

Intellectual disability impedes decision-making in organ transplantation

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CASE REPORT

Evaluation for renal transplant

Mr. B, age 21, who has a diagnosis of autism spectrum disorder and an IQ comparable to that of a 4-year-old, is referred for evaluation of his candidacy for renal transplant.

A few months earlier, Mr. B pulled out his temporary dialysis catheter. Now, he receives hemodialysis through an arteriovenous fistula in the arm, but requires constant supervision during dialysis.

At evaluation, Mr. B is accompanied by his parents and his older sister, who have been providing day-to-day care for him. They appear fully committed to his well-being.

Mr. B does not have a living donor.

Needed: Assessment of adaptive functioning

DSM-5 defines intellectual disability as a disorder with onset during the developmental period. It includes deficits of intellectual and adaptive functioning in conceptual, social, and practical domains.

Regrettably, many authors focus exclusively on intellectual functioning and IQ, classifying patients as having intellectual disability based on intelligence tests alone.^{1,2} Adaptive capabilities are insufficiently taken

into consideration; there is an urgent need to supplement IQ testing with neuropsychological testing of a patient's cognitive and adaptive functioning.

Landmark case

In 1995, Sandra Jensen, age 34, with trisomy 21 (Down syndrome) was denied a heart and lung transplant at 2 prominent academic institutions. The denial created a national debate; Jensen's advocates persuaded one of the hospitals to reconsider.^{3,4}

In 1996, Jensen received the transplant, but she died 18 months later from complications of immunosuppressive therapy. Her surgery was a landmark event; previously, no patient with trisomy 21 or intellectual disability had undergone organ transplantation.

Although attitudes and practices have changed in the past 2 decades, intellectual disability is still considered a relative contraindication to certain organ transplants.⁵

Why is intellectual disability still a contraindication?

Allocation of transplant organs is based primarily on the ethical principle of utilitarianism: ie, a morally good action is one that helps the greatest number of people. "Benefit" might take the form of the number of lives saved or the number of years added to a patient's life.

There is little consensus on the definition of *quality of life*, with its debatable ideological standpoint that stands, at times, in contrast to distributive justice. Studies have shown



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Clinical Point

Adaptive capabilities are insufficiently taken into consideration when assessing candidacy for transplantation



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that the long-term outcome for patients with intellectual disability who received a kidney transplant is comparable to the outcome after renal transplant for patients who are not intellectually disabled. In other studies, patients with intellectual disability and their caregivers report improvement in quality of life after transplant.

The goal of successful transplantation is improvement in quality of life and an increase in longevity. Compliance with all aspects of post-transplant treatment is essential—which is why intellectual disability remains a relative contraindication to heart transplantation in the guidelines of the International Society for Heart and Lung Transplantation. The society's position is based on a theoretical rationale: ie, "concerns about compliance."

Only 7 cases of successful long-term outcome after cardiac transplantation have been reported in patients with intellectual disability, and these were marked by the presence of the social and cognitive support necessary for post-transplant compliance with treatment.⁵ One of these 7 patients had a lengthy hospitalization 4 years after transplantation because of poor adherence to his medication regimen, following the functional decline of his primary caregiver.

Two-pronged evaluation is needed. Most patients undergoing organ transplantation receive a psychosocial assessment that varies from institution to institution. Intellectual disability can add complexity to the task of assessing candidacy for transplantation, however. In these patients, the availability and adequacy of caregivers is as important a part of decision-making as assessment of the patients themselves—yet studies of the assessment of caregivers are limited. The patient's caregivers should be present during evaluation so that their knowledge, ability, and willingness to take on post-transplant responsibilities can be assessed. More research is needed on long-

term outcomes of successful transplantation in patients with intellectual disability.

CASE CONTINUED

Placement on hold

The transplant committee decides to postpone placing Mr. B on the transplant waiting list. Consensus is to revisit the question of placing him on the list at a later date.

What led to this decision?

The committee had several concerns about approving Mr. B for a transplant:

- His history of pulling out the catheter meant that he would require closer post-operative monitoring, because he would likely have drains and a urinary catheter inserted.
- Maintaining adequate oral hydration with a new kidney could be a challenge because Mr. B would not be able to comprehend how dehydration can destroy a new kidney.
- His parents believed that, after transplant, Mr. B would not be dependent on them; they failed to understand that he requires lifelong supervision to ensure compliance with immunosuppressive medications and return for follow-up.

The committee's decision was aided by the rationale that dialysis is readily available and is a sustainable alternative to transplantation.

Mr. B's case raises an ethical question

We speculate what the team's decision about transplantation would have been if Mr. B (1) had a living donor or (2) was being considered for a heart, lung, or liver transplant—for which there is no analogous procedure to dialysis to sustain the patient.

References

1. Arciniegas DB, Filley CM. Implications of impaired cognition for organ transplant candidacy. *Curr Opin Organ Transplant*. 1999;4(2):168-172.

2. Dobbels F. Intellectual disability in pediatric transplantation: pitfalls and opportunities. *Pediatr Transplant.* 2014;18(7):658-660.
3. Martens MA, Jones L, Reiss S. Organ transplantation, organ donation and mental retardation. *Pediatr Transplant.* 2006;10(6):658-664.
4. Panocchia N, Bossola M, Vivanti G. Transplantation and mental retardation: what is the meaning of a discrimination? *Am J Transplant.* 2010;10(4):727-730.
5. Samelson-Jones E, Mancini D, Shapiro PA. Cardiac transplantation in adult patients with mental retardation: do outcomes support consensus guidelines? *Psychosomatics.* 2012;53(2):133-138.

Suggested Reading

- Baqi N, Tejani A, Sullivan EK. Renal transplantation in Down syndrome: a report of the North American Pediatric Renal Transplant Cooperative Study. *Pediatr Transplant.* 1998;2(3):211-215.
- Benedetti E, Asolati M, Dunn T, et al. Kidney transplantation in recipients with mental retardation: clinical results in a single-center experience. *Am J Kidney Dis.* 1998;31(3):509-512.
- Ohta T, Motoyama O, Takahashi K, et al. Kidney transplantation in pediatric recipients with mental retardation: clinical results of a multicenter experience in Japan. *Am J Kidney Dis.* 2006;47(3):518-527.

Clinical Point

More research is needed on long-term outcomes of successful transplantation in patients with intellectual disability