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End-of-Life Discussions in Patients with Heart Failure

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Abstract

Background—Although guidelines call on clinicians to conduct regular conversations about advance care planning and end-of-life (EOL) preferences with patients with heart failure (HF), research suggests that physicians often avoid these discussions.

Methods and Results—Between January 20, 2014 and January 18, 2016, Southeastern Minnesota residents hospitalized with acute decompensated HF (ADHF) at Mayo Clinic hospitals were enrolled into an observational cohort study that included the administration of face-to-face questionnaires. Risk of death (prognosis) was estimated using the Meta-analysis Global Group in Chronic Heart Failure score. Among 400 patients (mean age 77.7 years, 46% female, 48% preserved ejection fraction), only 69 (17%) reported previously discussing EOL wishes with their physician. Patients reporting prior EOL discussions more often had an advance directive (81% vs. 66%, $p=0.009$), recognized the term ‘hospice’ (96% vs. 87%, $p=0.027$), and had more favorable attitudes of dying and hospice ($p=0.030$). Resuscitation preferences and rates of completion of advance directives varied with prognosis, though patient-clinician EOL discussions did not.

Conclusions—The majority of patients hospitalized with ADHF did not recall discussing their preferences for EOL care with their physician. This represents an important modifiable gap in the optimal longitudinal care of HF patients.

Keywords

heart failure; end-of-life; advance care planning; prognosis

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INTRODUCTION

While advances in HF treatment have improved survival after diagnosis, HF still has a high associated mortality and half of individuals will die within five years of diagnosis.(1) However, the clinical trajectory preceding death can vary from patient to patient and is often unpredictable. As such, the importance of considering preferences for future care in advance of an acute event has been well-recognized. National HF guidelines recommend that clinicians engage patients and their family/caregivers in discussions about prognosis and wishes for end-of-life (EOL) care.(2,3) Furthermore, it is recommended that all individuals should document their wishes in the form of an advance directive (AD). To encourage clinicians to make time for these discussions, in 2016, the Center for Medicare and Medicaid Services began financially reimbursing clinicians for participating in advance care planning discussions (ACP) with their patients.

However, research has suggested that most patients with HF are not participating in ACP. One study of patients hospitalized with HF found that more than 80% did not have an AD. (4) Another study reported that only 41% of community patients with HF had an AD.(5) This may reflect that clinicians are not routinely initiating ACP discussions with their patients or reviewing their wishes for EOL care, as up to 30% of clinicians feel ill-equipped to broach these issues.(6) However, whether patients with HF report discussing their wishes for EOL care with their clinicians remains to be determined, as does the potential associations of these discussions with other aspects of ACP, including completion of ADs.

To address these gaps in knowledge, we aimed to determine if patients hospitalized with acute decompensated HF (ADHF) reported ever discussing their wishes for EOL care with their physicians and to assess the patient-level predictors of those discussions. Second, we examined whether EOL preferences differed by prognosis, as assessed using the validated Meta-analysis Global Group in Chronic Heart Failure (MAGGIC) risk score.(7)

MATERIALS AND METHODS

Study Design and Patient Population

Between January 20, 2014 and January 18, 2016, Southeastern Minnesota residents hospitalized with ADHF at Mayo Clinic hospitals in Rochester, Minnesota were prospectively recruited into an observational cohort study that included the administration of face-to-face questionnaires. Patients were included in the study if they had chronic HF, were hospitalized with ADHF meeting Framingham criteria, were at least 20 years old, and were residents of one of seven Southeastern Minnesota counties. Questionnaires were administered by a study coordinator. Patients were excluded if they were incapable of completing the questionnaires due to mental or physical limitations. All participants provided written authorization, and the study was approved by the Mayo Clinic Institutional Review Board.

Patient Characteristics

To determine whether patients had previously discussed their wishes for EOL care with their physicians, patients were asked, "Have you and your doctor discussed any particular wishes

you have about the care you would want to receive if you were dying?”(8,9)Topics discussed with their physicians, resuscitation preference, completion of AD, attitudes regarding dying and hospice, familiarity with terms ‘palliative care’ and ‘hospice’, patient activation, health literacy, health status, marital status, and education were assessed by questionnaire.(8–15) Further details on the survey items are included in the Supplementary Methods. Demographics, comorbidities, and prescribed medications were collected from the electronic medical record. The date of death was determined using death certificates filed in local counties, obituary notices, and electronic files of death certificates obtained from the State of Minnesota Department of Vital and Health Statistics. The Meta-analysis Global Group in Chronic Heart Failure (MAGGIC) risk score and associated 1-year mortality estimates were calculated using patient characteristics at the time of hospital admission (7,16).

Statistical Analysis

Missing data were minimal; most variables were complete and all had <1% missing. Differences in baseline characteristics in patients who did and did not report discussing their wishes for EOL care with a physician were examined using chi-square, t-tests and Wilcoxon rank-sum tests where appropriate. Differences in EOL preferences and planning in those who did and did not report prior discussions of their wishes for EOL care with their physician were examined using Fisher’s exact, chi-square and t-tests. Differences in EOL preferences and planning by prognosis (MAGGIC risk score as continuous variable) were examined using two sample t-tests. All analyses were performed using Stata Version 13 (College Station, TX). A $p<0.05$ was used as the level of significance.

RESULTS

A total of 498 patients were approached for inclusion in the study and 400 (80.3%) agreed to participate. Participant baseline characteristics are shown in Table 1. Non-participants were similar in age (mean age 75.8 vs. 77.7 years, respectively, $p=0.22$) and sex (49% vs. 46% females, $p=0.56$) to participants. The median (25th–75th percentile) time from hospital admission to completion of questionnaires was 2 (1–3) days.

Among 400 patients, only 69 (17%) reported previously discussing their wishes for EOL care with their physician, 330 patients reported they had not previously discussed their wishes for EOL care with their physician, and one patient had no response. Patients that had previously discussed their wishes for EOL care were more often married (68% vs 52%, $p=0.011$), anemic (84% vs 69%, $p=0.010$) and hyponatremic (30% vs 13%, $p=0.002$). Patients that reported previously discussing their wishes for EOL care with their physician more often reported that their physician talked about details if they got sicker (36% vs. 17%, $p<0.001$), how long they had left to live (17% vs. 6%, $p=0.001$), what dying might be like (13% vs. 3%, $p=0.002$), important things in life (39 % vs. 21%, $p=0.001$), and spiritual and religious beliefs (25% vs. 7%, $p<0.001$, Supplementary Table).

Patient preferences for prognostic information, resuscitation, prevalence of AD, recognition of the terms ‘palliative care’ and ‘hospice’, and attitudes about dying and hospice are shown in Table 2. Patients reporting prior EOL discussions more often had an AD, recognized the term ‘hospice’, and had more favorable attitudes of dying and hospice.

The observed 6-month and 1-year mortalities in this study were 26.5% and 36.5%, respectively. Of the 400 participants, predicted 1-year mortality by MAGGIC risk score ranged from 3.9–72.5% (median 22.7%). A step-wise increase in mortality with higher MAGGIC risk scores was observed (Supplementary Figure), though observed mortality appeared higher than mean predicted mortality across all quartiles. As such, MAGGIC scores were used to qualitatively stratify patients by prognosis. Patients with higher predicted mortality (worse prognosis) more often preferred no resuscitation ($p=0.002$) and had an AD ($p<0.001$, Figure).

DISCUSSION

Only 17% of this cohort of community patients hospitalized with ADHF reported previously discussing their preferences for EOL care with their physician. Patients reporting EOL discussions were more knowledgeable about EOL options and more likely to have completed an AD. Resuscitation preferences and rates of completion of ADs varied with prognosis, though patient-clinician EOL discussions and awareness and attitudes about EOL options did not.

Despite guidelines advocating for ACP discussions in patients with HF(2,3,17), only a small fraction of patients hospitalized with ADHF reported previously discussing their wishes for EOL care with their doctor. While this may reflect that physicians are not routinely having these discussions with patients, patients also may not recall discussions even if they occurred. Regardless, these data suggest there is room for improvement in the frequency and quality of patient-clinician EOL discussions.

We were surprised to find that there were very few systematic differences between patients who did and did not report discussing their wishes for EOL care with their physicians. While we anticipated that patients who reported prior EOL discussions would be older, sicker, and have a worse prognosis, that was not the case. This may signify that clinicians are not routinely relying on signs of advanced HF to trigger these discussions. Furthermore, while prior work has suggested that disease specialists may be more accurate at prognostication in advanced illness(18), we found no difference in the proportion of patients reporting prior EOL conversations in those followed by our multidisciplinary HF clinic compared with other clinics.

Patients that did report prior EOL discussions with their physicians more often had an AD, were more familiar with hospice, and had attitudes about dying and hospice that more closely aligned with palliative care principles. While the cross-sectional nature of these data precludes any conclusions about causality, it is reasonable to consider that these discussions may have had an impact on the patient's completion of ACP documents and knowledge of EOL options.

There are some limitations to acknowledge. First, patient responses to questionnaire items were open to misinterpretation. Second, we asked patients to recall prior discussions with physicians, and the possibility of recall bias exists. Finally, this study reflects the perceptions of patients with HF living in a single community. The study population is predominantly

Caucasian, which may limit the generalizability to populations of varying racial and ethnic diversity.

Conclusion

Despite increasing recognition of the importance of EOL discussions and ACP in patients with HF, patients perceive they are still occurring infrequently. This represents an important modifiable gap in the optimal longitudinal care of patients with HF. Efficacious interventions targeted at increasing the occurrence of EOL discussions in patients with HF are needed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS

ACP	advance care planning
AD	advance directive
ADHF	acute decompensated heart failure
BMI	body mass index
DNR	Do Not Resuscitate
EOL	end-of-life
HF	heart failure
MAGGIC	Meta-analysis Global Group in Chronic Heart Failure
NYHA	New York Heart Association

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HIGHLIGHTS

- The vast majority of patients hospitalized with acute decompensated heart failure say they have never discussed their wishes for end-of-life care with their doctor.
- End-of-life discussions were no more common in patients with worse prognosis.
- Patients who recall having discussions were more knowledgeable about end-of-life options and more likely to have completed an advance directive.

Figure. Advance Care Planning and End-of-Life Preferences According to Risk of Death

The mean (standard deviation) estimated 1-year MAGGIC mortality for patients responding 'yes' or 'no' to each patient-reported variable are shown. Data were analyzed using 2 sample t-tests with MAGGIC estimated mortality as a continuous variable and patient-reported variable as a yes/ no binary variable. P values <0.05 are designed with a *. Exact p values are: patient-physician end-of-life discussion p=0.14, patient indicates preference to receive prognostic information p=0.053, patient has an advance directive p<0.001, patient prefers no resuscitation p=0.002, patient recognizes term 'palliative care' p=0.94, and patient recognizes the term 'hospice' p=0.82.

Table 1

Patient Characteristics

Characteristic	Overall (n=400)	Did Not Discuss Wishes with Physician (n=330)	Discussed Wishes with Physician (n=69)	P value
Age, years, mean(SD)	77.7 (12.5)	77.3 (12.8)	79.2 (10.7)	0.25
Male, n (%)	216 (54.0)	172 (52.1)	43 (62.3)	0.12
BMI, mean (SD), kg/m ²	32.2 (8.2)	32.2 (8.3)	32.0 (7.8)	0.92
EF, mean (SD), %	45.7 (16.8)	45.9 (16.9)	44.7 (16.3)	0.59
Preserved EF, n (%)	193 (48.4)	163 (49.5)	29 (42.0)	0.26
Duration of HF > 18 months, n (%)	274 (68.5)	228 (69.1)	46 (66.7)	0.69
NYHA class IV on admission	264 (66.3)	218 (66.5)	45 (65.2)	0.84
Lived at home prior to hospitalization, n (%)	332 (83.0)	276 (83.6)	55 (79.7)	0.44
Followed in HF Clinic, n (%)	74 (18.5)	58 (17.6)	16 (23.2)	0.29
Psychosocial Characteristics				
Married, n (%)	218 (54.5)	170 (51.5)	47 (68.1)	0.011
Post-high school education, n (%)	188 (47.0)	151 (45.8)	37 (53.6)	0.23
Poor health literacy, n (%)	112 (28.1)	92 (28.0)	20 (29.0)	0.86
Patient activation score, mean (SD)	54.3 (7.3)	54.2 (6.9)	54.8 (9.1)	0.56
Health status fair or poor, n (%)	284 (71.0)	233 (70.6)	51 (73.9)	0.58
Comorbidities				
Hypertension, n (%)	337 (84.5)	275 (83.6)	62 (89.9)	0.17
Systolic blood pressure, mean (SD), mmHg	131.4 (23.8)	132.2 (23.5)	127.2 (25.2)	0.11
Diastolic blood pressure, mean (SD), mmHg	70.6 (17.0)	70.4 (16.4)	72.1 (20.0)	0.44
Diabetes mellitus, n (%)	182 (45.5)	147 (44.5)	34 (49.3)	0.47
Prior myocardial infarction, n (%)	115 (28.8)	97 (29.4)	18 (26.1)	0.58
Cerebrovascular disease, n (%)	84 (21.0)	67 (20.3)	17 (24.6)	0.43
Peripheral vascular disease, n (%)	72 (18.0)	65 (19.7)	7 (10.1)	0.061
Dementia, n (%)	11 (2.8)	10 (3.0)	1 (1.4)	0.70
COPD, n (%)	108 (27.0)	87 (26.4)	21 (30.4)	0.49
Depression, n (%)	70 (17.5)	59 (17.9)	11 (15.9)	0.70
Anemia, n (%)	288 (72.0)	229 (69.4)	58 (84.1)	0.010
Hyponatremia, n (%)	49 (16.2)	30 (12.7)	19 (29.7)	0.002

Characteristic	Overall (n=400)	Did Not Discuss Wishes with Physician (n=330)	Discussed Wishes with Physician (n=69)	P value
Creatinine, mg/dL *	1.4 (1, 2)	1.3 (1, 2)	1.5 (1.1, 2)	0.068
Charlson Comorbidity Index *	3 (1, 5)	3 (1, 5)	3 (1, 4.5)	0.19
Medications on Admission				
Beta-blocker, n (%)	329 (82.3)	269 (81.5)	59 (85.5)	0.42
ACE/ARB, n (%)	220 (55.0)	175 (53.0)	44 (63.8)	0.10
Loop diuretic, n (%)	336 (84.0)	278 (84.2)	57 (82.6)	0.74
Aldosterone blocker, n (%)	46 (11.5)	40 (12.1)	6 (8.7)	0.40
In-hospital Outcomes				
Hospital length-of-stay, days *	4 (3, 7)	4 (3, 7)	4 (3, 8)	0.49
Discharged to home, n (%)	285 (72.7)	234 (70.9)	49 (71.0)	0.91
In-hospital mortality, n (%)	8 (2.0)	7 (2.1)	1 (1.4)	0.99
30-day Mortality , n (%)	27 (6.8)	20 (6.1)	7 (10.1)	0.24

ACE/ARB= angiotensin converting enzyme inhibitor/ angiotensin receptor blocker. BMI= body mass index, COPD= chronic obstructive pulmonary disease, EF= ejection fraction, HF= heart failure, NYHA= New York Heart Association, SD= standard deviation

Differences in baseline characteristics in patients who did and did not report discussing their wishes for EOL care with a physician were examined using t-tests for continuous normally-distributed variables (age, BMI, EF, patient activation score, systolic blood pressure, diastolic blood pressure), Wilcoxon rank-sum tests for continuous non-normally distributed variables (creatinine, length of stay, Charlson), and Fisher's exact (dementia, in-hospital mortality) or chi-square tests (all others) for binary variables. Missing data included NYHA functional class on admission in two patients, EF in one patient, health literacy in one patient, hypertension in one patient, and heart failure clinic status in one patient. All other variables were complete.

* Numbers shown are median (25th, 75th percentile)

Table 2

End-of-Life Preferences and Planning Stratified by Prior End-of-Life Discussions

	Overall (n=400)	Did Not Discuss Wishes with Physician (n=330)	Discussed Wishes with Physician (n=69)	P value
Discussed EOL Wishes with Physician, n (%)				
Yes	69 (17.3)	--	--	
No	330 (82.5)	--	--	
Unsure/ no response	1 (0.3)	--	--	
Want prognostic information, n (%)				
Yes	249 (62.3)	202 (61.2)	46 (66.7)	0.40*
No	126 (31.5)	107 (32.4)	19 (27.5)	
Unsure/ no response	25 (6.3)	21 (6.4)	4 (5.8)	
Advance directive, n (%)				
Yes	274 (68.5)	218 (66.1)	56 (81.2)	0.009*
No	116 (29.0)	104 (31.5)	11 (15.9)	
Unsure/ no response	10 (2.5)	8 (2.4)	2 (2.9)	
Resuscitation Preference, n (%)				
Prefers attempts at resuscitation	213 (53.3)	176 (53.3)	36 (52.2)	0.98*
Prefers no resuscitation	166 (41.5)	138 (41.8)	28 (40.6)	
Unsure/ no response	21 (5.3)	16 (4.8)	5 (7.2)	
Recognize term, 'palliative care', n (%)	57 (14.3)	46 (13.9)	11 (15.9)	0.67
Recognize term, 'hospice', n (%)	355 (88.8)	288 (87.3)	66 (95.7)	0.027
Attitudes regarding dying and hospice scale score, mean (SD)	4.0 (1.5)	4.0 (1.5)	4.4 (1.6)	0.030

EOL= end-of-life, SD= standard deviation

* Those who answered 'unsure/ no response' were excluded from analysis

Differences in those who did vs. did not report discussing their wishes for end-of-life care with their physician were compared using 2-sample t-tests (attitudes regarding dying and hospice scale score) and chi square (all others).