Ethical considerations in live liver donation to children

Transplant professionals are often faced with ethical situations in practice. In the field of pediatric transplantation, these ethical dilemmas can be even more profound than in adults. Transplant professionals must have a firm foundation of professional and personal ethical principles in order to handle ethical situations they encounter. This paper provides an ethical review of issues that arise during live liver donation from a parent to a child. (*Progress in Transplantation.* 2010;20:186-190)

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Ethics is a division of philosophy used to assess moral questions in human life while providing structure to determine which rules apply to a situation.[1] Every day, health care providers must use ethical principles to determine right from wrong, to act in the best interest of others, and to avoid harm.[1] The basic ethical principles of autonomy, nonmaleficence, beneficence, and justice are put into practice when determining the plan of care for patients.

Organ transplantation and procurement have been topics of medical ethics since their origin, with living donor transplants also considered controversial from the start.[2] As the field progressed and the start of live donor transplantation began, ethical principles were examined further. The ethics committee of the Transplantation Society recommends that transplantation of nonrenal organs from living donors should be done only when the

> aggregate benefits to the donor-recipient pair, the benefits being survival, quality of life, [and] psychological and social well-being, outweigh the risks to the donor-recipient pair, which include death [and] medical, psychological, and social morbidities.[3]

Ethical concerns are applied to all living donor transplants, although liver transplantation may pose an even greater concern because, unlike patients with renal failure who can undergo dialysis, no successful alternative treatment options are available for patients with end-stage liver disease. Although hepatocyte transplantation and xenotransplantation have been tried, neither has been accepted as a clinical option.[4] Extracorporeal liver support systems, which are devices that artificially detoxify through hemodiafiltration, hemoperfusion, plasmapheresis, and hemodialysis, have been used; however, no benefit to survival has been proven for most of these techniques.[5] Bioartificial liver assist devices, which use liver cells to filter and metabolize, are also limited in performance.[5] Although the concept of combining artificial and bioartificial support seems promising, these methods still do not always eliminate the need for transplantation.[5]

In children, the use of "split" livers, or segmental grafts from deceased and live donors, has increased organ availability significantly while decreasing the mortality rate among children on the waiting list. Donation of the right lobe of the liver has been controversial because of widely variable reports of morbidity

and death among recipients and donors. The highest mortality rate for live liver donors occurred with right lobe donation, and the role of right lobar living donor liver transplantation remains unclear.[3] In children and infants, this increased risk is removed because they receive left lobes and left lateral segments from the live donors; however, published reports are not precise about which option is optimal. Outcomes with use of segmental liver grafts from both live and deceased donors in adults are similar to outcomes with whole-organ liver transplantation; however, research is conflicting when pediatric data are reviewed, with some reports suggesting comparable outcomes and other suggesting that outcomes for segmental livers are inferior to outcomes for whole-liver transplantation.[6]

The lack of availability of a successful bridge to transplantation through artificial means and the conflicting data regarding segmental liver transplantation create a more intense and critical situation when one is deciding about living donation.

Background

Pediatric living-related liver transplantation was first reported in Europe in 1985, then in the United States in 1987.[7] At that time, Broelsch et al[7] reported that use of living related transplants was associated with a significant survival advantage in children. The distribution of transplantation in children is shown in the Table.

Table Liver transplantation in children

Characteristic	2007	2008
Total liver transplants	6494	6319
Pediatric liver transplants	605	613
Sex		
Male	316	310
Female	289	303
Race		
White	313	331
Black	108	103
Hispanic	127	132
Asian	37	27
American Indian	4	6
Pacific Islander	6	5
Multiracial	10	9
Donor type		
Deceased	537	542
Living	68	71

Based on data from the Organ Procurement and Transplantation Network (http://unos.org/data/about/viewDataReports.asp).

Decision Making

When adults decide to donate a portion of their liver, they proceed through the donation process with a donor team that has established ethical considerations in their approach to donors.[8] Adult recipients also have input into the use of a liver donor and their personal ethical concerns surrounding the transplant. When the transplant is from a parent to a child, certain questions arise. Does the parent have the opportunity to proceed through the decision process with ethical consideration? Do they ever fully provide a true informed consent? If the parent is responsible also for all of the decision making of the child, then who is advocating for the ethical principles of the child? Because of these many issues, transplant teams have a living donation team with a donor advocate who is not a member of the transplant team of the recipient.[4] Currently in the United States, it is a federal requirement for living donor teams to have either a donor advocate or a donor advocate team. These advocates are to ensure moral, free from bias, individual care for the recipient and donor. A parent, however, cannot divide himself or herself into 2 teams.

Donation Principles

The advisory committee on organ transplantation of the US Department of Health and Human Services established a set of ethical principles and informed consent standards that should be used for all living donors.[9] The person who gives consent to become a live organ donor must be competent, willing to donate, free from coercion; medically and psychologically suitable; fully informed of the risks and benefits as a donor; and fully informed of the risks, benefits, and alternative treatments for the recipient. The advisory committee further states the benefits for the donor and the recipient must outweigh the risks of donation and transplantation and the donor must be participating voluntarily and can withdraw at any time.

Donation to a Child

Live liver donation from a parent to a child presents distinct ethical questions. Can a parent who has an acutely ill child who is facing death in a short time truly be deemed to have capacity to make decisions? Donors have expressed feeling so focused on helping the child that they were unable to rationally think through a decision about donation.[10] Society's automatic assumption that a parent would be willing to donate can be considered a form of coercion for the parent. Forsberg et al[11] concluded that their donors thought that it was impossible to discuss living parental liver donation as a choice given that their option was either to donate or let their child die. Based on the medical indication for transplantation, the margin of freedom between donating or not can be limited.[12]

Although the donor team determines medical, social, and psychological suitability of the potential donor, the simple act of agreeing to be evaluated may lead the donor team into assuming with certainty that the parent wants to donate. If the parent feels like he/she did not have a choice because the parent and the family see the donation as the obligation of the parent, this issue must be explored. Research shows that some donors feel they never really made a decision to donate; rather, agreeing to donate was an "automatic leap" after the donor became aware of the option.[10] Even if donors felt like they did not have a choice, it can be argued that seeing no choice and having reported donor emotions like fear may not compromise the voluntary choice for donation.[13] Conversely, is the feeling of having no choice the same as coercion?[14]

Although parents may be doing well psychologically by demonstrating the ability to make decisions for their child, decision making becomes more complex when parents must decide what is best for the child in addition to what is best for themselves and the rest of the family. Donors are informed of the risks and benefits of donation, but parents who already feel the pressure to save their child's life may not internalize the risks as being a true possibility. For example, women in 2009 still die during childbirth. Do any of us really consider that we may be one of the few to die? No matter how much education the donor team provides, or how extensive of an exploration they do into the medical and psychosocial life of the donor to help with the decision-making process, donor parents still may not accept the medical risks put upon themselves. How can parents balance and integrate morally significant family interests with the patient's interests in decision making?[15]

Altruism

In cases where the child's health status is declining, and no deceased donor liver is available, no alternative treatments are available for the patient. The use of altruism here may be supportive to the donor team as most parents cite altruistic motivation for donating, but has the team truly obtained informed consent? Was this informed consent a true demonstration of an autonomous decision? On the other hand, if a family member claims to fully understand the risks and is willing to donate, what would be the reason to stand in that person's way?[16] It has also been suggested that if the parent acknowledges the probability of success and that donation carries a risk of harm, the consent that comes from deep affection and concern could be considered valid.[14] Although the parent-infant relationship is inherently coercive, it may be possible for parents to give true informed consent for living donation.[11]

Autonomy

Autonomy is the ethical principle of living life free from control, interference, or limitations imposed by another person. Is a donor team capable of examining presence of autonomy in a parental donor? Informed consent and the right to self-determination are evaluated by donor teams with respect to the rules of informed and voluntary consent.[13] Innately in the situation of having a sick child, the parent's life is not free from interference and the parent's decision making has limitations. It isn't often that parents who are exploring living donation can make the decision on the basis of a personal choice. They are also responsible for the child, which is a controlling influence for the parent. If the child is getting sicker, pressure on the donor is greater. If parents feel that they cannot say no, is their decision a voluntary one?[16] In these cases, continued solicitation of the parent to donate qualifies as "forced choice," disrupting the parent's autonomy; however, the principle of paternalism can be examined here, which is ethically acceptable.[17]

Although parents may feel coercion and obligation to donate to their child from outside influences, a truly autonomous decision cannot be made without an accumulation of thoughts, opinions, and experiences from those around them. To obtain full autonomy, a person does not have to be completely free from outside influence. Given the involvement of health care providers, family members, and sometimes the patient, parents may still feel that they are making the decision to donate autonomously but they may truly not be fully autonomous.

Although parents have avenues to explore their autonomy in this decision, the child may not be a part of that choice. If a person can be considered autonomous without complete understanding of the situation, then this principle should be applied to the child. The United Nations, in its Convention on the Rights of the Child, recognizes that every child has a right to self-determination, dignity, respect, noninterference, and the right to make informed decisions.[9] Children of a certain age undoubtedly can understand that their mother or father is going to have a surgery to save them. Children could also recognize medical risk for their parent when put in appropriate terms. If a child does not want his/her mother or father to accept risk though saving his/her life, would the parent then choose not to donate?

Autonomous action is a variable ethical principle with different levels, thus a child can exhibit certain degrees of autonomy. Can children be given the right to decide for themselves if they are found competent to participate in their own medical decisions? Advances in pediatric practice include involving children in decisions that affect their lives.[18] Respecting the autonomy of the child is important when an undesirable

outcome is possible. How can a child emotionally sustain the guilt of their parent dying to save them? Will the siblings of the child be able to remove blame from the patient for the loss of their parent?

Nonmaleficence

The principle of nonmaleficence declares obligation for people to not cause harm. Although a liver transplant donor team provides a comprehensive workup for donors to determine lack of risk and harm, little has been published about psychological harm, financial harm, and social harm that may become a part of the potential donor's life no matter if they donated or not. Overall, the option of living donation for a family is provided by transplant teams with intent to do good, and future harm that does occur would be unintentional and without awareness on the part of the team that it would develop.

Parents asserting nonmaleficence in deciding to become a donor for their child are trying to eliminate pain and suffering, avoiding being offensive to those who "expect" them to donate, and trying to facilitate a better quality of life for their child. Although the donor team implements nonmaleficence in their care for a donor, ultimately the donor will experience pain, suffering that could be medical, psychological, or financial, and may feel responsible for worsening the child's life if transplant complications arise. Rejection of the organ may induce distress in the parent along with feelings of guilt. Death of the child from transplantation inevitably disrupts the family structure, which can have severe consequences such as divorce and stress on siblings. Financial disadvantages reported by donors inevitably affect the family unit as well.[19]

As discussed in the ethical principle of autonomy, children can understand nonmaleficence. A child may not want his/her parent's life disrupted further, which will also disrupt the rest of the family. The child may not want to accept the risk of harm to his/her parent or being the reason the parent's life changes for the worse. The child recipient can sense parental stress surrounding rejection of the organ or other complications, which the parent may feel more responsible for, given that it was his/her organ. This added stress could impede the child's ability to focus on his/her own health and getting better. Extreme stress after a transplantation confounded with feelings of guilt and shame, which are psychological risk factors, affects the overall long-term success of transplantation.[20]

Beneficence

Acting for the benefit of others, beneficence ensures that there is regard to a greater balance of benefit than harm. This ethical principle may sum up the reason behind parental choice to donate. Parents feel the moral obligation to act in the most beneficial way to their child. Speaking to donation, this principle allows parents to defend the right of their child, prevent further harm from liver failure, and remove the source of the harm by providing a healthy liver segment. Donation is the ultimate way for parents to rescue their child who is in danger.

Beneficence plays a large role in the donor team and may be one of the ethical principles that supported the inception of live liver donation. By providing the option of live donation, the donor team is providing a way for a parent to act benevolent. Often parents have no control over the progression of their child's illness, except through seeking the best possible care for their child. Providing a portion of their liver to their dying child is a way they can feel completely protective and helpful. The living donor option benefits society as a whole because it increases the pool of organs available for recipients.[17]

Although beneficence may be deemed a positive influence for the donor team and parent, who is determining whether beneficence is outweighing doing harm to the parent? Is it possible that benevolence can be misidentified? Possibly, the parent's choice to donate really was a result of feeling an "inescapable necessity."[21] Also, where does beneficence rear itself in defending parents who choose not to donate or feel like they have no choice? A consequence of beneficence can be ending up with nonbenevolent results.

Patients may understand their parent's benevolence but again, patients' ability to aver this ethical principle for themselves may not be noted. As parents want to defend and protect their child, the child may feel required to do the same for the parent. Children understand the strain that their long-term illness has on the family, and they may not want that to continue.

Justice

In recounting the ethical principle of justice, the ideas of righteousness, fairness, equity, and appropriate treatment owed to a person are described. Parents using justice to determine if they will donate a portion of their liver to their child would show no dissention in the decision. There would be no argument because parents see this as what is owed to their child, sustaining life. The donor team's clearance of all donors would be much less involved because clearing these donors is the fair and appropriate thing to do. In distributive justice, the team is providing decent care to the donor and the potential recipient as well as fairly disbursing their resources.

Looking at justice from another perspective, however, reveals that you are making the same relative contribution to goodness as well as making the same relative sacrifice.[22] In this case, an individual cannot be forced to donate an organ to another to save that person's life, even if the potential recipient is the person's

child.[1] Parents have the right to refuse an invasive surgical procedure even though it may benefit their child. Donor surgery does pose some risk to the health of the donor and the welfare of the family; therefore, a parent who recognizes this risk and chooses not to donate cannot be treated with disrespect.

Application of justice to the input of children in receiving a portion of their parent's liver is necessary as it is what is fair and appropriate. The child, whose parent may not want to donate, can argue through justice that his/her parent should donate as a standard of rightness. Compounding this issue are supportive data in research that define an immunological advantage of living-related transplantation in children, who have a significant reduction in rejection 1 year after transplant and the ability to reduce immunosuppression.[23,24] Bourdeaux et al[25] indicate that published reports are contradictory as far as immunological advantages and do not show a clear advantage for patient survival for living-related transplantation. Bourdeaux et al do, however, cite additional benefits including better outcomes in children younger than 2 years of age and lower rates of hepatic artery thrombosis.

Although it may be considered unjust to give a dying child special treatment over the parent's life, it is also unfair that the child is being punished by his/her worsening liver failure, over which they have no control. If indeed a parental graft has an immunological and technical advantage, then one would be able to argue more strongly in favor of having the child receive a living-related transplant.

Impact of Choice

Fundamental principles of medical ethics include autonomy, beneficence, nonmaleficence, and justice. Making ethical decisions using good ethical reasoning is not always straightforward, especially in cases of obtaining informed consent. The field of organ transplantation has many ethical quandaries. Children with liver failure face certain death without transplantation. The intense pressure put on parents who are offered living donation for their child is not unnoticed. As a result, for the purpose of any living donor, in the United States, it is a federal requirement for living donor teams to have either a donor advocate or a donor advocate team.

Parents must be clearly offered the option of living-related transplantation with regard to fundamental principles of medical ethics. In cases where parents may not be making the right decision for themselves to save their child, the donor team must be willing to apply their ethical practice standards to protect the parent. A parent who does not wish to donate must continue to be treated justly and respected by the donor and recipient transplant teams.

Children's involvement in the choices available surrounding their transplant is their right. The child's life, after all, is what is directly affected by the choice. A member of the pediatric transplant team must be willing to explore with the children their thoughts and beliefs surrounding live donor transplantation in regard to ethical principles. In cases where children are unable to provide input, an advocate on the transplant team must include ethical considerations on behalf of the recipient. In the case of live donation, medical decisions must be directed to both the child and the donor independently. Given the lack of clear separation of ties between the donor, the recipient, and the final decision, the transplant team must be certain of their personal ethical views if they want to obtain the best outcome for both the parent and the child.

Financial Disclosures

None reported.

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Continued on page 191

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