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Unique Challenges of Hospice for Patients with Heart Failure: A Qualitative Study of Hospice Clinicians

Hillary D. Lum, MD, PhD^{1,2}, Jacqueline Jones, PhD, RN³, Dana Lahoff, LCSW¹, Larry A. Allen, MD, MHS^{1,4}, David B. Bekelman, MD, MPH^{1,2,4}, Jean S. Kutner, MD, MSPH¹, and Daniel D. Matlock, MD, MPH^{1,4}

¹University of Colorado School of Medicine, Aurora, CO

²Veterans Affairs Eastern Colorado Health Care System, Denver, CO

³University of Colorado School of Nursing, Aurora, CO

⁴Colorado Cardiovascular Outcomes Research Consortium, Denver, CO

Abstract

Background—Patients with heart failure have end-of-life care needs that may benefit from hospice care. The goal of this descriptive study was to understand hospice clinicians' perspectives on the unique aspects of caring for patients with heart failure to inform approaches to improving end-of-life care.

Methods—This qualitative study explored experiences, observations and perspectives of hospice clinicians regarding hospice care for patients with heart failure. Thirteen hospice clinicians from a variety of professional disciplines and clinical roles, diverse geographic regions, and varying lengths of time working in hospice participated in semi-structured interviews. Through team-based, iterative qualitative analysis, we identified three major themes.

Results—Hospice clinicians identified three themes regarding care for patients with heart failure. First, care for patients with heart failure involves clinical complexity and a tailored approach to cardiac medications and advanced cardiac technologies. Second, hospice clinicians describe the difficulty patients with heart failure have in trusting hospice care due to patient optimism, prognostic uncertainty, and reliance on pre-hospice healthcare providers. Third, hospice clinicians described opportunities to improve heart failure-specific hospice care, highlighting the desire for collaboration with referring cardiologists.

Corresponding author: Hillary D. Lum, MD, PhD, University of Colorado Anschutz Medical Campus, Division of Geriatric Medicine, 12631 E. 17th Ave, Campus Mail Stop B-179, Aurora, CO 80045, Fax: 303-724-1918; Phone: 303-724-1911; Hillary.Lum@ucdenver.edu.

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Conclusions—From a hospice clinician perspective, caring for patients with heart failure is unique compared to other hospice populations. This study suggests potential opportunities for hospice clinicians and referring providers who seek to collaborate to improve care for patients with heart failure during the transition to hospice care.

Keywords

Hospice; Terminal Care; Heart Failure; Qualitative Research

Introduction

For reasons that are incompletely understood, hospice remains underutilized by patients with heart failure (HF) despite high mortality risk, distressing symptoms, depression and reduced quality of life.^{1, 2} The transition to hospice care for patients with HF also involves challenging care transitions. Clinical data relevant to prognostication, palliation of HF symptoms, and medication reconciliation are often unavailable to hospice clinicians at time of admission.³ In a 2003 survey of hospice medical directors, only a minority of hospice agencies had any HF-specific staff training, policies, or care plans for the management of patients with HF, especially related to advanced therapies such as implantable cardioverter-defibrillators (ICDs), intravenous inotropic infusions, or left ventricular assist devices (LVADs).⁴ A small study of New Hampshire hospice agencies found that home medication “comfort” kits prescribed by hospices for uncontrolled symptoms did not routinely provide medications known to treat HF-related symptoms such as furosemide and nitroglycerin.⁵

Despite guidelines and consensus statements that address palliative approaches in advanced HF,^{6, 7} there are no standards or identified best practices to guide care for patients with HF receiving hospice care. The purpose of this study is to enhance understanding of the perspectives of hospice clinicians regarding the unique needs of patients with HF related to transitioning from life-prolonging to comfort-focused care, the role and availability of cardiac therapies in the hospice setting, and opportunities to improve care for hospice patients with HF.

Methods

Design

We conducted a descriptive study using semi-structured qualitative interviews of hospice clinicians who had experience providing clinical care for patients with heart failure. We chose a qualitative study design because the complexities of factors that influence hospice care for patients with HF are difficult to measure quantitatively, particularly given the lack of established standards of quality care for this population. The study was approved by the Colorado Multiple Institutional Review Board. This research was supported by the National Institute on Aging (PI Matlock, 1K23AG040696).

Participants

Hospice clinicians (physician, advanced practice nurse, or nurse) were recruited through the Population-based Palliative Care Research Network.⁸ Twenty hospice clinicians volunteered

to participate in response to a study invitation letter. Interview participants were selected based on purposeful sampling to include a range of clinical disciplines (physician, advanced practice nurse, nurse) and geographic regions for maximum variation.⁹ Each clinician was from a different hospice agency. Informed consent was obtained from study participants who were interviewed. Clinicians were asked to describe their clinical practice setting and number of years in hospice clinical practice. Recruitment and interviews continued until no new information or themes were emerging from the interviews. We used a team approach to make a decision that the interviews had become redundant and no new themes were emerging.

Interviews

We conducted in-depth, semi-structured telephone interviews between October 2012 and May 2013. The interview guide was developed by the interdisciplinary research team (palliative care physicians, cardiologist, hospice medical director, and geriatricians) with input from a community-based hospice academic partner. It included open-ended questions to understand key differences or unique aspects of care for patients with HF compared to patients with other terminal diseases, perspectives on available cardiac therapies in hospice, and suggestions for improving hospice care for patients with HF (Online Supplement 1). Interviews were conducted by a research assistant with experience conducting qualitative interviews. Interviews were 20–60 minutes in length.

Data Analysis

Interviews were digitally audio recorded, transcribed, and then analyzed using a mixed inductive and deductive approach.¹⁰ Data analysis involved systematic organization of the data through open coding, and repeated, constant comparison across coded data to identify consistent themes.¹¹ We utilized a team approach to analysis, including regular meetings (HL, DM, JJ, DL) to discuss coded data and reach consensus on identified themes and their meanings. Initial coding reflected the primary areas of interest in the study including hospice clinicians' perspectives on the needs of patients with HF in hospice, medication-related issues and ways to improve care. After the main analysis was completed, two authors (HL and DM) each listened to three randomly selected interviews to reflect on whether the analysis accurately represented the interviews. To confirm the interpretation of the analysis for a cardiology and hospice and palliative care clinical context, we solicited input on major themes, interpretation and potential implications of this study using the qualitative analysis technique called triangulation. Triangulation is a process of convening individuals or groups with different perspectives to facilitate a deeper understanding and trustworthiness of the findings. For this study, we conducted multiple meetings, each 1 hour in length, with the larger multidisciplinary authorship team (which includes two geriatrician and palliative medicine specialists [HL and DD], an ICU nurse and qualitative researcher [JJ], a palliative care social worker and qualitative research assistant [DL], a heart failure specialist [LA], a palliative medicine and psychiatry specialist [DB], and a general internist and palliative medicine specialist [JK]), members of the community-based hospice academic partner, members of an academic palliative care group, and a multidisciplinary cardiovascular research group (see Acknowledgements). Input was incorporated into the final analysis which is presented here.

Results

Participants

Among the 13 participating hospice clinicians, there were six physicians, six nurses and one advanced practice nurse, representing the Midwest, West, South and East regions of the U.S who had between 7 and 23 years of clinical experience in hospice and palliative care (Table).

Unique Aspects of Caring for Patients with HF in Hospice

The overarching perspective described by participants was that caring for patients with HF in hospice is unique, compared to caring for other hospice patient populations. This quote captures this sentiment:

“The cancer patient has a downward slope and it’s pretty predictable...The HF patient crashes and gets better. ... They know that they can be very, very sick, and then go to a baseline that was not the same as before, but better than before. So their acceptance of the dying process is different.”

Three major themes that describe the unique aspects of caring for patients with HF in hospice emerged from the hospice clinicians’ experiences: 1) hospice care for patients with HF involves additional clinical complexity and a tailored approach to care; 2) patients often have difficulty trusting hospice care; and 3) opportunities exist to improve HF-specific hospice care.

HF Hospice Care Involves Additional Clinical Complexity and a Tailored Approach to Care

The first major theme from hospice clinicians was recognizing additional clinical complexity in end-stage HF, compared to other illnesses commonly cared for by hospices such as cancer and dementia. This clinical complexity necessitated a tailored care plan that included careful management of cardiac medications and advanced HF technologies (Online Table 1). With regard to unique aspects of cardiac medication management, hospice clinicians discussed considering discontinuing cardiac medications but emphasized a careful approach to maintaining, changing or discontinuing a HF regimen in order to support patient preferences. One clinician stated:

“Sometimes with these very hopeful patients, having the medications is the only control they have left... We don’t routinely stop medications without a lot of conversation.”

Hospice clinicians specifically noted the clinical complexity and the need for expertise related to care of HF patients with cardiac devices (i.e. ICDs) or advanced HF therapies (i.e., LVADs) (Online Table 1). Clinicians described a willingness to support these patients within hospice, and also noted the challenges inherent in providing that support. For instance, hospice clinicians described unique communication needs regarding a patient’s expectations of a cardiac device, whether hospice care aligns with their goals of care, and how the technology impacts quality of life and the dying process.

“I think what’s challenging from the physician perspective is that there are a lot of new interventions that are helpful for patients, and we are always trying to navigate that. Our organization just developed a new LVAD clinic. [LVADs are] used as a destination therapy for people and it has some symptom benefits. So we are asking, ‘Can people be in hospice with an LVAD? Is that a quality of life intervention?’ ”

Patients Have Difficulty Trusting Hospice Care

The second major theme that emerged from hospice clinicians was a perception that HF patients had difficulty trusting hospice care. The lack of trust seemed to relate to two sub-themes: 1) patient optimism about their prognosis related to HF; and 2) patient familiarity with prior healthcare from cardiologists, the emergency department, and hospital-based care (Online Table 2). Patient optimism about their prognosis made it difficult for many patients with HF to transition to hospice care. Clinicians noted that patients sometimes experience and survive multiple disease exacerbations, which might have contributed to a survival mentality. Several hospice clinicians noted that patients did not expect to die of HF and were resistant to discussing end-of-life care.

“HF patients are such optimists. Even when you (the clinician) say, ‘you have a 90% chance that you aren’t going to make it,’ that 10% chance to them is great. They say, ‘I’m a fighter,’ ‘I can hang in there,’ or ‘I can beat the odds.’”

The second sub-theme relating to patients’ ability to trust hospice care was patients’ reliance on prior healthcare providers including cardiologists, emergency care, and inpatient hospitalization as the sources of care with which they were familiar (Online Table 2). Hospice clinicians recognized that patients and family members were being asked to choose a new and unfamiliar medical care process. For instance, being directed to contact the hospice agency first to avoid the emergency department and hospital-based care during a HF exacerbation was a challenging change.

“It’s very common for patients to have very strong bonds to the doctors who have helped keep them alive for so long. They are so used to being in and out of the hospital for treatment, and by default they have a very trusting relationship with their cardiologist.”

Hospice clinicians described ways their agencies worked to decrease emergency care and hospitalizations. Through education, communication and trust-building, hospice clinicians described how their programs have been able to decrease emergency department visits. One clinician noted the importance of the hospice agency knowing its own limitations, including times when staffing transitions were predictable (i.e. nursing telephone triage shift changes) and might delay their ability to provide home support. Another clinician felt that the hospice agency could respond more quickly to a HF exacerbation by having intravenous furosemide available at home, in addition to oral furosemide. Effective and accessible communication was frequently emphasized, including the use of tele-medicine, “[Our hospice is] experimenting with tele-caring in the home. Perhaps seeing a face in addition to a voice might be one way to do that.”

Finally, as hospice clinicians talked with some HF patients who were having difficulty trusting hospice, the hospice clinicians identified that the patient's goals of care included ongoing hospital-based care, rather than avoiding future hospitalizations. In these cases, hospice clinicians referred patients to palliative care programs for appropriate support. These hospice clinicians recognized that outpatient palliative care programs, in contrast to hospice care, would be able to provide support to the patient alongside hospital-based care. These palliative care programs can play a critical role with ongoing goals of care discussions related to prognosis and unmet needs while the patient continues to pursue life-prolonging therapies.

Opportunities to Improve HF-specific Hospice Care

The final major theme noted by hospice clinicians was the need to improve HF-specific care in hospice. Clinicians described several opportunities to improve patient-centered HF hospice care in three sub-themes: 1) hospice clinicians' desire collaboration with primary care providers (PCPs) and cardiologists; and 2) hospices need HF-specific expertise and programs as part of hospice care; and 3) payment reform. (Online Table 3).

Clinicians described varied experiences and interactions with cardiologists and PCPs. Overall, they desired more collaboration between the referring provider and the hospice team to improve the transition to hospice care for patients with HF, recognizing challenges related to patient complexity, patient optimism about prognosis, and reliance of prior healthcare clinicians and services (Figure). Among the barriers to on-going collaborative care were a lack of clear financial payment structures to incentivize non-hospice provider involvement. The underlying prognostic uncertainty related to HF also delays referral: "One of the cardiologists once said 'I realize these patients are going to die, I just don't know which ones.'" Hospice clinicians described the desire to collaborate with cardiologists to provide clear communication, education and support to their HF patients receiving hospice care, particularly as relates to advanced HF therapies.

"There are cardiologists that are more involved and will talk to their patients and back up the hospice and palliative medicine physicians. Of course, those cases tend to go much better. On occasion you have the cardiologist who discusses end points before some of this technology is even used, and that's even better. We are finding patients whose cardiologists are more willing to talk to them versus handing them over to us with an ICD that's working and that they never addressed any of the issues [such as device deactivation]."

The second identified opportunity to improve patient-centered hospice care was a need for more HF-specific education for hospice nurses especially in rural areas (Online Table 3). Hospice clinicians are interested in more evidence to guide HF management in hospice, including prognostic tools, guidance for discontinuation of cardiac medications, and evidence on cost-effectiveness of HF-specific programs within hospices.

A third opportunity was the need for Medicare hospice payment reform since hospices face the risk of non-payment for patients who have long lengths of stay, which is more common in HF than cancer.¹² One hospice clinician described this challenge:

“We’ve had patients that we’ve had to discharge after a year or more because they were plateauing with HF. It’s a problem for hospices because clinically we’ve been cracked down for that, but the reality is we are trying to do our best. It’s a problem with most hospices and HF.”

Discussion

This qualitative study identified end-of-life care processes and unique needs related to providing hospice care for patients with HF. We found that hospice clinicians described additional clinical complexity in end-stage HF that necessitated a tailored approach to medication management, cardiac devices and advanced HF therapies to meet patient-specific goals and needs. Hospice clinicians also noted challenges patients with HF face in being able to trust hospice care and opportunities to improve HF-specific hospice care. This study reflects the challenges and efforts of hospice clinicians as they care for patients who transition to hospice care.

Our findings describe the efforts of hospice clinicians to individualize care to patient preferences and clinician’s perception of the lack of prospective evidence regarding effective symptom management and appropriate indications for discontinuing cardiac medications. While studies on the prevalence of symptoms among HF patients in hospice care have been conducted,^{13, 14} there is a need for research that develops and expands the evidence base for hospice-based practices and interventions in HF, similar to those being conducted among hospice patients with cancer diagnoses.¹⁵ Effective interventions and use of hospice care for patients with cancer has been enhanced by a solid and growing foundation of clinical intervention studies that address the complex needs of this patient population. The care of HF patients in hospice care lacks this evidence base, and limits how patients, families and healthcare providers understand the impact of hospice care. Hospice clinicians described a desire for more collaboration and continuity with referring providers, including cardiologists and PCPs. While there are financial and practical limitations to increased communication and care coordination, we are encouraged by examples of hospices that are building and maintaining geographic partnerships with providers that care for HF patients in order to provide early palliative care and assist with the transition to hospice care. Based on these findings, we have identified several opportunities where care for hospice patients with HF could be improved (Text Box). For example, a specific way to improve HF-specific hospice care includes initiating “warm hand-offs” between cardiologists, PCPs, and hospice clinicians at the time of admission to hospice. A hand-off is a specific transition of care process that should include clear HF-related care planning documentation¹⁷ from the cardiology provider to the hospice provider.

To our knowledge, this is the first study to highlight the perspectives of hospice clinicians who provide care for HF patients. Our study has limitations. First, the care described is based on a limited number of hospice clinicians and is not designed to be generalizable. We have attempted to increase the understanding and trustworthiness of our findings and interpretations by incorporating input from multiple perspectives involved in this process including a community hospice partner and a cardiology outcomes research group, in addition to other palliative medicine providers. While this sample included clinicians from

different disciplines, including physicians and advance practice nurses, further research is needed to explore how clinician background and training affects the perceived needs of HF patients receiving hospice care. Second, this study focused on the perspectives of hospice clinicians; further study is needed to understand the perspectives of referring providers, including cardiologists and PCPs, as well as other members of the hospice interdisciplinary team such as chaplains and social workers. These findings complement qualitative efforts that describe the perspectives of HF patients' and family members'.¹⁶

In conclusion, hospice clinicians described the need to use a tailored approach to hospice care and that HF patients faced significant difficulties in trusting hospice care. Many of the challenges and opportunities to improving hospice care for HF patients reflect the broader needs of individuals with advanced or serious illness. The Institute of Medicine's report, "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life"¹⁷ emphasizes the need for payment reform that aligns the availability and provision of medical services to the needs of patients and families. Future work should focus on research and quality improvement initiatives to develop HF expertise and evidence-based, interdisciplinary guidelines that improve end-of-life care for patients with HF who are receiving hospice care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Text Box. Practical Opportunities for Hospice Clinicians and Cardiologists to Improve HF-specific Hospice Care

- Initiate warm hand-offs – a clear transition of care process from cardiology provider to hospice provider
- Make clear recommendations on the need to continue or discontinue cardiac medications
- Develop care plans related to use and discontinuation of advanced cardiac therapies (i.e. LVADs, ICDs, inotropes)
- Seek cardiologist/hospice alignment regarding prognosis and the role of hospital-based care
- Adapt current HF patient education materials for the hospice setting
- Train hospice staff to assess and manage common HF-related symptoms

Figure 1.

Patients with HF in hospice care have unique needs that can be met through hospice-cardiology collaborations.

ICD: Implantable Cardioverter-Defibrillator

Table**Hospice Clinician Characteristics**

Hospice provider type	Years in Practice	Role
Nurse	8	Assessment of hospice eligibility
Nurse	14	Director of Nursing
Nurse	23	Director of Clinical Services
Physician	7	Chief Medical Officer
Physician	7	Hospice and palliative care home visits
Physician	11	Clinical Director
Nurse	7	Chief Clinical Officer
Advance Practice Nurse	2	Hospice face-to-face visits
Physician	Not given	Clinical Director
Physician	16	Clinical Director
Physician	14	Chief Medical Officer
Nurse	10	Chief Clinical Officer and home care nurse
Physician	9	Direct clinical care