The Ethics of Autonomous Decision Making in Organ Donation

Jillian Milano

Sacred Heart University

Abstract

Organ donation is a process that is necessary when one or more of a person's vital organs are failing or are not functioning to the extent that the person is severely ill or dying because of the organ's function. This can happen due to autoimmune diseases, hypertension, diabetes, or other medical conditions that a person may have. In order for an organ to be transplanted from the donor to the recipient, several criteria must be evaluated; this criterion includes but is not limited to blood type, size of organ needed, tissue matching, distance between the donor and recipient, and medical urgency for the recipient (UNOS Staff, 2020). There are different types of organ donation, which include living organ donation and donation after death, and the organs that can be considered for donation depends on whether or not the donor is living or deceased. In order for a person to donate their organs, they must consent to doing so; in the United States, a person can consent to becoming an organ donor by checking a box on their registration forms when getting their driver's license. In order for a person to register as an organ donor, they must be making the decision on their own without the influence or pressure from others; additionally, they must be of sound mind when making this decision. These attributes encompass the ability to make an autonomous decision, which is required for registration as an organ donor. In some cases of organ donation, most especially in donation after death, there has been controversy over whether or not the donor's decision to donate their organs should be respected or disregarded. This controversy becomes apparent many times when the family of a potential donor does not want their family member's organs to be donated. However, autonomy should be respected in those who want to be or who are registered as an organ donor, and in situations where autonomy cannot be respected, then the beneficence and nonmaleficence for the greater good should be considered and respected in its place.

Defining Autonomy, Valid Informed Consent, and Organ Donation

The most basic definition of autonomy from philosophical ethics is a person's rational capacity for self-governance or self-determination (Vaughn, 2006, p. 9). This means that a person is autonomous if they are of sound mind and are able to make decisions for himself or herself. For philosopher John Stuart Mill, he expands on it, believing that a person is autonomous if he or she directs his or her actions in such a way that they align with his or her own values, desires and inclinations (Taylor, 2014). In order for a person to make an autonomous decision, they must not be influenced by the views and beliefs of others. Differing from the beliefs of Immanuel Kant, Mills believes that a person can be autonomous and still have their decision be motivated by their desires; the only requirement is that their desires be desires of their own, and not the desires of others (Taylor, 2014). Autonomy in respect to organ donation requires that a person, prior to their death, makes the autonomous decision to become an organ donor through the organ registry, indicating so on their driver's license, or by expressing so to their family members and friends.

Informed consent is when information regarding the process and procedures for any intervention that a patient has in order for the patient to fully understand what the procedure is and what it entails. Informed consent is used "to help protect patients' autonomy and right to self-determination" (Iltis, 2015). Informed consent can only be provided when relevant information is enclosed to the patient, when the information is given to the patient who is making the decision and has the decisional capacity to do so, when the information is provided in a language that the person can understand fully and under circumstances that allow them to made the decision and communicate a free and voluntary informed consent based on the information provided to him or her (Iltis, 2015).

Organ donation is when organs or tissues are transplanted from a donor to a recipient and can be done as a living or deceased donation. In organ donation, the tissues, blood types, antibodies, height and weight of donor patients are cross-referenced with recipient patients, either after the donor patient has died or if a living patient has volunteered to do so. If the cross-referencing of tissues matches a donor patient with a recipient patient, then the organ can be transplanted to the recipient (UNOS Staff, 2020).

Types of Organ Donation

There are four main types of organ donation: living donation, deceased donation, Vascularized Composite Allografts (VCA), and pediatric donation (Donate Life Staff, 2020). This paper will focus on living and deceased donation and the decision making capacity of a person deciding to become a donor. Living organ donation is when a living donor donates their organs to a recipient and is not covered by a registration as an organ donor; it must be explicitly communicated with a transplant center or transplant hospital (Donate Life Staff, 2020). In order to be a living donor, informed consent is required from the potential donor (Lee, 2018). Living donation can be direct, non-direct or paired; in direct donation, the donor specifically names the recipient, such as a biological relative or person of close social connection; in non-direct donation, the donor is not related to or known by the recipient; in paired donation, which is traditionally done with kidney transplants, two pairs of living kidney donors and transplant candidates who are not able to donate to one another "trade" donors so that each candidate can receive a kidney (Donate Life Staff, 2020). Additional types of living donation include biological (where the donation occurs between two genetically related individuals) and emotionally related (such as between a husband and wife) (Walton-moss, Taylor & Nolan, 2005). In non-directed organ donation, the living donor is doing so without hopes to seek any psychological or

monetary benefit from doing so (Walton-moss, Taylor & Nolan, 2005). Organs that are eligible for living donation include one kidney, the third lobe of the right lung, and a portion of the liver, pancreas and intestines (Donate Life Staff, 2020).

Deceased donation occurs at the time of the organ donor's death. In order to be considered a viable donor according to Donate Life America, a nonprofit organization that works to increase the number of registered organ donors, the potential donor must have died due to fatal brain injury, such as bleeding, swelling or lack of oxygen to the brain (Donate Life Staff, 2020). However, there have been arguments that a person can be eligible for non-heart-beating organ donation after cardiopulmonary death as long as a person dies in accordance to the Uniform Declaration of Death Act (UDDA) (DuBois, 1999). Deceased donation, regardless of whether it is brain death or cardiopulmonary death, is not considered until all efforts to save the patient's life have been performed (Donate Life Staff, 2020). Once death has occurred, the potential donor's information is put into state and national organ donation registries to determine if they have personally authorized organ donation; if they are not found there, the decision to use the person as an organ donor is made based on any advanced directives that can be found or from the authorization of the potential donor's next of kin (Donate Life Staff, 2020). If there is no authorization for donation, then the potential donor's organs cannot be donated. Organs that can be donated in deceased donation include heart, lungs, liver, kidneys, pancreas, intestines, bones, tendons, and valves (UNOS Staff, 2020).

There is another form of organ donation that is not regulated by the United Network of Organ Sharing, otherwise known as UNOS, is a voluntary, nonprofit organization known as Life-Sharers. Life-Sharers is an organization in which people can register to be an organ donor and "promise to donate their organs upon their death, and they give fellow members first access to

their organs" (Bramstedt, 2006). This organization allows for those who are registered as an organ donor to have priority over those who are not registered as organ donors should they need an organ at any point in their life, should the organ be a match for them. This organization is not regulated by UNOS and does not practice ethically; by allowing prioritization of organ allocation to those who are registered as organ donors, it is not preventing harm, otherwise known as nonmaleficence, or actively promoting good to others, also known as beneficence, (Vaughn, 2006, p. 10), thus violating these ethical principles. Though these donors are autonomously making the decision to become organ donors, they are not allowing those who have autoimmune diseases or cancer, who may need an organ transplant and cannot register as an organ donor, from receiving the organ(s) they need to survive.

Becoming an Organ Donor

If a resident of the United States wishes to become an organ donor, they can do so by registering at the Department of Motor Vehicles when they take the test for their learner's permit or driver's license. This is possible due to a partnership that the Department of Motor Vehicles has with Donate Life in creating Driver's License Partners (Donate Life Staff, 2020). In doing this, a red heart will appear on his or her learner's permit or driver's license signifying that he or she is an organ donor. This partnership has allowed more than 150 million people to register as deceased organ, eye and tissue donors (Donate Life Staff, 2020). However, designation on a driver's license is not a form of valid informed consent; rather it is a form of authorization that is treated as an advance directive or a deep desire by the person by some healthcare professionals (Iltis, 2015).

Additionally, a person can register to become an organ donor through a registry with organizations such as Donate Life America or a Donate Life office at the state level (Donate Life

Staff, 2020) as well as by registering to become a living donor with a transplant center or hospital. In order to become an organ donor, the potential donor must provide valid informed consent as this protects the patient's autonomy and right to self-determination and ensures that they are not being coerced into making a decision that they do not want to (Iltis, 2015). Informed consent must be provided because, as Ana Iltis writes in her article *Organ Donation, Brain Death and the Family: Valid Informed Consent*, "it is plausible that people have a desire to donate but would change that desire if they had more information about the implications for their end of life care" (2015), which includes pre-mortem examinations and tests (Iltis, 2015).

Determining Organ Donation

A patient is in need of an organ transplant when they have a medical condition that causes one or more of their vital organs to fail (UNOS Staff, 2020). In an organ transplant, a functioning organ that has been donated by either a living or deceased donor is surgically put in place of the organ that has either minimal function or has stopped functioning to relieve the symptoms of the organ failure.

In order for an organ from a living or deceased donor to be allocated to the recipient, the potential donor and recipient must undergo medical and logistical examinations in order to determine whether or not the two are compatible. Criterion that are taken into consideration includes blood type, size of organ needed, distance between the potential donor and recipient, medical urgency, time spent waiting for the transplant, antibodies of each patient, and tissue matching (UNOS Staff, 2020). All of these criteria must match in order for the transplant to ensue.

Respecting Autonomy

If a person decides to become an organ donor, their decision must be respected as long as the person is of sound mind and is able to make an autonomous decision and as long as the decision was made based on the donor's deliberations and without coercion or manipulation (Gillon, 1985). It is not uncommon for the family of a registered deceased donor to challenge the autonomy or decision made by the donor. There are many cases where an organ donor's family does not wish for their loved one's organs to be donated after their death, even when their loved one is a registered organ donor or expressed their desire to be an organ donor (Shaw, 2017). It is my belief that in cases like this, the wishes of the family should not be granted when the deceased is a registered organ donor because that would be violating the autonomy of the patient. In regard to deceased organ donation, the respect for autonomy refers not to the autonomy of the dead and that family members or medical proxies should be making decision for the patient; the respect for autonomy refers to the autonomy of the living in the decisions that they made about their bodies after death (Sharif & Moorlock, 2017). If a patient wishes to be an organ donor after their death and their family prevents that from happening, they are violating that person's autonomy and are not respecting the decisions that their family member made prior to their death.

Though family can sometimes attempt to inhibit the donation of their loved one's organs, they can also be consulted to find out more information about what the patient's wishes were; relatives will typically have a more up to date perspective on the wishes of their family members (Sharif & Moorlock, 2018). It is important to establish what the most up to date wishes of the patient are as some patients change their mind about whether or not they want to be an organ donor but do not notify the registry of their change in mind.

Living Donation is Ethically Sound

Though it is only now on the rise, living organ donations can provide more recipients with life-saving organs quicker than if they were to wait for a donation from a deceased donor. Living donation practices three different forms of ethics; autonomy, beneficence and nonmaleficence. A person must make the autonomous decision to become an organ donor and must outwardly express the desire to become a living organ donor to a transplant organization or hospital; their registration as an organ donor with UNOS or Donate Life does not take effect until the donor is deceased. In many cases, living donors have a relationship to the patient that they are donating to, such as the friend of, sibling to or spouse of the recipient. When this occurs, the patient typically gets some sort of emotional benefit from the act of donating their organ and is practicing nonmaleficence.

When a family gets a diagnosis that requires an organ transplant, such as end stage renal failure, it is typical that every family member and friend of the person in need would get testing to see if they are a match for their family member. This is a form of nonmaleficence, which is to "first do no harm" (Walton-Moss, Taylor & Nolan, 2005); those who care about the patient are trying to do no harm to their loved one and give them the organ that they need. Some would argue that being a living donor is a violation of nonmaleficence due to the risk of harm to the donor that is included in the donation process; however, if the patient were to not donate their organ, the recipient is at risk for death, which is the ultimate harm to a person.

The living donor also practices beneficence, which is "the obligation to act in the best interests of the individual" (Walton-Moss, Taylor & Nolan, 2005). Though it is controversial how the organ procurement is acting within the best interest of the living donor, it is their

decision to make the donation as well as to put the beneficence of the recipient ahead of their own.

Donation After Cardiopulmonary Death

Many believe that it is not ethically permissible to perform organ recovery on patients who have not yet been pronounced brain dead (DuBois, 1999). Loss of brain function has been the determinant for death due to the fact that brain function cannot be replaced by mechanical functions. Some would argue that loss of circulatory and respiratory function, even if there is brain function, can be classified as death. However, it can be argued that irreversible loss of brain function is essential for determining death as it is detrimental and there is no recovering from that, whereas the loss of respiratory function can be replaced by a mechanical ventilator and loss of cardiac function can be mechanically replaced as well; the loss of circulatory and respiratory functions cannot guarantee a state of death (DuBois, 1999). While the brain provides personality, character and the decisional functional ability of a person, cardiopulmonary functions, though they can be provided for the patient artificially, "are essential to preserving 'integrative unity'" (DuBois, 1999). If a person is in a comatose state, where a ventilator is mechanically breathing for the patient and their heart is not pumping on its own, but the patient has brain function, they will not be able to live a life that is independent or that has great value of life if they wake up because they will not be independently perform actions, not to mention the negative effects that it will have on the patients psychosocial life.

Patients should be allowed to donate their organs after irreversible loss of cardiopulmonary function because that is still an irreversible loss of function that would cause the patient to be dependent on assistive devices for the remainder of his or her life. With determining death by using brain death, it most likely results in patients having to suffer severe

brain trauma, such as bleeding, swelling or lack of oxygen to the brain; by allowing donation after cardiopulmonary death, it allows many more patients to be considered for organ donation.

Anencephalic Organ Donation

An ethical dilemma occurs in the cases or organ donation from anencephalic infants. An anencephalic infant is an infant who is born with the absence of the cerebral hemispheres and a large part of the skull missing. However, though there is not a fully formed brain stem, most anencephalic infants are born with some level of brain stem function, though it slight (Botkin, 1988). This condition is fatal, and infants perish within a short period of time after birth. Since this condition is fatal, some parents wish to donate their infant's organs to those who need. However, many physicians do not feel comfortable with the use of anencephalic infants as organ donors due to the inability for an anencephalic infant to meet the criteria for brain death (Botkin, 1988). Since organ retrieval must occur while there is still blood and oxygen perfusing through the organs to ensure their viability, it would require that an anencephalic infant's organs be removed prior to the determination of death (Botkin, 1988), which can be seen by some physicians as effectively killing the infant.

However, "the Uniform Determination of Death Act defines death as (1) the irreversible cessation of circulatory and respiratory function or (2) the irreversible cessation of all functions of the entire brain, including the brainstem" (DuBois, 1999). An organ donor, based on these standards, can be any person as long as they die according to the UDDA classifications of death. Through this definition of death, an anencephalic infant's parents can choose to donate their child's organs in order to save the lives of other infants and children.

It would be ethically permissible for the parents of an anencephalic infant to choose to donate the infant's organs as this would be providing beneficence and nonmaleficence for those

who are in need of organ transplants (Powers, Schultz & Jackson, 2015). It is important that parents of an anencephalic infant are educated on what will happen and make the decision, not when they are in an emotional state, but over time and with the help and support of those close to them.

Legally Incompetent

In cases where the potential living donor patient is not of sound mind or competence to make the decision, the beneficence of both the donor and recipient should be respected and evaluated in the place of an autonomous decision. There are many people who are not deemed to be competent to make an autonomous decision; this includes minors and those with severe intellectual disabilities or mental health diagnoses, including schizophrenia and dementia (Lee, 2018). However, there are cases where these people still want to donate their organs to those in need, and judicial courts have given varying answers for cases where the potential donor is not considered legally competent to consent to the procedure (Lee, 2018). In cases like such, courts have used the Substituted Judgement Standard, otherwise known as the SJS, to allow a family member to act as a surrogate decision maker and to make the decision as the patient would have decided, had the person been competent or of sound mind (Lee, 2018); if there is no family member to act as a surrogate decision maker, a health care provider or lawyer can also act as a medical proxy to make decisions for the patient on their behalf.

Conclusion

Autonomy is the rational person's ability to make decisions, or self-govern, himself or herself; if a person is deemed to be legally competent and is not a minor nor is diagnosed with any mentally debilitating diagnoses. Organ donation can occur with either a living donor or a deceased donor; a living donor makes their wishes known to a transplant center or organization,

and a deceased donor registers as an organ donor with an organ registry or with the Department of Motor Vehicles, which alerts the organ registry organizations of the registration. In order to do this, the organ donor, either living or deceased, to provide autonomous, valid informed consent. This must and can only be provided when the patient is in a sound state of mind as well as after the patient is educated on the procedure, as well as what the preoperative and postoperative care and procedures entail. In cases where a potential organ donor is not deemed legally competent and is unable to make a sound and autonomous decision, a family member who knows the values and beliefs of the person in consideration can make the decision as a surrogate, and make the decision as the person would; in cases where this is not possible, a healthcare provider, lawyer or social worker can act as a medical proxy can make the decision for the person in question. In cases where it is ethically questionable as to whether or not a person should be allowed to donate organs, beneficence and nonmaleficence for both the donor and the recipient must be taken into consideration, and the decision must be made based on those outcomes. If the parent of an anencephalic infant wishes to donate their child's organs upon their death, that is ethically permissible as there is more benefit to doing so than harm. This also means that it is ethically sound for a person to donate their organs after the irreversible loss of cardiopulmonary function and not solely after the irreversible loss of brain function.

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