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Discordant Perceptions of Prognosis and Treatment Options Between Physicians and Patients With Advanced Heart Failure

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ABSTRACT

OBJECTIVES This study assessed patient and physician perceptions of heart failure (HF) disease severity and treatment options.

BACKGROUND The prognosis for ambulatory patients with advanced HF on medical therapy is uncertain, yet has important implications for decision making regarding transplantation and left ventricular assist device (LVAD) placement.

METHODS Ambulatory patients with advanced HF (New York Heart Association functional class III to IV, Interagency Registry for Mechanically Assisted Circulatory Support profiles 4 to 7) on optimized medical therapy were enrolled across 11 centers. At baseline, treating cardiologists rated patients for perceived risk for transplant, LVAD, or death in the upcoming year. Patients were also surveyed about their own perceptions of life expectancy and willingness to undergo various interventions.

RESULTS At enrollment, physicians regarded 111 of 161 patients (69%) of the total cohort to be at high risk for transplant, LVAD, or death, whereas only 23 patients (14%) felt they were at high risk. After a mean follow-up of 13 months, 61 patients (38%) experienced an endpoint of 33 deaths (21%), 13 transplants (8%), and 15 LVAD implants (9%). There was poor discrimination between risk prediction among both patients and physicians. Among physician-identified high-risk patients, 77% described willingness to consider LVAD, but 63% indicated that they would decline 1 or more other simpler forms of life-sustaining therapy such as ventilation, dialysis, or a feeding tube.

CONCLUSIONS Among patients with advanced HF, physicians identified most to be at high risk for transplantation, LVAD, or death, whereas few patients recognized themselves to be at high risk. Patients expressed inconsistent attitudes toward lifesaving treatments, possibly indicating poor understanding of these therapies. Educational interventions regarding disease severity and treatment options should be introduced prior to the need for advanced therapies such as intravenous inotropic therapy, transplantation, or LVAD. (J Am Coll Cardiol HF 2017;■:■–■)

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ABBREVIATIONS AND ACRONYMS

HF = heart failure

INTERMACS = Interagency Registry for Mechanically Assisted Circulatory Support

LVAD = left ventricular assist device

MedaMACS = Medical Arm for Mechanically Assisted Circulatory Support

The risk and benefits of left ventricular assist device (LVAD) therapy in patients with cardiogenic shock or inotrope-dependent advanced heart failure (HF), which are Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) patient profiles 1 to 3, have been well studied. However, the prognosis for ambulatory patients receiving oral medical therapy for advanced HF (INTERMACS profiles 4 to 7) is less well understood by patients and by their physicians. Patient-centered care for patients with advanced HF requires that patients understand possible outcomes and learn about potential treatment options including LVAD surgery which can improve quality of life and functional capacity for patients limited by HF symptoms, even when death is not imminent (1,2). However, patients may not full appreciate the invasive procedures that may be required for support during the post-operative period.

We hypothesized that there may be differences between patient perceptions of their HF disease severity and physicians' perceptions of patients' HF severity. Broader understanding of these differences may help facilitate better patient-physician communication regarding the advanced HF therapies of transplantation and LVAD placement. The aim of this study was to determine if there were differences between physician and patient perceptions of disease severity and the likelihood of requiring stage D interventions in INTERMACS profiles 4 to 7 patients with advanced HF. A secondary aim was to assess patient willingness to consider advanced HF treatment options in the context of other life-sustaining therapies.

METHODS

PATIENT SELECTION. Ambulatory patients with advanced HF (New York Heart Association functional classes III to IV, INTERMACS profiles 4 to 7) were enrolled in the prospective, observational MedaMACS (Medical Arm for Mechanically Assisted Circulatory Support) registry across 11 advanced HF-transplantation cardiology centers from May 17, 2013, to October 31, 2015. The overall goal of this registry was to better characterize and define the prognosis of outpatients with chronic advanced HF receiving oral (and not intravenous) medical therapy. Patient inclusion and exclusion criteria have been previously published but generally included patients with chronic advanced HF (diagnosis for at least 1 year and taking evidence-based medications for at least 3 months, unless contraindication or intolerance was documented), at least 1 prior HF hospitalization in the preceding year, and at least 1 other high-risk feature including another HF-related hospitalization; high natriuretic peptide level; poor functional status as assessed by cardiopulmonary exercise testing or 6-min walk; or a high-risk Seattle HF model score (3). The key exclusion criteria included current intravenous inotrope therapy, active listing for heart transplant, a congenital heart defect, a diagnosis of cardiac amyloidosis, or a noncardiac diagnosis anticipated to limit survival or functional status. All participating institutions were required to comply with local regularity and privacy guidelines and to submit the MedaMACS protocol for review and approval by their institutional review boards. Of note, this MedaMACS registry study was a larger and more distinct study that followed the initial screening pilot MedaMACS feasibility study that enrolled patients in a smaller group of centers between October 2010 and April 2011 (4,5).

CATEGORIZATION OF PHYSICIAN AND PATIENT PERCEPTIONS OF HEART FAILURE RISK. At the time of enrollment, the treating HF clinicians and enrolled patients were asked about their perceptions of HF prognosis. Specifically, physicians were asked for their best estimate of the likelihood that the patient would become sick enough to warrant urgent stage D intervention within 1 year (including home intravenous inotropic therapy, hospice, VAD placement, and/or urgent transplantation). The response choices included: "Highly Likely," "Moderately Likely," "Uncertain," "Moderately Unlikely," and "Highly Unlikely." Respondents were meant to use subjective judgment to discern among these choices, and only 1 selection was allowed for each study participant. The physician responses were divided into 2 groups: Physician-Perceived High Risk (if Highly Likely or Moderately Likely was selected) and Physician-Perceived Low Risk (if Uncertain, Moderately Unlikely, or Highly Unlikely was selected).

Similarly, patients with HF were asked to estimate how much longer they estimated they would live based on how they felt at the time of enrollment. Patient responses were divided into 2 groups: Patient-Perceived High Risk (those who estimated a life expectancy of less than 1 year) and Patient-Perceived Low Risk (those who estimated a life expectancy of greater than 1 year). Respondents were meant to use subjective judgment to discern among the categories, and only 1 selection was allowed for each study participant.