Published in final edited form as:

Palliat Med. 2020 July ; 34(7): 925–933. doi:10.1177/0269216320917873.

Building Trust and Facilitating Goals of Care Conversations: A Qualitative Study in People with Heart Failure Receiving Home Hospice Care

Dawon Baik¹, David Russell^{2,3}, Lizeyka Jordan³, Daniel D Matlock⁴, Frances Dooley³, Ruth Masterson Creber⁵

¹College of Nursing, University of Colorado, Aurora, CO, USA

²Department of Sociology, Appalachian State University, Boone, NC, USA

³Visiting Nurse Service of New York, New York, NY, USA

⁴School of Medicine, University of Colorado, Aurora, CO, USA

⁵Division of Health Informatics, Department of Healthcare Policy & Research, Weill Cornell Medicine, New York, NY, USA

Abstract

Background—Despite a majority of persons receiving hospice care in their homes, there are gaps in understanding how to facilitate goals of care conversations between persons with heart failure and healthcare providers.

Aim—To identify barriers and facilitators which shape goals of care conversations for persons with heart failure in the context of home hospice.

Design—A qualitative descriptive study design was used with semi-structured interviews.

Setting/participants—We conducted qualitative interviews with persons with heart failure, family caregivers, and interprofessional healthcare team members at a large not-for-profit hospice agency in New York City between March 2018 and February 2019.

Results—A total of 39 qualitative interviews were conducted, including with healthcare team members (e.g., nurses, physicians, social workers, spiritual counselors), persons with heart failure, and family caregivers. Three themes emerged from the qualitative interviews regarding facilitators and barriers in goals of care conversations for better decision-making: (1) Trust is key to building and maintaining goals of care conversations; (2) Lack of understanding and acceptance of hospice inhibits goals of care conversations; and (3) Family support and engagement promote goals of care conversations.

Author Contributions. DB drafted the original manuscript, analyzed, and interpreted study data. DB, RMC, DR, and LJ conducted qualitative interviews. DB, RMC, and DR made substantial contributions to the study design, data analysis, and manuscript revisions for important intellectual content. DM provided critical feedback to several drafts of the manuscript. FD assisted with organizing participants to be interviewed.

Conflict of Interest. The authors declare that there is no conflict of interest.

Conclusions—Findings from this study suggest that interventions designed to improve goals of care conversations in the home hospice setting should focus on promoting understanding and acceptance of hospice, family support and engagement, and building trusting relationships with interprofessional healthcare teams.

Keywords

goals of care; heart failure; hospice care; home care services; qualitative research

Introduction

Heart failure is an important global health problem affecting more than 26 million people worldwide¹ and associated with high morbidity and mortality rates.² People with heart failure experience a progressive decline in physical functioning, heart failure-related symptom exacerbation, and impaired quality of life.³ Heart failure treatments cost 1–2% of total healthcare expenditures in Europe and North America.⁴

As people with heart failure near the end of life, there is an urgent need for goals of care communication between people with heart failure, family caregivers, and healthcare providers to make end-of-life decisions that meet the values and desires of people with heart failure. Research shows that most people with life-limiting illness preferred to die at home; however, there was a discrepancy between the preferred place to die and the actual place of death.⁵ For example, in the United Kingdom, although there are gradually increasing numbers of people dying at home, only approximately 21% of British people die at home.⁶ Approximately 80% of Americans would prefer to die at home; but only 20% do so.⁷ As such, goals of care conversations should start early so that people with heart failure can engage in shared decision-making regarding care plans.²

A majority of people with life-limiting illness receive hospice services in their homes.⁸ Coylewright and colleagues examined patient-reported goals for care treatments among persons with aortic stenosis and found that approximately two-thirds of people were discharged to their homes for further medical care.⁹ However, little research has explored how goals of care conversations between people receiving home hospice services and healthcare providers occur. Specifically, there have been few studies investigating goals of end-of-life care conversations among persons diagnosed with heart failure. This is an important gap, given the unique needs and disease trajectory of heart failure at the end of life.¹⁰ To fill this gap, we sought to explore perspectives on end-of-life goals of care conversations among persons with heart failure, family caregivers, and healthcare providers. Specifically, we will identify factors which shape goals of care conversations within the home hospice setting.

Methods

Research question

What are the barriers and facilitators that shape goals of care conversations for persons with heart failure within the home hospice setting for better end-of-life decision-making?

Design

A qualitative descriptive study design¹¹ was used with semi-structured interviews. It allows us to understand how persons with heart failure, family caregivers, and healthcare providers perceive their experiences on goals of care communication in the context of cardiac home hospice (ontological justification)¹² by conducting interviews in the places where persons with heart failure live and healthcare providers work (epistemological justification).¹² The reporting of this study followed the consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist.¹³

Setting

This study was conducted at a large not-for-profit hospice agency in New York City between March 2018 and February 2019. This hospice agency maintains an average daily census of more than 1,200 patients and offers hospice services to diverse patient populations across all five boroughs of New York City.

Sample

Purposive sampling was employed to identify persons with heart failure receiving home hospice, family caregivers, and healthcare team members who met the eligibility criteria.

Participants

Inclusion criteria specified that persons with heart failure: 1) were 18 years or older, 2) had a primary diagnosis of heart failure, 3) were enrolled in a specialized cardiac home hospice program, and 4) were able to speak English. Inclusion criteria required that family caregivers were: 1) present during the home visits and 2) able to speak English. Healthcare providers were invited to participate in this study if they were: 1) caring for persons with heart failure in the cardiac home hospice program and 2) able to speak English.

Recruitment

We used two recruitment strategies. First, to recruit healthcare providers, research team members (DB, RMC, DR, LJ) presented the study purpose during weekly interprofessional team meetings. Alongside these meetings, we conducted one-on-one interviews in the hospice agency's conference room or private offices with healthcare providers who expressed interest in participating in the study. Second, to recruit persons with heart failure and family caregivers, a nurse practitioner employed by the hospice agency identified eligible persons with heart failure during routine home visits. When persons with heart failure and family caregivers expressed interest in participating in this study, the nurse practitioner and research team members conducted qualitative interviews in their homes.

Data collection

Prior to beginning the qualitative interviews, research team members (DB, RMC, DR, LJ) explained the study purpose to participants and obtained their informed consent. A semi-structured interview guide was developed through an iterative process. The interview guide was adjusted for each group of participants (i.e., healthcare providers, persons with heart failure, and caregivers). Interview items covered participants' perspectives on and

experiences with home hospice care, strategies to initiate goals of care conversations, and challenges of setting goals of care (e.g., “Tell me about the process of setting the goals of care that you develop with patients and caregivers,” “What are some challenges you face when setting goals of care?”). When needed, additional questions were asked to elicit further details (e.g., “Could you tell me more...?”). Research team members took field notes about participants’ comments and about interviewer observations (e.g., body language, gestures) for further data analysis. Sociodemographic data were collected prior to beginning the interview. All interviews were audio-recorded. Each interview lasted approximately 30–40 minutes. All personal information was anonymized. Study participants were given a \$25 gift card as a token of appreciation for their time. All study procedures were approved by the Institutional Review Boards at Columbia University, the Visiting Nurse Service of New York, and Weill Cornell Medicine.

Data analysis

A qualitative analysis of semi-structured interviews was conducted using a content analysis approach.¹⁴ Qualitative interviews were transcribed verbatim and coded using the Dedoose program (www.dedoose.com).¹⁵ Transcripts were compared with audio recordings to ensure accuracy. All interview transcripts were reviewed line by line. Segments of transcripts were assigned codes based on emergent categories or themes. A codebook was developed by the research team members through initial coding of each set of transcripts (i.e., separate codebooks were developed for healthcare providers and patients/caregivers). The codebooks were revised through discussions between the research team. Four of the research team members (DB, RMC, DR, LJ) held weekly meetings to discuss categories and themes and to reach agreement when there were differences in interpretation. Through the iterative process of merging, dividing or removing codes, codes were organized into themes according to similarity. Saturation was achieved through an iterative approach to data collection and analysis. Inter-rater reliability was assessed for frequently applied codes. Cohen’s kappa statistic ranged from 0.91 to 0.95 across four coding pairs, indicating excellent agreement.^{16,17}

Results

Qualitative semi-structured interviews were conducted with a total of 39 participants, including 32 healthcare providers, five persons with heart failure, and two family caregivers. Demographic characteristics of healthcare providers and persons with heart failure/family caregivers are shown in Tables 1 and 2, respectively. The mean age of healthcare providers was 48.3 (± 10.7) years, 81% of whom were women ($n=26$) and 75% nurses ($n=24$). The mean age for persons with heart failure and family caregivers was 82.6 (± 17.7).

Context of home hospice goals of care conversations

We begin by providing descriptions of how goals of care conversations take place between persons with heart failure, family caregivers, and healthcare providers. Contextual aspects were identified as being important to these conversations.

Initiating goals of care conversations—Goals of care conversations were conducted when healthcare providers visited a patient's home. During the first home visit, interprofessional team members (e.g., nurses, social workers) initiated a discussion about what persons with heart failure understood about hospice, their preferences for care (e.g., preferred place to stay at the end of life), and what hospice services were offered. Gradually, healthcare providers would introduce more sensitive goals of care topics with persons with heart failure and their family, such as advance directives (e.g., placing a do-not-resuscitate [DNR] order vs. remaining full code).

Identifying patient wishes and preferences—Through goals of care conversations with healthcare providers, most persons with heart failure expressed a preference for being at home during the end-of-life. Many persons with heart failure stated that they have not changed their goals of care regarding care plans and treatments since they were enrolled in hospice. They wanted to receive comfort care and experience “*pain-free dying*” at home. The home environment made them feel comfortable; one person said, “*It [home hospice care] made me feel so comfortable, where I could relax.*” In particular, persons with heart failure wanted to spend their remaining time with their family at home.

Three themes emerged from the qualitative interviews in goals of care conversations between healthcare providers and persons with heart failure receiving home hospice:

1. Trust is key to building and maintaining goals of care conversations;
2. Lack of understanding and acceptance of hospice inhibits goals of care conversations;
3. Family support and engagement promote goals of care conversations.

Trust is key to building and maintaining goals of care conversations

Building trust among persons with heart failure, family caregivers, and healthcare teams helped to facilitate goals of care discussions and improve shared decision-making.

Having good relationships—Persons with heart failure and family caregivers stated that feeling satisfied with home hospice care was positively related to having good relationships and building trust with healthcare providers. For example, one person with heart failure did not want to speak to anybody, but he enjoyed having a conversation about end-of-life with a spiritual counselor, and he and his wife were satisfied with hospice care through building trusting relationships with healthcare providers. One caregiver said,

Hospice care is so terrific... The other thing that they [hospice care agency] have is the spiritual advisor... We've just had a lot of stuff happening in the last six months in our lives... We needed to call him [spiritual counselor] because he is a wonderful person. He [person with heart failure] enjoyed talking to him [spiritual counselor]. So, whatever they said to each other, it was a positive experience. (Family caregiver 2)

On the other hand, some family caregivers were reluctant to let healthcare providers inform their loved one that they were dying and wanted to keep it a “*secret*” from their loved one.

These attitudes toward goals of care discussions by family caregivers presented barriers to building trusting relationships between persons with heart failure and healthcare providers.

Active listening and empathy—Healthcare providers stated that actively, empathetically listening to thoughts and preferences of persons with heart failure in hospice is important in developing trusting relationships. In turn, trusting relationships are essential to eliciting patients' frank thoughts about end-of-life preferences. One provider said,

I just get in the passenger's seat. I ride along with them [persons with heart failure], their thoughts and whatever...because as a whole, I feel like I could take anyone through anything in life... I've just been through so much. (Spiritual counselor 2)

Use of language concordance—Language concordance between persons with heart failure and healthcare teams builds trust and facilitates goals of care conversations. Family caregivers pointed out how language concordance between persons with heart failure and healthcare providers is important for managing symptoms and discussing goals of end-of-life care. For example, one son/caregiver described concerns arising from his mother's inability to speak English:

If the goal of the hospice is to make the patients more comfortable, then at the beginning with hospice, I have to deal with the language matter [for person with heart failure]... When she [Spanish-speaking healthcare provider] is out and I am not at home, this is the main problem for caring my mom. (Family caregiver 1)

Healthcare providers also highlighted that the key was not simply the mechanical production of the same language; the key was that linguistic understanding also involved cultural understanding. Many healthcare providers pointed out that when they did not speak the same languages of their patients, they had difficulty engaging in goals of care conversations and establishing trust and rapport with persons with heart failure. One provider said,

That [language discordance] has been difficult for me. We had to have an interpreter, and it's not really comforting for the patient or the family to have that. We're not really bonding. I [try to] develop really deep connections with all of my patients. (Nurse 1)

Lack of understanding and acceptance of hospice inhibits goals of care conversations

Lack of knowledge about hospice care—Despite the fact that primary care providers or cardiologists of persons with heart failure had explained the reasons for hospice referral, most people and their family caregivers lacked a clear understanding and knowledge about hospice, which hindered conversations about goals of care. One person with heart failure who had been enrolled in hospice for four-and-a-half years still had a limited knowledge of hospice and exhibited a reluctance to set goals of care for the hospice services (e.g., where to live). The person stated,

I didn't know much about it [hospice]. I just knew that I was done, and I didn't care where you took me. (Person with heart failure 3)

Some family caregivers had misperceptions of hospice care: they perceived hospice care as not including any care management for persons with heart failure at the end-of-life; such misperceptions limited their ability to make appropriate decisions about goals of care for their loved ones. One caregiver said, *“If I let him [person with heart failure] die at home without the care, it means that I’ve neglected him.”*

Moreover, healthcare providers pointed out discordance between patient preferences and their understanding of advanced directives, especially those related to resuscitation and DNR orders. For example, one healthcare provider identified a challenge regarding deactivating a defibrillator for persons with heart failure who had an implantable cardioverter defibrillator and chose a DNR order. One provider said,

I had a patient, and he has a DNR, but he didn’t want to deactivate his defibrillator. So, that was going against each other because he was DNR, but then if something happens, he would get a shock. (Nurse 13)

Not knowing precisely what one wants from hospice—Many persons with heart failure did not know exactly what to expect from hospice care. They simply followed their health proxy’s decisions about referral to hospice instead of thoroughly considering their end-of-life care options. One person said,

I really didn’t have any goals of care...I don’t even remember how I got into hospice. I think it was a decision that was made for me by my health proxy, cousin. (Person with heart failure 5)

One family caregiver wanted to make decisions regarding goals of care based on a loved one’s preference of care. However, because the loved one did not state exactly what he wanted for end-of-life care, the family caregiver was concerned that he/she might not meet the loved one’s desires and preferences at the end of life. The caregiver said,

My main concern is for him [person with heart failure] telling me exactly what he wants. We both resolved that we want to be cremated. But for him, I want him to tell me where he wants to have his services” (Family caregiver 1)

Lack of clarity in explanations about hospice prior to hospice referral—Healthcare providers indicated that primary care providers or cardiologists would sometimes describe hospice to persons with heart failure and family caregivers as a visiting nurse service that persons with chronic disease could receive in the home, rather than as supportive service for navigating the end-of-life. When healthcare providers established goals of care conversations, such less-than-clear explanations by some physicians caused persons with heart failure and family caregivers to be shocked about receiving hospice care, and they then sought clarification. One provider stated,

My experience is that sometimes you get patients who don’t even know they were referred to hospice. Their physicians or cardiologists say you need extra support at home, so we’re sending you on hospice. People who have no clue what hospice is think, oh, I am just going to get a nursing visit. They don’t understand the prognosis is that if your disease progresses the way that it should or the way it has

been you have less than six months to live...once I am able to set that boundary then I can pretty much tell where we're going. (Nurse 5)

Culture—Culture of persons with heart failure or family caregivers affected their level of acceptance of hospice as both barrier and facilitator of building goals of care conversations. Certain culturally-rooted beliefs and perceptions prevented patients and their family members from talking about goals of care in hospice. For example, some persons with heart failure and family caregivers did not want to ask or talk about hospice and end-of-life; they equated “*hospice*” with a “*death sentence*.” Those who have certain cultural beliefs held an “*expectation of a miracle*” that they would fully recover from their terminal condition by pursuing aggressive end-of-life treatments. On the other hand, cultural predisposition to acceptance of hospice/end-of-life among persons with heart failure and family caregivers facilitated goals of care conversations.

Family support and engagement promote goals of care conversations

Lack of family support—Family caregivers played a pivotal role in supporting a loved one's end-of-life care as well as in setting goals of care. Such support enabled persons receiving hospice services to remain comfortable at home and get on the same page with the healthcare team. However, many persons with heart failure did not live together with family members and lacked support from them. For example, one person with heart failure who received end-of-life care in a hospice unit wanted to live at home, but he said, “*There is nowhere to go.*” Such lack of family support limited persons with heart failure in setting goals of care based on their preferences. Regarding potential reasons about lack of caregiving support, healthcare providers indicated that low socioeconomic status made it difficult for persons with heart failure or families to supplement the care they received from hospice agencies with additional formal caregiving supports (e.g., private nurses or aides).

Patient characteristics—Family caregiver involvement depended on characteristics of the loved ones, including their age, cognitive ability, and understanding of hospice services. For example, family caregivers were more involved in goals of care conversations when persons with heart failure perceived themselves to be too old or cognitively impaired to make good decisions. A person said,

I'm just old. I'm very old, and I'm not even responsible for that [decision making about goals of care]. But most of these decisions are made by my daughter. She's much smarter than I am. (Person with heart failure 2)

Caregiver emotional distress—Family caregivers perceived caring for a loved one at the end-of-life to be traumatic. Healthcare providers indicated that the unique disease trajectory and needs of persons with heart failure necessitated a different approach to setting goals of care. They pointed out the often-unpredictable trajectory, the “*peaks and valleys*” of heart failure. As such, family members also go through these peaks and valleys, often experiencing symptoms of emotional distress such as anxiety and hopelessness, which precludes active engagement in the loved one's end-of-life care and establishment of goals of care.

Conflicting goals of care—Many persons with heart failure and family caregivers expressed different preferences for the end of life, which required healthcare providers to manage conflicts between persons with heart failure and family members when setting goals of care. Many conflicts centered on the patient's decision-making around placing a DNR order or electing to be full code. For example, while one person with heart failure accepted hospice/end-of-life and indicated a desire for a DNR, his family caregivers could not agree with the loved one's decisions and wanted him to remain full code.

Discussion

Main findings of the study

This study explored perspectives on goals of care conversations among persons with heart failure receiving home hospice, family caregivers, and healthcare providers. One of the most important findings from this study was the role of trust in building and maintaining goals of care conversations, which is consistent with findings from previous studies conducted in clinical and long-term care settings.^{18–21} Specifically, we found that having good relationships, active listening with empathy, and language concordance were all significant facilitators to building trusting relationships between persons with heart failure, family caregivers, and healthcare providers for effective goals of care conversations. This finding is similar to those documented by previous studies conducted in long-term care facilities²² and home health settings.²³ Bauer and colleagues reported that building trust in long-term care settings was contingent upon ongoing interaction, mutual sharing of medical information, listening to the perspectives of family members, and language/cultural concordance.²² Stajduhar and colleagues emphasized the importance of providers being nonjudgmental, empathetic, comfortable, identifying points of similarity with patients, and continuity with the patient/family caregiver for trusting relationships.²³

This study revealed that primary care providers' or cardiologists' unclear explanations about hospice and disease trajectory at the time of hospice referral might increase misunderstandings about hospice among persons with heart failure and their family caregivers. This finding is consistent with a previous study that explored provider perspectives on goals of care for hospitalized persons discharged to skilled nursing facilities.²⁰ Feder and colleagues reported that goals of care were often not discussed during hospitalization, which contributed to sick persons' limited awareness of their disease trajectory and unclear care goals. The lack of discussion around goals of care resulted in disconnected delivery of care due to difficulty initiating goals of care conversations in the long-term care facility.²⁰ Many studies pointed out that the lack of goals of care conversations were related to difficulty predicting prognosis and identifying when and how goals of care conversations should occur, healthcare providers' limited time and lack of training necessary to discuss goals of care, and lack of willingness to discuss goals of care among both patients and providers.^{19,20,24} The absence of goals of care conversations before referral to hospice inhibits appropriate decision-making about patients' end-of-life wishes, preferences, and quality of life.

The findings of this study suggest two ways in which facilitating goals of care conversations in the home hospice setting involved more engagement of family caregivers and healthcare

providers compared to clinical care settings and long-term care settings.^{18,20} First, family caregivers may have multiple responsibilities involving patients' self-care, symptom management, and decision-making in the home hospice setting. These responsibilities among family caregivers may increase their risk for physical and emotional distress.^{25,26} Second, healthcare providers might have more potential to build and maintain trusting relationships with persons with life-limiting illness and family caregivers because they may be more open to communication in the home setting. These positive relationships can facilitate effective goals of care conversations. Moreover, such trusting relationships might allow healthcare providers to deal with family dynamics or conflicts about goals of care that can arise between persons with life-limiting illness and family caregivers. However, there has been little research that examined and compared features of goals of care conversations between the home care setting and acute/long-term care settings. Thus, further research is needed to examine how goals of care discussions are navigated among persons with life-limiting illness-family-healthcare team interactions in various care settings for facilitating shared decision-making.

Strengths and limitations of the study

Despite increasing use of home hospice care, there has been little research examining how goals of care conversations take place between persons with heart failure, family caregivers, and the healthcare team in the home. To our knowledge, this study is the first to explore this topic. Using semi-structured interviews with persons with heart failure, family caregivers, and healthcare providers, we provided an in-depth understanding of how goals of care conversations occurred for better decision-making. Much of the previous research on the perspectives of goals of care discussion were conducted in clinical settings or long-term care facilities and have relied on healthcare providers' perspectives.^{19–21,23}

On the other hand, this study was conducted with a small number of persons with heart failure and family caregivers due to the acuity of persons receiving hospice care and the nature of home-based settings. Further research is needed to focus on the voices and perspectives of persons with heart failure and family caregivers. In addition, this study was conducted at a large not-for-profit hospice agency in New York; thus, the findings from this study might not be generalizable to different states, countries, or healthcare organizations.

Implications for research and practice

Results from this study point toward a number of areas for further research. The findings of this study revealed factors for building trust (e.g., active listening with empathy); subsequent studies might explore how healthcare providers could *implement these trust-building factors* in the home hospice setting to facilitate goals of care conversations and promote shared decision-making. Further studies should also develop guidelines and specific strategies for healthcare providers and persons with heart failure to discuss goals of care *across different healthcare settings* (e.g., during the hospital discharge period prior to home hospice) in order to improve cross-site care continuity in shared decision-making about goals of care. Family caregivers in the home hospice setting might experience more emotional distress due to multiple responsibility of a loved one's end-of-life care; thus, further studies should develop

the interventions that assess and reduce physical and emotional distress among family caregivers.

The hospice agency we studied served a racially and ethnically diverse sample of persons with heart failure. Given that disparate cultures have disparate attitudes about/predispositions toward goals of end-of-life care, there is a need for ongoing hospice training for healthcare providers about cultural awareness, sensitivity, and competence to reduce implicit or explicit biases.

Given growing interests in use of health informatics technologies in healthcare, mobile health technology platforms have major potential to help patients and families leverage hospice to effectuate end-of-life goals of care conversations in the home setting.^{27–29} Future studies are needed to identify the impact of mobile health technologies on (a) improving patients' understanding of hospice services, (b) facilitating home-based goals of care conversations specific to heart failure, and (c) contributing to shared decision-making.

Conclusion

This study explored perspectives on goals of care conversations among persons with heart failure, family caregivers, and healthcare providers within the home hospice setting. The findings from this study indicate that building trust, knowledge about hospice, acceptance of end of life, and family support and engagement are important factors influencing home hospice goals of care conversations that facilitate shared decision-making.

Funding.

This work was supported by National Institute of Nursing Research of the National Institutes of Health under Award Number T32NR007969 (Health Disparities through Informatics) and the Eugenie and Joseph Doyle Research Partnership Fund from the Visiting Nurse Service of New York.

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Key Statements

What is already known about the topic?

- As persons with heart failure near the end of life, there is an urgent need for goals of care conversations.
- Despite a majority of persons receiving hospice services in their homes, optimal strategies for facilitating goals of care conversations between persons with heart failure and their healthcare team within this setting have not been previously identified.

What this paper adds

- This study provides insights on how goals of care conversations take place among persons with heart failure receiving home hospice services, their family caregivers, and interprofessional healthcare team members.
- Trust is key to building and maintaining goals of care conversations for persons with life-limiting illness to make more appropriate decisions regarding end-of-life care.
- Providing end-of-life care in the homes of persons with heart failure might allow for interprofessional team members to engage family caregivers in goals of care conversations to a greater extent than in clinical care and long-term care settings.

Implications for practice, theory or policy

- Examining how goals of care discussions are navigated in persons with heart failure-family-interprofessional team interactions in various care settings is needed to make more appropriate decisions regarding end-of-life care.
- Family caregivers of persons receiving home hospice services often experience emotional distress due to multiple responsibility of a loved one's end-of-life care. Interventions should be developed to assess and reduce the physical and emotional distress of family caregivers from diverse backgrounds.

Table 1.

Demographic characteristics of interprofessional healthcare team members (n=32)

Variables	N (%) or Mean (SD)
Sex	
Female	26 (81.2%)
Male	6 (18.8%)
Age in Years	48.3 (10.7)
Race/Ethnicity	
White	15 (46.9%)
Black	11 (34.4%)
Hispanic	3 (9.3%)
Asian/Other	3 (9.3%)
Discipline	
Nurse	24 (75.0%)
Social Worker	4 (12.5%)
Physician	2 (6.2%)
Spiritual Counselor	2 (6.2%)
Education	
Associate degree	5 (16%)
Bachelor's degree	18 (56%)
Master's degree	6 (19%)
Doctorate/MD/DO	3 (9%)
Year of practice	
2–10 years	8 (25%)
11–19 years	8 (25%)
20 + years	16 (50%)
Year of practice in hospice	14 (44%)
1–4 years	
5–9 years	8 (25%)
10 + years	10 (31%)
Primary language	
English	19 (59%)
Spanish	5 (16%)
Chinese	4 (13%)
Hebrew, Yiddish or Russian	4 (13%)

Table 2.

Demographic characteristics of patients and caregivers (n=7)

Variables	N (%) or Mean (SD)
Sex	
Female	2 (28.6%)
Male	5 (71.4%)
Age in Years	82.6 (17.7)
Race/Ethnicity	
White	5 (71.4%)
Hispanic	1 (14.3%)
Other	1 (14.3%)
Role	
Hospice Patient	5 (71.4%)
Family Caregiver	2 (28.6%)
Primary language	
English	5 (71.4%)
Spanish	1 (14.3%)
Portuguese	1 (14.3%)
Financial Status	
Comfortable	4 (57.1%)
Have Enough to Make Ends Meet	3 (42.9%)