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A Tale of Two Failures: A Guide to Shared Decision-Making for Heart and Renal Failure



Heart failure and kidney disease are common and rapidly growing conditions in the United States. It is estimated that there are currently 6.5 million adults in the United States¹ and 23 million adults worldwide who suffer from heart failure.² Approximately 30 million Americans have evidence of chronic kidney disease (CKD).³ The presence of either condition is associated with a higher morbidity and mortality than the general population. Approximately 40% of patients with end-stage renal disease (ESRD) have heart failure. In this group, 27% will die from heart failure and associated complications.⁴ Having both diseases can complicate treatment for either condition. Even with advanced therapies such as hemodialysis (HD) and left ventricular assist devices (LVAD), these patients face limited prognosis and diminished function. Clinical nephrologists and cardiologists struggle with how to communicate prognostic worries to guide treatment decisions in this medically complex population. We here argue that shared decision-making (SDM) is the framework that in which physicians and patients work together to determine the best treatment plan based on prognostic information, patient values, and priorities.

LVADs are implanted as a bridge to heart transplant or as destination therapy in end-stage heart failure (ESHF). The REMATCH trial validated LVADs as destination therapy by demonstrating that patients who underwent LVAD implantation had a 1-year survival of 51%, and LVAD implantation conferred a 27% absolute reduction in 1-year mortality when compared with maximal medical management.⁵ Long-term dialysis (hemodialysis and peritoneal) is problematic when it comes to destination LVAD; most institutions consider LVAD implantation to be contraindicative in patients on dialysis, in part, due to the difficulty of placing these patients in outpatient dialysis units.⁶ Certainly, LVAD therapy has not proven beneficial in all populations. The 1-year survival rate after LVAD implantation has since improved to nearly 80% in the general population,⁷⁻¹¹ but this does not appear to be the case when both ESRD and ESHF are present. Bansal and colleagues recently examined United States

Renal Data System data and a 5% sample of Medicare beneficiaries without ESRD and determined that 51.6% of ESRD patients who had received LVADs died during their index hospitalization compared with only 4.2% of the LVAD recipients from the Medicare sample.⁷ The median time to death in the ESRD group was 16 days (interquartile range, 2-447 days) compared with 2125 days (interquartile range, 565-3850) for those without ESRD.⁷

In most centers, the presence of CKD defined as a sustained eGFR < 30 mL/min/1.73 m² is considered a relative contraindication to LVAD.⁶ It is widely believed that renal impairment secondary to cardiorenal syndrome (CRS), particularly CRS type II, is most amenable to improvement with LVAD therapy. A single-center study compared outcomes after LVAD placement among patients with a baseline eGFR < 40 mL/min/1.73 m² and >40 mL/min/1.73 m² in patients without evidence for chronic intrinsic (e.g., glomerulonephritis, diabetic kidney disease, or decreased function from aging) or structural disease who were not on dialysis. At 1 and 12 months after LVAD placement, survival in the <40 mL/min/1.73 m² group was 53% and 39%, respectively. Respective survival data in the >40 mL/min/1.73 m² group were 99% and 82%.¹¹ Furthermore, in a multicenter, retrospective cohort study, a higher CKD stage was associated with greater risk and severity of AKI, defined by KDIGO AKI criteria, after LVAD implantation.⁹ In multivariate analysis, eGFRs of 30–59 mL/min/1.73 m² at baseline had a hazard ratio for mortality of 2.24 (P = 0.008), and an eGFR < 30 mL/min/1.73 m² had a hazard ratio of 2.67 (P = 0.011).⁹ In ESRD and CKD populations, the mortality risk seems concentrated in the first 3 months after LVAD implantation. The occurrence of AKI after LVAD implantation was associated with increased mortality at 30 days (26.3% [AKI stage 2] vs 8.3% [no AKI]) and at 1 year (51% [AKI stage 2] vs 18.7% [no AKI]).⁹ Those who required dialysis after

implantation had the worst prognosis at 30 days, with a mortality rate of 30.3% with renal replacement therapy (RRT) vs 10.6% without RRT. The mortality difference was also present at 1 year after implantation (62.3% [RRT] vs 24% [without RRT]).⁹

Renal impairment, whether it is secondary to CRS or AKI of other cause, is associated with a more limited survival in patients who receive an LVAD than in non-LVAD patients with similar degrees of kidney dysfunction. Thus, for patients with CRS and AKI (who are also potential candidates for LVAD), it is important that patients have an informed understanding of what to expect after LVAD placement and how this compares with the general population. This shared decision-making (SDM) model, which has been endorsed by both the American Society of Nephrology and the Renal Physicians Association as the preferred approach to dialysis decision-making, has both the physician and the patient assume an active role.¹² The clinician educates the patient on the condition/procedure, the risks and prognosis, and addresses any concerns the patient may have. Then, the physician seeks input from the patient about his/her goals and values. If the patient is interested, the physician may also make a recommendation about what treatment plan will best achieve desired goals. Ultimately, the patient is encouraged to ask questions and make the final decision. In this way, both patient and physician share the decision-making process. SDM can be an effective way to prepare patients for what may come and empowers them to take control of their health.

The SDM model begins with prognostic information. Physicians often worry that disclosing prognosis will take away hope. On the contrary, in a study of advanced CKD patients, 97% of patients expressed a desire to know about life expectancy on dialysis. Over half of patients rated this knowledge as “an absolute need to know”¹³ for treatment decisions. A Canadian study of CKD stages 4 and 5D patients revealed that most patients had a poor knowledge of their illness trajectory and that only 10% of these patients discussed prognosis or end-of-life care with their nephrologist.¹⁴

Providing patients with prognostic information is integral to SDM. Because different patients may hold different values as to what is important to them, this information can shape treatment decisions in a variety of different ways. First, patients who do not discuss prognosis with their providers are more likely to both overestimate prognosis and choose more aggressive therapies.¹⁵ Second, patients may hold different values as to what is important to them. In a choice experiment with patients approaching ESRD, many were willing to trade a shorter life expectancy to reduce the burden of greater hospitalizations to gain more independence.¹⁶ Improved prognostic awareness may better match treatment decisions with patient priorities. Third, most patients interpret ‘survival’ as living well and quality of life rather than just living longer.¹⁷ Therefore, prognostic information should address survival as well as quality of life.

Understanding prognosis after LVAD placement in patients with ESHF, advanced CKD, ESRD, and AKI on a population level can help to inform discussions with patients. Although estimating prognosis in individual patients can be challenging, several prognostication tools are available to support practice in this area. One tool is the “surprise question”, that is, “Would I be surprised if this patient will die in the next year?” When providers caring for patients on dialysis were asked this question, 29.4% of patients for whom the provider would not have been surprised if the patient died in the next year had died at 1 year, compared with only 10% of other patients.¹⁸ The surprise question has also been recently validated in the CKD stages 4 and 5 population with similar results,¹⁹ suggesting that physicians should follow their clinical intuition. The surprise question has been validated in heart failure as a tool for triggering referral to palliative care.^{20,21} Another prognostication tool is the Charlson Comorbidity Index, which is a prognostic scoring system based on age and the presence of specific comorbid conditions.²² Mortality at 1 year ranges from 3–49% among patients with the lowest and highest Charlson scores.²² For patients with heart failure, prognosis can be estimated using the Seattle Heart Failure Model (SHFM), a calculator of projected survival at baseline and after interventions for patients with heart failure. This model is based on patient age, echocardiographic parameters, medications, and New York Heart Association (NYHA) Functional Classification and yields 1-, 2-, and 5-year survival data and mean life expectancy.²³

Prognosis is usually given to patients in survival percentages or periods of time and ideally should address the uncertainty around such estimates.²⁴ Smith and colleagues suggest 3 central tasks to manage uncertainty. The first is to normalize the uncertainty of prognosis, thus to reset expectations by helping the patient and family understand that we do not have definitive answers.²⁵ The second task addresses the surrogates’ and patients’ emotions surrounding the uncertainty of the prognosis. This is performed by acknowledging the emotions and the difficulty surrounding uncertainty. Finally, the third task is to help manage the effect of uncertainty on the patients’ and families’ abilities to live in the moment. Based on specific, prognostic information and given this uncertainty, one may present prognosis as ranges such as hours to days, days to weeks, weeks to months, months to years, or years.²⁴

When attempting to guide patients with ESRD and ESHF, there are good communication tools to help physicians to more effectively convey information. The “Ask-Tell-Ask” method²⁶⁻²⁸ promotes good communication between providers and their patients and helps show patients that the provider is willing to listen and engage in their care.²⁶ The first “Ask” is an open-ended question that gauges the patient’s level of understanding and readiness to engage in the conversation.²⁶⁻²⁸ The question can be, “What is your

understanding of your heart and kidney condition?" It can also be, "What have your doctors told you about your kidney (and/or) heart condition?" How patients answer these kinds of questions lends insight into their levels of knowledge, understanding, hopes and fears, and readiness to enter "the conversation". Next, before proceeding to "tell" the patient, it is important to first ask their permission to provide the information. For example, "Is it okay for me to tell you what I know?"²⁸ If the patient is willing, then the provider can begin to share information in the context of what they have learned from the patient about their level of understanding using straightforward language targeted to their education level and in a way that is sensitive to the patient's emotional state.²⁶⁻²⁸ It is important to avoid informational overload and aim to provide no more than 3 new pieces of information in short, easily digestible chunks.^{26,28}

The objective of the final "Ask" is to assess the patients' understanding and offer an opportunity for questions.^{26,28} The question can be, "We have just discussed a lot of new information, to make sure we are on the same page, can you tell me your understanding of the problem?" After reviewing anything that patients may not have understood, the provider should always conclude by asking and addressing any further questions from the patient. In addition to the challenges of information sharing, discussing prognosis is often a time of significant negative emotion, including anxiety, sadness, and shock. Although health-care providers often cannot "fix" the causes of these emotions, they can show emotional support by being present, listening, and expressing empathy. Expressing empathy is simply acknowledging the presence of emotion without judgment (e.g., "I can only imagine how hard this is").²⁸⁻³⁰ Research clearly demonstrates that health-care providers can learn to communicate in a more empathic fashion, and several communication tools have been published to support empathic conversations between patients and providers.²⁶⁻²⁹

Excellent communication is essential to SDM. The evidence available implies that patients with CKD, AKI, and ESRD do worse than the general population who develop ESHF and CRS. The prognosis for ESRD is particularly bad. As we learn more about the effects that CKD, AKI, and ESRD have on the morbidity and mortality of patients who develop CRS and ESHF, communicating this with patients will become paramount. Before entering a conversation, understanding the mortality risks and using clinical and prognostic tools to gauge overall prognosis is essential. Using appropriately designed communication tools, clinicians, not only nephrologists, can more effectively facilitate patient's appreciation of their conditions, options, and expectations. When uncertainty exists, a time-limited trial of renal replacement therapy may be warranted. Putting the tools into practice promotes improved provider-patient communication, and optimizes shared decision-making care. Using a shared decision-making model as discussed will reduce the health-care burden of patients who dually suffer from cardiac and renal failure.

Without health life is not life; it is only a state of languor and suffering—an image of death.—Francois Rabelais (1494 – 1553)

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