RESEARCH LETTER

Advance Care Planning and End-of-Life Education in Heart Failure: Insights From the NCDR PINNACLE Registry

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Advance care planning (ACP) and prognosis/end-of-life (EOL) education are recommended by several professional organizations and consensus guidelines in heart failure (HF) care.[1] Yet, these occur infrequently in HF care.[2,3]

A primary goal of the PINNACLE (Practice Innovation and Clinical Excellence) Registry was to track critical measures of quality improvement and outcomes. For HF, ACP and EOL education were identified as critical measures with education provided to clinicians. Given guidelines suggesting the importance of these metrics in HF care, data on ACP and EOL education were collected. Therefore, we examined (1) prevalence of ACP and EOL education in patients with HF and (2) variation in these metrics by patient, clinic, and provider characteristics.

The data utilized in this research were obtained from the American College of Cardiology Foundation's (ACCF) National Cardiovascular Data Registry (NCDR). Data are not publicly available, but requests for analyses can be submitted to the PINNACLE R&P Committee. Analyses are conducted by contracted Data Analytic Centers, which then provide aggregated and de-identified results to the stakeholder who submitted the research proposal.

Patients with HF (n=1 684 284) enrolled in the PINNACLE Registry, a prospective cohort for a range of cardiovascular conditions that are collected from 348 US outpatient academic and nonacademic cardiology practices from January 1, 2013 through June 30, 2018, were identified. Advarra approved this study and granted a waiver of written informed consent. An electronic medical record mapping algorithm is used to capture variables of interest and relevant data, although paper-based reporting forms may also be used. Data were limited to those documented and inputed into the registry by each participating practice. χ^2 for categorical variables and t tests for continuous variables were used. All analyses were performed using SAS Version 9.4 (SAS Institute, Cary, NC) by the Baim Institute for Clinical Research.

Rates of and variation in ACP and EOL education were calculated for 1 675 458 HF outpatients (see Table 1).

Documentation of ACP was found for 34.1% of patients ($Mean_{age}$=68.9±14.1). Documentation of ACP was low among patients with left ventricular assist device (34.1%) or other cardiovascular implantable electronic devices (pacemaker, 35.2%; ICD, 30.6%; CRT, 35.2%; CRT-D, 35.9%). Although a high rate of missingness, less than half of patients with New York Heart Association (NYHA) I–III HF (42–47%) had ACP documented compared with a higher rate among NYHA class IV (60.0%).

Documentation of EOL education was exceedingly rate, occurring in only 1.9% of patients, with similar rates for men and women (1.9%), but lower among Hispanic/Latinos patients (0.3%), and Black patients (1.6%) compared with non-Hispanic/Latino patients (2.0%), and White patients (2.5%). Documented EOL education was low among patients with NYHA class III (2.5%) or IV (1.4%) HF, although there was a high rate of missingness. Similarly, documentation was low among patients

Key Words: advance care planning ■ communication ■ decision making ■ heart failure ■ prognosis

Nonstandard Abbreviations and Acronyms

ACCF	American College of Cardiology Foundation
ACP	advance care planning
EOL	end of life
HF	heart failure
NCDR	National Cardiovascular Data Registry
NYHA	New York Heart Association

Table 1. Rates of ACP and EOL within Patient, Provider, and Practice Characteristics

Patient characteristics	ACP	EOL	Missing
Sex			0.0
Men	33.6	1.9	
Women	34.3	1.9	
Race			28.1
White	34.0	2.5	
Black	33.7	1.6	
Other	22.8	0.6	
Ethnicity			0.0
Not Hispanic/Latino	33.7	2.0	
Hispanic/Latino	38.4	0.3	
Current smoker	36.0	1.5	7.2
Insurance			26.1
Private	35.4	1.7	
Medicare	35.3	1.0	
Medicaid	37.8	0.4	
Other	31.8	0.2	
None	59.2	48.0	
Comorbidities			0.0
Dyslipidemia	34.3	2.2	
Diabetes	32.9	0.2	
Hypertension	34.2	2.1	
Myocardial infarction	35.4	2.2	
PCI/PTCA	39.1	2.1	
CABG	38.8	2.7	
Stroke/TIA	38.2	0.8	
Cardiac events			0.0
LVAD	34.1	0.0	
CRT	35.2	1.3	
CRT-D	35.9	1.3	
ICD	30.6	1.7	
Permanent pacemaker	35.2	1.4	
MAGGIC risk score quartiles			95.2
0–11	49.2	3.8	
12–16	53.4	3.8	
17–21	53.2	3.4	
22–45	51.6	2.4	

(Continued)

Table 1. Continued

Patient characteristics	ACP	EOL	Missing
MAGGIC risk score quartiles without NYHA			88.9
0–12	41.1	2.7	
13–17	42.9	2.0	
18–21	43.7	1.6	
22–42	42.0	1.1	
NYHA class			58.7
Class I	42.1	3.5	
Class II	46.5	4.3	
Class III	43.8	2.5	
Class IV	60.0	1.4	
Heart failure first diagnosed ≥18 months ago	29.9	1.3	0.0
Beta blocker	33.5	1.7	0.0
ACEi/ARB	33.5	1.5	0.0
Provider/Practice characteristics			
Provider type			0.0
Physician	33.8	2.0	
Nurse practitioner	37.2	1.7	
Other	31.8	1.1	
Geographic region			0.0
Northeast	35.3	0.1	
South region	32.2	1.5	
Midwest	42.8	6.0	
West region	29.0	0.3	
Location			0.1
Urban	37.5	3.7	
Suburban	31.8	0.4	
Rural	29.3	1.1	

Data presented are in percentages unless otherwise indicated. ACEi/ARB indicates angiotensin converting enzyme inhibitors/angiotensin receptor blocker; ACP, advanced care planning; CABG, coronary artery bypass graft; CRT, cardiac resynchronization therapy; CRT-D, cardiac resynchronization therapy defibrillator; EOL, end-of-life education; ICD, implantable cardioverter defibrillator; LVAD, left ventricular assist device; MAGGIC, meta-analysis global group in chronic heart failure; NYHA, New York Heart Association; PCI/PCTA, percutaneous coronary intervention/percutaneous transluminal coronary angioplasty; TIA, transient ischemic attack.

with cardiovascular implantable electronic devices (pacemaker, 1.4%; ICD, 1.7%; CRT, 1.3%; CRT-D, 1.3%).

Despite the importance of ACP and EOL discussions in patients with HF, this large contemporary outpatient evaluation reveals modest rates of ACP (<50%) and very low rates of EOL education (<2%), with substantial variation by patient and practice characteristics. Of note, there was little evidence of appreciably greater discussion in those with a poor prognosis, including those who were NYHA class III/IV, although the association is unclear given the high rates of missingness. These findings suggest that despite guideline recommendations, patients with HF have infrequently documented (and potentially infrequently received) ACP or EOL education, which may adversely affect a patient's ability to engage in informed

decision making. This is particularly important given the unpredictable disease trajectory of HF and the need for multiple treatment decisions by patients with advanced HF, increasing the likelihood that they may lack the knowledge and understanding to make these decisions.

Additionally, results from this study suggest a disconnect between consensus guidelines and routine clinical care, despite potential benefits by various stakeholders. Several factors may contribute to variation in ACP and EOL education, including access to care, provider time and resources, as well as provider confidence in these discussions. Future work is needed to understand these factors and improved ways by which to implement guideline-directed HF care. A multidisciplinary model which addresses barriers to care, such as limited care communication among team members, may help with ACP and EOL education. In addition, training in discussing ACP and EOL education be of great help to clinicians.[4] Increasing the amount of time and resources available to facilitate these discussions may also assist with improved reimbursement for care coordination and related interventions. Future research should test implementation efforts to increase engagement in these care aspects.

ARTICLE INFORMATION

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