Exclusion from Organ Transplant on the Basis of Ability

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The availability of organs for transplant is a persisting issue in the field of medicine. As transplant centers have autonomy over selection criteria for transplant, intellectual and developmental disability (IDD) is a consideration among many programs in the process of choosing transplant candidates. Although medical and legal protections, afforded by the Americans with Disabilities Act, are in place to protect against exclusion of patients with IDD, IDD is considered as a contraindication to transplant, marginalizing this patient population. Arguments in favor of considering IDD in organ transplant decisions include the potential utility of allocating organs away from individuals with IDD, a diminished quality of life for those with IDD compared to those without, as well as concerns of nonadherence in post-transplant care of the patient. Nevertheless, I will present the argument that these potential benefits of using IDD as medical criterion in transplant decisions are based in ableism and implicit biases concerning patients with IDD. Therefore, with justice and respect for persons at the forefront of organ allocation, intellectual and/or developmental disability should not contribute to a decision of organ transplant eligibility. Amidst high-stakes allocation considerations based on a shortage of organs, prioritizing just allocation through inclusive and ethically defensible policy must be at the forefront of medical decision-making.

At this moment, approximately 114,000 patients are waiting for a lifesaving organ transplant (1). Simply due to the lack of available organs for transplant, 20 people will die today (1). The persisting demand for transplantable organs, accompanied by a disproportionate number of organs available, illuminates the need to outline a program of organ allocation that maximizes the benefit of the recipients, as well as upholds the principles of justice and fairness in their rationing. As organ transplant centers develop a system for allocation, there is the potential to marginalize and discriminate against groups as recipients to offset the lack of transplantable organs. Although national strategies provide some guidance to a fair distribution of organs, selection criteria may vary from one transplant program to another (2). The opportunity for transplant centers to make their own decisions regarding transplant recipients leads to inequalities in the process of choosing transplant candidates. Transplant ethics boards have recognized discrimination in transplant allocation that takes place based on age, race, and socioeconomic status. However, exclusion based on ability is much less recognized, but just as (if not more) prevalent (3). Among transplant centers, intellectual and developmental disability (IDD) has been considered a criterion in choosing organ transplant recipients. Including IDD as a criterion calls into question whether principles of utility are basis enough to morally exclude based on ability. In this paper, I address the central dilemma of including IDD as a criterion in determining an organ transplant recipient.

The dilemma of whether to include IDD as a criterion in organ transplant decisions addresses the need to balance various principles that compose ethical organ transplant policy. One of these principles is utility, from which transplant coordinators attempt to ascertain which potential donor-recipient would maximize the benefit for the greatest number of patients from the transplant (2). Additionally, justice is one of the primary considerations in organ transplant decisions, morally obligating that organ allocation is equitable and indiscriminatory (4). Nevertheless, the need to ration organs poses the threat of marginalizing and discriminating against groups of recipients to offset the lack of transplantable organs. A consistent strategy across transplant centers concerning organ allocation is required to maximize the benefits of a transplant while avoiding marginalization of an already vulnerable population, such as those with IDD.

In considering the contribution of utility and equity to the formation of organ transplant policy, I will argue that IDD should not contribute to a decision of organ transplant eligibility due to a necessity to promote justice and inherent human dignity within transplant decisions. I will begin by outlining the historical exclusion of patients with IDD as organ transplant recipients, followed by a description of the current state of employing IDD as a criterion for transplantation. I will then present the counter argument to my own, which is a utilitarian perspective evaluating the potential benefits of using IDD as a criterion, and how this perspective can perpetuate already existing marginalization and injustice. I will then present my argument based on the principles of fairness and justice that calls for the inclusion of patients with IDD and calls for new guidelines and review of transplantation policy to maintain equity in organ allocation.

Background and Current State of IDD as an Organ Transplant Criterion

IDD is defined as "a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills" (4). These conditions envelop a wide range of cognitive abilities and can include patients on the autism spectrum as well as patients with Down syndrome, historically a group often focused on when determining transplant eligibility (4). Intellectual disability potentially includes deficits in abilities such as problem-solving, learning academically or from experience, and most commonly an IQ of less than or equal to 70 (5). Developmental disability is quite often evaluated by a patient's level of "adaptive functioning," with potential deficits present in social, conceptual, and practical skills (4). Assessment of a person's level of disability includes testing their cognitive function as well as their ability to adapt to and live in their environment (4). Although a diagnosis of IDD may be assumed to limit one's cognitive ability, societal and environmental factors can improve cognitive outcomes for patients with IDD (4). A societal understanding of disability as a fixed and defining characteristic can quite often place patients with IDD in a box of expected function, limiting their resources and support.

Historically, organ transplant centers have excluded patients with IDD as transplant recipients (5). National guidance in the late 1990s, most significantly by the American Society of Transplant Physicians, has asserted that IDD should not be used as a criterion in transplant listing (6). This same period coincided with Sandra Jensen receiving a heart-lung transplant, which made her the first patient with Down syndrome to do so (5). This feat is most notable due to the initial denial of the organs despite her congenital heart disease, leading to a significant campaign against discrimination against patients based on disability in the realm of the national transplant system (4). Today, legal protection provided by the Americans with Disabilities Act and national guidelines back the inclusion of patients with IDD as organ recipients on the basis that all patients have equal right to organs (5). Progress has been made in many transplant organizations that adopt this position (5).

Despite these medical and legal protections, evidence of the exclusion of patients with IDD continues. Persistent barriers include the center-specific freedom of choice in transplant listing and a lack of accommodations available for every step of the transplant process for patients with IDD (5). A 2020 study conducted by Anji Wall revealed that "most transplant programs consider genetic diseases and intellectual disability as absolute or relative contraindications to transplant listing decisions" (6). 60 percent of transplant centers report having serious reservations about giving a kidney to someone with a mild to moderate intellectual disability (7). It is empirically evident that discrimination based on ability persists despite the guidance of federal law. The variability of criteria between transplant centers highlights the ability for organization-specific biases to be reflected in their transplant allocation policies.

As organ transplant centers are called to consider and balance both utility and justice in their allocation of organs, dilemmas arise concerning the criteria by which some patients can be excluded or considered as a lower priority (2). Transplant ethics account for respect for persons, utility, and justice to form its policy (4). From these principles, ethicists can assert what considerations are at stake when a potential recipient has IDD. In the case of patients with IDD being considered as recipients, the exclusion of patients with IDD has been justified by claims of poorer patient survival, the potential for nonadherence post-transplant, and a supposed decreased quality of life (QOL; 8). Objections to the exclusion of patients with IDD as recipients include respect for the dignity of all individuals and a necessity for justice in transplant policy. Justice calls for the inclusion of patients with IDD as recipients due to their continued contributions to the donor pool (2). To combat the shortage of organs, policy regarding transplant eligibility requires analysis of both of these perspectives to answer the question of whether the exclusion of patients with IDD as recipients can be morally justified.

Benefits of Considering IDD in Organ Transplant Decisions

The primary arguments in favor of using IDD as a criterion for transplant are mainly identified in the application of the principle of utility in organ transplantation. John Stuart Mill's definition of morality primarily considers the "greatest happiness principle," stating that the moral act is that which produces the most net utility, or the greatest happiness for the greatest number (9). Mill specifically employs utilitarianism, in which the moral act produces as much net utility as any other action could in those circumstances. According to Mill, the principle of utility is effective because it allows the weighing of two actions against one another, a necessary task in the case of determining if a patient is fit to be a transplant recipient or not (9). Most significant to the application of utility in transplant decisions is the concern for all involved or affected by the act, or "the interest of every individual as nearly as possible in harmony with the interest of the whole" (9). In the case of organ transplantation, this considers not only the impact of receiving the organ(s) on the life of the potential recipients, but as well as the lives of those in the personal circle of the recipients and the physicians involved. Organ transplant policy, with the ultimate goal of allocating resources to the patients who will benefit most, is directed toward high transplant success rates (4). The remainder of this section will outline the assertions some make to describe how using IDD as a medical criterion can accomplish these aims.

With these defining characteristics of utility in mind, some ethicists assert that multiple benefits stem from the use of IDD as a criterion in transplantation policy. By the principle of utility, organs should be designated to those who will reap the greatest benefit graft and survival outcomes post-transplant, which is reason enough to use IDD to avoid allocating scarce resources to patients with poor outcomes (8). As the concern for graft and patient survivability has been used to support the argument for including IDD in determining an organ recipient, further studies have revealed that this argument is not supported by the gathered data (2). When comparing recipients with IDD to those without, there is no significant difference in graft or patient survival, confirming that patients with IDD would gain the same benefits of additional years of life and improved organ function from receiving a transplant (8). Therefore, it cannot be asserted that patients without disabilities would derive greater success from transplantation than those with disabilities.

A second argument in favor of IDD as a transplant criterion is the concern of nonadherence, meaning failure to follow a prescribed treatment or regimen in post-transplant care of the patient. Similar to the research that negates the concern for patient and graft survival, the available data shows no evidence of a higher risk of nonadherence in patients with disabilities (8). Deeming a likelihood of nonadherence as disqualifying a patient for organ transplantation would require that additional groups where nonadherence has been cited as a higher risk be excluded as well, which would include adolescents (4). For patients with IDD, quite often a support system is built to meet that patient's needs, comprising caretakers and a system of medical and social support that would promote adherence (8). The need for additional support and assistance may be higher in patients with IDD than those without, but this may be a reason to believe that these patients would be better supported and exhibit an improved likelihood of adherence (4, 8). Claiming nonadherence as a rationale to delegate an organ away from a patient with a disability would not increase the potential benefit gained from the transplant and would rather be unjust and discriminatory.

Some in favor of the use of IDD as a criterion for organ allocation assert that patients with disabilities do not have as great a QOL as those without (8). This claim defends the point of view that patients with a disability would not benefit from receiving an organ as much as a patient without a disability. QOL is defined by the World Health Organization as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (4). As described in this definition, QOL is individualistic and contextual based on the patient's situation. Therefore, objections to QOL arguments include a lack of empirical evidence supporting the claim that patients with disabilities have worse QOLs, the inability to objectively assess QOL, and the long-term variability of using subjective criteria to make objective decisions (2). Although QOL is often considered in organ transplant decision making, there is no evidence to suggest that a distinction can be made between the QOL of patients with disabilities compared to those without. QOL considerations attempt to apply subjective material to make objective claims concerning organ allocations. Therefore, QOL considerations are insufficient to call for the exclusion of patients with IDD as transplant recipients.

In describing the three broader categories (graft and survival outcomes, nonadherence, and QOL) of potential benefits in using IDD as a medical criterion in transplantation decisions, ethicists in support of IDD as a transplant criterion seek to pursue utility in transplant policy (8). Utility remains a necessary and critical consideration in transplant decisions, but a lack of evidence to support that benefit would be maximized by excluding patients with IDD proves there is no indication to do so (8). Using IDD to limit organ allocation to patients with disabilities would perpetuate the existing marginalization of the community and prevent an equitable distribution of justice. With limited data to support the utility of excluding patients with disabilities as recipients, there is a necessity to acknowledge how implicit biases in the medical field concerning patients with IDD can influence one's perception and decisions made in transplant scenarios (4). The supposed risks of including these patients in the transplants pool may very well be based on misconceptions related to patients with disabilities. Considerations such as QOL and graft survival are relevant in transplant decisions, but the medical field ought to avoid ableism, assess each patient tolerantly, and recognize the intersectionality of the identities of each potential recipient (8). Organ transplant policy must not be based on stigma and bias and should be applied on a patient-to-patient basis rather than excluding a group of patients who would benefit from receiving a transplant.

Rationale to Include Patients with IDD as Transplant Recipients

With justice as a primary consideration in transplant allocation decisions, there is a need to understand what constitutes fair and just allocation of resources in ethical theory. In applying natural law ethics to the issue of organ allocation, not only are the consequences of the allocation relevant (as is in utilitarianism), but the action of the allocation itself must be moral. The morality of an action itself is determined by its contribution to and/or hindrance of human flourishing and human good (10). A natural law tradition applied to bioethics presents that justice “requires us to give each person his or her due” to act morally in accordance with beneficence, which means doing good for others (10). Justice in decisions related to allocation of resources leads to the consideration of equity, or distributive justice. An Aristotelian understanding of distributive justice outlines that each should be given a “proportionate” amount as determined by their worth (11). To promote equitable organ donation, it must be considered what is proportionately granted, or just, to be received by the potential organ recipients. Within the discussion of just allocation of resources to patients, it is relevant to recognize rights possessed by every patient due to shared humanity and dignity. A guiding principle in natural law ethics is that “no human being should be treated as a mere means to further the goals of others” (10). This principle, developed from Kantian respect for persons as an end in themselves, applies to each patient; therefore, each patient, with a right to preserve their life and to flourish, has a right to an equitable share of the available resources (12).

To align organ transplant policy with the principles of justice and respect for persons, the inclusion of patients with IDD as patients possessing a shared human dignity calls for their equal inclusion as transplant recipients. Policy that excludes patients with IDD as organ recipients denies these patients the equal opportunity to the preservation of their life and the ability to flourish due to “natural disadvantages that limit individuals’ species and societal-relative functioning” (2). Although patients with IDD may not align with what is assumed to be “normal functioning” by some, they still belong to the “species functioning” of human beings (2). Organ transplant is directed towards providing the opportunity to patients an extended time of life and health, and just organ allocation policy provides this equal opportunity to patients with IDD. In the evaluation of how fit a patient is for a transplant, judgment of factors that contribute to the outcome of an organ transplant must not be related to arbitrary judgments of a patient’s social worth (4). There is an equal claim to transplantable organs by patients with disabilities as those without. To ensure equitable allocation of resources to the potential pool of recipients, assessments to determine transplant eligibility must be individualized to account for “their unique needs and provides accommodations to optimize physical access, communication, and management of behavioral issues” (5). Equal accessibility of organ transplants, a necessary good for the preservation of the lives of those suffering from organ failure, must be provided to patients with or without disability. To preserve justice in organ allocation, issues of scarce resources must be addressed by individualized evaluation, unbiased by individual physician’s perceptions of what constitutes normal functioning and higher QOL.

Even as the above arguments against the exclusion of patients with IDD as transplant recipients have a basis in natural law ethical theory, the lives of these patients should also be considered from a utilitarian perspective in their social contributions. The value of patients with IDD as members of the human community is solidified in their relationships, through which basic human goods are sought (2). The value placed on the relationships between patients with IDD and those in their support system not only aligns them with the respect of persons in natural law ethics but also points out that the relationships of these patients are to be considered in the discussion of utility as well (2). Teleological ethical theory must also consider how excluding patients with IDD as organ recipients will only augment the marginalization of this group of patients and impede the trust of the general public in the process and policy of organ transplantation (2).

Even with allocation considerations based on a shortage of organs, prioritizing just allocation through inclusive and ethically defensible policy must remain at the forefront. Due to the discrepancies in equal access and consideration of patients with IDD as transplant recipients, action must be taken to enforce this ethical perspective. The variability from one transplant program to another in considering IDD as a contraindication to transplant points to a need for a common procedural framework to promote consistency, fairness, and transparency (4). Consistency of policy and evaluation for fitness to receive a transplant calls for standardized criteria for determining candidacy for transplant to hold transplant coordinators accountable as well as a consistent definition and assessment of IDD to ensure it is not deemed as a barrier to transplantation. The development of these criteria by regional review boards as well as the development of evidence- or data-based guidelines for determining eligibility would aid in ensuring just access to transplantation (8). Transplant teams must continue to be studied for their use of IDD as a contraindication. Additionally, research must persist to continue confirming the lack of evidence-based rationale for excluding patients with IDD due to differences in graft survivability. Outside of access to organs for transplant, lack of proper support for patients with IDD persists in many areas of medical care, including inadequate access to proper care teams, insufficient education of physicians, and insurance gaps (8). A continued movement toward equitable medical resources for patients with IDD will also aid in educating decision-makers in transplant centers and guide the application of justice in providing these patients equal access to transplantation.

Conclusion

Respect for persons and justice, as well as a lack of evidence to support the assumed benefits of employing this criterion, morally prohibits IDD from being considered in transplant decisions. Despite a tendency historically for transplant centers to include IDD as a contraindication to organ transplant eligibility, this paper has outlined why the exclusion of patients with IDD as transplant recipients is against principles of justice and an inherent respect for human persons. Traditional arguments in favor of the use of IDD as a criterion for exclusion from organ transplantation include a concern for diminished graft and patient survival, nonadherence to pre- and post-transplant regiment, and a decreased QOL held by patients with IDD (4). These utilitarian arguments lack evidence to support their rationale and they open the door for implicit biases to play a role in determining transplant eligibility (8). With utility and respect for justice and persons at the forefront, transplant programs are called to include patients with IDD as transplant recipients due to their value as patients and to their community as well as to show respect for the individualized assessment of each potential transplant candidate. The baseline inclusion of patients with IDD as recipients is necessary to maintain a just and ethical allocation of organs. As some transplant centers continue to use IDD as a contraindication to transplant, standardized assessment and criteria for transplant eligibility, as well as a general improved social and medical support and access for patients with IDD, can help ensure justice remains at the forefront of organ transplant decision-making.

Further reflection on this topic may include evaluating the inconsistencies of care and support for patients with IDD in the generalized medical field. The contribution of implicit biases and stigma may not only affect these patients' access to transplantable organs but their access to proper, individualized care.

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