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“That Don’t Work for Me”: Patients’ and Family Members’ Perspectives on Palliative Care and Hospice in Late-Stage Heart Failure

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Heart failure (HF) exacts a tremendous physical, psychological, emotional and spiritual toll on patients and their families. Patients experience a wide array of troubling symptoms, including dyspnea, fatigue, pain, depression, and anxiety, and are not sufficiently informed about their disease and its management. In particular, patients with late-stage HF rarely experience high quality communication about prognosis and treatment planning. These communication deficiencies are associated with adverse outcomes and increased suffering for both patients¹⁻⁵ and family members.^{6, 7}

In an effort to improve the experience of people with late-stage HF and those who care for them, experts in both palliative care (PC) and HF care have called for collaboration between the two disciplines,⁸⁻¹² resulting in more HF patients being referred to PC services. The majority of HF patients however, are not referred for PC consultations.¹³ The purpose of this paper is to describe the perspectives of HF patients and their family members (FMs) that likely influence referral to PC services.

Background

Palliative care is a philosophy of care intended to improve the quality of life for patients and families confronting life-limiting illnesses. Palliative care focuses on anticipating, preventing and alleviating physical, psychological, social and spiritual sources of suffering. It is appropriate throughout the disease course and may be used alongside interventions with curative intent.^{14, 15} Hospice care, in contrast, is specifically geared toward people with short life expectancies who are no longer pursuing cure-oriented treatments.¹⁶ In addition, in the United States, hospice, unlike PC, has a capitated reimbursement structure; meaning that agencies providing hospice services are reimbursed at a fixed per diem rate. Palliative care clinicians care for those who elect hospice services and those who do not.

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Both hospice and PC initially focused on the care of people in the later stages of cancer. However in the last 10-15 years the definitions of both have been broadened to encompass all life-threatening conditions,¹⁷ including HF. In addition, leaders in HF care have endorsed the incorporation of PC services, including hospice, in the management of late-stage HF,^{9, 10, 18-20} and early reports indicate clinician satisfaction with an integrated approach.²¹⁻²⁴ Despite this, most HF patients are never referred for consultations with PC services. One of the identified barriers to PC referral is the conflation of hospice and PC. Factors contributing to the conflation of the two include the widespread use by health care professionals and lay persons of both terms to describe end-of-life care, and the referrals of large numbers of patients to PC services at or near end-of-life.²⁵⁻²⁷ The participants in this study shed light on *why* the conflation of hospice and PC is a barrier to PC in HF care.

Methods

Design

We conducted a qualitative descriptive study with the purpose of describing the experiences of a group of hospitalized HF patients and their family members (FMs) who were referred to an inpatient PC consultation service, and their perspectives on the role of PC in late-stage HF. A more detailed description of the study and its entire findings is presented elsewhere.²⁸

Setting and sample description

Forty participants were recruited over a 9 month period from an academic medical center in upstate New York. Participants were hospitalized patients and family members of patients receiving PC in the context of late-stage HF. The patient/family member dyad was the population of interest for the study because in PC the patient/family is the defined unit of care, and family members often participate in PC consultations. However, in several cases family members did not participate. Reasons for non-participation included: distance and weather prohibiting travel to hospital, patient participants reporting no family involvement, and patient participants' requests that family members not be approached for participation. The final sample size was 40 total participants, 24 HF patients and 16 family members, who participated in 40 interviews.

Patient participants (Table 1)—All 24 of the patient participants fit the criteria for NYHA Stage III or IV HF or ACC/AHA HF Class C or D. They ranged in age from 26 to 93 years with a median age of 71 years. Fifteen were men, 20 were Caucasian, and 4 African-American. Most participants were married and living with a family member in a single family residence. Most had multiple co-morbidities and had been hospitalized more than once in the previous year. Seven patient participants had implantable cardiac defibrillators (ICDs) upon admission. Three patient participants had left ventricular assist devices (LVADs), and 2 were heart transplant recipients. Most participants had significant functional impairment, spent most of their time sitting or lying, and required assistance with activities of daily living, but were generally mentally alert and able to take in adequate nutrition.

Family member participants (Table 1)—The majority of the 16 FM participants were married Caucasian females, either the spouse or adult child of the patient participant. They ranged in age from 29 to 76 years, with a median age of 53 years. All FM participants reported being directly involved in the care of the patient participants, providing at a minimum assistance with instrumental activities of daily living. Nine of the 16 described being engaged in direct care-giving activities including monitoring physical status, assisting with activities of daily living, medication administration, and coordinating appointments.

Data Collection and Analysis

We obtained human subjects approval from the university's institutional review board before data collection began. The primary author conducted and audio-recorded 40 semi-structured interviews with 24 hospitalized HF patients and 16 FMs who had been referred to the inpatient PC consultation service. When possible, 2 interviews were completed; one soon after the initial contact with the PC team and the second at the time of discharge. Data collection and analysis were on-going, simultaneous, and continued until saturation was achieved.^{29, 30} We used qualitative content analysis^{31, 32} to identify the salient components of the participants' experiences.

Results

Study findings were organized into four main themes: 1) Participants had little previous knowledge of PC and formed impressions based upon interactions with the team; 2) Participants described the overall role of PC as one of support; 3) All participants had a sense of prognosis which directed treatment goals; and 4) The conflation of PC and hospice was a barrier to PC in HF care.²⁸ The fourth theme—the conflation of PC and hospice is a barrier to PC in HF care—is discussed at length here. Originally participants were not asked about hospice. However because so many introduced the topic and/or defined PC as hospice or end-of-life care, their perspectives about hospice emerged as an important aspect of their overall experiences with and perceptions of PC in HF care.

Participants indicated that hospice would not work for them. They perceived that a set of hospice “rules” existed and that these rules were “deal-breakers” for HF patients. In fact, even those participants who agreed to a hospice plan of care expressed concern that the rules might impede the goal of a comfortable death. Four main rules were discussed: no aggressive measures for HF symptom management; no hospitalization for any reason; certain, imminent death is required; and forfeiture of familiar providers. According to these participants, their understanding of the rules of hospice came from the community, their referring team (RT) provider, and/or from members of the palliative care team (PCT).

The “rules” of hospice

No aggressive measures for HF symptom management—This was one of the most problematic rules for participants. They expressed concern that they or their loved ones would experience severe and distressing symptoms at home and not be allowed any of the medications or treatments that had worked for them in the past. For example, one FM reported that when her mother had another exacerbation of HF, which was characterized by severe shortness of breath, the interventions that had been successful in controlling her symptoms would no longer be an option. She reported that the RT provider explained the hospice/PC rules to her and the PCT reinforced them.

If Mom entered into the palliative care scenario and she had another episode and wanted to have the full treatment of IV lasix and all the rest of it to bring her back to where she needs to be, that would be inaccessible to her.

No hospitalization for any reason—Similarly, participants were convinced that if they agreed to hospice, then an acute care admission, under any circumstances, would be denied. When asked why she was so opposed to hospice, one elderly woman, who had multiple, long hospital stays in the previous months replied, “You can’t go to the hospital. That don’t work for me...I couldn’t go back in the hospital for anything. I don’t go along with that.”

Certain imminent death is required—Participants reported that hospice requires that death be certain and imminent, and if the patient does not die within a specified time, then

they would be “kicked out of hospice” and left without care, or they would be expected to pay out of pocket for their care. As one FM explained, “We understand that Mom’s condition is very serious...but she still has life left in her. We can’t take the chance...” Her mother, the patient, questioned, “Who would pay?”

Forfeiture of familiar providers—Participants also worried that they would be required to sever ties with their HF clinicians, with whom they had long-standing relationships. As one patient said, “I have a great support group here who are very knowledgeable about me, my problems, and how to deal with me. I don’t want to give that up.”

Variations in how PC is defined

Most participants reported that upon admission they were unaware of the existence of the inpatient PC service, and would have been unable to offer a definition of *palliative care*. As one FM said, “I didn’t want to say but never heard of [PC]. I had no clue what they did, what they’re all about, nothing.” After meeting with the PCT the participants were able to define PC and to discuss how they came to that understanding. Nearly half of the participants defined PC as end-of-life or hospice care. “Palliative care is basically a way to help comfort the family and patient through the difficult time...[They] come in here with the bad news when you are on your last leg and try to smooth things over and keep you calm and collected.” (FM)

Of note, several of those participants who equated PC with hospice reported basing their definition primarily on information from the RT provider. For example one FM when asked how she came to understand that PC is “the same as hospice,” she answered, “[his cardiologist] said he was hitting a wall, he wasn’t getting better. Then he said, ‘Have you ever heard of hospice? Then the [PCT] came.’”

Understanding of PC and the rules of hospice influenced treatment plans

In those cases in which PC and hospice were considered synonymous, the majority of participants predicted that PC would have no place in their current plan of care. As one young woman stated, “[PC] is not an option: it would be go home and wait my days out...I refuse to go by it.”

Several suggested that PC might play a role “down the road” if the current treatment plan failed and/or their disease became “really fatal.” One middle aged man suggested that he would consider PC if he had no further treatment options, that is, if his disease “got really, really fatal” and it was clear that he was “near the end of my end days.” He thought then PC could help him “make everything as smooth as possible.” Another FM participant suggested that if the current treatment did not work, then she would consider PC, which she felt was the same as hospice. “I would rather have the treatment [milirone] ‘cause that might make him feel better...plan B would be [PC].”

As indicated previously most participants were resistant to hospice and, therefore, to PC if they felt they were the same. However, even those participants who were accepting of hospice expressed concerns about the rules. For example, one FM whose father had been transferred to the inpatient palliative care unit and then transitioned to inpatient hospice care worried that if her father did not die within two weeks he would be forced out. “I guess the intended stay is 2 weeks... Our intention, of course, is to have him stay here. He’s comfortable; but what if he rallies?”

For those participants who did *not* define PC as hospice or end-of-life care, continued PC involvement was welcomed, even if participants predicted hospice would not be an option.

One participant was able to distinguish between hospice and PC. “I feel that [death and dying] is basically [PCT’s] expertise, but there is more to it than that. They [PCT] help you prepare for the journey...They help you feel at ease.” She reported during both interviews that her family was resistant to hospice because she needs “strong medicine” to manage her HF symptoms, and she would most likely never enroll in hospice. However, she predicted that she would continue to work with the PCT.

A few of the participants were aware that they were eligible for hospice based on a very limited life expectancy and marked functional decline, and were able to differentiate between hospice and PC. However, they still expressed reluctance, because of their concerns about the rules, to move from a palliative plan of care to a hospice plan of care.

Palliative care has such advantage over hospice in that they don’t have these time markers. (P)

My demise is coming soon, I know...I’m so tired but not ready to give up [my medications] just yet. (P)

In two cases the PC team was asked to work the system or “pull some strings” so that patients could go home with hospice. In one case, the PCT was able to arrange for the patient to go home with hospice with his LVAD still functioning, and on intravenous antibiotics. He died at home 2 ½ months later. His wife described it this way: “I said, ‘Hospice X will never take him. I know from all of my experiences with them’. [PC MD] said, ‘I’ll call the director and talk to him’, and he did it...made it happen”. Both the patient and FM participant in this case felt that the PCT was able to circumvent the *no aggressive measures rule*.

In the second case, the participant reported that the PCT was unable to work around the *no aggressive measures rule*. The participant, a middle-aged man who had received a heart transplant, and was being maintained on intravenous medications to control symptoms related to his failing heart, was referred to the hospice agency serving his geographical area. The RT and the PCT agreed that his prognosis was most likely three to six months. However, according to the patient, the hospice intake nurse reported that the agency was unable to provide the care he required. The RT attempted to wean him off of his milnirone infusion so that he could be discharged home with hospice care. However, he reported experiencing severe shortness of breath, fatigue, and chest pain until the infusion was restarted. With the assistance of the PCT his discharge plan was modified to include home with intravenous medications to control symptoms and prevent rejection of his transplanted heart, outpatient palliative care as needed and eventual readmission to the inpatient PC unit for his final days.

I don’t qualify for hospice...over this drug here (milnirone) and everything you gotta do to get it. I gotta be in the hospital another week...you’ll be doing exactly what you think you’re supposed to be doing and another group says “no, can’t do that”...This [milnirone] is the only thing that makes me feel almost normal...well I know I’m gonna progressively get worse and I feel that as I get worse [PCT] will step in more and more and more. And if I...come back here for final care...that’s where they’ll be.

In summary, nearly all of the participants expressed concerns about hospice care for patients with HF. In particular, they believed that aggressive symptom control and hospice care were mutually exclusive options. They felt the rules were designed to dictate exactly what care was delivered and how it was delivered, rather than to guide the reimbursement of that care. Furthermore, if participants equated PC with hospice care, which in many cases they did, then PC was not seen as a viable option for them in their current plan of care. If however,

they were able to distinguish PC from strictly end-of-life or hospice care, then they appreciated having the service available and planned to continue with it, even if they never transitioned to hospice care.

Discussion

Other researchers have reported that the conflation of PC and hospice by clinicians, is a barrier to PC in HF care.²⁵⁻²⁷ The findings from this study add to our understanding of why, from the perspectives of patients and family members, referral rates of HF patients to PC remain low. When asked about options for treatment or care, many mentioned that hospice was not an option because their perceptions of the hospice “rules”. They expressed great concern that increased suffering at end-of-life would be the result if they elected to pursue a hospice plan of care. Thus it is easy to appreciate why participants who equated PC with hospice declined PC. Even those who opted for hospice were worried that the “rules” might impede the goal of a peaceful, comfortable death.

Participants’ descriptions of the hospice “rules” suggest a mismatch between the needs of late-stage HF patients and the current policies surrounding the provision and reimbursement of hospice services. For example when making a referral to hospice the clinician certifies that the patient likely has a life expectancy of six months or less. However, many patients and clinicians feel that the uncertain trajectory of HF makes it very difficult to determine an accurate time-limited prognosis.^{26, 33-35} In addition, the per diem reimbursement rate for hospice is based on the assumption that redirecting from cure-driven treatments to those aimed at comfort results in lower costs of care. However, the palliation of HF symptoms often requires aggressive management of heart disease, which in turn sometimes necessitates the use of expensive intravenous medications or technical devices. For example, the use of intravenous inotropes is often effective in controlling very distressing symptoms in persons with advanced HF refractory to traditional medical management,^{36, 37} and management of distressing symptoms is consistent with a comfort plan of care. With the relatively low per diem reimbursement rate for hospice care however, many agencies cannot afford to provide these costly treatments and often do not have staff with the expertise to manage HF patients.^{36, 38}

Limitations

The main study limitation is that only a relatively small number of primarily Caucasian hospitalized patients and their FMs who had been referred to one PC service were included. We cannot draw any conclusions about the experiences of persons with HF not referred to PC, those who are followed by PC in the outpatient setting, of HF patients receiving care in other settings, or of the potentially unique experiences of ethnic minority persons with HF. In addition, in several cases, family members’ perspectives are missing as patients participated without family members.

Study Implications

Research—This study highlights the need to compare the experiences of late-stage HF patients who receive usual care with those who receive an integrated model of care.

Clinical—Results from the study also suggest a few practice changes that would improve the experience of hospitalized HF patients and their family members. For a start, clinicians could introduce PC as a philosophy of care that allows for the unpredictable trajectory of HF, rather than a system of care delivery introduced at end-of-life.³⁹ Based on what the participants of this study reported this would be more appealing to HF patients and their FMs.

In order for non-PC clinicians to introduce the concept of PC as suggested above education and dissemination initiatives aimed at increasing RT providers' understanding of the philosophy and scope of PC and of how an integrative model would be actualized will likely be required. Similarly, for PC clinicians to integrate effectively with HF care they will likely require training opportunities focused on the disease-modifying treatments that many HF will be receiving concordantly with PC.

Policy—The findings from this study underscore the need to examine current hospice guidelines which were developed largely to accommodate people with advanced cancer. Multiple researchers and expert clinicians have recently focused on modifying current hospice policies to better meet the needs of people with HF including reexamining the 6-month prognosis guideline,³³ and continuing interventions aimed at aggressively controlling the symptoms of HF⁴⁰.

Conclusion

The conflation of PC and hospice was viewed by the study participants as a barrier to PC involvement in HF care because they felt that the “rules” and policies around hospice were incompatible with excellent end-stage HF care. Despite this, nearly all participants reported that the involvement of the PC service improved their hospital experience; some markedly so.²⁸ At first glance it would appear that a simple solution would be to create distance between PC and hospice. However, the situation does not lend itself to simple solutions. After working with the PCT, many of the participants in this study redirected to a comfort care approach, and were very appreciative of the comprehensive and compassionate care rendered at or near end-of-life.²⁸ Providing care to people nearing death is an integral part of what PC services do. However, the scope of PC encompasses more than that. If patients with HF were consistently referred to PC earlier in their disease trajectory, as is currently recommended, then people would be much less likely to equate it with hospice care. Furthermore, if current policies were modified to facilitate the provision of care that is consistent with the needs and values of HF patients and families then they would not need to worry about “rules” hindering their quality of life.

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Table 1

Participant Demographics

	Patients	Family Members
Number	24	16
Age Range	26-93	29-76
Sex	16 males 8 females	2 males 14 females
Race	20 Caucasian 4 African American	14 Caucasian 2 African American