Published in final edited form as:

J Hosp Palliat Nurs. 2016 April ; 18(2): 110–114. doi:10.1097/NJH.0000000000000229.

Patients' Perceptions of Illness Severity in Advanced Heart Failure

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Heart failure (HF) impacts almost 6 million Americans, with this number expected to nearly double by 2030.¹ Complicating the high incidence of heart failure is a five-year mortality rate approaching 50% following initial diagnosis. Patients with advanced or Stage D heart failure face an even greater risk of rehospitalization and death. Within 30 days of a hospitalization, there is a 25% chance of readmission and an 11% mortality rate.² Heart failure is complicated further by its unpredictable trajectory.³⁻⁵ Although prognostication may be difficult, all healthcare providers, including nurses must remember that heart failure patients are at risk for sudden rapid decline and/or death.^{3,5,6} Yet, even with this risk, end-of-life treatments, including end-of-life conversations and referrals by nurses to the appropriate services, such as palliative care and hospice, are not widely used with the heart failure population in a timely manner, if at all.⁶⁻⁹

Although, the limited life expectancy of advanced heart failure warrants healthcare provider-patient conversations related to advance care planning and the course of heart failure, these conversations rarely occur. One of the main reasons for the lack of discussion is that both the patient and healthcare provider are waiting for the other person to begin the conversation.¹⁰⁻¹² Nurses typically believe it is the physician's responsibility to begin these conversations, so do not begin or encourage patients to have these discussions. Even if the conversation occurs, little progress has been made in the use of end-of-life services for this population because the discussion tends to focus on management and the next available treatment rather than advance care planning and end-of-life decisions. The use of palliative care has also been hampered by the lack of understanding of palliative care as an overarching philosophy, that is appropriate not just during the terminal phase of the illness, as with hospice care, but at any time during an illness.¹³ It is also hindered by limited availability of services,¹⁴⁻¹⁶ patients' refusals to accept services when offered,¹⁷ and a lack of understanding of the terminality of the disease.^{3,18-20} To help determine why end-of-life services may not be utilized in patients with advanced heart failure, this study investigated

the perceptions of illness severity and illness terminality in advanced heart failure patients with a <2-year predicted survival.

Palliative Care

Palliative care is an overarching philosophy of care that is provided by both generalists (basic palliative care providers) and specialists (healthcare providers certified in palliative care).²¹ The World Health Organization defines palliative care as improving quality of life for anyone with a life-threatening illness.²² As a philosophy, palliative care is delivered to all patients and their caregivers upon diagnosis with a serious/life-limiting illness through the terminal phase of the illness and post-death bereavement. The National Consensus Project for Quality Palliative Care (NCP) characterizes palliative care as both a philosophy and delivery of care provided by a coordinated interdisciplinary team of specialized and non-palliative care providers, where the patient's and family's needs and hopes for peace and dignity are communicated and supported through the illness, death, and after death. These services may be provided as part of or independently of life-prolonging care.²³ According to the NCP there are numerous domains of care including physical, psychological, social, spiritual, cultural, ethical/legal, end-of -life care and structure/process (coordination and continuum of care). These domains provide the principles of person-centered patient and family care, continuity, and collaborative care throughout the illness/death trajectory.

Palliative Care and Heart failure

The Heart Failure Society of America (HFSA) recommends a palliative care approach for advanced heart failure patients, enabling the palliative care specialist to work along with the primary practitioner to form an interdisciplinary team approach.²⁴ This patient-centered model allows for concurrent care without withdrawal of curative treatments. One of the difficulties with this approach is the lack of specification of the timing of when patients should be referred to the specialized palliative care team or hospice.²⁵ Another difficulty is when the appropriate conversations do not occur, it is unknown whether a patient wants life-prolonging treatments, even if quality of life is lessened versus quality of life with a shortened survival.²⁶

Palliative care consultations have been found to promote goal setting and improve outcomes of care in patients with heart failure and their family caregivers.^{27,28} Once patients and family caregivers fully understand all their options, treatments can align with their specific goals, preferences, and values to promote quality of life.^{29,30} Although a patient-centered approach would seem to address the issue of a lack of advance care planning and the referral to and acceptance of palliative care by patients and families, this has not been the case.³¹ Planning and use of services has been hindered by patients' religious and cultural backgrounds and preferences.⁹ It also is hampered by a lack of understanding or acceptance of the terminal course of heart failure by patients and families.^{3,18-20,31}

Purpose

To help determine why patients may not be receiving palliative care services, this study describes the perceptions of illness severity and terminality of advanced heart failure patients

(those with a <2-year predicted survival) during the terminal course of the disease. For those participants who died, the provision of palliative care and/or hospice at end of life was also explored.

Methods

As part of a longitudinal study (NIH/NINR R01 –5R01NR013419 –04) investigating the end-of-life trajectory of patients with advanced heart failure, 100 individuals with heart failure with a predicted survival of <1-year versus (n=40) <2-years (n=60) were interviewed. Predicted survival was determined by Seattle Heart Failure Model³² at time of enrollment. Following IRB approval from both hospitals, participants were recruited from two large heart failure centers, one located in an inner city and the other in a suburban/rural location. Participants were enrolled while hospitalized for an acute exacerbation or immediately following discharge. During the initial interview, participants were asked to describe their disease and where they see themselves in one-year. For participants who died during the study, services utilized at end of life were obtained through a chart review and/or during a post-death interview with the identified family caregiver. Two analytic teams blinded to patients' predicted survival completed qualitative thematic analysis³³ of the interviews. Research team members then met to participate in a group comparative analysis, where each participant was discussed to reach a consensus (if not independently agreed upon) as to whether participants understood the terminality of their heart failure based on the participants description of their heart failure and the answer to the question, “Where do you see yourself in one year?”

Results

The sample included 100 individuals with advanced heart failure. Forty had a predicted survival of < 1 year and 60 with < 2 years. Sample demographics are shown in Table 1. The majority of participants in both groups (80% in < 1year and 87% in <2 year) did not understand the severity or the terminality of their heart failure. Only 16% of the total sample perceived their heart failure as terminal. Out of the 51 participants who died during study enrollment, only 14% perceived heart failure as a terminal disease (see Tables 2 & 3). Many participants described their health deterioration as part of the aging process. Of the 49 participants who were still alive at the end of the study, 17 (35%) had a trajectory changing intervention; 10 received a heart transplant and 7 had a ventricular assist device implant.

Perceptions of Heart failure Severity and Terminality

The analysis of perceptions of illness included investigating participants' understanding of the heart failure disease process. In the initial interview, participants answered questions about what it was like living with heart failure. Participants told stories about their heart attacks or when symptoms like shortness of breath began. Conversations continued with major treatment decisions that occurred over their disease trajectory course. Participants reported their functional status as getting better or getting worse or back and forth over time. From this analysis, participants were categorized as either able to perceive or not perceive heart failure as end of life. In participants with a <1-year predicted survival, the understanding of the terminal course of heart failure ranged from denial, “I don't have an

illness", to partial knowledge, "I was always told it wasn't going to hurt me....it's just an inconvenience", to realization of terminality, "if you have any sense...you know what they are saying to you". The < 2 year survival group relayed comments such as: "I don't have heart failure," "when the doctor's explain things to me, I think I am being sold a used car," "when I ask what is going on...just more tests...like a fishing expedition." One participant said, "I ain't gonna get like this again", demonstrating a true lack of understanding of the disease trajectory. A clearer distinction about perceptions of the seriousness of heart failure occurred when patients answered the question: "Where do you see yourself in a year?" Exemplar quotes from the sample are presented by predicted survival in Table 4.

Palliative Care/Hospice Utilization

Fifty-one participants died at some point during their 2-year study enrollment. Charts were reviewed for these participants and a post-death interview was completed with the majority of family caregivers. During this interview, family caregivers were asked about services received at end of life. One of these participants died following admission to an outside rehabilitation facility and the caregiver was unavailable for the final interview, so the numbers reflect 50 deaths. Below is the breakdown of services:

- 22 of 50 (44%) received a palliative care consultation or received hospice care at some point during study enrollment
- 24 participants died in the hospital: 10 (42%) had a palliative care consult during terminal admission
- 26 died out of the hospital:
 - 6 (23%) had palliative care consults
 - 10 (38%) had hospice
 - 5 (19%) had both a palliative care consult and hospice

Discussion

Participants in this study were enrolled based on a Seattle Heart failure Model predicted survival of < 2 years and 97% of participants were a NYHA Class III or IV. Even with this advanced disease trajectory, the majority of the participants did not perceive heart failure as terminal and did not understand the progression of the disease. Most participants blamed either old age or other co-morbid conditions as causing their symptoms (e.g. feeling weak and/or unable to walk to the bathroom was typically blamed on arthritis or old age). Other studies have found similar results: patients, family caregivers, and even healthcare providers do not understand the prognosis³. Participants recalled discussions about the course of heart failure with the healthcare provider but stated that it focused on the next treatment option. Few participants remembered having discussions about the terminality of heart failure or advance care planning, and few had advance directives. These results are congruent with previous studies that showed that patients rarely had discussions with their healthcare providers about prognosis and treatment plans related to the prognosis²⁰. Thus, patients' future plans reflected their own understanding of heart failure and its progression and not necessarily the healthcare provider's understanding of the prognosis³⁴.

As seen in other studies, the lack of understanding and acceptance of the course of heart failure by both patients and health care providers, particularly with patients with advanced disease, resulted in few patients receiving palliative care referrals or hospice care and resources in general were underutilized.^{3,20,34} Similar to what was found in other studies, the majority of patients who died in the hospital only received a palliative care referral during the terminal hospitalization and most within a day of death,⁷ although the earlier palliative care is introduced the better the outcome.²⁷

Conclusions

Despite the limited predicted survival rate, the majority of patients did not view heart failure as a terminal disease and most patients were not offered services. Envisioning palliative care as a philosophy of care, delivered by all healthcare providers, would lead to incorporating supportive interventions from diagnosis to end of life even without patient understanding and acceptance of disease terminality. Nurses are situated perfectly through their educational background to provide caring, nurturing, and evidence-based information to patients and their caregivers about palliative care, hospice, and other services. As society's needs change and awareness of the issues surrounding end of life increases, nurses are called to advocate for those with advanced life-limiting illnesses and their families. Palliative care should be part of the management plan for all heart failure patients, not be restricted to end of life. If incorporated into routine care patient care would be enhanced. There also would not need to be a trigger for nurses to be reminded that a referral to the specialized service is warranted, since it is known that this trigger results in limited or late referrals.⁷

Implications

To follow the guidelines of the HFSA²⁴ and HPNA,³⁴ palliative care needs to be envisioned as a philosophy, not just a specialty service to be addressed by all practitioners including cardiac specialists and general practitioners, and nurses.³⁰ The majority of nurses by virtue of their education are prepared as “generalists” and are able to provide basic palliative care. Specialty palliative care can be provided at the registered nurse and advanced practice levels through advanced training and certification.

Due to the unpredictable heart failure trajectory and the risk of sudden death, early in the trajectory, discussions about advance care planning need to occur. Discussions need to occur during times of stability in addition to instability, since more thoughtful decisions can be made when the patient and caregiver are not stressed and worried about immediate survival.³⁶ These discussions will help with future clinical decisions and may help patients and their family caregivers have a realistic understanding of heart failure and its progression.

Acknowledgments

Funding: NIH, NINR, 5R01 NR013419-04, (Hupcey, Kitko, MPI)

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Table 1
Study Demographics

		Total Sample n=100	Predicted Survival SHFM < 1 year n = 40	Predicted Survival SHFM < 2 years n = 60
AGE	RANGE	36-89	37-88	36-89
	AVERAGE	66	66	66
GENDER		68 (68%) M	31 (46%) M	37 (54%) M
		32 (32%) F	9 (28%) F	23 (72%) F
RACE		12 (12%) Black	8 (67%) Black	4 (33%) Black
		88 (88%) White	32 (36%) White	56 (63%) White
NYHA Class (at enrollment)	II	3 (3%)	--	3 (5%)
	III	54 (54%)	18 (45%)	36 (60%)
	IV	43 (43%)	22 (55%)	21 (35%)

Table 2
Perceptions of Heart Failure as End of Life

Participants' Perceptions of HF as EOL	Predicted Survival SHFM < 1 year n = 40	Predicted Survival SHFM < 2 years n = 60	Patients who died 51/100 (51%)
Perceived as EOL 16% (16/100)	20% (8)	13% (8)	14% (7/51)
Did not perceive as EOL 84% (84/100)	80% (32)	87% (52)	86% (44/51)

Table 3
Perceptions of Heart Failure as End of Life in Participants who Died

Deaths 51/100 (51%)	Predicted Survival SHFM < 1 year n = 23 (58%)	Predicted Survival SHFM < 2 years n = 28 (43%)
Participants who died and did not perceive HF as EOL	59% (19/32)	48% (25/52)
Participants who died and perceived HF as EOL	50% (4/8)	38% (3/8)

Table 4
Exemplar Quotes from Participants about Heart Failure

Course of Heart failure/One Year Prediction	
<i>1 Year Predicted Survival</i>	<i>2 Year Predicted Survival</i>
I am trying to live 10 or 20 more years	Working and golfing more
Hopefully at home and back on my feet...doing things myself	...just adjust my life...not like this is a terminal disease
I will be in the grave	You are not going to be here forever...I'm not exactly 26 years old anymore