On Board

Interdisciplinary Team Member Perspectives of How Patients With Heart Failure and Their Families Navigate Hospice Care

David Russell, PhD ○ Elizabeth A. Luth, PhD ○ Dawon Baik, PhD, RN ○
Lizeyka Jordan, MPH ○ Ruth Masterson Creber, PhD, MSc, RN

Hospice agencies serve an expanding population of patients with varying disease conditions and sociodemographic characteristics. Patients with heart failure represent a growing share of hospice deaths in the United States. However, limited research has explored the perspectives of hospice interdisciplinary team members regarding how patients with heart failure and their families navigate hospice care. We sought to address this research gap by conducting qualitative interviews with hospice interdisciplinary team members at a large, not-for-profit hospice agency in New York City (N = 32). Five overarching themes from these interviews were identified regarding components that members of the hospice interdisciplinary team perceived as helping patients with heart failure and their families navigate hospice care. These themes included (1) "looking out: caregiving support in hospice care," (2) "what it really means: patient knowledge and understanding of hospice," (3) "on board: acceptance of death and alignment with hospice goals," (4) "on the same page: communication with the hospice team," and (5) "like a good student: symptom management and risk reduction practices." Interdisciplinary team members delineated several components that influence how patients with heart failure and their families navigate hospice services and communicate with care providers. Hospice agencies should consider policies for augmenting services among patients with heart failure to improve their understanding of hospice, supplement available caregiving supports for patients without them, and remove communication barriers.

KEY WORDS

caregiving support, heart failure, hospice, interdisciplinary team, patient communication

David Russell, PhD, is assistant professor, Department of Sociology, Appalachian State University, Boone, NC and Research Scientist at the Center for Home Care Policy & Research, Visiting Nurse Service of New York, New York.

Elizabeth A. Luth, PhD, is postdoctoral associate at the Weill Cornell Medicine Center for Research on End-of-Life Care, New York, New York.

Dawon Baik, PhD, RN, is assistant professor at the University of Colorado College of Nursing.

Lizeyka Jordan, MPH, is statistical analyst at the Center for Home Care Policy & Research, Visiting Nurse Service of New York, New York.

Ruth Masterson Creber, PhD, MSc, RN, is assistant professor at the Division of Health Informatics, Department of Healthcare Policy and Research, Weill Cornell Medicine, New York, New York.

Address correspondence to David Russell, Department of Sociology, Appalachian State University, ASU Box 32115, Boone, NC 28608-2115 (russelldj@appstate.edu).

This research was supported by a grant from the Eugenie and Joseph Doyle Research Partnership Fund.

The authors have no conflicts of interest to disclose.

Hospice encompasses services to support persons with terminal illness in managing pain and symptoms and in assisting with the emotional and psychosocial aspects of dying.[1] Hospices are serving an increasing number of patients with diverse characteristics, in terms of both diseases as well as racial, ethnic, religious, and cultural backgrounds.[2,3] Along with increased use of hospice and diversity in patient populations, there is concern over problematic trends in service usage, including referrals during the last days of life ("late referral") and hospice disenrollment ("live discharge").[2,4,5] The structure and organization of hospice service delivery may contribute to these problematic patterns of service utilization, including issues with language interpretation and cultural insensitivity among hospice providers.[6,7] These issues have prompted calls for more culturally competent care for people nearing the end of life.[8]

There are more than 6.5 million adults in the United States with heart failure, and this population represents a growing share of hospice patients overall.[3,9] Patients with heart failure face unique challenges once enrolled in hospice, including an unpredictable disease trajectory and high rates of live discharge relative to other diagnoses.[10,11] In addition, the current US health care environment presents a complex web of sociocultural impediments to hospice that shape patient decision making at the end of life.[12] Patients with heart failure who possess biomedical knowledge about their disease and its progression, the skills to communicate with health care providers, and the ability to mobilize available resources to cope with illness may

have more success with navigating health care interactions and organizations, including those within the hospice setting.[13] However, previous studies have not identified the various sociocultural components that influence how patients with heart failure and their families navigate hospice care. Existing research among the larger population of hospice patients and persons with advanced illness suggests several potential areas for study. For one, gaps in assistance from formal and informal caregivers pose considerable problems during the advanced stages of terminal illness, when individuals experience declines in physical functioning and distressing symptoms.[14,15] Poor knowledge about hospice is also common, including misperceptions regarding eligibility and coverage of services.[16] Limited understanding and unrealistic expectations of hospice services can increase the risk for hospitalization, especially when patient goals of care are not aligned with those of the hospice interdisciplinary team.[17] The hospice team may view patients whose health care goals are aligned with the hospice philosophy, including acceptance of death and a desire to avoid the hospital, as facilitating productive interactions. Conversely, patients who exhibit lesser acceptance of their terminal diagnosis or who are reluctant to engage in advance care planning may be perceived by the hospice team as barriers to care.[18] Patients' and caregivers' ability to recognize and communicate distressing symptoms to the hospice team, including seizures and shortness of breath, can prevent crises that trigger emergency calls resulting in hospitalization.[11,17,19] The ability of patients and families to communicate symptoms to the hospice team may be further compromised by language and cultural barriers. English-language proficiency has been associated with increased willingness to use hospice services among Hispanic populations and may facilitate access to information and acceptance of hospice.[20] Finally, patients with a greater understanding of self-management strategies, including knowing when and how to use medications to control symptoms of pain and discomfort, may be more likely to manage these symptoms.[21]

This study aimed to add to this existing literature by identifying themes from qualitative interviews with interdisciplinary team members regarding sociocultural components that influence how patients with heart failure and their families navigate hospice care. Interdisciplinary teams represent the core of hospice and palliative care services; are composed of physicians, nurses, social workers, and bereavement/spiritual counselors among other disciplines; and are responsible for coordinating a holistic plan of care for patients.[22] The interdisciplinary nature of hospice teams presents an opportunity not only to understand what they perceive as the most important components of hospice care but also to gain insight into the types of knowledge, attitudes, and resources that shape hospice care delivery for patients with heart failure.

METHODS

Study Setting and Sample

Qualitative interviews were conducted with interdisciplinary team members at a large not-for-profit hospice in New York City between 2018 and 2019. Interviews were part of a larger multimethod study investigating challenges to caring for hospice patients with heart failure.[11,23,24] Team members were sampled across disciplines and service areas throughout New York City. Interviewees were recruited during interdisciplinary team meetings, then provided informed consent, and completed the interview in nearby private offices. An iterative approach was used to develop interview questions about what team members perceive as the unique characteristics and challenges of serving hospice patients with heart failure, the range of sociocultural and contextual factors that influence how patients with heart failure and their families navigate hospice care, and their perspectives regarding facilitators and barriers to care delivery. A full list of the semistructured questions from these interviews is provided in the Figure. Interviews lasted approximately 30 to 45 minutes and were audio-recorded and transcribed verbatim. Interviewees received $25 certificates. Study procedures were approved by institutional review boards at the participating agency and its academic partners.

Data Analysis

Interview transcripts were analyzed using grounded theory methods.[25] The first step involved open coding of the first several transcripts, during which 4 members of the study team highlighted and labeled all potentially meaningful phenomena using Dedoose.[26] These 4 team members then met to compare the full list of codes for similarities and differences, with related codes being grouped together under parent categories. Interrater reliability was assessed for frequently applied codes and suggested good levels of agreement between coders (Cohen κ statistic ranged from 0.77 to 0.88). Preliminary themes emerged during the early stages of analysis. These preliminary themes were used to refine the interview guide for subsequent participants, using targeted questions to probe deeper discussions. Interviews were conducted until sufficient conceptual depth was reached across study themes.[27] Weekly meetings were convened among the study team to discuss coding schemas and progress with applying those coding schemas to all remaining transcripts. Upon completion of coding, the first author wrote extensive memos to elaborate on coding notes and expand upon ideas regarding themes in interdisciplinary team members' perceptions of sociocultural components that influence how patients with heart failure and their families navigate hospice care. These themes were then shared and discussed with the entire study team and revised for clarity. Identifying information has been removed

1. Can you tell me more about caring for heart failure patients at the end-of-life?

2. What are some of the unique characteristics or challenges about serving hospice patients with heart failure compared to patients with other illnesses like cancer?

3. Have you ever cared for a heart failure patient who was discharged from hospice or called 911? Our research data suggests that this is common among HF patients.
   a.   *If so, can you tell us more about that experience?*
   b.   *What were some of the challenges that you faced?*
   c.   *Did you observe anything about patients who called 911 and were hospitalized, in terms of their social, family, or cultural background?*
   d.   *In our analysis of agency data, we observed that Hispanic and African American patients have a higher risk of being hospitalized. Do you have any thoughts about why this might be the case?*
   e.   *We also observed that patients without a family caregiver were more likely to make the decision to leave hospice ("revoke their benefits"). Do you have any thoughts about why this might be the case?*

4. What helps heart failure patients stay comfortable at home *(i.e., specific hospice services, family/caregiver support)?*

5. Are there heart failure symptoms that make it more difficult for hospice patients to stay at home?
   a.   *How are you able to help keep symptoms under control in the home environment?*
   b.   *What symptom management strategies did you use to help manage the symptoms?*
   c.   *Timing of symptoms relative to events (death or discharge)*

6. Are there medications that make it more challenging to manage hospice patients with heart failure?
   a.   *Is there anything challenging about managing patients on inotrope drips specifically?*

7. Tell me more about the process of setting the "goals of care" that you develop with patients and caregivers.
   a.   *What topics are addressed? (i.e., treatments, palliative care, devices, etc....)*
   How (and when) is the "goals of care" plan developed?
   b.   *Who is included in that discussion (i.e., family members, caregivers, patient, providers--which ones)?*
   c.   *What are some challenges you face when setting goals of care?*
   d.   *Do you use any specific tools? If so, how do you use them to effectively talk with patients and their caregivers?*

8. Is there anything that you think would improve the cardiac home hospice program?

9. Is there anything you want to tell us about the care of heart failure patients in home hospice that we did not ask you about directly?

FIGURE.   Interview questions for hospice interdisciplinary team members.

from quotes, and all names referring to interviewees are pseudonyms.

RESULTS

The characteristics of 32 interdisciplinary team members who were interviewed are shown in Table 1. Most interviewees were female (81%) and nurses (75%), with an average age of 48 years. A smaller proportion of interviewees practiced disciplines other than nursing, including social work (13%), medicine (6%), or spiritual counseling (6%). Five themes were identified regarding sociocultural components perceived by interdisciplinary team members as shaping how patients with heart failure and their caregivers navigate hospice care. These themes are described hereinafter and illustrated with additional quotations in Table 2.

Looking Out: Caregiving Support in Hospice Care

Team members described how caregiving support for hospice patients with heart failure helped to supplement the services they received from hospice agencies. Team members identified these supports as the presence of "a lot of people helping out [in the home]," including formal support for hospice patients from privately hired caregivers and informal support from family members. Patients with higher incomes and wealth secured "quick access to health care providers" including privately hired nurses and aides who helped keep patients comfortable at home by providing emotional support and assisting with tasks such as administering medications to manage shortness of breath. Hospice patients without family caregivers or privately hired caregivers relied on the hospice team to be "looking out" for them. Patients who lacked a "support system" on "a consistent basis" were seen by team members as having

TABLE 1	Demographic Characteristics of Hospice Interdisciplinary Team Members (N = 32)	
Variable		**n (%)**
Sex		
Female		26 (81.2)
Male		6 (18.8)
Mean (SD) age, y		48.3 (10.7)
Race/ethnicity		
White		15 (46.9)
Black		11 (34.4)
Hispanic		3 (9.3)
Other		3 (9.3)
Team member discipline		
Nurse		24 (75.0)
Social worker		4 (12.5)
Physician		2 (6.2)
Bereavement/spiritual counselor		2 (6.2)

greater difficulty managing their symptoms and avoiding pain and suffering. Team members viewed gaps in caregiving support for hospice patients as contributing to their hospitalization risk: "And part of why people call [911] for any diagnosis when they go to the hospital, is that they do not feel like they have enough support in the home" (John, nurse).

What It Really Means: Patients' Knowledge and Understanding of Hospice
Hospice team members viewed patients with heart failure who were knowledgeable about hospice as better able to make use of hospice services and communicate with team members. However, team members stated that "most people do not understand what hospice is when they first come on" (Donald, nurse) and that many patients "do not really understand the whole concept" (Kimberly, nurse), despite providing their consent for hospice services. Understanding includes knowledge about how much and what types of hospice services patients would receive, differences between hospice and routine home health (visiting nurse) services, and awareness of one's terminal prognosis. Team members attributed this limited understanding to physicians who were "not really clear" in explaining their reasons for referring them to hospice. Physicians who

were less clear in explaining hospice to patients might describe hospice as a service to facilitate symptom management or provide additional in-home assistance. Team members suggested that, because patients with heart failure have historically been underrepresented in hospice, more education is needed for cardiologists and hospitalists about having open conversations with patients and families regarding the benefits and goals of hospice services. The limited explanations that some patients and families received from physicians about hospice led to confusion, including for some who "just think it's home care…and not realizing what it really means" (Kimberly, nurse). Robert (physician) described how patients would "hear they get additional help at home…without hearing the rest of it," alluding to a lack of comprehension among patients that they had a prognosis of 6 months or less to live. Team members worked to cultivate patients' knowledge through a "multistep conversation" involving talking to them about goals of care, advance directives, funeral arrangements, and the "process of dying" (Cynthia, nurse). Knowledge of the disease trajectory of heart failure and its associated symptoms, advance directives, medications, and therapies also provided material benefits to care. Examples included understanding how medications (eg, morphine) and therapies (eg, oxygen) could help patients manage heart failure symptoms or issues related to advance directives such as the implications of keeping a defibrillator activated alongside a standing "do not resuscitate" order.

On Board: Acceptance of Death and Alignment With Hospice Goals
Team members described having productive interactions with patients and family members who were "on board with hospice," represented by acceptance of death and dying and alignment with hospice goals. Hospice team members perceived acceptance of death and dying as facilitating hospice goal achievement because acceptance enabled "more of a dialogue" with team members, including communicating funeral and estate plans to social workers. Team members also mentioned prognostic awareness as promoting favorable attitudes toward advance directives, because team members perceived that these patients were "realistic" about "how much their body can do" (Susan, nurse).

Patients and families who team members described as not "on board" with hospice also expressed less acceptance and readiness for the end of life. Katherine (physician) stated that "it's not infrequent that we hear that 'I'm not going to die…this is not going to happen to me.'" John (nurse) described cases with "complete discord," characterized as disagreement among family members and an absence of "emotional readiness or openness" to hospice. Although Medicare hospice requirements dictate who is "clinically" appropriate for hospice care, team members

TABLE 2 Themes and Illustrative Quotes From Qualitative Interviews

Looking Out: Caregiving Support in Hospice Care
"If there is lack of family support, which happens a lot in my community and my population of patients…they kind of panic faster. They're home alone, having trouble breathing, and sometimes they will not call hospice, they'll call 911…it's fastest…it's three digits…that's it. It's all this hysteria. Oftentimes they are all alone or immediate family will show up…maybe, if they like. It's like they are left there." (Kimberly, nurse)

What It Really Means: Patients' Knowledge and Understanding of Hospice
"Their physicians say you need extra support at home, so we are sending you on hospice. People who have no clue what hospice is think, 'Oh, I am just going to get a nursing visit.' They do not understand the prognosis that if your disease progresses the way that it should or the way it has been you have less than six months to live. That is something I have been trying…I always try to do that from the beginning, like 'Do you know why you are here? Sometimes they do not know what program they are on. Sometimes the doctor might tell them 'We're putting you in something to manage your pain.' They're not really clear." (Pamela, nurse)

On Board: Acceptance of Death and Alignment With Hospice Goals
"Sometimes there's just complete discord, disagreement among themselves, and maybe generally. I mean, sometimes you cannot understand why they came on hospice to begin with, because no one seems to be on board with it…and there's no requirement that they are. I mean people who do not sign resuscitation, there's no requirement. We hope that they have come to us when they are ready, so clinically, they have to be ready. But there's a level of emotional readiness or openness to where—'this sounds like my choice now.'" (John, nurse)

On the Same Page: Communication With the Hospice Team
"We had to [rely on an interpreter line], and it's not really comforting for the patient or the family to have that. We're not really bonding. I develop really deep connections with all of my patients, because we talk a lot, you know, we speak the same language, and it's easy for us to communicate—I understand them and they understand me…. The language barrier is really an issue as far as calling 911, especially at night because most of the [hospice] nurses are English-speaking." (Alondra, nurse)

Like a Good Student: Symptom Management and Risk Reduction Practices
"The family was very involved and they were able to really manage and communicate with us exactly on the symptoms, and her husband had a very good…he was like, searching and informing himself of the care, and she knew how to manage her medication with a lot of teaching from us, and everything, to the point that she became very, very, very well-managed." (Maria, nurse)

noted that these same policies do not require patients to have advance directives in place upon enrollment and that patients and families may be admitted to hospice without being fully "on board." Team members associated misalignments between patient prognostic awareness and family readiness to forego conventional disease-directed treatments with an increased risk of disenrollment. Other signals that patients and family members were not "on board" with hospice included expressions of fear and denial about the future, when they "hear the word hospice and want to run the other way" (Kenneth, social worker) or where they "use hospice to get the service that they need, but not really…in terms of 'Oh, this is final, we are at the end'" (Lori, nurse). Team members described family members who "do not like to talk about death and dying" and who actively withheld prognostic and service information from patients for fear that sharing such information would hasten their death or cause depression. Tara (nurse) described how patient and family resistance to end-of-life conversations "makes it a little bit challenging and harder" to set goals of care and describe to them "what's coming." Team members viewed patients who expressed an openness to talking about death and dying with the hospice team and those who indicated goals of care that were aligned with the hospice philosophy as being "on board."

On the Same Page: Communication With the Hospice Team

Multiple team members mentioned understanding what information is important to communicate to the hospice team as an important factor in patient comfort and continuous hospice enrollment. Tara (nurse) described how patients and families "work very well with us" when "they know that any change [in symptoms] is significant." This sociocultural component is especially important for hospice patients with heart failure, who can experience rapid, sudden, and dramatic changes in their disease trajectory. Families and private aides often communicate patient symptoms to the hospice team and contribute to conversations on setting goals of care when the patient is unable to do so. Nancy (nurse) described how "getting on the same page" was dependent "on how verbal they [patients and families] are." Communication between patients, families, and the hospice team was necessary for building trust and rapport. Team members indicated that building trust with patients and family members was an iterative process that occurs "over the course of time." Establishing trust and rapport with patients and families enabled team members to "steer them into where you would like them to be" (Donna, nurse) so that they can "use the service in the way that it will be effective for them" (Kenneth, social worker).

Dmitry (social worker) noted that "connecting [with patients] on a human personal level" allowed them to "talk about things that are more sensitive," especially among those who are "not ready to discuss death and dying, or funeral arrangements." Team members described establishing trust and rapport as more difficult when patients and families were "fiercely fighting" hospice, by pursuing curative treatments or declining advance directives.

Language and cultural concordance between patients and team members facilitated communication. Conversely, an inability to speak a patient's language presented an obstacle to therapeutic interactions and educational interventions: "If you do not speak the same language, you cannot really take care" (Susan, nurse). Maria (nurse) noted that "you cannot really provide 100% teaching if there's that barrier language [sic]." Team members relied upon interpreter lines as a "last resort" and as something that "does not really work when the patients are really sick." Team members perceived language barriers as an obstacle to building trust with patients and families and as limiting their ability to "understand the whole prognosis."

Like a Good Student: Symptom Management and Risk Reduction Practices

Team members described having productive interactions with patients with heart failure who proactively took medications, engaged in symptom self-management, and complied with medical directives. They expressed frustration with patients who refused hospice services, resisted medical advice, or failed to adjust their health behaviors after receiving self-management instructions. Amber (nurse) described 1 patient who was compliant with medical advice by illustrating how he was "following through like a good student," being "in-tune with his body," and "very receptive to teaching."

Patients with heart failure were labeled by hospice team members as being noncompliant in cases where they did not follow dietary recommendations to prevent fluid overload or were resistant to using morphine to manage pain and shortness of breath. Team members noted that fearfulness among patients and family members that "morphine is going to kill them" prevented some from administering the medication, precipitating a "very uncomfortable death." Team members would spend extra time with patients they viewed as being less compliant with medication regimens. Donald (nurse) described how he spent significant time "just getting their [medications] together, talking to their cardiologist, trying to figure out what they should be taking versus what they are taking." Team members viewed patients "willing to accept" medical equipment such as hospital beds, oxygen, and wheelchairs or walkers as better able to manage their conditions at home. Family caregivers were important partners in facilitating patient self-management, including with medication administration,

reinforcing educational interventions, and learning about the patient's condition.

DISCUSSION

Our results revealed 5 overarching themes regarding components that members of the hospice interdisciplinary team perceived as shaping how patients with heart failure and their families navigate hospice care. These themes included (1) "looking out: caregiving support in hospice care," (2) "what it really means: patient knowledge and understanding of hospice," (3) "on board: acceptance of death and alignment with hospice goals," (4) "on the same page: communication with the hospice team," and (5) "like a good student: symptom management and risk reduction practices."

Team members described caregiving support as a crucial resource for hospice patients with heart failure to avoid crises and emergencies that lead to hospitalization and hospice disenrollment, events that are prevalent in this population.[11] Family caregivers were viewed by the hospice team as being especially significant. Family caregivers provide a broad spectrum of tasks for community-dwelling older adults, including functional assistance, health care coordination, and disease management.[28,29] Caregiving support becomes increasingly important to hospice patients during periods of policy change when agencies implement cost-cutting measures that push support personnel to the margins of care.[30] Team members also acknowledged other components they felt helped patients with heart failure and their families navigate hospice, including a familiarity with hospice that helped them set realistic expectations for care, prognostic awareness and understanding of their condition, alignment with hospice goals of care, and alertness to changing symptoms that prompted communication. Principal among these components was the extent to which patients with heart failure and their families were viewed by hospice team members as being "on board" with hospice, identified by their awareness of dying and alignment with hospice philosophy. Previous qualitative studies have highlighted the range of awareness and understanding that persons with advanced heart failure have about the course of their illness—spanning from denial (eg, "I do not have an illness") to greater realization of one's terminal prognosis (eg, "if you have any sense…you know what they are saying to you").[31] The limited awareness among patients with heart failure described by team members in our study is likely influenced by interactions with health care providers, including physicians, who may not clearly communicate prognostic information or reasons for referral to hospice. Mixed messages from physicians combined with fragmented care have been shown to undermine patient awareness.[32]

Team members also identified communication as an important component that impacted their ability to establish

trust with patients and families. Communication plays an integral role in the provision of compassionate care, facilitating the ability of team members to notice subtle cues and details, establish connections, and respond to pain and suffering.[33] Language concordance between patients, families, and team members facilitates communication and trust. Conversely, language barriers can inhibit educational interventions and symptom communication, as well as cause misunderstandings and frustration.[34]

CONCLUSION

On the basis of the findings of our study, we recommend that hospice agencies consider policies for augmenting services among patients with fewer resources and supports. For example, hospices could target continuous 24-hour support to patients without family caregivers or those with difficulties managing symptoms, not only for patients who are having an acute crisis. Continuous care services have been shown to mediate socioeconomic disparities in transfers between home and institutional hospice settings[35] and could help to reduce unplanned hospitalizations. In addition, programs that provide in-home support to family caregivers, including respite and home-delivered meals, have been shown to reduce burden in caregivers of hospice patients.[36] Spiritual support for patients with advanced illness, including visits from chaplain or clergy, could also serve as a bridge to help patients and families navigate end-of-life discussions with the hospice team.[37] Additional strategies for improving hospice care include community outreach activities aimed at increasing awareness of hospice services, incorporating family members into the referral and treatment process, bridging language barriers for patients and families, and increasing cross-cultural sensitivity and diversity among hospice staff.[34]

Acknowledgment

References

1. NHPCO. Hospice care. https://www.nhpco.org/about/hospice-care. Accessed May 8, 2019.
2. NHPCO. *Facts and Figures: Hospice Care in America*. Alexandria, VAs: National Hospice and Palliative Care Organization; 2018. https://39k5cm1a9u1968hg74aj3x51-wpengine.netdna-ssl.com/wp-content/uploads/2019/07/2018_NHPCO_Facts_Figures.pdf.
3. MedPAC. *Report to the Congress, Medicare Payment Policy.* Washington, DC: Medicare Payment Advisory Commission; 2019.
4. Prsic E, Plotzke M, Christian TJ, Gozalo P, Teno JM. A national study of live hospice discharges between 2000 and 2012. *J Palliat Med*. 2016;19(9):987-990.
5. Russell D, Diamond EL, Lauder B, et al. Frequency and risk factors for live discharge from hospice. *J Am Geriatr Soc*. 2017; 65(8):1726-1732.
6. Carrion IV, Bullock K. A case study of Hispanics and hospice care. *Int J Humanit Soc Sci*. 2012;2(4):9-16.
7. Rising ML, Hassouneh DS, Lutz KF, Lee CS, Berry P. Integrative review of the literature on Hispanics and hospice. *Am J Hosp Palliat Care*. 2018;35(3):542-554.
8. Periyakoil VJ. The need of the hour: culturally competent care for seriously ill patients. *J Palliat Med*. 2020;23(4):440-441.
9. CDC. Facts about heart failure in the United States. https://www.cdc.gov/heartdisease/heart_failure.htm. Accessed April 16, 2020.
10. Cross SH, Kamal AH, Taylor DH Jr., Warraich HJ. Hospice use among patients with heart failure. *Card Fail Rev*. 2019;5(2): 93-98.
11. Russell D, Baik D, Jordan L, et al. Factors associated with live discharge of heart failure patients from hospice: a multimethod study. *JACC Heart Fail*. 2019;7(7):550-557.
12. Mrig EH, Spencer KL. Political economy of hope as a cultural facet of biomedicalization: a qualitative examination of constraints to hospice utilization among U.S. end-stage cancer patients. *Soc Sci Med*. 2018;200:107-113.
13. Shim JK. Cultural health capital: a theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *J Health Soc Behav*. 2010;51(1):1-15.
14. Waldrop DP, Meeker MA. Crisis in caregiving: when home-based end-of-life care is no longer possible. *J Palliat Care*. 2011;27(2): 117-125.
15. Burns CM, Abernethy AP, Dal Grande E, Currow DC. Uncovering an invisible network of direct caregivers at the end of life: a population study. *Palliat Med*. 2013;27(7):608-615.
16. Cagle JG, Van Dussen DJ, Culler KL, et al. Knowledge about hospice: exploring misconceptions, attitudes, and preferences for care. *Am J Hosp Palliat Care*. 2016;33(1):27-33.
17. Phongtankuel V, Scherban BA, Reid MC, et al. Why do home hospice patients return to the hospital? A study of hospice provider perspectives. *J Palliat Med*. 2016;19(1):51-56.
18. Yancu CN, Farmer DF, Leahman D. Barriers to hospice use and palliative care services use by African American adults. *Am J Hosp Palliat Care*. 2010;27(4):248-253.
19. Phongtankuel V, Paustian S, Reid MC, et al. Events leading to hospital-related disenrollment of home hospice patients: a study of primary caregivers' perspectives. *J Palliat Med*. 2017;20(3): 260-265.
20. Park NS, Jang Y, Ko JE, Chiriboga DA. Factors affecting willingness to use hospice in racially/ethnically diverse older men and women. *Am J Hosp Palliat Care*. 2016;33(8):770-776.
21. Carrion IV, Cagle JG, Van Dussen DJ, Culler KL, Hong S. Knowledge about hospice care and beliefs about pain management: exploring differences between Hispanics and non-Hispanics. *Am J Hosp Palliat Care*. 2015;32(6):647-653.
22. Wittenberg-Lyles E, Parker Oliver D, Demiris G, Regehr K. Interdisciplinary collaboration in hospice team meetings. *J Interprof Care*. 2010;24(3):264-273.
23. Baik D, Russell D, Jordan L, Matlock DD, Dooley F, Masterson Creber R. Building trust and facilitating goals of care conversations: a qualitative study in people with heart failure receiving home hospice care [published online ahead of print]. *Palliative Medicine*. 2020. https://doi.org/10.1177/0269216320917873.
24. Masterson Creber R, Russell D, Dooley F, et al. Use of the Palliative Performance Scale to estimate survival among home hospice patients with heart failure. *ESC Heart Failure*. 2019;6(2):371-378.
25. Corbin JM, Strauss A. Grounded theory research: procedures, canons, and evaluative criteria. *Qualitative Sociology*. 1990; 13(1):3-21.
26. Dedoose. Web application for managing, analyzing, and presenting qualitative and mixed method research data. SocioCultural Research Consultants, LLC. www.dedoose.com. Accessed June 11, 2020.
27. Nelson J. Using conceptual depth criteria: addressing the challenge of reaching saturation in qualitative research. *Qualitative Research*. 2017;17(5):554-570.

28. Chase JD, Russell D, Rice M, Abbott C, Bowles KH, Mehr DR. Caregivers' perceptions managing functional needs among older adults receiving post-acute home health care. *Res Gerontol Nurs*. 2019;12(4):174-183.

29. Riffin C, Van Ness PH, Wolff JL, Fried T. Family and other unpaid caregivers and older adults with and without dementia and disability. *J Am Geriatr Soc*. 2017;65(8):1821-1828.

30. Cain CL. Agency and change in healthcare organizations: workers' attempts to navigate multiple logics in hospice care. *J Health Soc Behav*. 2019;60(1):3-17.

31. Hupcey JE, Kitko L, Alonso W. Patients' perceptions of illness severity in advanced heart failure. *J Hosp Palliat Nurs*. 2016;18(2): 110-114.

32. Stacey CL, Pai M, Novisky MA, Radwany SM. Revisiting 'awareness contexts' in the 21st century hospital: how fragmented and specialized care shape patients' awareness of dying. *Soc Sci Med*. 2019;220:212-218.

33. Way D, Tracy SJ. Conceptualizing compassion as recognizing, relating and (re) acting: a qualitative study of compassionate communication at hospice. *Communication Monographs*. 2012; 79(3):292-315.

34. Jovanovic M. Cultural competency and diversity among hospice palliative care volunteers. *Am J Hosp Palliat Care*. 2012;29(3): 165-170.

35. Barclay JS, Kuchibhatla M, Tulsky JA, Johnson KS. Association of hospice patients' income and care level with place of death. *JAMA Intern Med*. 2013;173(6):450-456.

36. Empeno J, Raming NT, Irwin SA, Nelesen RA, Lloyd LS. The hospice caregiver support project: providing support to reduce caregiver stress. *J Palliat Med*. 2011;14(5):593-597.

37. Steinhauser KE, Fitchett G, Handzo GF, et al. State of the science of spirituality and palliative care research part I: definitions, measurement, and outcomes. *J Pain Symptom Manage*. 2017; 54(3):428-440.

For more than 106 additional continuing education articles related to hospice and palliative care, go to NursingCenter.com.