

Advance Care Directives in Patients with End-Stage Heart and Lung Disease



Billings J,³ Tennstedt S,¹ McDermott S,¹ Kasten L,¹ Portenoy R,² Grinke, K.³

From New England Research Institutes, Watertown, MA (1), Beth Israel Medical Center, New York (2), and the Massachusetts General Hospital, Boston, MA (3). Supported by NINR grant NR05154)

BACKGROUND

Congestive heart failure (CHF) and Chronic Pulmonary Disease (CPD) are among the four leading causes of death in persons age 65 and over, afflict 4.6 million and 16 million Americans respectively, and result in almost \$25 billion in annual health care expenditures. The experience of patients and their families facing these conditions is highly complex and distinct from other illnesses, yet the symptom profiles, distress, and many other features commonly experienced by patients and their caregivers dealing with these two diseases have received much less attention than for cancer and AIDS. We studied the prevalence and multidimensional nature of symptoms experienced by patients with advanced stages of CHF and CPD, especially the impact of symptoms on the distress and quality of life of both patient and family caregiver. Other variables included sociodemographic characteristics, quality of life, mental health, functional status, family burden, resource utilization, costs (from insurance records), and several measures of disease status. We report here an investigation of the factors associated with having a health care proxy (HCP) and/or a living will (LW).

METHODS

DESIGN

- Four-year prospective observational study
- Interviews every 3 months for 30 months
- Patients from the Massachusetts General Hospital in Boston and Beth Israel Medical Center in New York.
- Eligibility
 - Diagnosis of CPD (FEV1 <30% due to primary pulmonary disease) OR CHF (ejection fraction <35%; NYHA Class III or IV)
 - Life expectancy \geq 3 months
 - Community dwelling

MEASURES

- Symptoms: *Memorial Symptoms Assessment Scale (MSAS)*
- Function: *Sickness Impact Profile (SIP-68)*
- Quality of Life: *Multidimensional Index of Life Quality (MILQ)*
- Patient Psychological Well-Being: *Rand Mental Health Inventory (MHI-5)*
- Inventory of co-morbid conditions: *Charlson Comorbidity Index*
- Medications, health care utilization, advanced care planning and informal care

RESULTS

Percent with Advance Directives (AD), Health Care Proxies (HCP), Living Wills at Baseline (n=203)

No advanced directive	30%
Discussed treatment preferences with family	59%
Discussed treatment preferences with physician	37%
HCP	69%
Living Will	29%
HCP and Living Will	27%
Of those with advance directive	
AD in possession of family	93%
AD in possession of lawyer	70%
AD in possession of physician	47%

Factors Associated with Having a Living Will or Health Care Proxy (HCP) at Baseline (n=203): Results of Logistic Regression

Variable	Odds Ratios Predicting	
	Living Will	HCP
CPD vs CHF	0.57	0.72
Site 1 (BINY)	0.94	1.35
Male	0.57	0.61
Race: White	6.65**	1.12
Married	0.74	1.38
Age (5 year increase)	1.35**	1.20*
Mental Health Index	1.03	1.03
Quality of Life	1.01	1.03
Comorbidity	0.84	1.06
SIP		
Physical Function	0.98	1.01
Psychological Function	0.98	1.01
MSAS		
Number of Symptoms	0.88	0.95
Total Symptom Burden	48.6*	3.04

* p < 0.05 ** p < 0.01

CONCLUSIONS

Patients in this study with advanced heart and lung disease are in frequent and regular contact with health care providers and often have been hospitalized for these conditions, but report minimal communication with their physicians about end-of-life treatment preferences.

- 30% have no proxy and fewer than one-third have a living will.
- Less than half of patients in this study report discussing treatment preferences with their physicians, while less than half of those patients with LWs have shared them with their physician.