Challenging Cases: Ethics in Transplantation

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Disclosures

No disclosures

Objectives

- Recognize challenging conditions requiring liver and/or Intestinal Transplantation
- Discuss medical, social and ethical issues in patients requiring transplantation
- Discuss possible approaches to overcome the challenges

Case #1

- In Summer of 2021 we received a 2 y/o female as referral from Texas.
- She had a primary diagnosis of short gut syndrome s/p resection from NEC (~30 cm of SB), chronic anemia, septo-optic dysplasia and developmental delay

- She was Gtube and TPN dependent due to oral aversion and poor enteral tolerance.

- She was admitted to her home hospital on 7/14/2021 with severe septic shock refractory to fluids and vasopressors due to bowel infarction secondary to volvulus, requiring emergent surgical intervention.

Case #1

- On 7/17/2021 she went back to the OR for her second small bowel resection, bowel anastomosis, and abdominal closure.
- She now has 6cm proximal small bowel, 2cm terminal ileum, IC valve and entire colon remaining
- She was now Ultra short gut and was transferred to the Nebraska Medicine PICU for further management and IRP evaluation.
- While in IRP developed cholestasis with advance hepatic fibrosis (liver disease), secondary to TPN Cholestasis likely
  - Also with hypopituitarism with central hypothyroidism, growth hormone deficiency, and central adrenal insufficiency, oral aversions, gastrostomy tube dependent.

Case #1

- **Growth & Development:** septo-optic nerve dysplasia with global developmental delay, able to sit independently, does not crawl or walk, is non-verbal

- Participates in speech therapy and feeding therapy, is on waitlist for PT/OT

- Now with intestinal failure and advance liver disease needing a liver and small bowel transplant

- What do we do?
  - Patient has significant developmental delay, does not talk, does not walk, will not be able to take care of herself when older
- Do we question if the patient should receive a transplant?
- Do we, as a Transplant Center, have standards to determine candidacy for transplantation based on Cognitive Development?

Case #2

- Former 25-0/7 week, twin female, ~ 5 months now
- Transferred from another state
- Dx: Necrotizing enterocolitis (NEC) totalis, Infant developed portal venous air and progressed to pnematosis and perforation. Penrose drain was placed, visualization of bowel appeared necrotic. She had complete liquefication of entire small bowel and the entire transverse colon was necrotic as well
- SBS – with duodenum anastomosed to the descending colon

Case #2

- Nutrition: had to be started on TPN due to prior feeds intolerance
- Developed TPN cholestasis
- Multiple line related infections
- Due to prematurity she also had Periventricular leukomalacia (PVL), apnea, anemia, Retinopathy, BPD

- She is now 18 months old and meets criteria for a liver-small bowel transplant!

PVL Periventricular leukomalacia

- **Brain injury** that affects the white matter of the brain, specifically the area around the ventricles (fluid-filled cavities). It is **most common in premature infants**, especially those born before 32 weeks of gestation.

- PVL occurs when there is a l**ack of blood flow** (ischemia) or oxygen (hypoxia) to the white matter near the ventricles.

- Symptoms of PVL may not be present immediately after birth but can develop over time. They can include:
  - Motor problems, such as spasticity (stiff muscles), weakness, or delayed motor milestones
  - Seizures
  - Developmental delays
  - Cognitive problems
  - Vision or hearing problems

- The prognosis for PVL varies depending on the severity of the damage. Some children may have mild symptoms and live full and active lives, while others may experience significant disabilities

What do we do?

Patient with PVL there is a big chance that she can develop severe cognitive impairment (CI)

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Is it ethical to withhold organ transplantation from a child with significant developmental delay?

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Did you know...

- Every center that performs solid organ transplant has a list of criteria they use to determine eligibility for transplant
- The use of NDD in pediatric solid organ transplant listing decisions is varied and inconsistent across active programs.
- Active pediatric solid organ transplant programs across the United States, Survey showed:
  - 39% of centers stated they never or rarely considered neurodevelopment status in making the decision.
  - There were 43% that said they always or usually do consider NDD in decision making about giving an organ to a child with NDD
  - Most of the time the process is informal (62%) and not a single center described their process was explicit or uniform

Richards, Crawly & Magnus, 2008

Disability Act of 1973

- One of the first that addressed discrimination against people with disabilities
  - It states that someone with a disability cannot be excluded from any participation or benefits from any program which receives federal financial assistance

- IN 1990 - AMERICANS WITH DISABILITY ACT WAS SIGNED TO PREVENT DISCRIMINATION AGAINST PEOPLE WITH ANY TYPE OF DISABILITY.

The "Final Rule" Department of Health and Human Services 42 CFR Part 121 Organ Procurement and Transplantation Network (OPTN)

- In 1998, the Department of Health and Human Services (HHS) issued a final rule, known as the OPTN "final rule," to govern the Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS), requiring the implementation of new organ allocation policies.

- Organs should be equitably allocated to all patients, giving priority to those patients in most urgent medical need of transplantation, in accordance with sound medical judgment

- But... The criteria used in listing those who need and qualify for transplantation vary from one transplant center to another

(42 CFR Part 121, 1998)

Three most common concerns for excluding individuals with ID

(1) concerns about the patient's potential inability to follow a post-transplant regimen

(2) individuals with intellectual disability have a lower quality of life that justified allocating scarce organs to individuals with normal cognitive ability who will get more benefit

(3) individuals with intellectual disability often have a shorter life expectancy and have other comorbidities that decrease the benefit of organ transplantation

1. Ethics of Organ Transplantation in Persons with Intellectual Disability
2. Ross, Lainie Friedman
3. The Journal of Pediatrics, Volume 235, 6 - 9

The National Council on Disabilities met in September of 2019- directed by Chairman Neil Romano - **Report of Bioethics Series Examines Organ Transplant Discrimination**

- Provided an overview of the ways people with disabilities are discriminated against in the organ transplant and procurement processes

- “We live in a world where organ denials are based on disability, rather than suitability,” said NCD Chairman Neil Romano. “Receiving an organ to save your life should never be jeopardized because of fears, myths, and stereotypes about disability.

- **Key Findings:**
  - A disability will generally have little or no impact on the likelihood of the transplant being successful
  - If a person with a disability receives adequate support, the person’s disability should also have very limited impact on the ability to adhere to a post-transplant care regimen
  - The Americans with Disabilities Act and Section 504 of the Rehabilitation Act prohibit organ transplant centers from discriminating on the basis of disability.
  - UNOS/OPTN has proposed organ procurement policies that pose serious risk to people with disabilities.
  - There are laws that prevent discrimination, but they are rarely enforced

The OPTN Final Rule is not intended to be the sole source of ethical guidance for formulating allocation policies, as it enumerates the minimal legal/governmental policy requirements that must be included in a just allocation policy.

Transplant Organization's view

- Transplant organizations has expressed that patient with disabilities should not be excluded from consideration for transplant solely on their disability
  - United Network for Organ Sharing (UNOS)
  - American Society of Transplantation

While others

- Still question or raise concerns about candidacy for transplant if there is a disability and even consider it a contraindication
  - American Association for the Study of Liver Disease (AASLD)
  - International Society for Heart and Lung Transplant

Now, is it Ethical to deny transplantation to patients with Disabilities or Developmental delay?

- Common Ethical Principles:
  - Autonomy –right of individual to control his own person
  - Beneficence-doing good
  - Non-maleficence-avoid causing harm
  - Justice-fair distribution of benefits and risks

Autonomy: right of individual to control his own person

Parents give consent for their child, and it must be in the best interest of the child, and it is based on the fact that the child will eventually reach autonomy, which may never happen.

(Birchley, 2010)

Beneficence: do good to others

- People die every day while waiting for an available organ to be transplanted
- Should there be a consideration to allocating organs to people who will get the most benefit?
- According to the American Academy of Pediatrics, using that thought to discriminate against people with disabilities is unethical

(Statter, Noritz & Committee on Bioethics, Council on Children with Disabilities, 2020)

Non-maleficence: avoid causing harm

When a transplant center decides to list a patient, they are either saving their life or certain that they will be improving quality of life

Justice: fair distribution of benefits and risks

In organ transplantation, justice ethics focuses on fair and equitable access to life-saving resources, considering factors like medical urgency, waiting list time, and potential for long-term benefit, while avoiding bias and ensuring transparency in the allocation process.

OPTN. Ethical Princioples in the allocation of human organs, june 2015

Ethics Committee

It is a multidisciplinary team composed of physicians, nurses, social workers, administrators, chaplains and other employees

- A great option for transplant centers to use for addressing these matters
- In solid organ transplantation, ethics committees are the gate keepers that deal with moral philosophy when moral values are in conflict
- Allocation of medical resources, especially resources with absolute scarcity such as organs for transplant, is a difficult task. Medical, surgical, and ethical considerations should be evaluated
- Often, no good solution to a dilemma in these medical ethics exists.

Toker & Salzer, 2012

American Journal of
TRANSPLANTATION

AST | ASTS

PERSONAL VIEWPOINT Free Access

Access to transplantation for persons with intellectual disability: Strategies for nondiscrimination

Ashton Chen, Mahwish Ahmad, Andrew Flescher, William L. Freeman, Stephanie Little, Paulo N. Martins, Robert M. Veatch, Aaron Wightman, Keren Ladin

First published: 24 December 2019 | https://doi.org/10.1111/ajt.15755 | Citations: 17

Ongoing thoughts...

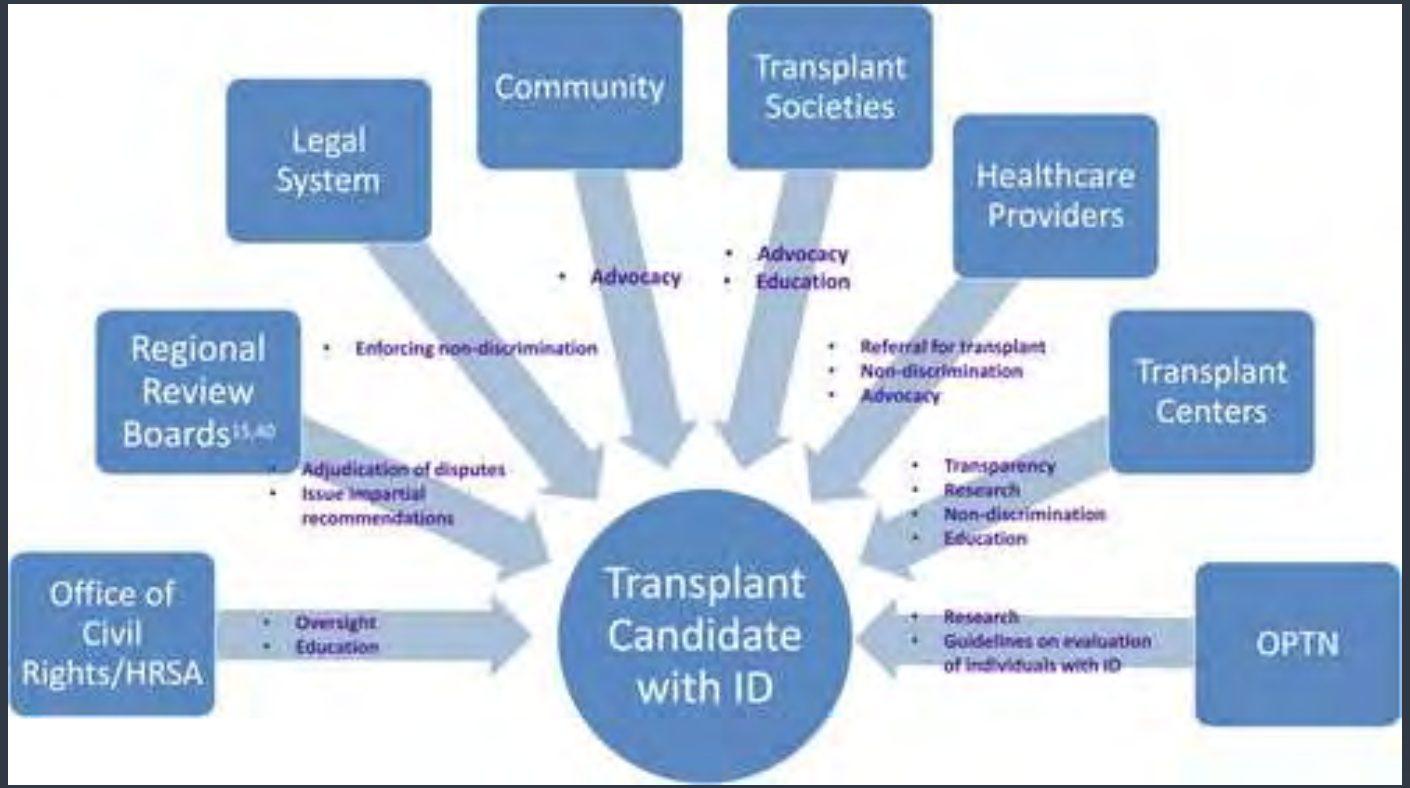
ID criterion remains controversial because of its potential to be discriminatory, subjective, and because its relationship to outcomes is uncertain.

Using ID as a contraindication to solid organ transplantation is not evidence-based and reduces equitable access to transplantation, disadvantaging an already vulnerable population

Fair treatment for persons with ID in referral and evaluation for transplantation requires a balance between utility, equity, and autonomy

- Specifically, justice requires that transplant centers implement the following:
  - 1) evaluate all patients' intellectual and adaptive functioning in a clear, evidence-based, and systematic manner;
  - 2) focus the evaluation on evaluating need and potential to benefit; and
  - 3) evaluate and supplement social support to improve potential transplant candidates' chances at success rather than as a means of excluding them.

Chen et al. American Journal of Transplantation. 12-24-2019


Legal System
Community
Transplant Societies
Healthcare Providers
Regional Review Boards[15,40]
Transplant Centers
Office of Civil Rights/HRSA
Transplant Candidate with ID
OPTN
Advocacy
Advocacy
Education
Enforcing non-discrimination
Referral for transplant
Non-discrimination
Advocacy
Adjudication of disputes
Issue impartial recommendations
Transparency
Research
Non-discrimination
Education
Oversight
Education
Research
Guidelines on evaluation of individuals with ID

Overcoming Barriers

- Transplant centers may face difficulty meeting the complex needs of patients with ID
- Accommodating these needs may exceed the capacity of some centers and may require additional supports
- Better data are needed about how frequently ID is used as a contraindication, how ID is evaluated, and the specific supports needed to ensure success.

- Transplant center–level interventions:
  - **Removing disincentives (ex. decreasing cost coverage) for listing patients with ID**
  - **Ensuring adequate social support**
  - **Multidisciplinary teams and shared decision-making**

- Regional and national-level interventions
  - **Development of evidence-based guidelines**
  - **Developing Regional review boards**
  - **Education**

- "It is morally troubling to compare the quality of different children's lives for the purposes of excluding those who's lives are not considered good enough to save"

- Formally removing ID as a contraindication to transplant is a necessary first step.

Thank you for your attention

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