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"I'd Have to Basically Be on My Deathbed": Heart Failure Patients' Perceptions of and Preferences for Palliative Care

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Abstract

Objectives: To identify patient perceptions of how and when palliative care (PC) could complement usual heart failure (HF) management.
Background: Despite guidelines calling for the integration of PC into the management of HF, PC services remain underutilized by this population. Patient preferences regarding delivery of and triggers for PC are unknown.
Setting/subjects: Individuals with New York Heart Association Class II–IV disease were recruited from inpatient and outpatient settings at an academic quaternary care hospital.
Measurements: Participants completed semistructured interviews discussing perceptions, knowledge, and preferences regarding PC. They also addressed barriers and facilitators to PC delivery. Two investigators independently analyzed data using template analysis.
Results: We interviewed 27 adults with HF (mean age 63, 85% white, 63% male, 30% Class II, 48% Class III, and 22% Class IV). Participants frequently conflated PC with hospice; once corrected, they expressed variable preferences for primary versus specialist services. Proponents of primary PC cited continuity in care, HF-specific expertise, convenience, and cost, whereas advocates for specialist care highlighted expertise in symptom management and caregiver support, reduced time constraints, and a comprehensive approach to care. Triggers for specialist PC focused on late-stage manifestations of disease such as loss of independence and absence of disease-directed therapies.
Conclusions: Patients with HF demonstrated variable conceptions of PC and its relevance to their disease management. Although preferences for delivery model were based on a variety of logistical and relational factors, triggers for initiation remained focused on late-stage disease, suggesting that patients with HF may misconceive PC is an option of last resort.

Keywords: communication; heart failure; palliative care

Introduction

Heart failure (HF) is a chronic and life-limiting condition affecting >6.5 million adults in the United States.[1] Advances in HF therapy have improved patient survival; however, physical and psychosocial distress remains high for patients and caregivers, particularly in advanced disease.[2,3] This gap has proven challenging to breach with standard approaches to disease management.[4,5] Palliative care (PC) is an overarching approach to care that aims to improve quality of life (QOL) and reduce suffering among patients with serious illness and their families.[6] PC can be delivered by

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clinicians with specialized training in PC (''specialty PC''), or by nonspecialized clinicians incorporating basic palliative domains into more general care delivery (''primary PC''). Early PC research focused predominately on patients with cancer[7]; however, emerging research regarding its effectiveness in HF has demonstrated that PC improves symptom management and QOL[8–10] in addition to reducing readmission rates and hospitalization costs in this population.[11–14] Both the American College of Cardiology and American Heart Association have recommended specialty PC consultation for patients with advanced HF.[15,16]

Despite promising evidence and strong professional recommendations, integration of PC into HF management remains limited.[17] Less than 3% of patients admitted to the hospital in the United States with a primary diagnosis of HF are seen by a PC service[18]; research suggests that penetrance of PC into HF care in Europe is comparably low.[19,20] Barriers to the provision of specialty PC are numerous. Patients and caregivers conflate the term ''PC'' with hospice and may decline referral, describing HF as a nonterminal diagnosis.[21] Lack of awareness of the role of PC, prognostic uncertainty, and fragmentation of care across multiple clinicians further complicate referral to specialty PC services for HF patients.[22,23] These challenges are compounded by a lack of standardized referral criteria, which may result in failure to identify individuals with unmet palliative needs. Current informal triggers for PC consultation are weighted toward HF-specific health status measures, which focus heavily on symptom burden and function. Such focus may fail to capture other sources of distress, such as unmet psychosocial concerns.[24–27] Lastly, the specialty PC workforce is limited and resources are currently skewed toward oncology.[28] This constellation of barriers has generated a need to investigate alternative mechanisms of PC delivery for patients with HF, such as primary PC. Primary PC, in which needs are met by primary providers, represents an opportunity to optimize PC delivery in HF patients by consolidating care under one provider equipped to manage symptoms, prognosticate, and guide patients in future planning.

Previous study exploring PC needs in HF have focused upon providers,[23] or upon characterizing beliefs about specific components of care, such as device deactivation.[29,30] In this qualitative study, we explored patient attitudes toward and perceived need for PC as well preferences for PC delivery, including patient-identified triggers for specialty PC referral.

Methods

Design

We conducted semistructured qualitative interviews to allow for in-depth exploration of topics. The University of Pittsburgh Institutional Review Board (IRB) approved this study.

Sample and recruitment

Candidates were identified by staff at an advanced HF clinic, or from general medicine inpatient wards, both at an American academic tertiary care hospital. Potential respondents were approached in person with a description of the study, and, if interested, asked to provide informed consent. They were interviewed telephonically after discharge from the clinic or ward. Recruitment criteria included (1) New York Heart Association (NYHA) Stage II–IV HF as identified by the patient's clinician, (2) ability to speak and comprehend English, and (3) no significant hearing or cognitive impediments prohibitive of participating in a telephone interview. Participants were compensated with $50 upon interview completion.

Data collection. We developed and pilot tested an interview guide informed by the National Consensus Project for Palliative Care's 2013 *Clinical Practice Guidelines for Quality Palliative Care.*[31] The interview guide comprised 10 domains containing 24 questions exploring the respondent's PC understanding and needs. Participants were asked about their prior knowledge of PC, and misconceptions were clarified by the interviewer. They were subsequently exposed to a standardized definition of PC (Table 1),[32] although the term ''supportive care'' was used to introduce PC in keeping with studies suggesting that this terminology may be associated with favorable patient perceptions.[33] Subsequent questions explored the extent to which participants' care needs were being met within their current care system, and their preferences regarding how care might be structured to meet their needs (Appendix Table A1). To identify delivery preferences, respondents were asked from whom and how they would ideally receive components of PC (e.g., symptom management and psychosocial support).

Interviews were conducted over the telephone by a medical anthropologist with extensive qualitative expertise. Demographic and medical information was collected from patients and supplemented by chart review upon study enrollment. Interviews were audiorecorded and transcribed verbatim.

Analysis. We used template analysis, a qualitative analytic technique that combines elements of content analysis and grounded theory,[34] yielding a hybrid inductive/deductive approach to theme identification. Data analysis was performed iteratively by two investigators, with multiple intermediate consensus meetings to discuss and arbitrate discrepancies. In total, 10 of 27 (37%) transcripts were coded by both investigators to establish and monitor intercoder consistency; the remaining 17 were coded by one individual. Using the constant comparative method, we juxtaposed new text units with existing coding to ensure stability of previously identified themes,[35] and determined that we had achieved thematic saturation when repetition of themes was

TABLE 1. STANDARDIZED DEFINITION OF PALLIATIVE CARE PROVIDED TO RESPONDENTS[55]

PC is specialized health care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of an illness, and it is based on need, not prognosis. The goal is to improve quality of life for both the patient and the family.
PC is provided by a specially trained team of physicians, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

PC, palliative care.

Table 2. Respondent Characteristics

Characteristic	*Full sample*	*NYHA II*	*NYHA III*	*NYHA IV*
N (%)	27	8 (30)	13 (48)	6 (22)
Recruitment site—advanced HF clinic	20 (74)	7 (88)	10 (77)	3 (50)
Demographics				
Mean age (years)	64	69	62	60
Race—Caucasian	23 (85)	6 (75)	11 (85)	6 (100)
Race—black	4 (15)	2 (25)	2 (15)	0
Gender—female	10 (37)	5 (63)	4 (31)	1 (17)
Post-high school education	18	4 (50)	11 (85)	3 (50)
Currently married	16 (59)	5 (63)	6 (46)	5 (83)
Currently employed (full or part time)	5 (18)	0 (0)	2 (15)	3 (50)
Medical characteristics				
Mean left ventricular ejection fraction	38 (10–75)	43 (15–75)	35 (15–75)	32 (12–75)
No additional comorbidities	4 (15)	1 (13)	2 (15)	1 (17)
One additional comorbidity	3 (11)	0 (0)	2 (15)	1 (17)
Two additional comorbidities	11 (41)	4 (50)	5 (38)	2 (33)
Three or more comorbidities	9 (33)	2 (38)	4 (31)	2 (33)

HF, heart failure; NYHA, New York Heart Association.

noted.[32] NVivo software (version 11, QSR International) was used to manage the coding and analysis.

Results

Of 35 patients approached, 27 (77%) agreed to participate in the study. Participants had a mean age of 63 years, and the majority were male and Caucasian (Table 2). A majority (60%) had HF with reduced ejection fraction, and 74% were recruited from an advanced HF clinic (vs. 26% from general medicine inpatient wards). Interviews had a mean duration of 47 minutes (range 29–82). During qualitative analysis, respondents demonstrated (1) enthusiasm for components of PC but ambivalence about the service by name, (2) variable preferences for mechanism of PC delivery, and (3) consistency in identification of late-stage triggers for specialist referral, such as dramatic loss of independence and lack of treatment options (Table 3).

Table 3. Themes Identified during Analysis

Theme	*Subthemes*
Limited knowledge of PC	Minimal baseline understanding of PC Conflation of PC with hospice Positive view of PC after exposure to a standard definition, but not willing for palliative involvement yet
Preferences for specialty vs. primary PC	Preferences for primary PC included Confidence in their current providers and providers' knowledge of HF Continuity of care Cost Convenience Preferences for specialist PC included Expertise in symptom management Improved delivery of care and management of caregiver-related issues Time constraints
Triggers for specialist involvement	Absence of concrete timeframe for referral Dramatic loss of independence and exhaustion of treatment options cited as trigger points

Theme 1: Respondents expressed enthusiasm for PC components, but associated the name with end of life

Respondents reported minimal prior understanding of supportive or PC. Only 2 of 27 (7%) reported prior engagement with the service. The majority of respondents citing preexisting knowledge of PC inaccurately conflated it with hospice:

> Respondent (66F, NYHA II) [PC is…] what you're going to do to make me comfortable at the end. What will be or could be done to make me comfortable.

After exposure to a standard definition of PC,[22] many respondents reacted positively to what they perceived as a comprehensive approach to care:

> Respondent (40M, NYHA III): It seems to me that PC takes the holistic approach beyond what the medical community would immediately do.

However, most continued to affirm they were not yet ''ready'' for what they viewed as end-of-life care.

> I:[What] would need to happen for you to make you feel like you would like [specialist PC]?
>
> Respondent (57F, NYHA II): Oh, gosh. I'd have to be down and out, basically. Yeah, I'd have to be basically on my death bed.

Theme 2: Expertise and trust drove preferences for method of PC delivery

After discussing the fundamental competencies of PC, respondents were asked whether they would be interested in delivery of these services by their cardiologist or by a specialist. Thirteen of the 27 expressed confidence that their cardiologist could provide PC, 13 were interested in specialist consultation; 1 voiced ambivalence. Rationales for preferring a specific care model centered around three themes: expertise, trust, and feasibility.

Respondents who expressed interest in primary PC highlighted the intimacy and continuity of the relationship with their cardiology team. Some voiced high levels of confidence in their HF providers and their expert understanding of the individual's disease:

> Respondent (55M, NYHA IV): I've been with that team for so many years. They've never led me wrong. [My doctor's] a God-sent man, him and his team. I just would rather he [provided PC] because he knows what he's talking about. No doubt when he tells you something.
>
> Respondent (79M, NYHA III): Because I think [my HF team] should have more knowledge and ability with the HF than anyone else.

Other respondents cited continuity in care:

> Respondent (40M, NYHA III): … I see my cardiologist as kind of the primary quarterback from my heart disease… I think it would be okay if [PC] came from him or came from someone who worked within his office.''

Cost and convenience also impacted enthusiasm for primary PC:

> Respondent (59M, NYHA IV): A lot of times, you're in the hospital, you have all these doctors coming in, and you don't even have any idea who they are until they'll send me [a bill]. I don't believe in that. I believe in one doctor should make a decision, that's it.
>
> Respondent (81M, NYHA II): If I had a specialized doctor, would I have to travel? See, that's the handicap.

Respondents who expressed interest in consultation with a PC specialist also cited expertise as instrumental in informing their preferences:

> Respondent (65M, NYHA IV): [They've] seen this possibly more than what the cardiologist has.
>
> Respondent (57F, NYHA II): I would think a specialist would be the one to go to. Because [my cardiologist has] got a lot of other things going on at the same time, so specialist would be the one I would pick.

Specialists were thought to be superior at addressing care delivery and caregiver support-related issues:

> Respondent (83F, NYHA II): I just feel that [PC specialists] have been through it more and know how to deal with the family probably better and have to take the time to do it. And they spend a lot of time with us and it was very helpful.

More pragmatic advantages of specialist PC included reduced time constraints:

> Respondent (51M, NYHA III): I think doctors have enough on their plate; nurses have enough on their plate. The guy that specializes in [PC…] can kind of focus on that.

Theme 3: Patients consistently endorse late-stage triggers for PC

Respondents answered nonspecifically when asked to identify a point in their disease progression for referral to specialist PC:

> I: What would have to happen for you to want to see a PC specialist?
>
> Respondent (79M, NYHA III): I don't know. I guess if I slow down or something happens, I would like to. Maybe then.

On further exploration, two explicit triggers for PC referral emerged. The first was a dramatic loss of independence:

> Respondent (60M, NYHA III): If somebody has to put me into a [nursing] home, then I think I might need some real help there.
>
> Respondent (66F, NYHA II): It would be when I can't help myself.

The second trigger was the exhaustion of treatment options, as defined in collaboration with their cardiology team. This preference persisted even after receipt of a definition of PC that clearly distinguished it from hospice (Table 3).

> Respondent (49F, NYHA II): Maybe where—after an honest conversation with my cardiologist or whatever—we've exhausted everything that was going to improve my quality of life.
>
> Respondent (67M, NYHA III): If things worsened, if I was having much more frequent discharges of my [implantable cardioverter-defibrillator] and medications had run their course, if you will, if they've tried various med[ication] blends and different approaches, and it seemed to—''Here's where I am, and now I've got to live with this condition until the damn thing stops,'' then I might be interested [in PC].

Discussion

Our study is the first to discuss general PC preferences directly with HF patients, and sheds new light on the challenges of optimizing PC delivery to this population. Proposed solutions to improving PC integration into HF management have included optimizing primary PC[36] as well as developing rigorous and clinically relevant triggers for specialist referral that are informed by patient preferences.[11] Existing criteria for these triggers are often based on diagnosis and prognosis[37]; to our knowledge, no prior study has explicitly assessed HF patients' understanding, attitudes, and preferences regarding PC delivery. We included patients with a wide range of disease severity to capture preferences that might educate more timely integration of PC across the spectrum of HF care. Regardless of disease stage, respondents based their preferences on one of two major factors: strength of relationship or ease of access.

Although the majority of our respondents met referral criteria for PC,[16] they demonstrated little awareness that PC is a recommended component of HF management. They often conflated PC with hospice, findings consistent with earlier study.[33,38] Participants cited diverse rationales for provider preference, generally focusing on one of two themes: relationships (expertise, continuity, and depth) and feasibility (convenience and cost). Many respondents with close relationships with their cardiologist cited clinical competence and continuity of care as arguments for primary PC; others noted the costs and logistical challenges associated with seeing an additional provider. Meanwhile, those respondents interested in specialist PC were attracted by specialists' expertise in delivering comprehensive and QOL-focused care as well as by a perceived reduction in provider time constraints. PC delivery *in vivo* is rarely exclusively specialist- or primary-provider driven, and our findings suggest that easily identifiable priorities may provide a means of stratifying some patients to early specialist referral.

Physical and psychosocial needs begin early and vary over the course of chronic illness,[39] and HF patients in particular report varying levels of agency over the course of their care.[40] Referral criteria need to account for these complexities in perceived control and trajectory.[41] Patient-identified triggers may serve as an ideal starting point from which to develop needs-based triggers for specialty PC referral, as cardiology teams are ideally positioned to provide first-line symptom management alongside discussions of goals of care. Although providers often express discomfort about discussing these topics with patients, studies suggest advance care planning initiated by HF providers is highly valued by patients and caregivers, does not increase anxiety or distress, and may reduce length of stay.[42,43]

A prior study of provider attitudes regarding PC referral in HF demonstrated that limited knowledge about PC and conflation with hospice acted as barriers for provider referral of HF patients to PC. In that study, physical decline was cited as a major trigger for specialist consultation.[23] Our study suggests that similar beliefs impact patient preferences. This agreement between providers and patients suggests that interventions to optimize education and the referral process might improve PC access in HF management. However, both time points cited for specialist referral (exhaustion of therapeutic options and loss of independence) are frequently seen in late- or end-stage disease. Further study may identify and test time points for earlier-stage PC intervention similar to those used for oncology patients.[44] However, the knowledge and attitudinal barriers steering many patients and providers away from PC may not be overcome by education or even by alternative interventions such as systematization of referrals or the development of standardized referral triggers, but may require a broader societal shift in how PC is understood.[45] Our respondents expressed enthusiasm for the content of PC if not the terminology used to describe it, suggesting that integration of PC into HF care should focus predominantly on content over nomenclature of delivery.

Our findings suggest that primary PC may be an acceptable delivery option for many patients with HF, particularly those patients who enjoy long and trusting relationships with their cardiologists and those with limited financial or geographical resources. Nonetheless, models of specialty and primary PC are not an either–or proposition. Core tenets of PC, customized for HF and rigorously evaluated, should be woven into standard HF management alongside mechanisms promoting timely referral to specialist services when indicated. The integration of needs-based patient-initiated triggers, such as those identified in this study, with objective clinical criteria could help identify patients at greatest need for specialist involvement.[45] Existing tools designed to trigger PC referral in chronic illness, such as the Needs Assessment Tool: Progressive Disease (PC-NAT)[46] and the Supportive and Palliative Care Indicators Tool (SPICT),[47] if utilized routinely throughout care, may provide a means of facilitating palliative-oriented discussion between patients and cardiologists and allowing for early identification of high-need patients; however, they are unlikely to overcome ongoing conflation of PC with end of life and thus may not facilitate specialist referral.

Although existing studies of PC integration into HF management have focused on specialist teams,[8,12–14,48] more recent study demonstrates benefit from collaborations between PC and HF providers, particularly with regard to improvements in QOL, reduction in depression and anxiety, and communication regarding goals of care.[10,26,49] Given constraints in the specialty PC workforce, models of primary PC are needed to improve the provision of early longitudinal attention to PC needs by cardiology clinicians. An ongoing randomized controlled feasibility trial is evaluating the impact of a nurse-led primary PC intervention in outpatient cardiology.[50] Furthermore, our study reinforces the need for broader discussion about the value and role of PC beyond end-of-life care.

Limitations

Respondents were drawn from a single institution, and were predominantly male and Caucasian, all of which may limit generalizability, given evidence of higher rates of HF-related hospitalizations in black and Hispanic populations.[51,52] However, given prior studies demonstrating barriers to and misconceptions regarding PC among these populations[53,54] we expect that our findings would be reinforced in this population. Thirty percent of our respondents had NYHA II disease, and may not have experienced a serious decline in health prompting insight into future care needs. Identification of themes in this type of study is inherently subjective and variable depending on the coder; however, our methodology was sound and consistent with that employed by other researchers. Our sample was small but large enough to support thematic saturation based on observations that themes can emerge in as few as 6 interviews, and thematic saturation be achieved after 12.[32]

Conclusions

In this sample of adults with HF, many participants demonstrated limited knowledge about PC and its role in their disease management; many persistently conflated PC with hospice. Preferences and motivations for models of PC (primary and/or specialty) varied by respondent, but predominantly centered on end- or late-stage disease. Further research is needed to delineate mechanisms for early integration of PC into HF, to increase provision of primary PC in HF management, and to develop mechanisms for improving awareness of PC among patients and providers.

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Author Disclosure Statement

No competing financial interests exist.

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Appendix Table A1. Semistructured Interview Guide

Domain	*Question*
Physical aspects of care	Thinking about your HF, which symptoms most affect your quality of life?
Psychological aspects of care	Many people living with HF say they experience depression, sadness, or anxiety. I am curious about your experiences with depression or anxiety since you were diagnosed with HF. Have you had any feelings of sadness or depression? What about feelings of anxiety?
Social aspects of care	How do you feel that your HF has impacted your relationships with your loved ones?
Spiritual aspects of care	What role does spirituality play in your life? How do your spiritual practices impact how you deal with having HF?
Ethical and legal aspects of care (i.e., advance care planning)	Do you have a cardiac device, like a defibrillator, or a pump? What kind of discussions have you and your cardiologist had about that device if your HF gets worse?
Outcomes that matter to patients with HF	What are you hoping to get out of your health care regarding HF?
Perceptions of supportive care	How familiar are you with the term ‘‘supportive care’’? Can you please tell me what you know, or what you have heard about it?
Perceptions of PC	Do you think there will come a point in the progression of your HF where you would like to see a PC specialist? What would that/those points be?
Closing	Given everything we have talked about today, what does/would high-quality HF care look like to you?

HF, heart failure; PC, palliative care.