

Ending Disparities for Individuals with Intellectual and Developmental Disabilities in the Organ Transplantation Process

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At each step of the organ transplantation process, significant disparities exist for patients with intellectual and developmental disabilities (IDD).¹⁻⁵ While some jurisdictions have attempted to stop this inequity, patients with IDD remain underserved, experiencing reduced access to care and poor health outcomes.^{1,6} Many physicians lack the expertise to determine accurate patient outcomes and are prone to define IDD as a contraindication for transplantation.⁴ Despite empirically similar post-transplantation survival rates between individuals with and without IDD, organ transplantation is not equitably opportune.^{3,7} Physicians can better fulfill their duty to fairly serve their patients through compassionate care and proper education on medical outcomes. Nondiscrimination policies should be adopted at federal, state, and institutional levels to improve access and outcomes for patients with IDD, particularly those in need of organ transplants. In this study, we identify five systematic flaws which contribute to discrimination against patients with IDD. In response, we recommend solutions that can be implemented at federal, state, and institutional levels to: (1) improve physician-patient interactions, (2) debunk false assumptions garnered by physicians about the patient population, (3) encourage equitable treatment opportunities for patients, (4) incite better transparency in the patient evaluation process, and (5) foster a sustainable system of donated resources.

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Transplantation Process

Healthcare is grossly inaccessible to individuals with intellectual and developmental disabilities (IDD).¹⁻⁵ Despite approximately one to two percent of the global population having IDD, these individuals experience poorer health outcomes than the general population, which places them at higher risk of chronic conditions at younger ages.^{1,6} Scholars have suggested that these disparities are the unfortunate sequelae of a “cascade of disparities,” whereby inadequate attention to care needs, health promotion, or access to quality healthcare services results in a higher prevalence of adverse conditions.¹ In

addition, many physicians report feeling ill-equipped to treat the IDD population, leading to individuals with IDD feeling singled out in healthcare interactions, feeling unprepared, or unable to understand the purpose of certain procedures.⁴

These disparities are particularly apparent in transplant centers around the United States.^{3,7,8} Many physicians are unaware that post-operative survival rates are virtually identical among patients with and without IDD, and they are inclined to deny transplants to individuals with IDD solely because of that

diagnosis.^{3,7} Patients with end-stage organ failure are typically evaluated by multidisciplinary teams including physicians, social workers, financial counselors, and nutritionists, often with opportunities for patients and their families to question clinical recommendations.⁹ This model should, in theory, add an extra level of protection for patients from overt discrimination and unfair decisions. Despite this, biases against the IDD population remain in the organ transplantation process. Sixty percent of US transplant centers report having serious reservations about giving a kidney to someone with mild to moderate intellectual disability.³ According to a survey in 2006, 38 percent of transplant centers denied listing a child for transplant solely on the basis of a coexisting neurodevelopmental disability.⁷

Fortunately, US lawmakers have begun to address this discrimination at the state level.³ California has served as a pioneer in state-issued anti-discrimination legislation. In 1996, it

enacted a law prohibiting the denial of organs for individuals with IDD solely on their disability, after a woman named Sandra Jensen was denied a heart-lung transplant twice due to her diagnosis of Down Syndrome.¹⁰ In recent years, the number of states with similar laws has grown to 34.¹¹ While this is an important start, truly addressing this disparity requires action across all levels of government and agencies. The Charlotte Woodward Organ Transplant Discrimination Prevention Act, introduced at the federal level in February 2021, would prohibit transplantation-related discrimination by providers based on an individual's disability.¹¹⁻¹³

Work still needs to be done to address ongoing disparities in the organ transplantation process. The following article identifies five systematic flaws which have permitted discrimination against individuals with IDD and proposes solutions to address them.

1. Physicians are unprepared to work with patients with IDD.

The story of Paul Corby has become an important call for the healthcare community to improve communication and care for patients with IDD. For Paul, a resident of Pennsylvania with autism and several psychiatric conditions, complaints of vomiting, chest pains, persistent cough, rapid palpitations, and anorexia were dismissed as anxiety for three months before his doctors recommended cardiac testing. In truth, Paul was in urgent need of a heart transplant.³ In general, physicians are less likely to recognize the need for organ transplants and refer their patients with IDD for formal

evaluation.^{3,4,7,8} In a survey conducted in 2004 by the National Work Group on Disability and Transplantation, only 52 percent of individuals with IDD requesting referral for transplant evaluations received one; approximately one-third of those with a referral never received a formal evaluation.⁷ Historically, many syndromes once thought to be “lethal” (e.g., Down Syndrome with duodenal atresia) were predisposed to premature death due to providers' decisions to forgo life-sustaining treatments.¹⁴

Solution

Physicians must be educated on promoting cultural competency and compassion for their patients.^{4,5,7,8,15} The first focus of this training should be disability humility, which encourages physicians to learn about the experience, culture, history and politics of disability.¹⁶ Second, this education should encompass cultivated care, relating to a comprehensive, coordinated,

caring, culturally competent, and continuous level of care for patients.⁵ While all medical schools in the United States follow basic curricular guidelines for pathophysiology, diagnosis and treatment of diseases to retain accreditation and prepare students for national board exams, public health threads including social determinants of health are largely

individualized by each program.¹⁷ A mandatory national curriculum should be established to educate physicians on the complexities of cultural competency in treating patients with IDD. Physicians must be educated on promoting cultural competency and compassion for their patients.^{4,5,7,8,15} The first focus of this training should be disability humility, which encourages physicians to learn about the experience, culture, history and politics of disability.¹⁶ Second, this education should encompass cultivated care, relating to a comprehensive, coordinated, caring, culturally

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2. Medical professionals garner false assumptions about transplant survival.

Physicians commonly report false assumptions about patient quality of life and post-transplant outcomes.^{3,14-16} In reality, individuals with disabilities self-report a similar quality of life as individuals without a disability.³ Despite this, some physicians have cited a presumed low quality of life as reason to deny transplants for their patients with disabilities.³

Many providers also falsely assume that post-operative survival of patients with disabilities is inherently lower than patients without disabilities.¹⁸ Evidence suggests that intellectual disability is not, in fact, associated with patient or graft survival among solid organ transplant recipients.

Solution

Quality of life is a reasonable factor to guide medical decision making; however, it should be based factually (i.e., by patient self-report) and not guided by the bias-laden assumptions of medical providers. Physicians have a duty to follow an evidence-based approach to evaluate patients and consider primarily the organ system involved to prognosticate transplant survival.^{3,15,16,19, 20} A study of multiply handicapped kidney transplant recipients – the majority of whom had IDD – showed excellent patient and graft survival alongside significant improvements in patient

and caretaker quality of life.²¹ One solution may consider reframing transplantation eligibility to target a vulnerable population, a model which has already been implemented.²² For example, early liver transplantation (<6 months after last alcohol use) for severe alcoholic hepatitis improved survival in patients who would have otherwise been excluded from the life-saving intervention. Similarly, providers and patients would benefit from a comprehensive decision-making framework to assess transplant eligibility specifically for individuals with IDD.

3. There is a lack of social support offered to patients with IDD.

Physicians are less likely to offer the same treatments to patients with IDD compared to the general population.^{3,7} Patients are often turned away due to lack of a support system, or their competence in managing postoperative care is misjudged due to inadequate assessment

of their support systems. Additionally, physicians are less likely to offer life-extending treatment alternatives (known as “bridge therapies”) to individuals with IDD while waiting for a transplant.³ For instance, Paul Corby was denied alternatives such as a left

ventricular assist device while he awaited his heart transplant. The decision to deny Paul available medical intervention unnecessarily

supported an accelerated decline in his condition.

Solution

Physicians must provide the same services to patients with and without IDD, when medically appropriate. Institutions must improve counseling on post-operative care at a level that is appropriate to their patient's comprehension.^{3,7,15,19} This includes inviting support individuals to aid in medical decisions and disseminating health information in a format that is easily understandable and accessible. The state of Maryland established an exemplary model, instating a policy that requires

reasonable modifications to provide access to transplant services and ensure that these services are not denied due to the absence of auxiliary aids and services.^{3,19,23} Additionally, the bill urges providers to consider home- and community-based services for successful post-operative care.²³ All states should adopt policies modeled after Maryland to provide the social support necessary and encourage a successful transplantation process for all individuals.

4. Institutions lack transparency in the organ allocation process.

In the absence of a state- or federal-level nondiscrimination act, hospitals and organ transplant centers have minimal grounds holding them accountable for implicit discrimination against transplant candidates with IDD. The federally mandated

multidisciplinary approach to organ allocation is a respectable first step in improving transparency of the process.⁹ However, when faced with discrimination, patients still lack the means or access to information necessary to challenge this systemic failure.³

Solution

In order to protect patients and ensure accountability in the organ transplant system, it is necessary to establish greater transparency. A national online complaint system or phone hotline could address this issue. One model is a national healthcare grievance redress platform

rolled out in Lebanon in the form of a hotline, website and mobile app.²⁴ In addition, Advisory Committees should be founded within each transplant institution to review cases involving discrimination and ensure fair patient listings.^{3,15}

5. Individuals with IDD face discrimination as organ donors.

Individuals with IDD also face discrimination upon request to become living organ donors.^{14,19,25} In a previous commentary, Wightman and colleagues argue that the organ pool would become more limited if the waitlist grows but resources do not.¹⁴ As it is unjust to exclude individuals with IDD from receiving a

transplant, it is also unjust to deny them the opportunity to donate an organ. It is a human right for all individuals, including those with IDD, to make independent decisions which affect their health and relationships; denying the opportunity to become a donor undermines this autonomy.

Solution

Equitable access to evaluation for living donor candidacy must be standard of care. The organ pool will remain sustainable if equity is encouraged in organ receipt and donation.^{3,14} When the healthcare industry succeeds in eliminating discrimination for receiving organs, one can only expect to sustain these resources

with a similar level of organ donation. One solution is a national effort to educate physicians about IDD-based discrimination in evaluation of living donor candidacy. The practicality of this initiative again relies on improving the standardization of public health curricula across medical education programs.¹⁷

Conclusion

It is important to reiterate that empirically, patient survival rates following transplantation are similar between individuals with and without IDD.^{7,19} Despite this, organ transplantation is not equitably available to patients with IDD.^{3,5,6} This issue has become especially relevant during the COVID-19 pandemic, when states used existing transplant guidelines as models for distributing life-saving resources such as ventilators.²⁶

This article has proposed several initiatives to be adopted broadly at federal, state, and institutional levels to improve access and outcomes for patients with IDD. In sum, efforts should be made to (1) improve physician-patient interactions, (2) debunk false assumptions garnered by providers about the patient

population, (3) encourage equitable treatment opportunities for patients, (4) incite better transparency in the patient evaluation process, and (5) foster a sustainable system of donated resources.

There are many sophisticated considerations involved in organ allocation, including the scarcity of solid organs for transplant and the value of a holistic approach in candidacy evaluation. None of these considerations justify denying life-saving measures to an exclusive population with favorable projected transplant outcomes. Physicians can better fulfill their service to patients when they are equipped with sufficient education on medical outcomes and provide compassionate care for patients who have IDD.

About the Authors

Ms. Erin Jarvis is a medical student in the class of 2023 at Lewis Katz School of Medicine with a clinical interest in neurodevelopmental disabilities. She has been an active board member of the AADMD student chapter since her first year, promoting improved healthcare and inclusivity for individuals with intellectual and developmental disabilities. She graduated from the University of Pittsburgh with a degree in biological sciences and psychology in 2014. Ms. Jarvis was responsible for conducting an initial literature review and drafting the manuscript.

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Conflicts of Interest

The authors declare no conflict of interest.

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