

Giving Voice to Patients' and Family Caregivers' Needs in Chronic Heart Failure: Implications for Palliative Care Programs

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Abstract

Background: The American College of Cardiology Foundation/American Heart Association (ACC/AHA) Guidelines for the Management of Heart Failure recommend palliative care in the context of Stage D HF or at the end of life. Previous studies related to heart failure (HF) palliative care provide useful information about patients' experiences, but they do not provide concrete guidance for what palliative care needs are most important and how a palliative care program should be structured.

Objectives: Describe HF patients' and their family caregivers' major concerns and needs. Explore whether, how, and when palliative care would be useful to them.

Design and participants: Qualitative study using in-depth interviews of 33 adult outpatients with symptomatic HF identified using purposive sampling and 20 of their family caregivers.

Approach: Interviews were transcribed verbatim and analyzed using the constant comparative method.

Key results: Overall, patients and caregivers desired early support adjusting to the limitations and future course of illness, relief of a number of diverse symptoms, and the involvement of family caregivers using a team approach. A diverse group of participants desired these elements of palliative care early in illness, concurrent with their disease-specific care, coordinated by a provider who understood their heart condition and knew them well. Some diverging needs and preferences were found based on health status and age.

Conclusions: HF patients and their family caregivers supported early integration of palliative care services, particularly psychosocial support and symptom control, using a collaborative team approach. Future research should test the feasibility and effectiveness of integrating such a program into routine HF care.

Introduction

PALLIATIVE CARE NEEDS in chronic heart failure (HF) are evident from the substantial physical and psychosocial burdens that patients and families experience with this highly morbid and life-limiting illness. Patients report a high prevalence of breathlessness, fatigue, pain, anxiety, and depression¹⁻³ and experience high mortality rates.⁴⁻⁶ The American College of Cardiology Foundation/American Heart Association (ACC/AHA) Guidelines for the Management of Heart Failure generally recommend palliative care at the end of life

or when HF is refractory to medical therapy, with marked symptoms at rest requiring interventions such as transplant, mechanical support, or hospice (Stage D HF).⁷ However, if palliative care is considered only at late stages in HF,⁸ patients and their families may miss opportunities to benefit from palliative care earlier in the illness. Furthermore, HF management programs and routine HF care usually focus on the disease-specific aspects of HF and do not systematically or comprehensively address palliative care needs.^{9,10} This is due in part to lack of evidence to guide how the palliative care needs of patients with HF should be addressed.

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Although previous studies related to HF palliative care provide useful information about HF patients' experiences, they do not provide concrete guidance for what palliative care needs are most important and how a palliative care program should be structured. For example, studies have focused on patients with New York Heart Association (NYHA) class III–IV HF and have described the experience of living with HF,^{11–13} patients' limited understanding of illness^{13–16} and prognosis,^{12,16} and end-of-life preferences.^{17–19} Assessment of patient and family views of the relative importance of particular palliative care needs and their preferences for what should be provided when and by whom would provide critical guidance toward the design and implementation of palliative care in HF.

We conducted a qualitative study of outpatients with symptomatic HF to learn about patients' and their family caregivers' major concerns and needs and to explore whether and how palliative care would be useful to them. We asked participants to describe what was most difficult and important for them, their needs around specific palliative care domains (symptoms, psychosocial issues, decision making, and the future of illness), and how and when these care needs should optimally be addressed.

Methods

Design

We conducted in-depth, semi-structured, one-on-one interviews with HF patients and separate interviews with their family caregivers from 2007 through 2008 in order to inform the design of a palliative care intervention to address HF patients' and caregivers' expressed needs and preferences. Informed consent was obtained and all study procedures were approved by the Colorado Multiple Institutional Review Board.

Sampling and recruitment

We used purposive sampling to include patients who varied in terms of age and health status and were likely to contribute to our understanding of unmet needs and preferences related to palliative care. Eligible patients had a HF diagnosis from their doctor and NYHA functional class II–IV. A cardiologist member of the research team confirmed the diagnosis of HF. Patients with a diagnosis of dementia were excluded. Providers in outpatient cardiology and geriatric clinics at the University of Colorado Hospital identified and recruited potential subjects. Medical records of potentially eligible patients were reviewed for age and health status. As the study proceeded, we targeted recruitment to include older patients to achieve a range of ages in our sample. Sampling and interviews continued until thematic saturation was achieved. Of the 38 patients approached for interviews, 3 refused because they were not interested and 2 refused because they felt they were too ill to participate. Patients were asked to identify a caregiver for interviews: "Can you think of the one person beside a healthcare provider who helps you the most with your heart condition?" All caregivers approached about the study gave informed consent and participated. Caregivers and patients were interviewed separately in the clinic or at their homes.

Data collection

The interview guide was developed to understand HF patients' and their family caregivers' major concerns and

needs and to learn how palliative care might be useful to them, both in terms of content and structure. The palliative care domains assessed in interviews were based on the National Consensus Project's conceptual model of palliative care (Table 1).²⁰ The word "palliative" was not used in the interview guide to avoid asking participants to decide whether their needs in these domains were palliative. We chose an open-ended approach to inquiring about issues related to advance care planning and death/dying by asking about "the future." The interview guide was revised after presentations to primary care and palliative care research groups, review by two qualitative researchers, and pilot testing with three patients. Two interviewers (CTN, JHR) experienced in qualitative methods conducted in-depth, semi-structured, 60- to 90 minute interviews with 33 HF patients and 20 caregivers. Interviews were digitally recorded, transcribed verbatim, and entered into ATLAS.ti²¹ for coding and analysis.

We reviewed patients' medical records for HF etiology, current therapies, most recent ejection fraction, NYHA class, and brain natriuretic peptide (BNP). After each interview, participants provided sociodemographic data, time since diagnosis (patients), and caregiving information (caregivers). Patients also completed the Kansas City Cardiomyopathy Questionnaire (KCCQ), a self-report measure of HF-specific health status.^{22,23} The overall summary score (range 0–100) combines symptom burden, physical

TABLE 1. INTERVIEW DOMAINS AND SAMPLE QUESTIONS

Interview domains	Sample questions/probes ^a
Major concerns and needs	What is most difficult or distressing for you about your heart condition? If you could have <i>anything</i> you wanted to help you with your heart condition, what would that be?
Physical aspects of care	Can you tell me about any of your symptoms that might need better treatment? How do you deal with symptoms?
Psychological and psychiatric aspects of care	What would you do if you felt down, frustrated, or worried? What do you think might help you if you had these feelings?
Social aspects of care	Who do you talk to about (issues mentioned throughout interview)? Caregivers: How do you help [patient]? What is it like to care for [patient]?
Future of illness	When you think about your heart condition and what lies ahead for you (say, the next months or 1–5 years), what comes to mind for you? What have you thought about the future of your condition? What information would help you plan for the future?
Structure and processes of care	Who should be involved with helping you with [your symptoms, feeling down, talking about the future, etc.]?

^aCaregivers were asked similar questions. The questions were reframed for the caregiver interviews.

functional limitation, and quality of life. Higher scores reflect better health status.

Analysis

The primary goal of the analysis was to identify unmet needs, salient concerns, and preferences that would inform the development of a patient- and informal caregiver-centered palliative care intervention for an outpatient setting. Thus, patient and caregiver data were analyzed and are presented concurrently. We used the method of constant comparison derived from grounded theory,^{24,25} employing a team approach to analysis and maintaining an audit trail documenting the analytic process. Codes were developed by two primary coders (DBB, CTN) who met weekly to discuss coded data, reconcile differences, and reach consensus on code labels and their definitions. Initial codes were based on the interview guide topics to identify content of interest, such as “most difficult,” “most helpful,” or “future.” Subsequently, we created more granular codes within the broader, high-level codes. Text within and between codes was compared to develop themes. Within each broad category of codes (e.g., care team, future), we classified the more granular codes and each of the quotes according to whether they were expressed by caregivers or patients. We developed tables displaying the counts of the granular codes and quotes to search for patterns, similarities, and differences, comparing across and within caregiver and patient interviews. As a secondary analysis, in order to plan for tailoring of an intervention to relevant subsets of HF patients, we also searched for differences in concerns, needs, and preferences among older versus younger patients and NYHA II versus III/IV. As final steps in the analysis, we created figures to visually display key themes; these were modified based on feedback from primary care and palliative physicians, cardiologists, and qualitative researchers.

Observer triangulation (using a multidisciplinary research team and data coding by more than one person), participant triangulation (comparing perspectives of both the patients and their caregivers), and member checking (eliciting feedback on all of the results from patients to confirm their accuracy) were all employed to increase validity of the findings.

Results

Sample characteristics

A total of 72 hours of interviews were completed with 33 patients and 20 family caregivers. Patients were predominantly older, male, and white; caregivers were predominantly wives or daughters of the patients (Table 2).

Overview

Participants and caregivers described the profound impact HF had on their lives as well as their thoughts about what would be helpful in adjusting to HF and moving forward with their lives to the extent possible. These perspectives informed the content, structure, and timing of services designed to improve quality of life for both HF patients and their caregivers. The results are structured to reflect these key themes that should guide development of a palliative care intervention in HF (Table 3).

TABLE 2. PARTICIPANT CHARACTERISTICS

	Patients (n = 33)	Informal caregivers (n = 19 ^a)
Age, median [IQR], years	64 [51, 77]	59 [51, 74]
Women, n (%)	10 (30.3)	18 (94.7)
Race, n (%) ^b		
Black	7 (21.2)	
White	17 (51.2)	
Other	8 (24.2)	
Comorbid conditions, n (%)		
Hypertension	22 (66.7)	
Diabetes	14 (42.4)	
Atrial fibrillation	20 (60.6)	
Stroke	4 (12.1)	
COPD	11 (33.3)	
NYHA class, n (%)		
II	11 (33.3)	
III	13 (39.4)	
III	4 (12.1)	
Ejection fraction, median [IQR]	31.0 [23.0, 42.5]	
BNP, median [IQR], pg/mL, n = 32	354 [117, 525]	
Ischemic etiology, n (%)	13 (39.4)	
Time since diagnosis, median [IQR], n = 25	5 [3, 13]	
Health status, median [IQR], n = 29 ^c	54.2 [43.8, 69.3]	
Current therapies, n (%)		
Implantable cardioverter-defibrillator	16 (48.5)	
Biventricular pacemaker	9 (27.3)	
Ventricular assist device	1 (3.0)	
ACE inhibitor or ARB	28 (84.9)	
Beta-blocker	24 (72.3)	
Loop diuretic	28 (84.9)	
Antidepressant	14 (42.4)	
Opioid	7 (21.2)	
Relationship to patient, n (%)		
Wife or partner		9 (47.4)
Daughter		6 (31.6)
Other (relative, ex-spouse, son)		4 (21.1)
Lives in the same household, n (%)		12 (63.2)
Hours per week caring for patient, n (%) ^d		
< 1		2 (11.1)
1–5		4 (22.2)
6–8		3 (16.7)
> 8		9 (50.0)
Attend medical appointments with patient, n (%)		
Occasionally		6 (31.6)
Often		5 (26.3)
Almost all of the time		8 (42.1)

^a20 completed interviews; 19 completed surveys.

^bA patient could select more than one racial/ethnic category.

^cKansas City Cardiomyopathy Questionnaire, scale range 0–100.

^dN responding = 18.

IQR, interquartile range; COPD, chronic obstructive pulmonary disease; NYHA, New York Heart Association functional class; BNP, brain natriuretic peptide; ACE, angiotensin-converting enzyme; ARB, angiotensin receptor blocker.

TABLE 3. KEY THEMES INFORMING THE DEVELOPMENT OF A PALLIATIVE CARE INTERVENTION IN HF

Key theme	Definition	Findings
Content	Topics that should be addressed by the intervention	<ul style="list-style-type: none"> • Adjustment to the limitations and future course of illness • Alleviation of symptoms • Providers should be “familiar with my heart condition.” • Informal caregivers should be involved, particularly to enhance communication and coordination of care. • Use a “team approach.” • At the beginning of illness • Throughout illness
Structure	How should services be provided and who should provide them	
Timing	When should services begin and how long should they last?	

HF, heart failure.

Content of intervention

1. Help us adjust to the limitations and future course of illness.

Almost all patients and caregivers consistently described the need for help adjusting to the limitations and future course of HF:

“Certainly the most difficult issues are the emotional ones and the planning things. It would be good to have help with those things.”
(Spouse to Male, Aged 56, NYHA III)

a. Adjusting to the limitations of illness: The most difficult part of living with HF.

Needing help adjusting to the limitations of illness emerged in a variety of ways. Two-thirds of patients and caregivers said that the most difficult part of living with HF was “what [the patient] can’t do.” Patients with worse symptoms (NYHA III/IV) were more troubled by limitations. The most common patient request in response to the question, “If you could have anything you wanted to help you with your heart condition” was for help with increasing activity level, energy, or mobility.

Both patients and caregivers said that additional support would help with adjusting to the limitations of illness:

“After my first heart attack, I was scared to go home. There’s an adjustment.” (Male, Aged 69, NYHA II)

“The most helpful thing would be [to have] someone to talk to about this. Somebody to just kind of unload on sometimes. Cause you can’t unload on [patient]. And he can’t unload on me sometimes, too.”
(Spouse to Male, Aged 56, NYHA III)

Additional support could be as simple as asking patients how they are doing with HF in the context of their life:

“Most of [the providers] are just there for the medical part. They are not there to ask how you are really doing.” (Female, Aged 49, NYHA III)

Many had received additional support in the form of psychosocial care and/or antidepressants provided by a mental health professional. They were generally satisfied with this support, although some wished this care could have been provided by their cardiac providers.

Older patients or those living with HF for many years had adapted well to the limitations of illness. They adapted by adjusting their activities (“learning what I CAN do” or limiting/pacing activities), connecting with others socially, and adjusting mentally:

“You have to look at the whole big picture and think I’m stuck like this forever. You have to get over being tired of being sick...it takes patience.” (Male, Aged 54, NYHA III)

“I’m telling you this is part of life. At the hospital, I see those people in a wheelchair, and then I’m thinking, I’m not so bad off. There is always worse. And I am thankful, very thankful that I’m alive.”
(Male, NYHA II, age 71)

b. Adjusting to the future course of illness.

Caregivers and patients asked for help adjusting to and planning for the uncertain course of illness. They wanted more detail about the expected course of illness, although they described different and diverse needs. Many caregivers wanted to know the illness milestones, points at which they should be concerned, how patients’ needs would change over time, and what resources would be needed.

“I know he’s not going to get better...we’ve already faced that reality. How long before he starts getting weaker? What things is he not going to be able to do? What things are we going to have to do to make sure he can get around, be comfortable and do the things he wants to do? And how much can he do? At what point does he not drive anymore? At what point does he need a wheelchair? Or will that happen? Not knowing is hard.” (Spouse to Male, Aged 56, NYHA III)

“Is this going to last a day? A week? Five years? 20 years? I’m planning a funeral for someone that might live 20 years from now because I don’t understand.” (Spouse to Male, Age 34, NYHA II)

Patients had greater variability in their perspectives about the future than did caregivers. Some patients expressed a desire to learn more about their prognosis and illness trajectory, whereas others were less interested in these discussions. Of this latter group, all had NYHA III/IV HF, and several viewed their avoidance of “future topics” as related to the enormity and immediacy of day-to-day limitations. These limitations involved a daily struggle and uncertainty in the context of which “the future” seemed irrelevant:

“So for the future, there again, it’s like I don’t see much for now. So I haven’t been [thinking about the future]. Because it is just so uncertain. I mean the future to me is my next appointment and that is really all I’ve thought about.” (Male, Aged 50, NYHA III)

Some patients indicated that they avoided talking about the future because it is difficult to talk about, and they feared burdening their caregivers. Patients suggested the need for counseling around how to deal with uncertainty in illness:

“You can control it for a while but not forever, and then what’s going to happen? I worry about that.” (Female, Aged 61, NYHA III)

“People need some kind of counseling.” (Male, Aged 50, NYHA II, referring to uncertainty about a heart transplant)

2. Reduce symptoms, but can you really do anything to help?

Patients described fatigue and shortness of breath as the most common and distressing aspects of living with HF. However, many patients and caregivers were pessimistic about what could be done to alleviate these two symptoms:

"I don't think there is anything that can be treated any better."
(Male, Aged 77, NYHA IV)

"There's the shortness of breath, but I don't know what they could do to help that, that they haven't [already]." (Spouse to Male, Aged 89, NYHA III)

Patients complained of other bothersome symptoms, such as pain, dry mouth, and constipation. Several patients described the scope of their symptoms as most difficult:

"I think it's more than being able to deal with one specific symptom. The hardest part is to understand you are going to deal with them all." (Male, Aged 53, NYHA III)

Structure of intervention

1. Who: The provider should be "familiar with my heart condition."

The majority of participants expressed a preference that the health care provider who helps patients and caregivers live with and adjust to illness should know them well and be familiar with their heart condition; a number of participants endorsed nurses and doctors for this role. Patients wanted to feel comfortable with providers and were less interested in meeting new ones. Eight patients (24%) and eight caregivers (40%) recommended a mental health professional be part of the team.

2. What: Involve caregivers and facilitate communication and coordination.

Caregivers in particular said that providers should involve family and facilitate better communication and coordination and continuity of care.

"Communicate with the family as much as possible what's going on. Giving information to the family is really very important." (Spouse to Male, Aged 50, NYHA III)

Caregivers specifically desired help communicating with the person they cared for:

"If she could express her concerns to us without worrying about 'Well, I don't want to worry them.' Worry us! She doesn't need to keep it all to herself." (Daughter to Female, Aged 61, NYHA III)

Additionally, many patients and caregivers asked about the possibility of a support group.

3. How: Use a "team approach."

Patients and caregivers both liked the idea of a "team approach":

"A team approach could help people move forward and deal with the things they need to deal with and have those hard conversations that they are avoiding." (Sister to Female, Aged 47, NYHA II)

Timing of intervention

Patients and caregivers clearly expressed the need for help adjusting to illness at or shortly after the diagnosis of HF and then over time when needed.

"I wish there had been somebody there to really drum it in, in the beginning. 'Hey, you really need to make these adjustments in your

life...and [you need to] involve the family.'" (Spouse to Male, Aged 53, NYHA III)

"People should be given advice right off the bat—what is going to happen?" (Male, Aged 57, NYHA III)

A final note: It's not for everyone

Four patient participants were not interested in the proposed care team. They either felt "there was nothing else that could be done" to help them, or that they had been stable and wanted to keep the things the way they were, or they were afraid that a "care team" would comprise another layer of providers without coordination with existing providers. Other concerns included the burden of yet another appointment or trip to the hospital. Two people feared that a care team might infringe on their independence. A few patients who were neutral about the idea of help adjusting to illness said they could have used it earlier in their illness but were doing well at the time of the study interview.

Discussion

Overall, patients with HF and their family caregivers desired early help adjusting to the limitations and future course of illness, relief of a diverse number of symptoms, and the involvement of family caregivers using a team approach. A diverse group of participants desired these elements of palliative care *early in illness*, prior to Stage D HF or at the end of life, *concurrent with their disease-specific care*. This support should be offered by a provider who understands their heart condition and knows them well.

Adjusting to the limitations and future course of illness: An important role for palliative care services

Three important insights related to adjusting to the limitations and future course of illness emerged from this study. First, the idea that living well with HF involves adjusting to the limitations of illness has not been well characterized in the literature. This finding complements previous research showing that difficulty adjusting to the limitations of illness is a major predictor of depression in patients with HF.²⁶ Participants, particularly family caregivers, stressed the need for additional support and mental health assistance to help with adjustment. A UK HF palliative care program found mental health assistance to be one of the most important elements of its services.²⁷ Many suggested a support group to help with adjusting to illness and to supplement HF education. Group visits²⁸ or phone-based counseling to help patients emotionally adjust to the limitations of illness and to develop new interests and activities²⁹ are potentially useful interventions to address these needs.

Second, patients and caregivers differed in their desire for "anticipatory guidance." Although caregivers were almost uniformly interested in "anticipatory guidance" about what to expect in the future, patients varied in their preferences. Whereas several previous studies have emphasized patients' interest in discussing prognosis,^{12,18} a number of patients in this study were not interested in discussing the future. As in palliative care for other conditions, the different needs of patients and caregivers should be considered in HF palliative care.

Third, focusing specifically on patients' experiences, uncertainty in their illness manifested both on a daily basis by changes in fatigue, breathlessness, and functioning, as well as over the course of illness, by periodic decompensations and the imminent possibility of death. When engaging patients in advance care planning, providers should be aware of patients' perspectives on the inherent uncertainties and the multiple meanings of "the future." The day-to-day existence of living with HF, which has emerged in other studies,¹¹ can make advance care planning difficult for some HF patients. For many, their "future" is the next day or week and is primarily concerned with functioning and abilities to generate income or conduct household duties. An intervention to address uncertainty in illness has shown preliminary success in cancer patients.³⁰ Future research in HF palliative care should investigate ways to help patients and families address the multiple facets of uncertainty.

Implications for HF palliative care service provision

Regarding the structure and timing of HF palliative care, several findings are consistent with reports from the UK that address HF palliative care services, including the importance of coordination of care, caregiver support, and provision of services throughout illness, prior to the end of life.³¹ Involving family caregivers, strongly advocated by participants, is generally not a part of contemporary HF care or disease management programs, which remain focused on the individual patient. Participants prefer providers familiar with patients' heart condition are involved in addressing palliative care needs. This supports conclusions from consensus statements^{10,32} and reviews³³ that advocate for a palliative care service model that is well-integrated into HF care.

Given participant concerns about care coordination and their preference for a provider familiar with the patients' heart condition, a "team approach" as suggested by participants may be particularly effective. The collaborative care model, found to be successful and cost-effective for depression³⁴ and other illnesses³⁵ would make a reasonable starting point. Collaborative care involves: (1) the use of allied health professionals to educate patients, provide close follow-up, track progress and outcomes, and facilitate additional visits or treatments; and (2) consultation with a specialist who provides supervision and clinical advice, particularly with patients who are not improving.^{34,36}

Applying this care model to palliative care, a nurse or social worker already involved with the HF patient's care could be trained to provide basic palliative care and collaborate with the patient's primary HF provider and a palliative care team. For example, a nurse could be trained to provide evidence-based palliative symptom treatments to supplement disease-focused HF treatments. The nurse could meet regularly with a palliative care team to review patients and their symptom management using a collaborative care, team-based³⁷ approach. This model addresses barriers to concurrent cardiology and palliative care service provision⁹ and contrasts with the prevailing model of hospital- and cancer-based palliative care in which a specialist palliative care team provides consultation. An integrated model also offers the opportunity to address other chronic care needs

including providing information and support (e.g., using structured telephone support or group visits)^{14-16, 28,38} and care coordination, core elements of chronic care voiced by participants.^{37,39,40}

Several considerations and limitations of this study should be noted. It was challenging to develop an interview guide that was both open-ended enough to allow an understanding of participants' needs and preferences, and at the same time specific enough to elicit useful information on how to structure a palliative care program. Findings relevant to subpopulations (NYHA functional class, age) should be interpreted with caution given the small sample size. Patients reported their time since diagnosis and this may be subject to recall bias. External validity may be limited by population recruitment from one center, as many of the patients were being seen by HF specialists. In addition, patients were younger on average compared with community samples. However, our study recruited a population with a range in age and health status and thus is likely to represent a range of perspectives.^{11-13,15, 18}

In conclusion, our findings provide guidance for provision of palliative care to HF patients. Early in HF and then as-needed, programs should involve family caregivers, focus on helping patients and families adjust to the limitations and future of illness, and provide symptom relief complementing disease-specific strategies. Training a nurse or social worker to incorporate these services using a collaborative care, team approach is one care model that our study supports. Future research should test the feasibility and effectiveness of integrating such a program into routine HF care.

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Author Disclosure Statement

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