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HEART FAILURE AND IMAGING

BEGINNER

CASE REPORT: CLINICAL CASE

# Shared Decision Making in Cardiac Transplantation During the COVID-19 Pandemic

## Patient Refusal of Transplantation

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**ABSTRACT**

Shared decision making with patients in advanced heart failure is critical when making decisions on therapies such as left ventricular assist device implantation and cardiac transplantation. We describe a case wherein the risks of coronavirus disease-2019 affected the decision of a patient regarding proceeding with cardiac transplantation. **(Level of Difficulty: Beginner.)** (J Am Coll Cardiol Case Rep 2020;2:1365–7) © 2020 The Authors. Published by Elsevier on behalf of the American College of Cardiology Foundation. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Shared decision making (SDM) with patients in advanced heart failure focuses on prognosis, patient values, and preferences (1). For patients listed for cardiac transplantation, SDM about donor selection involves the mandated disclosure of donor characteristics that may increase infectious risks (2–5). During the ongoing coronavirus disease-2019 (COVID-19) pandemic, more extensive discussion on COVID-19–specific infectious risk is necessary, as well as disclosure of increased recipient risk as a result of hospital admission (in the case that the recipient is an outpatient) and immunosuppression following transplantation. We describe a case of patient refusal of transplantation solely because of concerns about COVID-19.

**LEARNING OBJECTIVES**

- To describe the importance of SDM for patients with advanced heart failure.
- To highlight that outcomes other than survival are important to patients awaiting cardiac transplantation.
- To emphasize the need for ongoing discussion with patients regarding individual risks during the COVID-19 pandemic.

## HISTORY OF PRESENT ILLNESS

A 68-year-old man with dilated cardiomyopathy whose guideline-directed medical therapy had failed underwent implantation of a HeartMate 3 (Abbott, Abbott Park, Illinois) left ventricular assist device (LVAD) in January 2019 as a bridge to cardiac transplantation. His early post LVAD course was unremarkable, and after recovery from surgery and

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**ABBREVIATIONS AND ACRONYMS**

**COVID-19** = coronavirus disease-2019

**LVAD** = left ventricular assist device

**SDM** = shared decision making

**UNOS** = United Network for Organ Sharing

completion of cardiac rehabilitation, his transplant evaluation was completed. The option of accepting "high-risk hearts" and hepatitis C donors was discussed; he declined these options and was listed as a United Network for Organ Sharing (UNOS) status 4 patient in October 2019. As his time on LVAD support continued, he developed complications, including recurrent gastrointestinal hemorrhage and ventricular arrhythmias. These complications increased the urgency of his need for cardiac transplantation. Because of concerns about further LVAD-related complications, as well as an increasing concern about death, he requested possible options to increase his probability of receiving a donor heart in an expedited time frame. "High-risk" and hepatitis C donors, as well as possible participation in a clinical trial evaluating the safety and efficacy of an organ care system to assess donor hearts that do not meet the current standard donor heart acceptance criteria (6), were again discussed, and he consented to all options.

In the wake of the COVID-19 pandemic, because of the potential increased risk to transplant recipients, our program made the decision to review donor offers only for UNOS status 1 to 3 patients and select UNOS status 4 patients. After discussion of risks and benefits of and alternatives to such an approach, the patient agreed to remain listed for cardiac transplantation.

## PAST MEDICAL HISTORY

His past medical history was notable for type 2 diabetes mellitus, remote prostate cancer, and ventricular tachycardia.

## MANAGEMENT

On May 1, 2020, a donor became available, and the patient was contacted by the transplant surgeon. The patient was screened for symptoms of COVID-19 and possible exposure. He denied symptoms and verified that he had been at home without exposure to anyone who was ill. He was than informed that a suitable donor (who tested negative for COVID-19) was identified, and that although the exact risks of transplantation during the pandemic are unknown, with his medical complications during LVAD support, the survival benefits of transplantation in his case likely outweighed the risk of COVID-19 during the current pandemic. He asked for further clarification. We informed him that we had successfully performed 2 transplant procedures during this era without any COVID-19- related adverse events and that his cardiac transplantation would take place at a COVID-19-free hospital (7), although there was still theoretically a greater chance of exposure to COVID-19 at the hospital than at home. He had concerns about undergoing cardiac transplantation in an facility that he had never been to and was particularly uncertain about moving forward when he was told that the hospital had a policy of no visitation during the pandemic.

The patient ultimately declined the organ. He cited concerns over possible COVID-19, isolation from his family because of the hospital's restricted visitor policy, and a preference to wait until the pandemic had "settled down." He asked whether he would lose his "spot" on the list and was reassured that he would remain listed. He again expressed fear of contracting COVID-19 and concern over prolonged separation from his family.

## DISCUSSION

SDM in cardiac transplantation may be more important now than ever before. SDM is needed both at the time of initial listing for transplantation and then again at the time an organ is available for the patient. Risks and benefits at the time of transplantation have generally centered on the organ itself (e.g., high-risk or hepatitis C-positive donor organs), but in current times other factors affect a patient's decision and need to be clearly communicated. The uncertainty surrounding the pandemic, including prevention and treatment of COVID-19, and the risks of remaining on the transplantation list or LVAD support complicate an already challenging conversation. Outcomes beyond survival need to be explicitly conveyed to patients, including major adverse events, quality of life, and burden of caregivers (1). In our patient's situation, fears of contracting a serious viral infection and isolation from his family both before and after cardiac transplantation affected his decision.

Informing patients of up-to-date risks highlights the importance of rapid data collection and reporting of outcomes for transplant recipients. Despite discussing all of this before fielding donor offers, the patient refused cardiac transplantation when he was informed of a suitable donor and cited reasons of fear and lack of family support in the hospital. Clearly, theoretical discussions of competing risks and benefits with a sole focus on survival are not adequate. Ongoing discussions with listed patients, with provision of individual competing risk assessment, COVID-19 risk mitigation strategies, and factors related to the patient's experience during hospitalization, will be needed for the foreseeable future.

## CONCLUSIONS

SDM is paramount in the care of patients with advanced heart failure who face decisions regarding therapies that carry significant risks as well as benefits. Currently, those decisions for patients listed for transplantation must include possible COVID-19 exposure during hospitalization and increased risk of COVID-19 during heightened immunosuppression after cardiac transplantation. Other considerations, including the anticipated patient experience during hospitalization, are also important. These risks and considerations need to be discussed with wait-listed patients, with ongoing updates provided because the risks are shifting.

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**KEY WORDS** cardiac transplant, cardiomyopathy, chronic heart failure