# Transplant in a patient with comorbid psychiatric illness: An ethical dilemma

## ERIC N. BOYUM, MD, DOUGLAS BROWN, PHD, AHMED M. ZIHNI, MD, MPH, JASON D. KEUNE, MD, BARRY A. HONG, PHD, IRA J. KODNER, MD, FACS AND SHUDDHADEB RAY, MD, MPHS PUBLISHED NOVEMBER 1, 2014 • Bulletin of the American College of Surgeons

This article addresses a difficult ethical dilemma that transplant surgeons may potentially encounter: whether a patient with a psychiatric illness is a good candidate for a liver transplant. This case study illustrates the challenges involved when considering the ethical principles of patient self-determination, distributive justice of scarce medical resources, "social worth," and protection of vulnerable patient populations. Are patients with psychiatric illness able to provide consent for transplantation? Is it possible to avoid misallocating valuable donor organs and, at the same time, fairly allocate these resources? This article seeks to answer these questions and provide insight into this ethical dilemma.

## Case study

A surgeon member of an interdisciplinary transplant team is called to consult on a patient admitted to a large community hospital. The patient is a 45-year-old man with a history of schizophrenia, obesity, dyslipidemia, and type II diabetes mellitus. He has been diagnosed with nonalcoholic steatohepatitis (NASH). After several days in the hospital, his model for end-stage liver disease score has worsened to 22. The admitting service now wishes to consult the transplant team about the possibility of liver transplantation for this patient.

While reviewing the patient's chart, the surgeon comes across the patient's psychiatric history. Since his diagnosis with schizophrenia at the age of 18, the patient has had numerous exacerbations of his psychotic symptoms in addition to problems with executive functioning—the brain process that controls reasoning, planning, and decision making. Since his mid-20s, he has been unable to live independently and currently lives with his sister. His parents live out-of-state and have not spoken to the patient in many years. His last psychiatric hospitalization was five years ago, and he receives federal disability. The patient has been adherent to his psychiatric treatment plans, attends his psychiatry appointments, and has never used alcohol, tobacco, or drugs. He has never attempted suicide and is not currently suicidal or homicidal. His current treatment includes oral haloperidol. For 10 years he was treated with olanzapine, a common side effect of which is weight gain; notably, the patient became morbidly obese over this period of time. His weight gain likely contributed to his development of NASH.

The surgeon speaks with the patient about his condition and what would be required of him post-transplantation at a level the surgeon considers appropriate for the patient's mental capacity. The surgeon concludes that the patient understands most of what has been said, but also recognizes that his understanding of the entire transplantation process is not comprehensive. In the end, the patient states that he wants the surgeon to save his life.

The team's evaluation proceeds. Assuming that no medical or surgical contraindications for transplantation arise during the rest of the work-up, the following four options are available to the transplant surgeon:

- Postpone making a decision about the transplant until the patient's surrogate gives written informed consent
- Recommend that the transplant team wait to place him on the transplant list
- Conclude this patient is a poor transplant candidate and recommend that the team not place him on the transplant list
- Conclude this patient is a good transplant candidate and recommend that the team place him on the transplant list

### **Discussion of options**

### Option 1: Wait until the patient's surrogate gives informed consent

This option is based on an assessment that informed consent for a surgical procedure with significant risk may not be possible for someone with a major psychiatric illness. Informed consent is dependent upon the decisional capacity of the patient or the patient's surrogate. Decisional capacity requires the ability to understand the basic facts involved in the

medical decision, to appreciate the personal significance of the medical decision, to assess all available information, and to express a clear and consistent choice. In other words, the patient or the patient's surrogate is consistent in choosing among available options.<sup>1,2</sup>

Some health care professionals may argue that the stringency of establishing a standard for capacity in a single patient should be determined by the level of risk attendant to the result of the decision.<sup>2,3</sup> In this case, the risks inherent with the decision to accept an organ and the patient's responsibility of caring for the organ after transplant are great. Incapacity might be suspected, but not concluded, due to the patient's diagnosis of schizophrenia. Based upon the potential for poor outcome or the ineffective use of valuable and scarce medical resources, it could be argued that this patient's mental illness should at least require a formal capacity assessment, which may preclude him from making the decision.

A term often confused with capacity is legal competency, which must be assessed by trained personnel within the legal system. Decision-making capacity in these situations is determined clinically rather than legally. Therefore, the treating physician must, based on his or her best clinical judgment, assess the patient's ability to complete cognitive tasks and make a determination regarding the patient's decisional capacity.<sup>3</sup> Although a number of instruments are available to assist clinicians in assessing capacity, a formal guideline or best practice for assessment of decisional capacity has yet to be developed.<sup>2,3</sup>

If the patient is evaluated clinically and considered incapable of making a reasonable decision, a surrogate decision maker must be identified. If the patient has not formally established a durable power of attorney for health care-related matters, then the treating physician should turn to the patient's family for a surrogate who either knows the patient sufficiently to represent the patient's values and goals or who is otherwise capable of making decisions based on the patient's best interests. In many states, decision-making responsibility among family members for patients without decisional capacity follows a hierarchy that prioritizes parents above siblings. However, in this case, it would be ethically compelling for the treating physician to turn to the patient's sister with the expectation that she is available, knows the patient well, and is invested in the patient's well-being.

This option is not available for potential organ recipients with psychiatric illnesses who lack decisional capacity and for whom a surrogate decision maker cannot be identified.

# Option 2: Recommend waiting to place him on the transplant list

Following multidisciplinary evaluation of transplant candidates, sometimes the decision is made to wait in order to monitor one or more factors used in the final decision to list a patient for organ transplantation or to gather other information; these candidates are to be reconsidered for transplantation at a later time.

In this case, a final decision may be postponed for a number of reasons. The surgeons may decide to monitor the patient's mental status further for a number of reasons, including the decision to obtain a written plan from his psychiatrist for management of the patient's psychiatric symptoms post-transplantation, to further assess his support system, or to enroll him in social and/or financial support programs as needed. The American Medical Association (AMA) formally encourages transplant teams to intervene to overcome such obstacles to post-transplantation care whenever possible.<sup>4</sup>

Current United Network for Organ Sharing (UNOS) criteria dictate that listed candidates are given priority based on medical urgency and time spent on the waiting list.<sup>5</sup> Thus, although it may be reasonable to await further evaluation of this patient before making a decision, it is still important to proceed expeditiously.

### **Option 3: Recommend leaving him off the transplant list**

This option is based on the assessment that severe psychiatric illness may complicate the post-transplantation course to such a degree that commitment to "distributive justice" (that is, equitable rationing of scarce resources) requires that organs be allocated to patients without these co-morbidities.

Awareness that psychosocial factors affect the survivability of organs post-transplant has been integrated into government regulation of transplant decisions. The U.S. Department of Health and Human Services' Centers for Medicare

& Medicaid Services (CMS) requires that every transplant candidate receive a comprehensive psychosocial evaluation. To be reimbursed for transplant services, the facility must evaluate candidates "for issues that could affect the patient's compliance with the post-transplant treatment that is necessary to maximize the chances of a successful transplant, such as substance abuse or behavioral or psychiatric issues."<sup>6</sup> Furthermore, federal law mandates transparency of outcome statistics, and CMS takes these data into account when determining re-approval of transplant centers.<sup>6</sup> This mandate creates an incentive for transplant programs to recruit the lowest-risk transplant candidates available, although professional organizations and transplant programs also recognize the difficulties candidates with mental illness may face in these situations.

Current American Association for the Study of Liver Diseases practice guidelines for the evaluation of liver transplant candidates note that "psychosocial issues often are the greatest deterrent to successful liver transplantation."<sup>7</sup> A survey of American transplant programs (72 liver, 217 kidney, and 127 cardiac transplant programs) found that schizophrenia, past or present suicidality, intellectual disability (defined as IQ <70 by the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*), and substance abuse disorders all numbered among the contraindications to heart, liver, and kidney transplants.8 Among all programs surveyed, the rate of denying a transplant for psychosocial reasons alone was between 2.8 percent and 5.6 percent.8 Specifically, among surveyed liver transplant programs, the rate varied by site from 0 percent to 20 percent.<sup>8</sup>

## **Option 4: Recommend placing him on the transplant list**

Some physicians strongly believe that they should serve as the patient's advocate regardless of the potential for misallocation of scarce medical resources. The World Medical Association's Statement on Human Organ Donation and Transplantation proposes that transplant physicians' ethical obligation to seek the well-being of their patients should usually be primary.<sup>9</sup> Physicians should be careful that this ethical obligation does not lead to unethical and illegal tactics to get a patient transplanted. In 2003, three Chicago, IL, medical centers were forced to settle lawsuits after an insider at one of the centers alleged irregularities, suggesting that physicians at the medical centers had intentionally misdiagnosed and hospitalized their patients to accelerate the process of receiving a transplant organ.<sup>10</sup>

Proponents of this option might also argue that this patient's mental illness is not severe or unstable enough to classify him as a high-risk transplant candidate. A total of 31 of 48 (67.4 percent) liver transplant programs surveyed in one study excluded patients with active psychotic symptoms.<sup>8</sup> As such, the number of schizophrenic patients having received a donor organ is small. Case series have shown both positive and negative outcomes regarding graft survival following transplantation.<sup>11,12</sup> It is unclear whether the factors that made these candidates acceptable transplant candidates despite their psychotic illness might have improved their post-transplantation outcomes.

Some health care professionals may recommend listing this patient based upon the assertion that denying transplantation due to mental illness constitutes a social worthiness judgment—that is, based on aspects of a patient's social status rather than medical criteria. The AMA's Council on Ethical and Judicial Affairs has stressed that social worth should not be factored into the allocation of scarce medical resources.<sup>4</sup>

### **Ethical bottom line**

Decisions regarding transplant organ allocation rely on a two-step process. The first step involves the procurement of donor organs and the decision as to which transplant candidate will receive these organs. The U.S. Congress passed the National Organ Transplant Act of 1984 to create a national organ procurement and allocation organization known as the Organ Procurement Transplantation Network (OPTN) to carry out these duties.<sup>5,13</sup> UNOS has contracted with the federal government since 1986 to administer the OPTN.<sup>5</sup> Regional organ procurement organizations (OPOs) coordinate organ procurement and contract to allocate these organs to participating regional transplant hospitals.<sup>5</sup> Federal law mandates that both OPOs and transplant hospitals hold membership with the OPTN, which provides oversight of their transplant procedures and outcomes.<sup>6</sup> Since 2000, the UNOS criteria that dictate organ allocation to listed candidates have been based primarily on medical urgency.<sup>14</sup>

The second step regarding transplant organ allocation involves listing decisions made by multidisciplinary teams at transplant hospitals, such as the team described in this case study. Each transplant hospital has a standard set of criteria that an interdisciplinary transplant team follows when making listing decisions for the transplant candidates that present to their hospital. The variability of these criteria between transplant programs is well known, especially with regard to psychosocial criteria.<sup>8</sup>

Discussion about listing transplant candidates with mental disorders reached a public forum in 1995 with the case of Sandra Jensen. When Ms. Jensen was denied transplantation at two centers because she had a cognitive disability, a third-party physician argued that the decision violated the Americans with Disabilities Act of 1990 (ADA). One team reversed its decision before legal action was filed, and Ms. Jensen received her transplant. The decision launched a national discussion about the appropriateness of transplantation for patients with mental disabilities.<sup>5</sup> Some argue that even using non-diagnosis–based criteria, such as a history of medication noncompliance, might violate the ADA if the behavior occurs more frequently in people with mental illness.<sup>15</sup> To date, UNOS has not provided ethical guidance to programs regarding the eligibility for transplant of people with mental illnesses or disabilities. In the absence of guidelines from national transplant organizations, the decision to provide a transplant organ to a patient with psychiatric illness therefore requires careful consideration of ethical principles in addition to a complete medical and psychosocial evaluation.

# References

- Kodner IJ, Siegler M, Freeman DM, Choctaw WT. Chapter 52: Ethical and legal considerations. In: Wolff BG, Pemberton JH, Wexner SD, Fleshman, JW. *The ASCRS Textbook of Colon and Rectal Surgery*. 1st ed. New York, NY: Springer; 2006.
- 2. Dunn LB. Nowrangi MA, Palmer BW, Jeste DV, Saks ER. Assessing decisional capacity for clinical research or treatment: A review of instruments. *Am J Psychiatry*. 2006;163(8):1323-1334.
- 3. Appelbaum PS. Assessment of patients' competence to consent to treatment. N Engl J Med. 2007;357(18):1834-1840.
- 4. American Medical Association. Council on Ethical and Judicial Affairs. Ethical considerations in the allocation of organs and other scarce medical resources among patients. *Arch Intern Med.* 1995;155(1):29-40.
- 5. Whitehead AT. Rejecting organs: The organ allocation process and the Americans with Disabilities Act. *Am J Law Med.* 1998;24(4):481-497.
- 6. U.S. Government Printing Office. Department of Health and Human Services. Centers for Medicare & Medicaid Services. Medicare program; Hospital conditions of participation: Requirements for approval and re-approval of transplant centers to perform organ transplants. *Federal Register*. 2007;72(61):15198-15280.
- 7. Murray KF, Carithers RL Jr. AASLD practice guidelines: Evaluation of the patient for liver transplantation. *Hepatology*. 2005;41(6):1-26.
- 8. Levenson JL, Olbrisch ME. Psychosocial evaluation of transplant candidates: A comparative survey of process, criteria, and outcomes in heart, liver, and kidney transplantation. *Psychosomatics*. 1993;34(4):314-323.
- 9. World Medical Association. World Medical Association Statement on Human Organ Donation and Transplantation. October 2006. Available at: <u>http://www.wma.net/en/30publications/10policies/t7/</u>. Accessed September 12, 2014.
- Schoenberg N. A man of principle. *Chicago Tribune*. January 25, 2004. Available at: <u>http://articles.chicagotribune.com/2004-01-25/features/0401250502\_1\_liver-patient-illinois-hospital</u>. Accessed September 12, 2014.
- 11. DiMartini A, Twillman R. Organ transplantation and paranoid schizophrenia. *Psychosomatics*. 1994;35(2):159-161.

- 12. Coffman KL, Crone C. Rational guidelines for transplantation in patients with psychotic disorders. *Curr Opin Organ Transplant*. 2002;7(4):385-388.
- 13. U.S. Department of Health and Human Services. Organ Procurement and Transplantation Network. Ethical principles in the allocation of human organs. Available at: <u>http://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-in-the-allocation-of-human-organs/</u>. Accessed October 8, 2014.
- 14. U.S. Department of Health and Human Services. Organ Procurement and Transplantation Network. Policies. Available at: <u>http://optn.transplant.hrsa.gov/governance/policies/</u>. Accessed October 8, 2014.
- 15. Orentlicher D. Psychosocial assessment of organ transplant candidates and the Americans with Disabilities Act. *Gen Hosp Psychiatry*. 1996;18(11):55-125.