THE STUDENT VOICE

The Ethics of Organ Donation in Patients Who Lack the Capacity for Decision Making

Lauren Lee, DNP(c), MSN, MPA, FNP-C, RN

Free and informed consent is the legal and ethical basis for organ donation from living donors, and is a requirement for making an autonomous health decision. In clinical practice, health-care providers are required to respect four bioethical principles: respect for autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2012), with the best interest of their patients in mind. Yet there are bioethical concerns behind organ procurement from living donors who have never attained capacity, do not yet have the capacity, or have permanently lost the capacity for decision making. A consensus statement by the Live Organ Donor Consensus Group (Abecassis et al., 2000) protects these donors' well-being and autonomy, but there still is a need to raise ethical awareness about the decision-making process regarding vulnerable potential donors. Health-care providers who are staff members in transplant clinics should be aware of the current consensus statement, commit to essential bioethical principles surrounding organ donation, and advocate for vulnerable living donors.

Keywords: bioethical principles; organ donation; vulnerable donors; ethical awareness; autonomy; substituted judgment

Organ transplantation from one person to another has challenged medicine since the first cornea transplant was performed in 1906 (Organdonor.gov, n.d.). Recently, the demand for organ transplantation has exceeded the supply in the United States. As of April 2018, America has more than 114,925 people who are on the waiting list for a new kidney, liver, heart, or lungs (Organ Procurement and Transplantation Network [OPTN], 2018a). The total number of transplants performed in 2017 was 34,768, with living donors as the source of 6,181 organ transplants (OPTN, 2018b). From 1988 to 2018, data on transplants in the United States showed that 67% of recipients were between the ages of 35 and 64; 57% and 43% of organs have come from deceased and living donors, respectively. Of living donors, 62% were women and 38% were men. As of May 2018, individuals on the national waiting list were 42% White, 29% African American, 19% Hispanic/Latino, and 10% Asian, Native Hawaiian, and other Pacific Islander (OPTN, 2018c).

The option of procuring organs from living donors offers the best temporary solution to the organ shortage problem (Testa & Siegler, 2014). One reason is

Lauren Lee, DNP(c), MSN, MPA, FNP-C, RN, is a nurse clinician at Columbia University Medical Center in New York City, New York.

recipients' high survival rates from unrelated living donors (Kher & Mandelbrot, 2012). This demand for living donors drives consideration as donors of people who cannot consent to the donation.

BIOETHICAL ISSUES

The gold standard of health care mandates health-care providers to uphold bioethical principles of respect for autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2012). It is providers' primary duty to maintain patients' best interests by respecting their autonomy (including facilitating informed consent), avoiding harm (non-maleficence), providing medical benefit (beneficence), and practicing in such a way as to ensure justice.

Informed consent is the legal and ethical basis for organ donation from a living donor, and is a requirement for honoring an autonomous health decision (Gordon, 2012). To protect live donors' well-being and autonomy, the Live Organ Donor Consensus Group and the assembled representatives of the transplant community developed a consensus statement to protect living organ donors (Abecassis et al., 2000). It states that the potential living donors should be "competent, willing to donate, free from coercion, medically and psychosocially suitable" (p. 2919). The overall goal of the consensus statement is to ensure that the "welfare of potential and actual donors remains preeminent in the process of live organ donation" (p. 2919). Yet there are still bioethical concerns surrounding living organ procurement from particular people who have never attained capacity, do not yet have the capacity, or have permanently lost capacity for decision making. It is misleading to call these people donors, if they do not have the ability to express their intention to donate (Broeckx, 2013).

Van Assche, Genicot, and Sterckx (2014) emphasize that organ donation by living donors relies on an important balance between respect for donors' autonomy and their voluntary will to help people who are in need of organ transplantation. Such a process requires expression of the donors' determined will after they receive thorough information about what procedures they are undergoing, and how these procedures will impact their future lives. If the organ is to be taken from a vulnerable donor who cannot consent, the balance is lost and numerous ethical problems arise.

In the medical field, the tests used to declare an individual's decisional competency include the Roth, Meisel & Litz Formulation, the President's Commission Study, the Sliding Scale Model, and the MacArthur Treatment (Weyrauch, 2013). Since competency calls many factors into question, especially "patient self-determination, autonomy, and beneficence" (Weyrauch, 2013, p. 766), such tests can be used to determine the decision-making capacity of patients. When patients are "unable to properly exercise certain individual rights and legal prerogatives due to mental incapacity," they can be legally defined as "incompetent" (Weyrauch, 2013, p. 766). Examples of individuals who have been deemed decisionally incapacitated include minors, and those diagnosed with schizophrenia, dementia, or severe intellectual disabilities (Public Legal Education and Information Service of New Brunswick, 2015, p. 3; Weyrauch, 2013). By definition, then, mentally incapable individuals are considered unable to exercise autonomy with regard to medical decisions.

The option of procuring organs from living donors offers the best temporary solution to the organ shortage problem; this demand for living donors drives consideration as donors of people who cannot consent to the donation.

REVIEW OF SELECTED CASES

In the United States, in the years after donation of organs by living donors became prevalent but before the publication of the consensus statement from the Live Organ Donor Consensus Group, courts gave varied answers to requests to obtain organ donation from patients who could not consent. The court cases reviewed in this section are historical examples involving vulnerable donors who could not express their thoughts or decisions about organ donation due to biological challenges.

In “Strunk v Strunk (445 S.W.2d 145, 1969),” a state court in Kentucky allowed physicians to remove a kidney from a 27-year-old donor who had an approximate I.Q. of 35 and a mental age of 6 years old, to donate to his older brother (Hall, Orentlicher, Bobinski, Bagley, & Cohen, 2018). Similarly, in “Little v Little (576 S.W.2d 493, 1979),” the Fourth District Court of San Antonio, Texas stated that it would grant permission for organ transplantation to the recipient, who was not in mortal danger but had a prognosis of the need for lifelong kidney dialysis. In this case, the donor was a 14-years-old with Trisomy 21. In these two cases, the courts used the Substituted Judgment Standard (SJS) to decide whether the donor would benefit from organ donation. The SJS allowed family members to act as surrogates and “decide as the patient would have decided, if only he or she had been competent” (Broström, 2007, p. 5).

On the other hand, in “Lausier v Pescinski (i 67 Wis.2d 4, 1975),” the Wisconsin Supreme Court denied a family’s request to transplant a kidney from a donor with a diagnosis of catatonic schizophrenia to his sister. Because the symptoms of catatonic schizophrenia resulted in emotional withdrawal from the world, the court deemed the donor unable to benefit psychologically from donating an organ to his sister (Friedman, 2000). In this case, the court acknowledged the donor’s right to autonomy and applied the principles of beneficence, non-maleficence, and justice to support the decision of denying the organ transplantation.

ANALYSIS

Organ donation policy in the United States must balance respect for potential donors with the goal of helping the population in need of organ donation. In seeking and receiving legal permission for organ donation, courts and surrogate decision makers need to weigh the harm that organ donation could do to a donor against the benefit to a recipient. Mentally incapacitated donors are prevented from grasping the full consequences of organ donation. In other words, they are unable to have the will to either donate or not donate their living organs. If surrogates make decisions for these individuals, there is an inherent invasion of donors’ autonomy and voluntary will to donate organs, which can in turn interfere with maintaining their right to non-maleficence, beneficence, and justice. The following section will examine the medical information donors need to understand, possible conflicts that health-care providers who are working in transplant clinics could encounter, and the importance of education provided to surrogates about organ donation.

On the donor’s side, health professionals, courts, and families must consider potential future clinical complications a donor might face, and the risk of mortality associated with organ donation surgery itself. The risk of mortality from kidney removal is estimated to be 0.031% (Van Assche et al., 2014). Kidney donation comes

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with a lifelong commitment to potential medical treatments as a consequence of losing an organ that otherwise would be present. There is a need to monitor for complications such as hypertension, proteinuria, renal failure possibly needing dialysis and/or transplantation, psychological sequelae such as depression or resentment, or even death (Kher & Mandelbrot, 2012). Thus, it is crucial for donors to comprehend the existence of possible long-term health consequences related to organ procurement. Despite the presence of organizations that provide information regarding risks involved in organ donation, vulnerable donors may be unable to understand these risks well enough to make well-informed, autonomous medical decisions.

Another ethical issue arises when a surrogate decision maker appears not to be acting in a donor's best interests. Indeed, "surrogate decision makers may be guided by their own opinions and judgments" (Van Assche et al., 2014, p. 7). Surrogates might value the recipient more than a vulnerable donor, believing that the recipient has more hope of independently succeeding in society. In the previously discussed Lausier vs Pescinski case, the potential donor (a brother of a terminally ill patient in renal failure) was determined to have a mental age of 12, and had expressed no consent to the transplant. Consequently, the Wisconsin court decided that "there is no statutory authority given the county court to authorize a kidney transplant or any other surgical procedure on a living person" (Altschuler, Sgroi, & Ryniker, 2010, p. 442). Without the protection of the court (since the consensus statement from the Live Organ Donor Consensus Group was 25 years in the future), the vulnerable brother may have undergone a painful, risky procedure with potential long-term health consequences, purely for the medical benefit of his competent sister.

CONCLUSION

To facilitate the well-being of live organ donors, the informed consent process must keep donors' best interests as of primary importance. Nurse clinicians who practice in transplant clinics should be knowledgeable about the 2000 Live Organ Donor Consensus Group's statement, commit to the essential bioethical principles surrounding organ donation, and advocate for vulnerable people who are being considered as potential living donors. These experts should work toward promoting the ethical rights of people with compromised autonomy, by getting involved in educational discussions in social media and local communities. Overall, such collective efforts will help to carry out our responsibility to protect vulnerable patients from harm.

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