Speaking from the Heart: Self-Defined Heart Failure Goals beyond Advance Care Planning

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LIFECOURSE

- Builds upon an expanded set of palliative care domains to promote whole person care
- Uses a family-oriented approach to understand needs, leverage strengths, and empower families to effectively support their loved ones
- Asks patients and caregivers to articulate individualized goals and take part in decision making
- Includes a trained lay healthcare worker as the primary contact across settings and over time

BACKGROUND

Patients living with advanced heart failure face increasingly complex care decisions and must weigh the benefits and risks of medical treatment options with personal values. Goals are often determined by standard guidelines and medical plans, which focus on physical symptoms. When patients are asked about their goals, they identify both medical and non-medical areas of importance that can help guide care decisions. If goals show predictable changes over time, providers can anticipate the need to revisit goal discussions.

RESEARCH QUESTION

What is the nature and evolution of medical and nonmedical goals identified by advanced heart failure patients who are in the last 2-3 years of life?

DATA

Lay health care workers prompted patients to define their goals for living with serious illness during monthly visits. Goals were documented in the electronic medical record and tracked over time. The goals of 30 heart failure patients with the longest amount of follow-up before death were examined.

Table 1.Characteristics of 30 Heart Failure Patients

Characteristics	Mean/N	SD/%
Follow-Up, months	19.6	6.1
Comorbidities	5.3	1.4
Married	15	50%
Caucasian	28	93%
Female	10	33%
Education		
HS or less	9	30%
Some College to Bachelor's	14	47%
Grad/Professional School	6	20%
Missing	1	3%
Baseline Residence		
Home	24	80%
Nursing Home	3	10%
Assisted Living	3	10%

Figure 1. Example of Serious illness Goals Documentation in the Medical Record

JOANNE'S STORY

The things Joanne wants her healthcare team to know about her:
"I want to stay in my home as long as possible."
"I want to spend time doing things I love, being with people important to me."

What Matters Most to Joanne at this time?
"I want to stay in my house as long as possible."

Joanne has stated the following related goals and plans:

Focus 1 Description: "Never give up hope of staying home"

Focus 2 Description: "I want to get off or take less pain medications."

Focus 3 Description: "I want to have more energy and stamina."

Focus 4 Description: "I always hope to make a trip to visit friends & family, here and in Europe."

Focus 5 Description: "Protect my assets and get my affairs in order to leave some money for my family."

Focus 6 Description: "Discuss my health with family"

Focus 7 Description: "I don't want to go back to the hospital unless I have severe pain."

Focus 8 Description: "The cancer is back. I do not want to treat it."

Focus 9 Description: Daughter: "help to manage mom's health"

Focus 10 Description: Daughter: "plan for future needs"

ANALYSIS

Goals were deductively coded using an expanded version of the palliative care domains from the National Consensus Project Palliative Care Guidelines. Quantitized results were summarized by domain and duration to examine how goals evolved as patients neared end of life.

FINDINGS

Table 2. Summary of Patient Goals by Domain

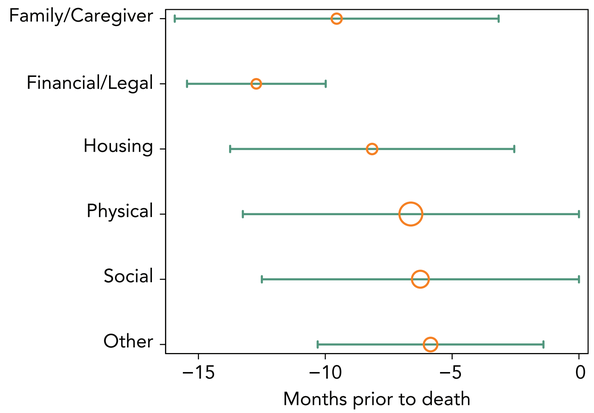
Non-physical goals constitute 60% of goals identified by advanced heart failure patients, indicating the importance of a whole person care approach. Family/caregiver, financial/legal and housing concerns previously existed within the NCP Social domain. The expanded domain set used for this analysis allows a refined examination of social goals.

Domain	Goals (N=287)		Prevalence among patients (N=30)	
	N	%	N	%
Physical	116	40%	27	90%
Social	63	22%	24	80%
Financial/Legal	20	7%	15	50%
Housing	24	8%	14	47%
Family/Caregiver	23	8%	8	27%
Other*	41	14%	20	67%

** Other includes end-of-life, ethical, legacy/bereavement, psychological, and spiritual goals.*

On average, whole person self-defined goals begin to surface 15 months prior to death. This preliminary analysis reveals that patients identify different types of goals at different times in their illness trajectory. While physical and social goals are prominent and carry through until death, patients identify upstream non-medical concerns that affect their health and well-being.

Figure 2. Median Onset of Goals by Domain



CONCLUSIONS

- While physical goals are prominent, they were often short lived and time specific.
- Non-physical goals were collectively higher in number, equally prevalent, and sustained for longer periods of time over the illness trajectory.
- Financial/legal, housing, and family/caregiver goals started earlier than physical and social goals and described patients concerns of where and how they will live, and about time with and concern about the wellbeing of loved ones.
- End-of-life, ethical, legacy/bereavement, psychological, and spiritual goals were the least prevalent and may indicate the need for intentional exploration by the care team.
- Goals that sustained through death evolved to a global nature, indicating a desire to maintain a sense of hope, meaning, and purpose in the face of physical decline.

CONSIDERATIONS

This study offers an initial exploration of when and for how long different types of patient identified goals occur and is not intended to represent the experience of all heart failure patients.

- Preliminary data were collected over time as procedures for articulating goals were defined.
- Examination of medical and life events is needed to better understand the contextual elements affecting goal evolution.
- Duration of goals may be influenced by length of service in the program.
- Future research might include the level of importance patients assign to their goals.

IMPLICATIONS

- Advance heart failure concerns include medical and nonmedical needs.
- Serious illness goals of care conversations could start 2-3 years prior to death.
- Ongoing discussions about goals of care may allow for integration of patient concerns into care decisions. We have an opportunity to support nonmedical goals.

ACKNOWLEDGEMENTS

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