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CLINICAL RESEARCH

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;5:663–71)
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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 fully 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).

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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 <1 year) and Patient-Perceived Low Risk (those who estimated a life expectancy of >1 year). Respondents were meant to use subjective judgment to discern among the categories, and only 1 selection was allowed for each study participant.

OUTCOME MEASUREMENTS. Originally, data were to be collected prospectively for patients over a specified 24-month follow-up period. However, due to loss of funding for ongoing data collection, this report represents analysis of all available data after a mean follow-up of 13 ± 9 months. In addition to the baseline physician and patient questionnaires regarding HF prognosis, demographics, clinical characteristics, laboratory test results, echocardiography, and hemodynamic and functional status data were collected at enrollment. The outcomes of interest in this study were stage D HF endpoint, which included death, transplantation, or LVAD placement. These measurements were reassessed in addition to collection of interval events at 1 month, 1 year, and 2 years after entry into the study. Additional phone calls to measure interval events were made at 6- and 18-month time intervals.

PATIENT PERCEPTIONS OF LIFE-SUSTAINING THERAPIES. At enrollment, patients were asked to complete a questionnaire about their opinions about LVAD therapy and willingness to undergo a variety of common life-sustaining therapies. The patients did not receive any additional education or supplementary materials about LVAD placement or life-sustaining therapies because the goal of this analysis was to discern what happens in real-world clinical care. These survey responses were analyzed among the Physician-Perceived High-Risk cohort because this is the group of patients with whom the discussions regarding advanced HF treatment options of transplantation and LVAD placement and other life-sustaining therapies have usually started. In addition, HF patients who would want or consider a LVAD were queried about their willingness to undergo additional, more common life-sustaining therapies including chest compressions, mechanical ventilation, dialysis, transfer to an intensive care unit, or a feeding tube.

STATISTICAL ANALYSIS. All statistical analyses were performed centrally at the University of Alabama at Birmingham Data and Clinical Coordinating Center. Numerical data were reported as mean ± SD or count (percentage). Univariate comparisons between the cohorts of patients based on differing perceptions of HF risk were performed using the chi-square test of Fisher's exact test for categorical variables and the 1-way ANOVA test for continuous variables. A generalized linear model was used to assess interactions between physician and patient perceptions of high versus low risk. Kaplan-Meier survival curves and log rank tests were used to demonstrate unadjusted survival differences among the various cohorts of patients. Patient opinions about LVAD and life-sustaining therapy survey data were reported as percentages for qualitative descriptive analysis. Commercial software SAS version 9.4 (SAS Institute, Cary, North Carolina) was used for all statistical analysis.

RESULTS

A total of 161 patients were enrolled between May 17, 2013, and October 31, 2015. Physicians identified 111 patients (69%) of this cohort as being high risk for urgent transplantation, LVAD placement, or death within the year after enrollment and 50 patients (31%) as being low risk. By contrast, patients' estimation of life expectancy were not in line with physicians' estimate of prognosis. Of the total cohort of 161 patients, 138 patients (86%) thought they would live longer than 1 year, whereas only 23 patients (14%) thought they would live <1 year.

Among the overall cohort, most patients were judged to be INTERMACS profiles 5 and 6 and had similar demographic characteristics. Compared to Physician-Perceived Low-Risk patients, the Physician-Perceived High-Risk patients were older; had lower INTERMACS profiles; were followed by the treating program for a shorter length of time; were less likely to be receiving an angiotensin-converting enzyme inhibitor/angiotensin receptor blocker; had worse renal function; had higher natriuretic peptide levels; and had higher pulmonary artery pressures (**Tables 1 and 2**). In addition, compared to Patient-Perceived Low-Risk patients, the Patient-Perceived High-Risk cohort received greater use of warfarin and had lower blood pressure and lower cardiac output (**Tables 1 and 2**).

The overall number of study endpoints among the entire study population was high after a mean follow-up of 13 ± 9 months. Of 161 patients, 100 (62%) were alive without a transplant or LVAD, whereas 61 patients (38%) experienced one of the following endpoints: 33 patients (21%) died, 13 patients (8%) received a transplant, and 15 patients (9%) underwent LVAD implantation. This overall high number of endpoints was high regardless of physician- or patient-perceived risk (**Figure 1**). Specifically, among the 111 Physician-Perceived High-Risk patients, 45 patients

TABLE 1 Patient Characteristics at Enrollment

	Physician-Perceived		Patient-Perceived	
	High Risk (n = 111)	Low Risk (n = 50)	High Risk (n = 23)	Low Risk (n = 138)
Demographics				
Age, yrs	60 ± 11	56 ± 10*	63 ± 10	58 ± 11
Males	68	62	70	66
Race				
African-American	27	36	13	33
White	72	60	87	65
Other	1	4	0	2
Married or domestic partnership	58	63	61	60
Post-high school education	10	13	7	12
Heart failure characteristics				
Cause of heart failure				
Ischemic cardiomyopathy	41	34	39	38
Idiopathic dilated cardiomyopathy	35	48	35	40
Other cause	24	18	26	22
Implantable cardioverter-defibrillator present	87	78	91	83
Cardiac resynchronization therapy present	35	21	43	29
INTERMACS patient profile				
4-Resting symptoms	17 (15)	4 (8)*	6 (26)	15 (11)
5-Exertion intolerant	40 (36)	8 (16)*	9 (39)	39 (28)
6-Exertion limited	48 (43)	28 (56)*	6 (26)	70 (51)
7-Advanced NYHA functional class III	6 (5)	9 (18)*	2 (9)	13 (10)
Inotrope therapy required in preceding 6 months	19	17	30	16
Number of cardiac hospitalizations in the preceding 12 months				
1	32 (29)	14 (28)	5 (21)	41 (30)
2	40 (36)	21 (42)	8 (35)	53 (39)
3	15 (13)	11 (22)	2 (9)	24 (17)
4 or more	24 (22)	3 (6)	8 (35)	19 (14)
Prior transplant and/or DT-LVAD evaluation	23	26	22	24
Reason for initial referral to advanced HF program				
Cardiac transplant and/or DT-LVAD evaluation	48 (43)	12 (24)	12 (52)	48 (35)
Evaluation of severe heart failure	45 (41)	20 (40)	8 (35)	57 (41)
New diagnosis heart failure within same institution	6 (5)	8 (16)	1 (4)	13 (9)
Unknown	12 (11)	10 (20)	2 (9)	20 (15)
Length of time followed by program				
<3 months	34 (31)	9 (18)*	12 (52)	31 (22)
3–12 months	20 (18)	8 (16)*	1 (4)	27 (20)
1–2 yrs	19 (17)	6 (12)*	3 (13)	22 (16)
>2 yrs	38 (34)	27 (54)*	7 (31)	58 (42)
Medication usage at the time of enrollment				
ACEI or ARB	52	76*	48	62
Beta-blockers	87	96	78	92
Aldosterone antagonist	63	66	57	65
Loop diuretics	93	92	95	92
Digoxin	47	53	45	50
Hydralazine	33	27	43	29
Nitrate	36	35	38	35
Warfarin	45	44	68	41†
Aspirin	64	60	65	62
Statin	55	53	61	54

Values are mean ± SD, %, or n (%). *$p < 0.05$ for comparison of Physician-Perceived High vs. Low Risk. †$p < 0.05$ for comparison of Patient-Perceived High vs. Low Risk. p values were not adjusted for multiple comparisons.

ACEI = angiotensin-converting enzyme inhibitor; ARB = angiotensin receptor blocker; DT-LVAD = Destination Therapy Left Ventricular Assist Device; HF = heart failure; NYHA = New York Heart Association.

TABLE 2 Clinical Characteristics at Enrollment

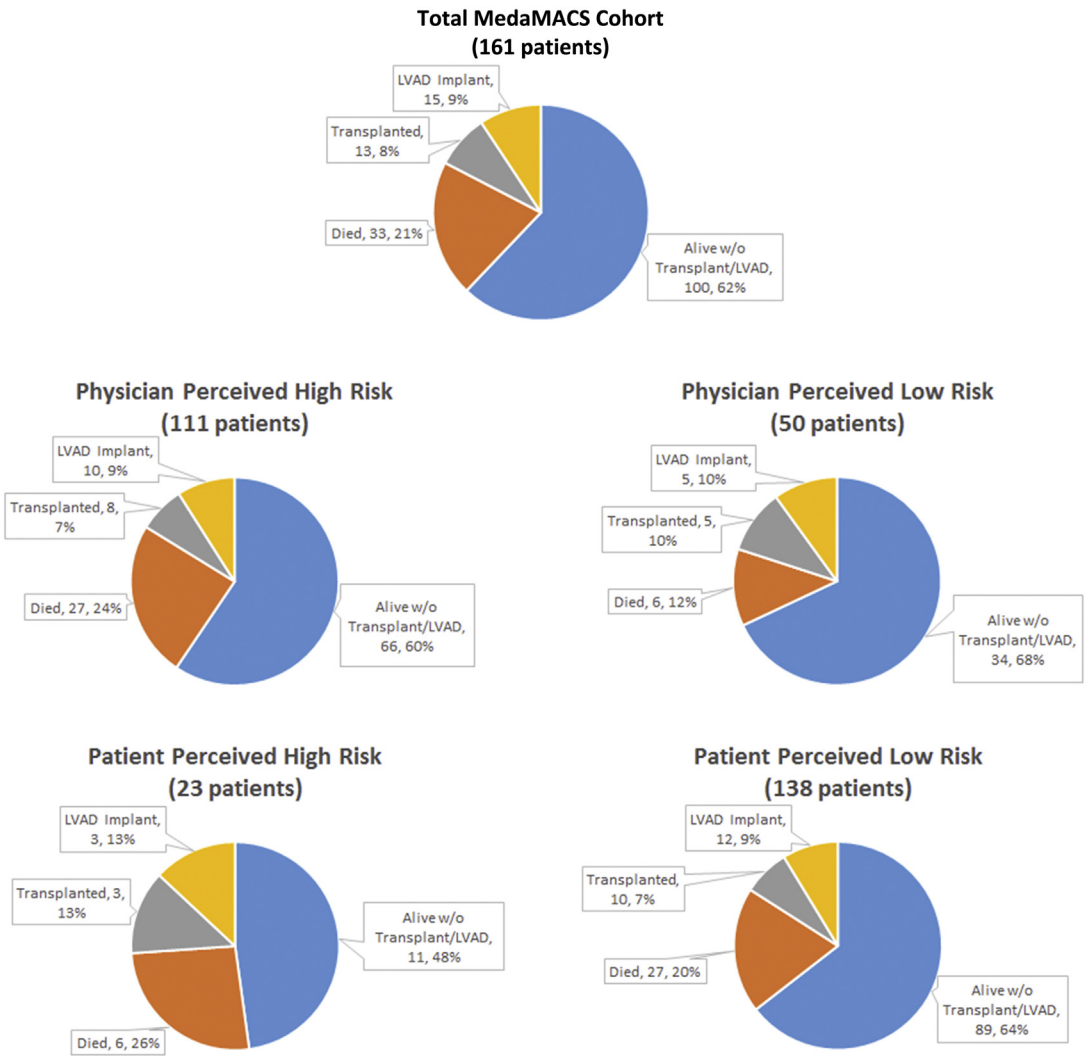
	Physician-Perceived		Patient-Perceived	
	High Risk (n = 111)	Low Risk (n = 50)	High Risk (n = 23)	Low Risk (n = 138)
Vital signs				
Weight, kg	93 ± 26	90 ± 24	92 ± 29	92 ± 25
Height, cm	173 ± 10	171 ± 10	175 ± 10	172 ± 10
Body mass index, kg/m^2	31 ± 8	31 ± 9	29 ± 8	31 ± 8
Heart rate, beats/min	80 ± 15	79 ± 14	79 ± 13	80 ± 15
Systolic blood pressure, mm Hg	109 ± 67	114 ± 19*	104 ± 14	112 ± 15†
Diastolic blood pressure, mm Hg	67 ± 10	70 ± 11	63 ± 8	69 ± 11†
Laboratory values				
Sodium, mmol/l	137 ± 4	137 ± 4	136 ± 4	138 ± 4
Potassium, mEq/l	4.1 ± 0.5	4.2 ± 0.5	4.2 ± 0.5	4.1 ± 0.5
Blood urea nitrogen, mg/dl	38 ± 22	28 ± 13*	39 ± 24	34 ± 19
Creatinine, mg/dl	1.6 ± 0.7	1.4 ± 0.5*	1.4 ± 0.5	1.5 ± 0.6
Alanine aminotransferase, U/l	30 ± 32	43 ± 60	31 ± 23	35 ± 45
Aspartate aminotransferase, U/l	30 ± 14	38 ± 37	32 ± 13	33 ± 25
Total bilirubin, mg/dl	1.1 ± 0.7	1.2 ± 0.9	1.2 ± 0.5	1.2 ± 0.8
NT-pro B-type natriuretic peptide, pg/ml	6,225 ± 5,408	2,903 ± 2,820*	6,181 ± 4,462	5,289 ± 5,150
Albumin, g/dl	3.8 ± 0.6	3.9 ± 0.6	3.7 ± 0.5	3.8 ± 0.6
Pre-albumin, mg/dl	20 ± 7	24 ± 9	18 ± 7	21 ± 7
Total cholesterol, mg/dl	127 ± 42	140 ± 44	107 ± 15	135 ± 45
Uric acid, mg/dl	10 ± 6	8 ± 3	9 ± 3	10 ± 6
White blood cell count, K/μl	7 ± 2	7 ± 2	7 ± 2	7 ± 2
Hemoglobin, g/dl	13 ± 2	13 ± 2	13 ± 3	13 ± 2
Hematocrit, %	38 ± 6	40 ± 6	39 ± 8	39 ± 6
Platelets, K/μl	220 ± 78	207 ± 66	201 ± 75	218 ± 75
International normalized ratio	1.7 ± 0.7	1.9 ± 2.3	1.6 ± 0.6	1.8 ± 1.6
Lymphocytes, %	20 ± 8	25 ± 10*	19 ± 9	22 ± 9
Baseline exercise testing and functional status				
6-min walk, m	207 ± 149	173 ± 171	180 ± 168	199 ± 155
Gait speed, m/s	1.0 ± 0.4	1.2 ± 0.5*	0.9 ± 0.2	1.0 ± 0.4
Peak oxygen uptake V_{O_2} (ml/kg/min)	11.6 ± 3.4	13.4 ± 7.0*	10.1 ± 1.6	12.2 ± 4.7
Peak oxygen uptake predicted, %	43 ± 12	40 ± 18	29 ± 11	43 ± 13
Ventilatory efficiency, VE/VC_{O_2}	37 ± 11	35 ± 8	34 ± 1	36 ± 11
Peak respiratory exchange ratio	1.1 ± 0.1	1.1 ± 0.1	1.1 ± 0.2	1.1 ± 0.1
Echocardiographic and right heart catheterization hemodynamic data				
Left ventricular ejection fraction, %	21 ± 6	22 ± 7	21 ± 7	21 ± 7
LV dimension diastole, cm	6.5 ± 0.9	6.5 ± 1.0	6.6 ± 0.9	6.5 ± 0.9
Right atrial pressure, mm Hg	12 ± 6	11 ± 6	14 ± 6	11 ± 6
Pulmonary artery systolic pressure, mm Hg	53 ± 13	47 ± 14*	56 ± 13	51 ± 13
Pulmonary artery diastolic pressure, mm Hg	26 ± 7	22 ± 9*	27 ± 8	24 ± 8
Pulmonary wedge pressure, mm Hg	22 ± 8	19 ± 9	23 ± 9	21 ± 8
Cardiac output, l/min	4.4 ± 1.5	4.7 ± 1.3	3.8 ± 1.8	4.6 ± 1.3†
Cardiac index, l/min/m^2	2.1 ± 0.7	2.3 ± 0.6	1.6 ± 0.5	2.3 ± 0.7†

Values are mean ± SD. *$p < 0.05$ for comparison of Physician-Perceived High vs. Low Risk. †$p < 0.05$ for comparison of Patient-Perceived High vs. Low Risk. p values were not adjusted for multiple comparisons.

(40%) experienced an endpoint with 27 deaths (24%), 8 transplants (7%), and 10 LVAD implants (9%) (Table 3). These rates are very similar to those of the Patient-Perceived Low-Risk cohort, where, of the 138 patients who estimated their life expectancy to be >1 year, 49 patients (36%) experienced an endpoint with 27 deaths (20%), 10 transplants (7%), and 12 LVAD implants (9%) (Table 3).

Although physicians were more likely to flag patients as higher risk than the patients were, there were no statistically significant differences in survival or surgical HF therapies between Physician-Perceived High-Risk versus Low-Risk and Patient-Perceived High-Risk versus Low-Risk cohorts. Risk perception also did not track rehospitalization frequency.

FIGURE 1 Events After 13 ± 9 Months Among MedaMACS Patients



Interim events among MedaMACS patients stratified by physician and patient perceptions of risk for progression of heart failure after a mean follow-up of 13 ± 9 months. LVAD = left ventricular assist device; MedaMACS = Medical Arm for Mechanically Assisted Circulatory Support.

Physicians' and patients' perceptions of risk were combined to form a high-risk cohort (including patients who were perceived as high risk by both physicians and themselves [n = 22]) and a low-risk cohort (including patients who were perceived as low risk by both physicians and themselves [n = 49]) to determine if there were differences in prognoses among these cohorts. There was a suggestion that the combined high-risk cohort appeared to have higher all-cause mortality rates (Figure 2) and lower survival rates free of death, transplantation, or LVAD implantation (Figure 3).

PATIENT OPINIONS ABOUT LVAD AND LIFE-SUSTAINING THERAPY SURVEY DATA. Among the Physician-Perceived High-Risk cohort, patients' perceptions of their own life expectancy were incongruent with their physicians' perceptions, as 22 patients (21%) estimated a life expectancy of <1 year, 23 (22%) estimated a life expectancy of 2 to 5 years, and 45 (42%) estimated a life expectancy of >5 years (Table 4). Furthermore, only 51% had a designated health care proxy or power of attorney, and only 37% had discussed treatment options regarding life-sustaining therapies with their physicians. Opinions on specific treatments were also inconsistent, as 77% of patients responded that they would consider LVAD implantation, yet many among this group would have

TABLE 3 Clinical Outcomes Based on Physician- and Patient-Perceived Risk for Poor Outcome Within 1 Yr of Enrollment

	Physician-Perceived		Patient-Perceived	
	High Risk (n = 111)	Low Risk (n = 50)	High Risk (n = 23)	Low Risk (n = 138)
Mortality	27 (24)	6 (12)	6 (26)	27 (20)
Ventricular assist device received	10 (9)	5 (10)	3 (13)	12 (9)
Transplant received	8 (7)	5 (10)	3 (13)	10 (7)
Alive without LVAD or transplant	66 (60)	34 (68)	11 (48)	89 (64)
Inotropes required	13 (12)	6 (12)	3 (13)	16 (12)
At least 1 rehospitalization	41 (37)	12 (24)	9 (39)	44 (32)
Total number of rehospitalizations	1.5 ± 1.8	1.3 ± 2.2	1.6 ± 1.7	1.4 ± 2.0

Values are n (%) or mean ± SD.
Abbreviation as in Table 1.

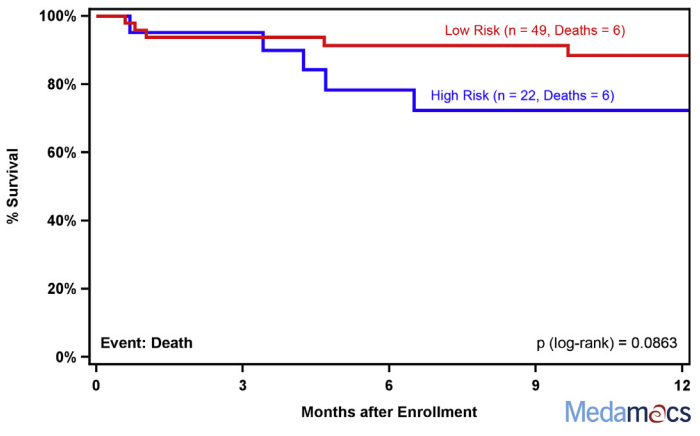
declined other simpler forms of life-sustaining therapy. For example, of the patients willing to consider LVAD implantation, 52% declined ventilation, 46% declined dialysis, and 63% declined a feeding tube (Table 4).

DISCUSSION

Among ambulatory patients with advanced HF taking oral medical therapy who were hospitalized within the previous year, the risk of progression to stage D therapies is high, regardless of whether the treating HF physicians or patients themselves identified high risk. More importantly, there was a discrepancy between patients and physicians among this group of INTERMACS profile 4 to 7 patients, where the physicians felt that more than two-thirds of these patients were at high risk for stage D intervention in the upcoming year. Despite receiving care at predominantly referral-based advanced HF-transplant cardiology centers, only 14% of these same patients felt they were at high risk. These data are consistent with other reports suggesting patients with HF often tend to underestimate the severity of their disease process and overestimate their own prognosis (6). Discordant perceptions of illness between physicians and patients may be a barrier to conversations about prognosis and treatment options. These data highlight the urgent need to better inform patients of available HF treatment options and explore individual thresholds for considering LVAD therapy while patients are still ambulatory (7).

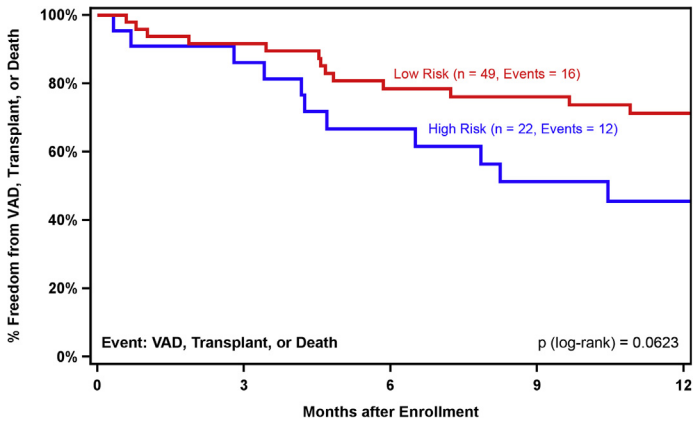
These findings illustrate the difficulty in determining prognosis in advanced HF. Neither physicians' nor patients' perceptions of HF risk correlated with survival or need for urgent transplant or LVAD implant. Despite 40% of patients experiencing an endpoint in the Physician-Perceived High-Risk cohort, the other 60% did not, suggesting that physicians may at times overestimate risk. By contrast, even among Physician-Perceived Low-Risk patients, the number of events was high, as it has been demonstrated that advanced HF clinicians as well as patients tend to underestimate the risk in these ambulatory, advanced HF patients (8). A unique aspect of these data is the potential additional prognostic value of combining physicians' and patients' perceptions of HF risk into a combined predictive model. There did appear to be a strong suggestion that the combined high-risk cohort that included physicians' and patients' perceptions of risk had differing outcomes compared with the low-risk cohort. Given the limited accuracy of a number of currently available HF prognostic models (9), the potential role of incorporating patients' opinions regarding their own disease state as a novel variable in newer HF prognostic models warrants further exploration.

FIGURE 2 Kaplan-Meier Survival by Initial Perceptions of Heart Failure Prognosis



The High-Risk cohort included patients that both physicians and patients perceived as high risk, whereas the Low-Risk cohort included patients that both physicians and patients perceived as low risk. Patients were censored at time of transplantation or ventricular assist device placement.

FIGURE 3 Kaplan-Meier Freedom From VAD Placement, Transplantation, or Death by Initial Perceptions of Heart Failure Prognosis



The High-Risk cohort included patients that both physicians and patients perceived as high risk whereas the Low-Risk cohort included patients that both physicians and patients perceived as low risk.

Finally, patients expressed incongruent opinions regarding the advanced HF treatment options in relation to other life sustaining therapies available for this group of patients. Among the physician identified high risk patients (those who one would have expected to have some discussions regarding life-sustaining therapies), only half had a power of attorney and only a third had discussions regarding life-sustaining therapies with their physician. Among the patients in this group who were willing to consider LVAD placement, arguably one of the most invasive forms of life support available, two-thirds would not have wanted a much simpler intervention such as a feeding tube. A willingness to consider an LVAD insertion rather than less invasive supportive measures may reflect the considerable burden of HF among these still-ambulatory patients, the hope that mechanical support can relieve symptoms, and a failure to appreciate the complex nature of this and other cardiac surgical interventions.

TABLE 4 Patient Opinions Regarding LVAD and Life-Sustaining Therapies Among Physician-Perceived High-Risk Patients

Patient Survey Question at Time of Enrollment	Affirmative Response Among Physician-Identified High-Risk Patients
What is your best estimate of how much longer you have to live?	
Less than 1 yr	21
Between 2 and 5 yrs	22
More than 5 yrs	42
Don't know	15
I have a designated health care proxy or power of attorney	51
I have talked to my physician about life-sustaining therapies	37
How would you feel about having an LVAD placed?	
I would want or consider a LVAD	77
I would refuse a LVAD	23
Opinions about life-sustaining therapies among patients who would consider an LVAD	
I would want any and all life-sustaining therapies available.	54
I would NOT want the following life-sustaining therapies:	
Do not want: chest compressions	33
Do not want: breathing machine	52
Do not want: kidney dialysis	46
Do not want: transfer to intensive care unit	15
Do not want: feeding tube if unable to eat	63

Values are %.

These findings underscore the many uncertainties and challenges faced by clinicians in having complex discussions regarding end of life and goals of care in an era of increasing clinical workload and decreasing time with patients. Physicians eliciting patient perceptions of their own level of illness may serve as an opportunity to approach the subject of advanced HF therapies. In addition, these findings suggest the need for educational interventions and decision aids to facilitate patient education about treatment options and HF prognosis as a supplement to face-to-face clinician-patient visits. Indeed, a recent randomized control trial of a video decision support tool did find that patients randomized to such an intervention found it to be acceptable and did have greater knowledge about end-of-life options afterward (10). Studies using such novel educational formats and decision aids are ongoing in patients facing destination therapy LVAD therapy and could be important in the future (11). Taken together, these data support the systematic introduction of scheduled reviews of prognosis and treatment options for patients with advanced HF (2).

STUDY LIMITATIONS. A major limitation of this study is that categorization of physician and patient HF risk as well as patients' opinions about LVAD and life-sustaining therapies were made at the time of enrollment. It is likely that both perceptions of risk and patients' opinions regarding life-sustaining therapies and LVADs might have changed with their disease course, particularly immediately prior to the endpoints of death, LVAD implantation, or transplantation. It is also possible that some patients might not have understood that some life-sustaining therapies such as a feeding tube would be anticipated to be temporary, which might have influenced their responses. Although physicians were asked about risk of death or advanced therapy at 1 year, we included outcomes beyond 1 year to take advantages of longer term outcomes available in this cohort but acknowledged that risk prediction beyond 1 year was challenging for both

patients and physicians. It is worth noting that a substantial number of these patients were referred to the enrolling centers for evaluation for LVAD or transplantation and that some of the patients had undergone a formal LVAD or transplantation evaluation, which might have shaped risk perception. Furthermore, more than half of the patients were followed by the participating LVAD/transplant program for at least a year, suggesting that a large percentage of patients might have had some exposure to and discussions of these concepts before enrollment.

CONCLUSIONS

Among ambulatory, advanced HF patients receiving oral therapy who were hospitalized for HF within the previous year, the risk of progression to transplantation, LVAD insertion, or death is relatively high. Physicians identified most patients in this cohort were at high risk for such progression, whereas patients tended to underestimate the severity of their illness. Despite discordant perceptions of illness severity, neither physicians nor patients were particularly accurate at predicting events. Despite a manifest concern for poor prognosis in this cohort of patients, robust discussions regarding life-sustaining therapies seem to be lacking. As there are growing treatment options, most notably with LVAD therapy, available for this cohort of advanced HF patients, earlier discussion regarding disease severity and treatment options are needed so that patients may make well-informed decisions.

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PERSPECTIVES

COMPETENCY IN MEDICAL KNOWLEDGE: Ambulatory patients with advanced HF on oral therapy who were hospitalized for HF within the previous year had a high risk of progression to transplant, LVAD implantation, or death; however, few patients recognized themselves to be at such risk for such disease progression. Furthermore, patients expressed inconsistent attitudes towards lifesaving treatment options, suggesting poor understanding of these therapies. As there are growing treatment options available for this group of patients, most notably with LVAD therapy, earlier discussions regarding HF prognosis and treatment options are needed to allow patients to make well-informed decisions.

TRANSLATIONAL OUTLOOK: Improvements in LVAD technology have resulted in the broader application of this life-saving therapy to patients with advanced HF. Despite the availability of this therapy, the present study highlights the difficulties that patients face as they attempt to integrate their own disease prognosis in relation to the timing and desire for LVAD implantation as well as other forms of life-sustaining treatments. As medical and device treatments for advanced HF continue to evolve, it will be important to incorporate patient-centered educational processes to facilitate the appropriate application of these treatments to the growing advanced HF patient population.

REFERENCES

1. Breathett K, Allen LA, Ambardekar AV. Patient-centered care for left ventricular assist device therapy: current challenges and future directions. Curr Opin Cardiol 2016;31:313–20.

2. Allen LA, Stevenson LW, Grady KL, et al. Decision making in advanced heart failure: a scientific statement from the American Heart Association. Circulation 2012;125:1928–52.

3. Ambardekar AV, Forde-McLean RC, Kittleson MM, et al. High early event rates in patients with questionable eligibility for advanced heart failure therapies: results from the Medical Arm of Mechanically Assisted Circulatory Support (Medamacs) Registry. J Heart Lung Transplant 2016;35:722–30.

4. Stewart GC, Kittleson MM, Cowger JA, et al. Who wants a left ventricular assist device for ambulatory heart failure? Early insights from the MEDAMACS screening pilot. J Heart Lung Transplant 2015;34:1630–3.

5. Stewart GC, Kittleson MM, Patel PC, et al. INTERMACS (Interagency Registry for Mechanically Assisted Circulatory Support) profiling identifies ambulatory patients at high risk on medical therapy after hospitalizations for heart failure. Circ Heart Fail 2016;9:e003032.

6. Allen LA, Yager JE, Funk MJ, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. JAMA 2008;299:2533–42.

7. Estep JD, Starling RC, Horstmanshof DA, et al. Risk assessment and comparative effectiveness of left ventricular assist device and medical management in ambulatory heart failure patients: results from the ROADMAP study. J Am Coll Cardiol 2015;66:1747–61.

8. Gorodeski EZ, Chu EC, Chow CH, Levy WC, Hsich E, Starling RC. Application of the Seattle heart failure model in ambulatory patients presented to an advanced heart failure therapeutics committee. Circ Heart Fail 2010;3:706–14.

9. Alba AC, Agoritsas T, Jankowski M, et al. Risk prediction models for mortality in ambulatory patients with heart failure: a systematic review. Circ Heart Fail 2013;6:881–9.

10. El-Jawahri A, Paasche-Orlow MK, Matlock D, et al. Randomized, controlled trial of an advance care planning video decision support tool for patients with advanced heart failure. Circulation 2016;134:52–60.

11. McIlvennan CK, Thompson JS, Matlock DD, et al. A multicenter trial of a shared decision support intervention for patients and their caregivers offered destination therapy for advanced heart failure: DECIDE-LVAD: rationale, design, and pilot data. J Cardiovasc Nurs 2016;31:E8–20.

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