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## Prognostic Awareness and Goals of Care Discussions Among Patients with Advanced Heart Failure

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### Abstract

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**Background:** Prognostic awareness (PA) – the understanding of limited life expectancy – is critical for effective goals of care discussions (GOCD) in which patients discuss their goals and values in the context of their illness. Yet little is known about PA and GOCD in patients with advanced heart failure (HF). This study aims to determine the prevalence of PA among advanced HF patients and patient characteristics associated with PA and GOCD.

**Methods:** We assessed the prevalence of self-reported PA and GOCD using data from a multisite communication intervention trial among advanced HF patients with an implantable cardiac defibrillator at high risk of death.

**Results:** Of 377 patients, (mean age 62 years, 30% female, 42% non-white), 78% had PA. Increasing age was a negative predictor of PA (OR=0.95, 95% CI 0.92, 0.97,  $p < 0.01$ ). No other patient characteristics were associated with PA. Of those with PA, 26% had a GOCD. Higher comorbidities and prior advance directives were associated with GOCD, but were of only borderline statistical significance in a fully adjusted model. Symptom severity (OR=1.77, 95% CI 1.19, 2.64,  $p 0.005$ ) remained a robust and statistically significant positive predictor of having a GOCD in the fully adjusted model.

**Conclusions:** In a sample of advanced HF patients, the frequency of PA was high, but fewer patients with PA discussed their end-of-life care preferences with their physician. Improved efforts are needed to ensure all advanced HF patients have an opportunity to have GOCD with their doctors. Clinicians may need to target older HF patients, and continue to focus on those with signs of worsening illness (higher symptoms).

**Registration:** [Clinicaltrials.gov - NCT01459744](https://clinicaltrials.gov/ct2/show/study/NCT01459744)

## INTRODUCTION

Heart failure (HF), which affects more than 6 million American adults and at least 26 million people worldwide, is a chronic, progressive illness with an unpredictable trajectory marked by intermittent acute, potentially life-threatening deteriorations and gradual functional decline.<sup>1, 2</sup> Advances in HF therapies (e.g. implantable cardioverter defibrillators (ICD), mechanical circulatory support, cardiac transplant)<sup>3-8</sup> mean increased survival for patients into old age<sup>9</sup> and HF continues to be associated with high morbidity and healthcare utilization.<sup>10</sup> One-year mortality may approach 50% in New York Heart Association (NYHA) class IV patients, defined as having symptoms at rest.<sup>11, 12</sup> The unpredictable trajectory of advanced HF<sup>13</sup> and the ongoing risk of death<sup>14</sup> make it complicated to discuss goals of care. At the same time, patients and caregivers consider effective communication important to high quality care,<sup>15-17</sup> and cardiology quality guidelines<sup>18, 19</sup> promote the integration of goals of care conversations into routine clinical practice for all patients with HF.

Despite these relatively poor outcomes, little is known about HF patients' awareness of having an incurable disease and a shortened life expectancy, often called prognostic awareness (PA).<sup>20, 21</sup> Among cancer patients, those who received more information about their prognosis were more likely to have trust in their oncologist, and have both peace of mind and hope.<sup>22, 23</sup> Likewise in advanced cancer, goals of care discussions (GOCD), in which patients share their goals and values in the context of a serious illness, are associated

with improved quality of life, lower costs of care, decreased family burden,<sup>24</sup> improved family satisfaction<sup>16</sup> and better bereavement outcomes.<sup>24, 25</sup> Although 70% of patients with HF expressed a strong desire for prognostic information when their physicians felt that they were likely to die in the next 12 months<sup>26</sup>, some data suggests that physicians are less likely to have GOCD with patients with HF.<sup>27–30</sup> Furthermore, patients with HF may overestimate their life expectancy compared with model-based predictions for survival.<sup>31</sup> However, prior studies have not explored the association between PA and GOCD in patients with HF. We analyzed data from a multisite communication intervention trial among advanced HF patients with an ICD who were at high risk of death<sup>32</sup> to determine the prevalence of PA among advanced HF patients. We also identified patient characteristics associated with PA and with GOCD.

## METHODS

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### Description of Parent Study

We conducted a cross-sectional secondary analysis of baseline data from patients enrolled in the Working to Improve diScussions about DefibrillatOr Management (WISDOM) trial, a 6-center, cluster randomized-controlled study to evaluate the effect of a multi-component communication intervention on conversations between HF clinicians and their patients regarding ICD deactivation and advance care planning.<sup>33</sup> The study was performed within the advanced HF practices at: Hospital of the University of Pennsylvania (Philadelphia, Pennsylvania), Mayo Clinic (Rochester, Minnesota), Montefiore Medical Center (Bronx, New York), Mount Sinai Hospital (New York, New York), University of Colorado Hospital (Aurora, Colorado), and Yale New Haven Hospital (New Haven, Connecticut). The trial enrolled patients with advanced HF who had a high likelihood of dying within 12 months after enrollment, as predicted by either the number of HF-related admissions<sup>34</sup> or ADHERE criteria<sup>14, 35</sup> as has been previously described.<sup>36</sup> Patients also had to be at least 18 years old, have an active ICD (i.e. not deactivated before enrollment), speak English or Spanish, and have consistent phone access. During the consent process, patients were informed that this was a trial about symptoms and quality of life, without sharing information about communication, prognosis or ICD deactivation to avoid the Hawthorne effect and potential patient harm.<sup>33</sup> Patients were enrolled in inpatient and outpatient settings between September 2011 to February 2016 and data collection continued until the last quarter of 2017. Baseline data were collected by patient interview shortly after study enrollment by a local, non-blinded research coordinator either in person or by telephone and abstracted from patient medical records at baseline by trained research coordinators.

Each site's Institutional Review Boards approved the study. This trial was listed on [clinicaltrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT01459744) - NCT01459744.

## Outcomes

Defining patient understanding about prognosis and goals can be difficult in survey research, given that both of these concepts are nuanced and complex. As such, we based our questions on what others have done in longitudinal studies of patients with serious illness. We defined PA as a “yes” response to the baseline interview question: “Has your doctor ever told you whether you could die from your heart disease?”<sup>37</sup> This question is taken from a longitudinal survey of patient preferences and understanding of disease; the study from which the question is adapted included 56 patients with advanced HF<sup>37</sup>. We defined having a GOCD when a patient answered “yes” to the baseline interview question: “Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?”<sup>24</sup> This question is taken from a longitudinal survey of patients with advanced cancer, and in their study, the authors used this single question as defining whether a GOCD had occurred.<sup>24</sup>

## Covariates

We obtained covariate data from both patient interviews and chart review at baseline. For demographics, we included age, education, race, and income by self-report; insurance status was taken from chart review. For HF-related characteristics, we included HF-related quality of life (Kansas City Cardiomyopathy Questionnaire (KCCQ)),<sup>38</sup> the number of HF-hospitalizations, candidacy for mechanical circulatory support and cardiac transplant, and patient-reported previous receipt of defibrillator shocks, all taken from the time of enrollment. For measures of illness severity, we included the number of comorbidities (baseline chart review); functional status measured by the Katz’s activities of daily living (ADLs) (baseline interview)<sup>39</sup>; anxiety measured by the Hospital Anxiety and Depression Scale (HADS) (baseline interview) (total score is 0 to 42 with depression and anxiety subscores each ranging from 0 to 21 and higher scores indicating worse symptoms)<sup>40</sup>; and symptom burden and symptom severity using the Memorial Symptom Assessment Scale (MSAS) at baseline interview.<sup>41</sup> We used cutoff scores of 11 points on the HADS-anxiety and HADS-depression subscales.<sup>42</sup> We defined advance directive documentation as having either a healthcare proxy, living will or do-not-resuscitate order, identified in chart review.

## Statistical Analysis

We described patient characteristics and prevalence of PA using means and percentages. We compared the relationship of patient characteristics to having PA using t-tests and  $\chi^2$  tests, as appropriate. Of those with PA, we assessed the association of patient characteristics with GOCD, using t-tests or  $\chi^2$  tests, as appropriate. For PA and GOCD assessments, we also conducted multivariable logistical regression controlling for patient baseline covariates demonstrating statistically significant associations at the bivariate level. For the PA model, in addition to adjusting for demographic characteristics (age, sex, race, ethnicity) and study site, *a priori*, we controlled for the following clinical variables that would potentially be related to conversations about PA: documented advance directives (a marker of contemplation of healthcare preferences), receipt of ICD shocks (a reminder of one’s disease)<sup>43</sup> and anxiety (as anxiety may reduce the desire to hear PA).<sup>23</sup> For the GOCD model, we included covariates that emerged as significant in the bivariate model, in addition

to demographic characteristics (age, sex, race, and ethnicity) and study site, which we had chosen to include *a priori*.

We used Stata 15.1 to estimate these models.

## RESULTS

### Sample characteristics

Of the 439 patients with baseline data, we had PA data for 423 (96%) and 377 (89%) had complete covariate data. (Table 1) Of the 46 subjects who were dropped for this analysis for missing data, the majority of the missingness was related to HADS or self-reported race. Of this final sample, patients had a mean age of 62 years (+/- 14 years), 30% were female, 10% were Hispanic and 42% were non-white. The HF-related factors of the sample demonstrated that they were relatively sick: the average KCCQ quality of life score was 6.5 (range 0–10), 47% had 2 or more HF hospitalization in the prior year, 47% of the subjects were candidates for mechanical circulatory support, and 42% had received ICD shocks before enrollment. Overall, 102 (27%) had completed an advance directive (22% healthcare proxy, 14% living will, and 2% do-not-resuscitate order).

### Outcome: Prevalence of Prognostic Awareness (PA) and Characteristics Associated with PA

Of the 377 patients who constituted the sample reported in this analysis, 293 (78%) reported PA. (Figure 1, Table 1) In bivariate analyses, patients with PA, as compared to those without PA, were younger (mean age of 61 vs. 68 years,  $p$ -value  $< .01$ ) and were more likely to have had at least two HF admissions in the last year (51% vs. 33%,  $p$ -value  $< .01$ ). Demographics (sex, race, ethnicity), documented advance directives, HF-related factors (e.g. number of HF admissions, receipt of ICD shocks), and illness severity markers (i.e., functional status, number of comorbidities, anxiety, symptom number and symptom severity) were not associated with PA. In a multivariable analysis, controlling for demographic characteristics, documented advance directives, HF-related factors, and illness severity markers (e.g. number of comorbidities and anxiety) as determined *a priori*, only increasing age was inversely associated with PA (OR = 0.95, 95% CI, 0.92, 0.97,  $p < 0.01$ ) (Table 2). In other words, younger patients were more likely to have PA. When we added study site to the prognostic awareness model, there was no change in the findings.

### Outcome: Characteristics Associated with Goals of Care Discussions (GOCDs)

Among those with PA, 76 (26%) reported having a GOCD with their physician. Of note, none of the patients ( $n=84$ ) who lacked PA had a GOCD. In bivariate analyses, those who had a GOCD were likely to have: more comorbidities (3.70 vs. 3.11,  $p$ -value = 0.02), a documented advance directive (42% vs. 24%,  $p$ -value  $< 0.01$ ), more symptoms (median MSAS number 5 vs. 4,  $p$ -value = .02), and higher symptom severity (median MSAS severity 1.0 vs. 0.7,  $p = 0.01$ ), as compared to those who did not have a GOCD. ADL difficulty was not associated with GOCD. In multivariable analysis (controlling for age, sex, race, ethnicity, number of comorbidities, chart documented advance directive, and symptom severity), clinical measures predictive of more GOCD included chart documented advance

directives (OR = 1.90, 95% CI, 1.06, 3.40,  $p = 0.03$ ), higher numbers of comorbidities (OR = 1.19, 95% CI 1.01, 1.40,  $p = 0.03$ ), and higher symptom severity (OR = 1.64, 95% CI 1.13, 2.39,  $p < 0.01$ ). (Table 3) When we added study site to each model in a sensitivity analysis, chart documented advance directives and number of comorbidities were no longer significant predictors of goals of care discussions yet symptom severity continued to be a significant and robust predictor (OR=1.77, 95% CI 1.19, 2.64,  $p < 0.005$ ),  $p < 0.01$  (Supplemental Table 1)). When we ran a sensitivity analysis including the same seven covariates from the GOCD model, there were no significant changes in the results of the PA model. (Supplemental Table 2)

## DISCUSSION

Our findings show that three-fourths of adults with advanced HF and high risk of mortality had PA. None of the HF-related markers or illness severity were associated with PA, whereas younger patients were more likely to have PA. Among those with PA, there was also a surprisingly low rate (26%) of GOCD. Only symptom severity was robustly and consistently associated with GOCD, whereas comorbidities and prior chart documentation of goals of care was only of borderline significance in our fully adjusted models.

Our findings of the relatively high prevalence of PA (78%) was higher than other studies.<sup>31</sup> Yet the low rate of completed advance directives, which may represent a surrogate marker of PA, are consistent with the results of other studies that examined rates of advanced directive completion among patients with HF.<sup>44</sup> Similarly, qualitative studies have suggested that physicians do not discuss the life-limiting nature of HF with their patients and rarely discuss goals of care with HF patients<sup>45</sup> even though data demonstrate that patients with HF would want this information.<sup>46</sup> In one cross-sectional cohort study, patients with NYHA HF Class II and III reported that they would want to have discussions with their clinician about what to expect in the future.<sup>47</sup> Nonetheless, no other studies have examined the patient characteristics associated with PA and GOCD in a sample of advanced HF patients at high-risk for death.

Understanding which factors are associated with PA in patients with HF may help improve goals of care conversations. We did not expect a lower prevalence of prognostic awareness among older patients. This finding contradicts a prior study which demonstrated higher survival expectations of younger patients with HF when compared to HF survival model predictions.<sup>31</sup> However, awareness that you may die from HF is distinct from estimates of how long one might survive. Our finding may suggest that physicians are less likely to inform their older patients that they will die from their HF. This may be because clinicians expect older adults to be aware of their prognosis, or perhaps clinicians assume that others involved in their care would disclose their prognosis. Furthermore, it may be that clinicians feel a different sense of obligation or urgency in discussing prognosis with younger patients, who may be less likely to expect their life to come to an end soon. Finally, younger patients do not expect to have HF or to die young, and therefore they may encourage their clinicians to disclose prognosis in response to their existential distress. To our knowledge, this unexpected finding has not yet been explored in the literature and merits further study. However, given that informed consent conversations around ICD implantation should indeed

both include a discussion about prognosis and deactivation because the goal of an ICD is to save a person from sudden death,<sup>48</sup> it is puzzling that not all patients understood their risk for mortality. The extremely low rate of GOCD among advanced HF patients with PA represents a “missed opportunity” for clinicians to provide these patients context for their ongoing medical care<sup>48</sup> and to record patients’ wishes in a documented advance care plan. Patients with more symptoms were more likely to have these conversations, suggesting these patient characteristics may trigger their physicians to engage in GOCD discussions. Alternatively, patients’ increased symptoms may have reinforced that they were seriously ill leading to increased PA and the initiation of GOCD. It is encouraging that there was a trend toward significance among patients who completed advance directives to also report a GOCD, as patients often complete these documents without the benefit of a discussion with a medical provider.<sup>49</sup> It is important to note that unlike a HCP or a living will, a DNR order is more likely to be the result of a discussion with their physician. It also reinforces the idea that patients who have contemplated their future healthcare needs may be more likely to discuss their goals of care with their physician. These findings highlight the importance of PA as a precursor, though not a requisite, to having a goals of care discussion.

With the addition of study site into the multivariable models, the chart documented advance directives and number of comorbidities were no longer significant in the goals of discussion model. We hypothesize that this may be related to the fact that study site may be a proxy measure for sociodemographic differences in patient population served by the different medical centers. (This is due to the fact that the study involved randomization at the site level not the patient level; thus there are differences in the characteristics of patients based on geographic region.) Future research is needed to examine how sociodemographic and clinical characteristics may affect prevalence of and patient characteristics associated with prognostic awareness and goals of care discussions.”

Of note, other illness severity markers, including functional status, were not associated with GOCD, implying that even in cases where patients have difficulty caring for themselves, the dependency does not prompt physicians to discuss goals of care or prompt patients to initiate these conversations. Although symptoms of HF may be more overtly burdensome, loss of function should also trigger a GOCD.

Although we found that there are specific factors associated with PA and GOCD, our data demonstrate that there are opportunities to improve clinicians<sup>48</sup> training to assure that advance care planning occurs with all patients with advanced HF. Communication skills training enables clinicians to help patients understand their illness, and elicit their goals and values if they became more sick. Specifically, the communication strategy of “Ask-Tell-Ask”<sup>50</sup> can be used to better understand if patients and/or their families heard information that has been shared. In the first “ask”, the clinician can find out what others clinicians have told them about their heart failure. For example, “*What have the doctors told you so far about your heart?*” In the “tell”, the clinician can fill in the gaps in understanding, and share what they understand about their HF, in succinct terms without medical jargon. If appropriate, the clinician could include an estimate of prognosis. For example, “*In spite of our best efforts, your heart failure is getting worse.*” In the second “ask”, the clinician can clarify what the patient actually heard. “*I imagine this is surprising, can you tell me what*



*you will tell your partner when you go home?”* Resources to teach primary palliative care communication skills include the Center to Advance Palliative Care’s (CAPC) foundational Vital Talk training modules (<https://www.capc.org/collaborations/vitaltalk/>).

## Limitations

While this multi-site study provides several new insights into communication and PA in advanced HF, there are some limitations to our study. First, this sample only includes patients with ICDs; nonetheless, ICDs are highly prevalent in the population of patients with advanced HF and therefore, these individuals are more likely to meet the definition of advanced HF (AHA/ACC Stage D HF).<sup>13</sup> Second, the outcome questions for PA and GOCD are patient-reported and physician-centered; therefore, may not reflect what patients were told by their clinicians, may not reflect PA information patients gleaned from other sources, and finally, may not capture all of the potential nuances of these outcomes. While goals of care conversations are complex multipart discussions that take place over time, we still believe our study is one of the first to examine these concepts in patients with advanced HF via a comprehensive randomized trial relating to patient preferences and outcomes. Finally, this was an advanced HF sample and therefore, the results may not be generalizable to a population with less advanced HF. Rates of PA may be lower in these less sick populations. In spite of these limitations, the data demonstrate that there are opportunities to improve the quality of the conversations between patients and their physicians in the setting of advanced HF.

## Conclusions

In light of the unpredictable disease trajectory of HF, it is critical that these patients and their families better understand their prognosis and have opportunities to discuss their treatment preferences in the context of their prognosis and illness trajectory. Quality guidelines in both cardiology and palliative care<sup>18, 19</sup> encourage the integration of conversations about prognosis and goals of care into routine clinical practice for all patients with HF, regardless of age or symptoms. The low rates of conversations in this study demonstrate an opportunity to improve the care for these patients and their families. Through improving clinicians’ communication skills, PA and GOCD can be enhanced. This will achieve the gold standard of patient-centered care, in which patients receive treatments aligned with their preferences. This research aims to be a first step in this process, by bringing an awareness to the current landscape of communication around PA and GOCD among a sample of patients with advanced HF at high-risk for death.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Abbreviations

<b>HF</b>	heart failure
<b>PA</b>	prognostic awareness
<b>GOCD</b>	goals of care discussion
<b>MSAS</b>	Memorial Symptom Assessment Scale
<b>ADLs</b>	activities of daily living
<b>NYHA</b>	New York Heart Association
<b>ACC/AHA</b>	American College of Cardiology/American Heart Association
<b>ICD</b>	implanted cardiac defibrillator
<b>KCCQ</b>	Kansas City Cardiomyopathy Questionnaire
<b>HADS</b>	Hospital Anxiety and Depression Scale

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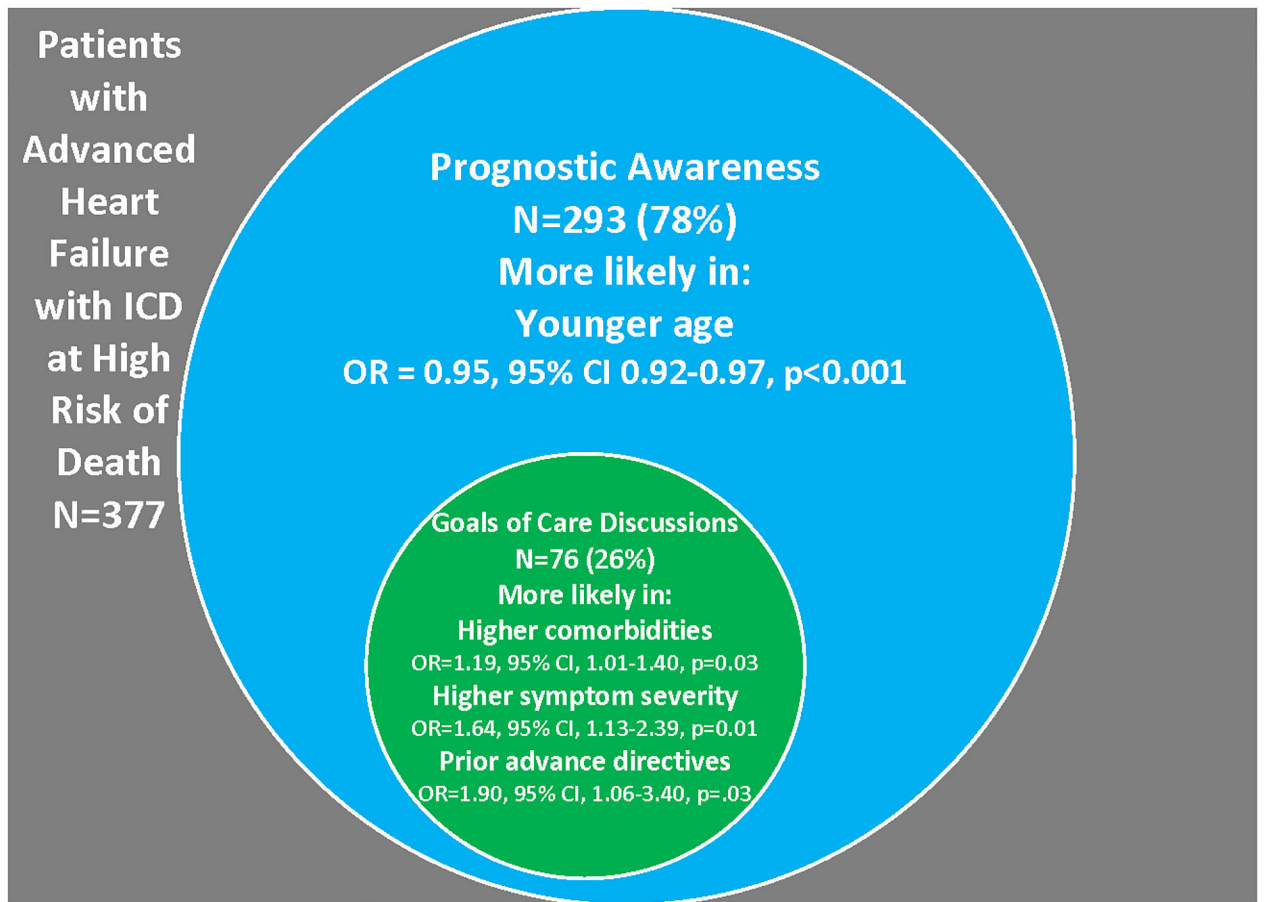
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**What is new?**

- In this sample, three-fourths of adults with advanced HF and high risk of mortality understood that they could die from their HF.
- None of the HF-related markers or illness severity were associated with being told that they could die from their HF, or having prognostic awareness (PA). Yet, younger patients were more likely to be aware that they could die from their HF.
- Among those with PA, there was a low rate (26%) of discussing their goals of care. Only comorbidities, number of symptoms and their severity, and prior chart documentation of advance directive were associated with GOCD.

**What are the clinical implications?**

- Discussing prognosis and goals of care is particularly complex due to the unpredictable trajectory of advanced HF and the ongoing risk of death. Therefore, it is critical that these patients and their families better understand their prognosis and have opportunities to discuss their treatment preferences in the context of their prognosis and illness trajectory.
- Although we found that there are specific factors associated with increased conversations about PA and GOCD, there are still opportunities to improve clinicians training to assure that advance care planning occurs with all patients with advanced HF.



**Figure 1:**

Prognostic awareness and goals of care discussions among a sample of patients with advanced heart failure. Patients were enrolled in a clinical trial of a clinician-centered intervention to improve conversations about management of implantable defibrillators and advance care planning. The size of each shape is proportional to the number of people within the shape.

**Table 1:**

Demographics of study samples of patients with advanced heart failure

	Total Sample (N = 377)		PA (N=293)		No PA (N=84)		p-value*	Goals of Care Discussion (N =293)		p-value*		
	No.	%	No.	%	N	%		GOCD (N=76)	No GOCD (N=217)			
DEMOGRAPHICS												
Age, mean (SD), years	377	62.4 (13.6)	293	60.7 (13.5)	84	68.4 (12.4)	<.001	76	61.0 (11.8)	217	60.5 (14.0)	0.77
Male	262	69.5	205	70.0	57	67.9	0.71	59	77.6	146	67.3	0.09
Hispanic <sup>‡</sup>	38	10.1	29	9.9	9	10.7	0.83	5	6.6	24	11.1	0.26
White	219	58.1	174	59.4	45	53.6	0.34	49	64.5	125	57.6	0.29
Married/Partner	214	57.2	165	56.7	49	59.0	0.70	45	59.2	120	55.8	0.61
High School Education or Less	145	40.9	114	40.6	31	41.9	0.84	32	42.1	82	40.0	0.75
Medicaid	103	27.5	81	27.9	22	26.2	0.75	22	29.7	59	27.3	0.69
Income <\$20K	106	36.3	85	37.1	21	33.3	0.58	27	41.5	58	35.4	0.38
Chart Advance Directive	102	27.1	85	29.0	17	20.2	0.11	32	42.1	53	24.4	0.003
HF-RELATED												
KCCQ QOL, median <sup>‡</sup>	372	7.0	290	7.0	82	7.0	0.47	74	6.0	216	7.0	0.06
Candidate MCS	176	46.7	139	47.4	37	44.1	0.58	31	40.8	108	49.8	0.18
ICD shocks received	158	41.9	130	44.4	28	33.3	0.07	38	50.0	92	42.4	0.25
> 2 HF admits	177	47.0	149	50.9	28	33.3	0.01	39	51.3	110	50.7	0.93
ILLNESS SEVERITY												
No ADL difficulty <sup>§</sup>	172	45.6	130	44.4	42	50.0	0.36	33	43.4	97	44.7	0.85
Severe ADL difficulty <sup>§</sup>	47	12.5	35	12.0	12	14.3	0.57	10	13.2	25	11.5	0.71
HADS Anxiety	44	11.7	39	13.3	5	6.0	0.06	15	19.7	24	11.1	0.06
# comorbidities	377	3.0	293	3.0	84	3.0	0.66	76	3.7	217	3.1	0.02
MSAS severity, median	377	0.8	293	0.8	84	0.8	0.19	76	1.0	217	0.7	0.01
# MSAS symptoms, median	377	4.0	293	4.0	84	4.0	0.20	76	5.0	217	4.0	0.02
Site							0.20					0.001



	Total Sample (N = 377)			Prognostic Awareness (N = 377)				Goals of Care Discussion (N =293)			
	PA (N=293)		No PA (N=84)	p-value*	GOCD (N=76)		No GOCD (N=217)		p-value*		
	No.	%			N	%	N	%			
Mount Sinai	79	21.0	54	18.4	25	29.8	49	22.6	5	6.6	
Pennsylvania	69	18.3	53	18.1	16	19.1	40	18.4	13	17.1	
Colorado	59	15.7	49	16.7	10	11.9	35	16.1	14	18.4	
Mayo	39	10.3	33	11.3	6	7.1	18	8.3	15	19.7	
Montefiore	66	17.5	50	17.1	16	19.1	42	19.4	8	10.5	
Yale	65	17.2	54	18.4	11	13.1	33	15.2	21	27.6	

Table reports results descriptive statistics of 3 different samples of patients with advanced heart failure. Column A is the total sample. Column B is Column A divided into those patients with and without prognostic awareness. Column C is the subsample of those patients with prognostic awareness who had a goals of care discussion with their clinician about their wishes if they were dying.

Abbreviations: ADL = Activities of Daily Living; HADS = Hospital Anxiety Depression Scale; HF = Heart Failure; ICD = Implantable Cardioverter Defibrillator; KCCQ = Kansas City Cardiomyopathy Questionnaire; MCS = Mechanical Circulatory Support; MSAS = Memorial Symptom Assessment Scale

\* P-value based on chi-square test or t-test

† Race and ethnicity categories are not mutually exclusive.

‡ QOL scored 0 – 10; MSAS severity scored 0=not present to 4=causes very much distress

§ No ADL difficulty: “no difficulty” with any ADL; Severe ADL difficulty: “a lot of difficulty” or “can’t do” for any ADL

**Table 2:**

Logistic Regression Predicting Prognostic Awareness (N=377)

	<b>OR</b>	<b>P-value</b>	<b>95% CI</b>	
Age per year	0.95	<.001	0.92	0.97
Male	1.24	0.47	0.69	2.22
Hispanic *	0.60	0.24	0.25	1.42
White	1.74	0.07	0.96	3.13
Number of comorbidities	1.08	0.31	0.93	1.25
Chart documented advance directives	1.72	0.09	0.91	3.22
Number admissions for heart failure				
1 (vs. 0)	0.91	0.80	0.44	1.88
2+ (vs. 0)	1.64	0.19	0.78	3.45
ICD received shocks	1.26	0.41	0.73	2.17
HADS anxiety	2.20	0.13	0.79	6.16

Table reports results of multivariable analysis of our sample of patients with advanced HF who had prognostic awareness, defined as having answered “yes” to the question “Has your doctor ever told you whether you could die from your heart disease?”

Abbreviations: HADS = Hospital Anxiety and Depression Scale, ICD = Implantable Cardioverter Defibrillator;

\* Race and ethnicity categories are not mutually exclusive.

**Table 3:**

Logistic Regression Predicting Goals of Care Discussions for Patients with Prognostic Awareness (N=293)

	OR	P-value	95% CI	
Age per year	0.99	0.44	0.97	1.01
Male	1.93	0.06	0.99	3.78
Hispanic *	0.50	0.20	0.17	1.44
White	1.14	0.68	0.61	2.15
Number of comorbidities	1.19	0.03	1.01	1.40
Chart documented advance directives	1.90	0.03	1.06	3.40
MSAS physical symptom severity	1.64	0.01	1.13	2.39

Table 3 reports results of multivariable analysis of our sub sample of patients with advanced heart failure who had prognostic awareness and also had a goals of care conversation, defined as having answered “yes” to the question “Has your doctor ever told you whether you could die from your heart disease?”

Abbreviations: MSAS = Memorial Symptom Assessment Scale

\* Race and ethnicity categories are not mutually exclusive.

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