with organ donation, and of the alternatives. The benefits would need to substantially outweigh the risks for both donor and recipient. All five conditions endorsed by the AAP should be met (2), and the case should further be considered by a third-party ethics panel for a comprehensive and unbiased assessment. An advocacy team of organ transplant experts is crucial to present a complete, unbiased picture of benefits and risks to the family, and to minimize potential medical and psychological harm to the daughter. Ultimately, full agreement would be required from all parties - parents, daughter, physician, surgeon, and relevant-health authorities. Although organ donations from minors can be performed in rare circumstances, it is ethically complex. It is remarkably unlikely that all necessary conditions would be met for it to be performed in this scenario.

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