

**EFFECT OF ORGAN SHORTAGES ON PEDIATRIC ORGAN DONOR AND  
RECIPIENT SELECTION**

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By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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As the demand and necessity for organ transplants increase each year, organ shortages have become an increasingly pressing issue within medicine. The demand for organs heavily outweighs the supply, as over 100,000 patients needed a transplant in 2019, while less than 60% of the population were registered organ donors (Lewis et al, 2020, p. 2). Within pediatrics, there is little research on the rates of organ donation, but shortages have caused patients to have higher mortality risks and spend longer periods on the waitlist (Godown et. al, 2016, p. 1093).

The limited availability of organs for transplant has resulted in different processes and methods to be used to increase pediatric donations and allocations to recipients. To increase the usage of organs, premortem intervention methods that strengthen organs prior to the donor's death have been assessed and considered for use in order to increase the success of the transplant for the recipient (Brierley & Shaw, 2016, pp. 425-426). In addition, more transplant programs are obtaining pediatric organs from deaths not resulting from brain death (Lewis et al, 2020, p. 2). Some of these alternative methods have been criticized for being ethically unjust, arguing that the donor child's best interest is not taken into account (Brierley & Shaw, 2016, pp. 425-426). On the other hand, a lack of pediatric organ donors results in implicit bias and discrimination in determining pediatric transplant recipients (Statter & Noritz, 2020, p. 3). Children with disabilities are historically not considered for organ transplants (Statter & Noritz, 2020, p. 1), and nonwhite race and ethnicity are significant predictors in waitlist mortality (Almond et al, 2009, p. 719).

As organ shortages and underutilization continue to be an issue, it is imperative to identify the social groups involved and affected by the shortages and analyze the morality of the decision-making strategies for both organ donors and recipients. The purpose of the technical project is to conduct research and analysis on past heart donor and heart recipient data in order to

optimize donor heart matches and increase recipient survival post transplantation. The STS topic will examine the limited supply of organs and the role that affiliated social groups and ethics impact the overall pediatric donor and recipient selection process by using the Actor-Network Theory (ANT) framework, which was developed by Latour (1991), Callon (1986), and Law (1986). Together, the technical topic and the tightly coupled STS topic will address the uncertainty and ethical implications related to pediatric donors and recipients within the field of heart transplantation with the intent to inform future research within the field.

## **PEDIATRIC ORGAN SHORTAGES WITHIN THE ACTOR NETWORK THEORY ORGAN TRANSPLANT ACTORS**

Actor Network Theory (ANT) is an approach to analyzing the interconnection of technologies, referred to as artifacts, and their associated social groups, referred to as actors (Jolivet & Heiskanen, 2010, p. 6748). In this analysis, organ transplants are the artifact, and the main actors influenced by organ transplants are the donor and recipient social groups. Both the donor and recipient social groups divide into three separate sub-groups: the patient, the parents or guardians, and the entire medical staff that cares for and interacts with the patient. Figure 1 on page 3 provides a visual representation of the aforementioned Actor Network Theory of organ transplants and its connected social groups.

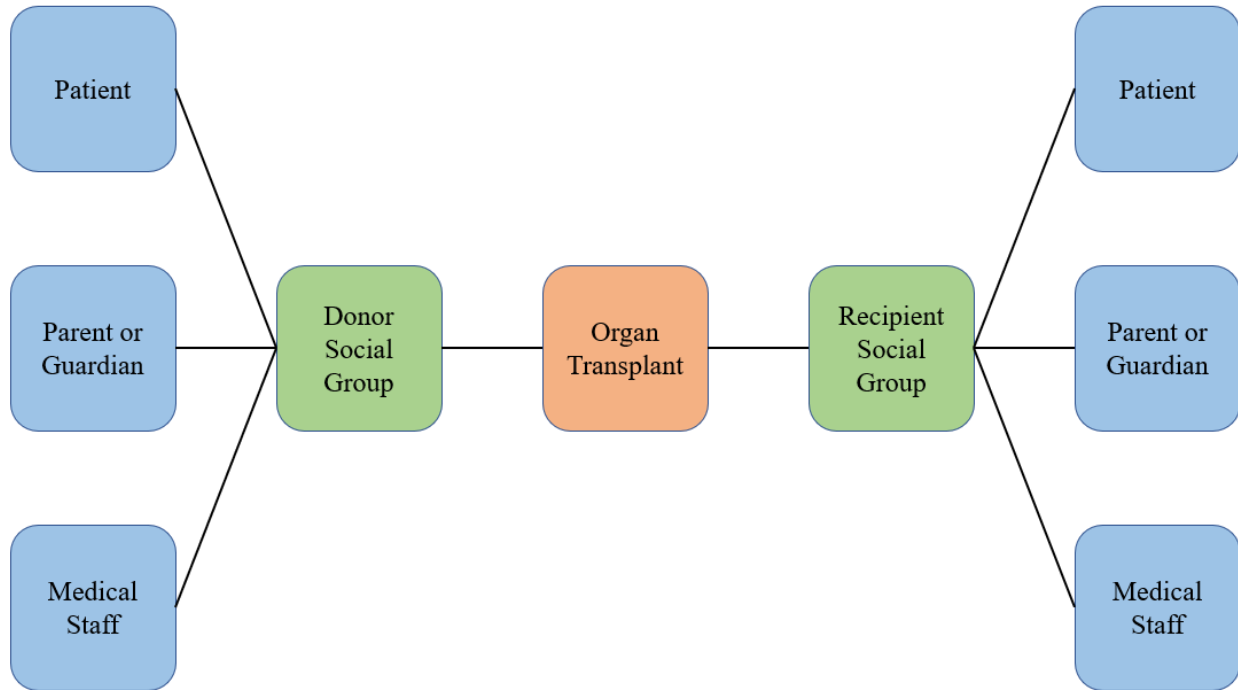


Figure 1: Organ Transplant Actor-Network Theory Diagram: The artifact, organ transplant, connects to two general social groups: donors and recipients. Each group includes the patient, parent or guardian of the patient, and the medical staff treating the patient (Wright, 2020).

## DONOR SOCIAL GROUPS

As shown below in Figure 2, the donor social groups are heavily impacted by the surge of increased efforts to raise organ donation rates within pediatrics (Lewis et. al, 2020, p.1). Some of the various implemented strategies have raised many ethical concerns within the medical community related to consent and the devaluing of the donor's health in order to save the recipient (Brierley & Shaw, 2016, p 427).

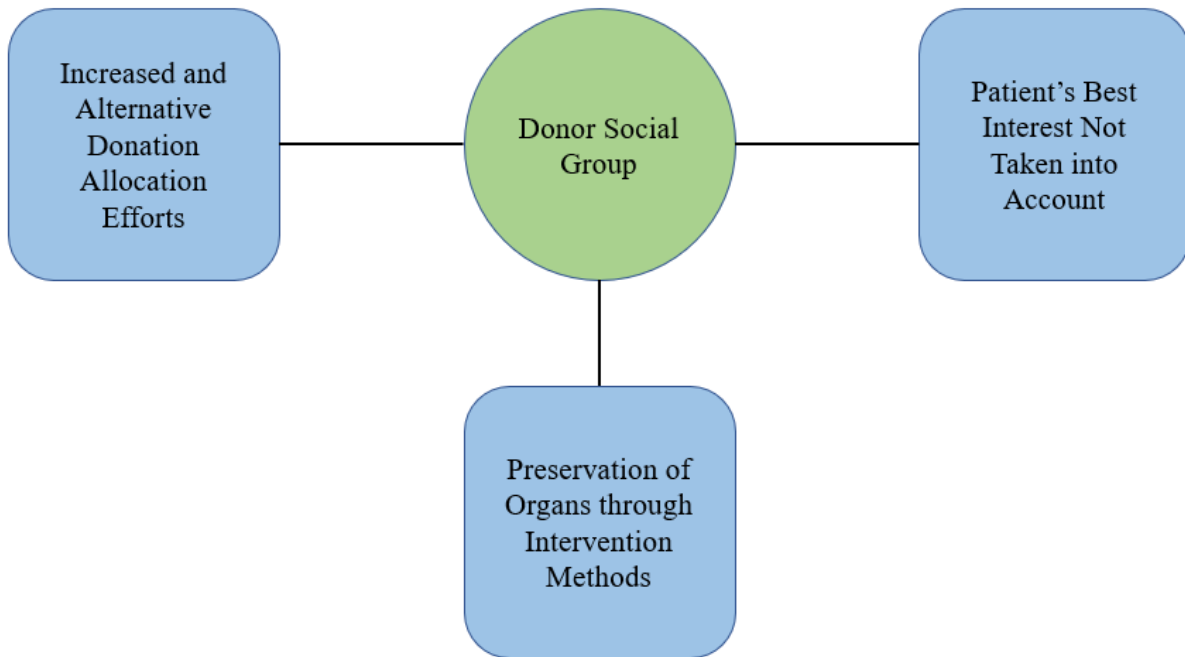


Figure 2: Organ Shortage Effect on Donor Social Groups: The lack of available organs has caused increased efforts to raise organ donation rates, the research of new technologies for organ preservation, and a lack of consideration of the child’s best interest (Wright, 2020).

**Medical Staff**

An influential member in the organ transplant process is the doctor, as they are responsible for accessing the patient’s condition and recommending whether the patient is suitable to be an organ donor (Ahmad et. al, 2019, p. 375). In the United States, when assessing a patient for organ donations after determination of death, doctors follow the dead donor rule (DDR), a policy developed to raise public trust in organ donations, which states that organ donors must be deceased before vital organs can be procured, and the organ donor’s death must not result because of organ procurement (Nikas et al., 2016, p. 239). While the dead donor rule is only “an ethical norm” that is followed in the medical community, all states have also legally adopted the Uniform Determination of Death Act (UDDA), which states that brain death and loss of circulatory and respiratory function are “valid criterion for death” (Nikas et al., 2016, pp. 237-238).

As the organ shortage increases nationally, both the Dead Donor Rule and the UDDA have been criticized for encouraging unethical organ procurements (Nikas et al., 2016, p. 239). The UDDA outlines that the determination of brain death should be completed “according to medical standards” (Nikas et al., 2016, p. 251). This ambiguous wording has led to extreme variability in evaluation methods and tests to determine brain death among states, hospitals, and individual doctors (Nikas et al., 2016, p. 251), and critics argue that brain death as described in the UDDA was defined with the intent to alleviate the organ shortage and increase vital organ transplants (Nikas et al., 2016, p. 249).

Due to the ambiguity and variability of brain and circulatory death assessments, trust in doctors’ methods for determining a patient’s death is decreasing (Nikas et al., 2016, p. 249). Some critics question the validity of a patient declared brain dead when they also have other active bodily functions. A survey from 2006 reported 25% of respondents worried that by declaring themselves as organ donors, doctors will not attempt to save or improve their health because of the increasing need for organs (Nikas et al., 2016, p.250).

The organ shortage has raised doubts of the true intentions of the rules and laws followed by the medical community as people believe that doctors and physicians may not be acting in their best interests, and instead are taking a utilitarian approach to obtain organs to save additional lives. The continued distrust in the medical community’s evaluation of donor patients has the potential to have significant effects on organ donation rates, as patients and their families are concerned about their overall medical care.

### **Parents and Guardians**

Parents and guardians play an important role in the ethical considerations related to consent and determining the best interest of their child (Brierley & Shaw, 2016, p. 426). In the majority

of cases, parents provide consent on behalf of their children to make organ donations, but in instances where the donor and recipient are siblings, critics express concern as to whether the parents can truly act in the best interest of both children (Zinner, 2004, p. 130). For example, many live kidney donations between siblings have been resolved in court due to concerns that “the minor donor does not receive any physical benefit from the surgery” (Kim, 2003, p. 240). While supporters of parents providing consent for sibling-to-sibling transplants believe that in general, most parents understand the values of their children and can arrive at the best decision (Zinner, 2004, p. 131), others disagree, arguing the difficulty of separating the best interests of both children and claiming that their focus on the benefits of the child receiving the donation may cause them to ignore the risks associated with the child donating (Zinner, 2004, p. 130).

As the demand for organs continues to be greater than the supply, parents may turn to more sibling-to-sibling transplants because of lack of availability through organ waitlists. This increase in sibling-to-sibling transplants due to a lack of available resources can cause ethical concerns, as parents unintentionally prioritize the improved health of their child in need of an organ over the potential risks and harms to the child donating.

## **Patient**

The methods in which organs are procured raise ethical concerns related to the donor patient. Most organ transplants result from procuring organs from a patient that is declared brain dead, but organ donations can also occur after circulatory death, which is when the patient has a “permanent loss of consciousness capacity and brainstem functioning” (Lewis et al, 2020, p.2). Donations after circulatory death (DCD) are very controversial, especially within pediatrics, as there is “uncertainty surrounding wait-time before declaring death after cessation of cardiac pulsation” (Ahmad et. al, 2019, p. 373). Coupled with the complexity of declaring death, organs

retrieved from circulatory death patients also have many limitations because of timing. As the time between organ extraction and completing the organ transplant increases, the possibility of health issues, such as an infection or rejection of the organ by the recipient, occurring due to the transplant increase as well (Brierley & Shaw, 2016, p.425). To alleviate this issue, doctors consider using premortem intervention methods on patients to strengthen and maintain the functioning of the potential donated organs (Brierley & Shaw, 2016, p. 424). One key criticism of using premortem intervention methods is that the donating child's best interest is not taken into account in the decision, as utilizing these methods could considerably harm or possibly cause an earlier death for the patient (Brierley & Shaw, 2016, p. 426). For example, Brierley and Shaw (2016) describe three intervention methods specifically: moving the patient's death location closer to the organ recipient or organ retrieval center, delaying or postponing the time of death until an ideal time to retrieve the organ, and improving the quality of organs to be donated by administering drugs and medicine to the organ donor. All three methods benefit the organ recipient; the first two methods result in a reduction of time between organ extraction and transplantation, and the last method allows the organ to be strengthened and preserved before being transplanted. However, all three examples present potential harmful health risks to the organ donor, as the focus is placed on improving the recipient's outcome rather than caring for the dying donor (Brierley & Shaw, 2016, p. 426).

Proponents of premortem intervention methods approach the idea with a utilitarian perspective (Brierley & Shaw, 2016, p. 427); they suggest that the ability to save multiple lives outweighs the possibility of losing one. From the perspective of needing to address the organ shortage, premortem intervention methods are considered useful, but the possibility of harming or exposing a life to risks, especially a child, to benefit another has strong unethical implications.



## RECIPIENT SOCIAL GROUPS

As shown below in Figure 3, the lack of available organs for pediatric patients is resulting in the implementation of alternative strategies to exclude or prioritize certain patients. These strategies have caused the organ receipt process to be more selective, as certain groups are given priority (Wightman & Freeman, 2020, p. 44) and in some cases, marginalized groups are excluded or not considered to receive organ donations for reasons such as race (Klass, 2020, para. 18) or disability (Statter & Noritz, 2020, p. 1).

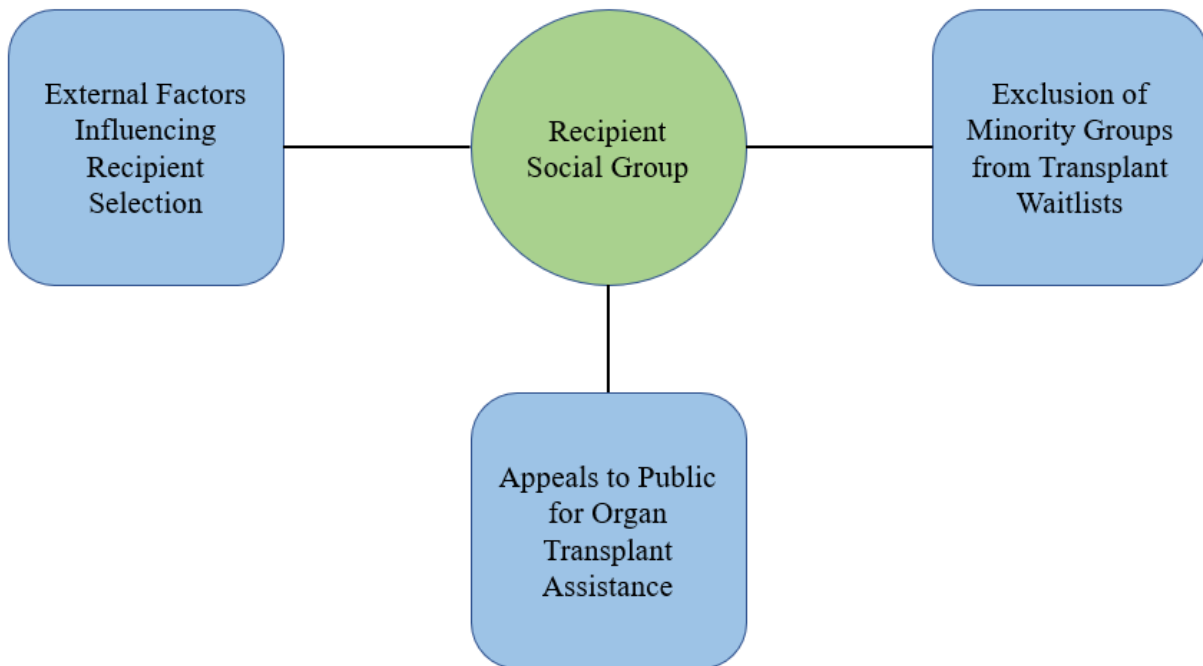


Figure 3: Organ Shortage Effect on Recipient Social Groups: The lack of available organs has caused additional factors to be considered for waitlist recipients, public appeals to obtain organ donations, and the exclusion of marginalized groups from organ transplants (Wright, 2020).

## Medical Staff

Nurses play a crucial role in determining patients that should be recommended to receive an organ transplant (Garcia, 2020, p. 119). Because they interact with patients on a daily basis, nurses are well aware of patients' physical health and can identify patients who would benefit

from receiving a transplant (Garcia, 2020, p. 124); however, in determining a patient to be an organ recipient, many factors not related to the recipient's physical state affect the decision, such as proximity to the donor and whether the patient has "the most time to gain from receiving an organ" (Garcia, 2020, p. 122). In many instances due to location, marginalized groups have less access to proper medical care, which has led to disproportionate diagnoses of medical conditions and delayed referrals for necessary medical care like transplants (Klass, 2020, paras. 14-15, 18). Additionally, whether a patient has a neurodevelopmental delay may influence the choice of recipients for organ transplantation, but has been shown to vary in weight of consideration among different transplant programs; a survey from 2009 reported that 43% of US transplant programs include neurodevelopmental delay as a factor in determining transplant eligibility while 39% of programs do not (Garcia, 2020, p. 123).

The inclusion of other factors outside of the patient's health status can lead to implicit biases influencing the decisions by nurses and the medical staff as to who is selected to an organ transplant waitlist, which can lead to the exclusion of patients who desperately need and deserve organ transplants. While there is already limited organ availability for patients on the waitlist, the exclusion of patients from even having the opportunity to receive an organ due to additional factors raises additional ethical concerns.

### **Parents and Guardians**

The lack of available organ donors and increasing long recipient waitlists have caused parents of waitlisted patients to take matters into their own hands. Some parents are creating emotional appeals through news and social media outlets to ask the public for help in ascertaining an organ for their child (Wightman & Freeman, 2020, p. 43). Parents of ill children generally feel an obligation and responsibility to find ways to provide for their child and fight for

their best interest, but critics question the morality and truthfulness of their actions (Wightman & Freeman, 2020, p. 4). While parents are acting in their child's best interest, public appeals abuse the "identified victim effect," a concept in which people are more likely to help a specifically identified person rather than just a general issue or problem (Wightman & Freeman, 2020, p. 43). In addition, this strategy to obtain organ donations raises ethical concerns, as some parents include partial or complete falsehoods in their stories to the public. This continued practice will also cause biases to occur, as people with the greatest means and privilege have the strongest ability to obtain access to organ donations (Wightman & Freeman, 2020, p. 44). As more public pleas gain media attention, the focus is shifted away from the organ shortage problem, and "challenges the legitimacy of the transplant system as a whole" by implying that the patient is "ethically special" and should receive special priority and treatment for their illness (Wightman & Freeman, 2020, p.44).

While parents are doing what they believe is best for their child, their actions threaten to destroy the public's trust in the fairness of the organ allocation process as some children have the potential to receive preferential treatment, even as supply of available organs is very low.

### **Patient**

Due to the ongoing organ shortage, available organs are allocated to patients on the waitlist who are "likely to experience maximal benefit" (Statter & Noritz, 2020, 1). This line of thinking has led to children with intellectual and developmental disabilities (IDDs) to be historically excluded as transplant recipients. An IDD is defined as "a group of developmental conditions characterized by significant impairment of cognitive functions which are associated with limitations in learning, adaptive behaviour and skills" (Statter & Noritz, 2020, p. 1). There is considerable variability among transplantation programs in how disabilities are evaluated

(Garcia, 2020, p. 123), which has led to individual biases towards patients among different transplant programs and contributes to the methods in which patients are referred to be added to organ transplant waitlists (Statter & Noritz, 2020, p. 2). Statter and Noritz (2020) argue that defining an IDD as a social instead of a medical criterion gives advantages to patients without IDDS (p. 3).

In addition to limiting accessibility to waitlists, organ shortages are also causing high mortality rates for patients on organ transplant waitlists. More specifically, a study analyzing the heart transplant waitlist from 1999-2006 indicated that nonwhite race is a significant predictor in waitlist mortality (Almond et. al, 2009, p. 721). Reasons for this difference include access to proper medical care and treatment the patient received, and the progression of the patient's disease (Almond et al., 2009, p. 726).

Demographics, such as disability, race, and geographic location, have a strong influence in a pediatric patient's ability to not only get on the waitlist but also obtain a needed organ transplant. As availability of organs are limited, certain groups are being excluded as biases play into the waitlist selection process.

### **NEXT STEPS**

The lack of available organs has resulted in unethical and inequitable practices to occur within the organ transplant donor and allocation process. On both the donor and recipient sides, the medical staff is implementing different methods to determine which patients should be donors and recipients. The widespread variability in their evaluation methods has the potential to dismantle the public's trust in the organ allocation process as a whole. Similarly, parents and guardians' use of different methods to obtain organs for their children raise ethical concerns, as some children are able to receive transplants at the expense of others. Finally, the patients

themselves are the most directly affected by the organ shortage; donor patients are at risk of being harmed in order to benefit the recipient, and some patients desperately in need of transplants are being excluded due to the consideration of other factors. To prevent these issues from occurring, it is paramount that uniform procedures are established for evaluating potential organ donors and for selecting waitlist recipients. Instituting standardized procedures for all transplant programs will strengthen the trust in the organ allocation process, alleviate the possibility of unethical actions occurring, and eliminate potential implicit biases from influencing the decision making process.

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