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Caregivers' Perceptions of Illness Severity and End of Life Service Utilization in Advanced Heart Failure

Windy Alonso, MS, RN^{a,*}, Judith E. Hupcey, EdD, CRNP, FAAN^a, and Lisa Kitko, PhD, RN, FAHA^b

^a Pennsylvania State University College of Nursing 1300ASB/A110 90 Hope Drive Hershey, PA 17033 United States of America

^b Penn State College of Nursing 307H Nursing Sciences Building University Park, PA 16802 United States of America

Introduction

Heart failure impacts nearly 6 million Americans and 5% of those have reached an advanced stage of illness, Stage D.¹ Stage D heart failure (HF) is characterized by symptoms at rest that are refractory to medical treatment and is further complicated by a five-year mortality rate of nearly 50%; yet, many of these patients do not perceive the severity of their illness and have a limited understanding of the terminal nature of the disease.^{2,3} It is projected that by 2030 the United States will have upwards of 8 million HF patients.⁴ These 8 million patients will, at some point in their trajectory, require the help of an informal caregiver to assist them with managing their illness, and thus, creates a large number of HF caregivers that will need care and support themselves as they navigate this difficult course.

HF has an unpredictable trajectory with times of severe exacerbations followed by periods of stability. The erratic disease course lends itself to confusion among patients and caregivers in the throes of the trajectory. Hupcey and colleagues³ recently reported that Stage D HF patients are unaware of the severity of their illness and lack understanding of HF as a terminal disease despite the presence of severe symptoms. These same trajectory fluctuations make caring for a patient with HF a roller coaster ride, often leaving family caregivers unsure of what may lie ahead. This uncertainty is often cited as a barrier to accessing palliative care and end-of-life services, even for Stage D HF patients.⁵ The purpose of this paper is to describe family caregivers' perceptions of the severity and terminality of HF, when their loved one had a less than two year predicted survival and to determine whether palliative care and other end-of-life services were used at end of life.

*Corresponding Author: Windy Alonso wwa103@psu.edu.

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Background

Through the trajectory of end-stage heart failure, patients and their caregivers would benefit from palliative and end-of-life services. Since 2005, clinical guidelines have suggested palliative care, advance care planning, and end-of-life services for this population;² however, these services are not frequently offered or when offered, refused by the patients and caregivers.^{5,6} Many caregivers of patients with HF have reported the caregiving experience to be much worse than they expected, yet, HF caregivers remain reluctant to seek support, and often choose to forego palliative care and end-of-life services despite unmet physical needs.⁷ Although the basis for this apparent contradiction is unknown, there are several barriers to end-of-life conversations in HF that have been suggested in the literature including: patient/caregiver issues, healthcare provider difficulties in beginning the conversation, disease-specific unpredictability and organizational issues.⁸ These factors have contributed to few HF patients and caregivers benefiting from palliative and end-of-life services compared to patients with cancer despite a greater number of HF-related deaths.^{2,9,10}

A widespread lack of understanding of supportive care by clinicians exists, including the care of HF patients.¹¹ Clinicians lack confidence in initiating the conversations and are hesitant to suggest palliative care due to misconceptions of the role of palliative services in HF.^{5,12} Often clinicians place the onus for the discussion of end-of-life goals and needs for supportive services on patients and caregivers with the assumption that the conversation will occur when the family is “ready.”¹³ This assumption is a double-edged sword in HF since, as mentioned above, patients and caregivers may not fully comprehend the severity of HF or that the final outcome is death;³ both of which impede their ability to articulate “readiness” to accept supportive services or discuss end-of-life plans. Ultimately, this chicken-or-egg scenario leads to most palliative care or hospice referrals in HF occurring when death is imminent despite the known benefits of early referral.

Patients and caregivers unrealistic expectations of the disease trajectory and lack of recognition of heart failure as a terminal diagnosis can have a significant impact on end-of-life care.³ This gap in caregiver knowledge may interfere with the acceptance of supportive and end-of-life services that could be valuable to improve physical and psychosocial outcomes for patients in Stage D HF. In fact, caregiver denial of terminality was shown to lead to increased inpatient treatment during in-home hospice resulting in patients dying in the hospital rather than home as they had planned.¹⁴ Therefore, this study aimed to assess how caregiver perceptions of HF severity and terminality impacted initiation and utilization of these supportive services in Stage D HF.

Purpose

This study describes family caregivers of advanced HF patients (those with a <2-year predicted survival) perceptions of illness severity and acknowledgement of HF terminality during the terminal course of the disease and utilization of palliative care and hospice services prior to the patient’s end of life.

Methods

A descriptive qualitative design and content analysis as described by Krippendorff¹⁵ was utilized. The study was approved by the University's Institutional Review Board. Written informed consent was obtained from all participants upon enrollment.

Participant Recruitment

Eighty family caregivers, who were enrolled in a longitudinal study (NIH/NINR grant # 5R01-NR013419) investigating the end-of-life trajectory of patients with advanced HF, were interviewed. Caregivers were recruited from either an inner city or an academic medical center that serves an area that includes nearby urban and rural locations. Initial screening was conducted by the project coordinator via medical chart review of hospitalized patients to identify patients with a diagnosis of Stage D HF. Following confirmation of a Stage D HF diagnosis, a predicted survival time was calculated using the Seattle Heart Failure Model (SHFM).¹⁶ The SHFM has been previously described and validated.^{16,17} Caregivers whose loved one had a predicted survival of less than two years were approached. To be considered for enrollment, caregivers were the patient's primary, unpaid caregiver. Caregivers that were unable to communicate in English or not reachable by telephone were excluded. Participants were compensated for their time in the form of gift cards redeemable at nationwide and regional merchants.

Data Collection

Interviews were conducted, using a semi-structured interview guide, by one of the study's principle investigators, who is experienced in qualitative data collection, the project coordinator, and a research assistant who were both trained by the study P.I.s in qualitative interview techniques. The initial interview was the lengthiest at 45-60 minutes, followed by monthly interviews ranging in length from 15-30 minutes. Post-death interview lengths varied based caregiver wishes and ranged from 10-60 minutes. The caregivers were interviewed while their loved ones were hospitalized, during a HF clinic visit, or via telephone for post-death interviews. Caregivers were followed for up to two years or one follow-up interview if the patient died prior to study completion.

During the early interviews (1 month through 3 months), caregivers were asked to describe the patient's heart failure (what they understood about it, its progression, how the patient was doing) and where they saw the patient in one-year. In the parent study, monthly interviews continued through the two-year study enrollment period or until the patient died. However, the results reported from this subset analysis are based only on initial interviews to assess the caregivers' understanding of HF severity and terminality and post-death interviews to assess service utilization.

Post-death interviews were completed with 34 of the 40 caregivers whose loved ones died during study enrollment. Interviews were conducted between one and three months following the death of the patient. These interviews discussed palliative care, end-of-life service utilization, and caregiver experiences of caring for a patient with heart failure who died. Service utilization was confirmed through medical chart review.

Data Analysis

All the interviews were read and individually analyzed by the study's PIs and four PhD students. The PIs each analyzed 40 caregivers' interviews and the PhD students each analyzed 20 caregivers' interviews. An independent qualitative content analysis¹⁵ was done by each team member. During these individual analyses team members were instructed to determine if they thought the caregiver understood the severity of their loved one's HF and if they believed their loved one was dying based on the question *Where do you see [patient] in one year?* Quotes were required to justify categorization. The individual analyses were followed by a group comparative analysis, where each interview was discussed to reach a consensus as to whether caregivers understood the severity and terminality of HF based on their description of their loved one's heart failure.

Several strategies were employed to ensure the trustworthiness of the qualitative data and subsequent findings throughout the analysis process. Recorded interviews were transcribed by an independent, professional transcriptionist and then cleaned and checked for accuracy by the project director. To assure dependability, an audit trail was documented during the team analysis sessions. Any discrepancies in coding were reviewed by the research team and discussed among the coders and investigators until a consensus was met. To assure credibility, the final categorizations and subsequent content justifications were agreed upon by all members of the research team which included the two P.I.s of the parent study, four PhD students, and the project director.

Results

The sample included 80 family caregivers of patients with Stage D heart failure with a predicted survival of less than two years. Sample demographics are shown in Table A.1. The majority of caregivers were the patient's spouse or partner, the next largest group was the patients' children. Caregivers were experienced at caregiving, providing care for an average of 10 years (SD = 12 years). Qualitative content analysis revealed that fifty-four of the eighty (68%) caregivers did not perceive the severity of the patient's illness and 53/80 (67%) did not realize their loved one was dying during the initial interview period despite a SHFM predicted survival of less than two years.

Disease Severity

Assessment of perception of disease severity was made using responses to the inquiry: *Describe what you understand/know about HF.* An example of a quotation that articulated a lack of caregiver understanding of the severity of a Stage D HF diagnosis was:

We were told that people live with a lot worse HF than her, if you learn to manage this you go on living for a long time.

Additional exemplars from caregiver interviews that failed to express an understanding of HF severity can be found in Table A.2. with a comparison to caregivers who expressed sentiments that indicated an understanding of severity. Rather than expressing an understanding that HF was contributing to their loved one's decline, caregivers often blamed "old age" or comorbid conditions. Comments such as these were common:

He forgets how old he is...there aren't too many couples our age. Usually one of them is gone by this time.

We are also frequently reminded and often talk about it, that at our age we are not going to live much longer...we're going to die.

The few caregivers that did understand the severity of their loved one's HF made comments like:

It's hard to know it's not getting any better. I'm happy to know he's held on I'm accepting that it's not going to get better.

Disease Terminality

To determine an understanding of the disease trajectory, caregivers were asked, *Where do you see the patient in one year?* Those caregivers who expressed an understanding of illness severity were more likely to indicate an understanding of the terminality of HF and to acknowledge that they expected the patient to be dead in a year. The majority of the caregivers that understood the severity of heart failure expected a heart failure-related death in the next year (22/26) compared to 5 out of 54 that did not perceive illness severity. Overall, few of the caregivers (33%) expressed an understanding of the terminal nature of the HF disease trajectory. Responses that indicated an understanding of terminality included any mention of death or a declining health status or suggestion by the caregiver that the patient would be dead in the next year. Twenty-seven (of 80) caregivers did make these types of comments. Including:

In a year? Possibly without a husband

I know he'd say the same thing, probably dead.

While those who did not express an understanding of the severity of heart failure expressed more hopeful expectations for the future. Table A.3 contains a sample of caregivers' descriptions of where they see their loved on in one year.

Of the forty patients that were alive at the end of data collection, 14 (35%) received a ventricular assist device (VAD) implantation or heart transplant. The caregivers of these patients were likely to express hope for the future related to the prospect of a new heart or augmentation device. One caregiver said *If it sustains life, bring it on.* [talking about VAD]. A caregiver caring for a patient on the transplant list remarked We'll keep coming back until they find a heart for him.

Analysis of Caregivers Whose Loved One Died of HF

Despite the majority of caregivers being unaware of HF severity and/or terminality, forty of the patients died during study enrollment. Post-death interviews were conducted with thirty-four of these caregivers. The other six caregivers were unreachable for follow up.

Interviews of the forty caregivers of patients that died during the study were reviewed and compared to the larger sample. The majority of caregivers for these patients did not perceive the severity of heart failure (60%) and also did not realize their loved one was reaching end of life (70%). Caregivers did not indicate an understanding of HF severity or realize their

loved one was dying even when declining health was apparent and death was imminent. One caregiver discussed the frequent exacerbations of HF without recognizing the patient's status as declining,

It seems to me that everybody these days is really good at patching you up. They find out what's the matter and they patch you up and then something else and they patch you up...whatever is wrong, they're going to patch it up.

Following the death of this same patient who had frequent hospitalizations, the caregiver said,

I never thought when he went to the hospital with a bloody nose that would be the time he wouldn't come home

Forty-eight percent of the patients that died during study enrollment (19/40) received palliative care consultations and/or end-of-life (hospice) services. This included 4 patients that received palliative care consultations alone, 6 that received hospice alone and 9 that received both palliative care and hospice services. Eight of the 19 (42%) patients that received services died in the hospital. However, three of these patients received referrals to end-of-life services only hours before death despite lengthy terminal hospitalizations and multiple admissions prior to their terminal admission. A 2×2 chi-square test indicated a significant relationship between perceiving illness severity and service utilization with those patients whose caregivers' perceived illness severity being more likely to have received palliative care or end-of-life services $\chi^2(1, N=40) = 4.8287, p = 0.028$. The relationship between acknowledgement of disease terminality and service utilization did not reach statistical significance.

Discussion

This is one of the first studies to describe the perceptions of disease severity and terminality in the caregivers of advanced HF patients and the impact these perceptions have on palliative care and end-of-life services utilization. The vast majority of caregivers in this study did not perceive the severity of the patient's HF nor did they realize their loved one was dying. Previous studies have shown that patients may overestimate survival by upwards of 40% when compared to models like the SHFM¹⁸ and Stage D HF patients are often unaware of their own illness severity and the terminal trajectory of HF despite severe symptoms.³ Selman and colleagues¹⁹ reported that caregivers of advanced heart failure patients commonly hope for symptom improvement and periods of stability despite awareness of a declining status which was also noted in the caregiver's comments in this study. As one caregiver mentioned I looked at it as 'he's going to get better and he's going to be able to go home.' I'm sure that's everybody's wish when you have a loved one as sick he was.

We found that caregivers that did not understand the severity of HF were also unlikely to comprehend the terminal nature of the disease. According to Waldrop et al.²⁰ in order for caregivers to comprehend the terminal status of a dying patient they had to first receive and assimilate concrete disease-specific information, observe the progression of the disease and become aware of patient personality and role changes. There was some evidence that the caregivers in this study were missing these three experiences in caring for their loved ones

with HF. For example, many caregivers relayed incorrect information on HF and disease progression during their interviews when asked what they understood about HF. Some of the caregivers were caring for patients that had been newly diagnosed with Stage D HF which may have resulted in a limited observation of changes in the patients' personalities or roles. However, others had been caring for Stage DHF patient for many years which would have assumingly provided opportunities for all of the experiences outlined by Waldrop and colleagues necessary for comprehension of disease terminality.²⁰

Caregivers in this study frequently did not perceive the severity of the patient's illness. This lack of understanding was related to palliative care and end-of-life service utilization in a Chi-square test with those not expressing an understanding of illness severity being less likely to utilize services. Without realistic perceptions of disease severity and the EOL trajectory for advanced HF patients, caregivers may also be less likely to participate in advance care planning and goals of care discussions, or more likely to refuse referrals to supportive services including palliative care and hospice.

Several of the patients in the study who received end-of-life services, received them too late in their illness to realize the full benefits of the referral. Late or missed referrals to palliative care and end-of-life services are commonly reported in the literature across terminal illnesses⁶; however, HF caregivers have been found to be significantly less likely to seek services despite unmet needs⁸. Delayed referrals prohibit caregivers from accessing the full range of services offered with palliative care and hospice, and also increase the likelihood of dying in the hospital.^{21,22} Ideally, patients and caregivers should be referred to palliative services upon initial diagnosis of Stage D HF.

Patient and family readiness has been cited as a significant barrier to palliative care referral in terminal illness.⁶ Our results indicate that the majority of caregiver participants did not comprehend the severity of the patient's heart failure or recognize heart failure as a terminal disease. Clinicians need to be more forthcoming when describing heart failure severity and the terminal nature of the disease. Caregivers and patients may be more willing to accept services when presented with realistic expectations for their loved one's heart failure trajectory.

Numerous studies in the literature support the notion that the advanced heart failure trajectory is unpredictable and can contain unexpected twists and turns^{2,23}. This uncertainty has led to hesitation among providers to prognosticate for patients and families⁵. The course of advanced heart failure may always be uncertain; however, it is the responsibility of the provider to acknowledge this uncertainty and be sure patients and caregivers entertain the possibility of death at any time following diagnosis²⁴. Effective and frequent advance care planning and goals of care discussions could help caregivers as they grieve the inevitable death of their loved ones.

Limitations

Although data were collected from both a city hospital and an academic heart failure center which provides care to both urban and rural patients a limitation of the study was the homogeneity of the sample, consisting of White/Caucasian participants. Future studies

should include a more diverse sample from multiple settings. Every effort was attempted to capture post-death interviews for all caregivers that experienced loss of their loved one during study enrollment; however 100% was not achieved. Caregiver awareness of illness severity and/or terminality may have been influenced by the caregiver's frequency of interactions with the patient. For example, caregivers that lived with the patient may have had more realistic expectations versus those caring from a distance. However, this phenomena was not assessed in this study and could be the impetus for future work.

Implications

This study has implications for HF clinicians practicing in all settings. Nurses in inpatient and outpatient settings are positioned to provide essential HF education and basic palliative care, and encourage advance care planning that may assist caregivers at the end of life.²³ In addition, when interacting with patients and caregivers, nurses should be actively assessing home management capabilities and the need for any supportive services from the outset of advanced HF diagnosis.

From our study, it is evident that caregivers may be misinterpreting the expectations for the patient's prognosis and the HF trajectory provided by specialty clinicians or primary care providers. These providers should be more diligent when evaluating patient and caregiver understanding and their expectations should be regularly assessed so misinterpretations or misunderstanding can be addressed and correctly articulated to patients and caregivers when discussing goals of care. All clinicians working with HF patients should advocate for the earlier involvement of palliative care and subsequently, end of life services.

Family caregivers are often so preoccupied with caring for their loved one that they tend to fail to perceive the severity of their loved ones' heart failure, which may lead to poor preparedness for death. In addition, end-of-life services are often focused on physical symptoms and ignore associated psychosocial distress in patients and caregivers.²⁵ Caregiver needs are secondary to patient symptom management and quality of life maintenance.⁶ In order to establish a family-centered approach to palliative and end-of-life services, caregiver needs will have to become a priority.²⁶ Future studies should investigate how caregiver perceptions of HF severity and terminality can be linked to the acquisition and utilization of supportive and end-of-life services and the subsequent well-being of the caregiver during the bereavement period.

Conclusions

Ongoing discussions of goals of care initiated by healthcare providers, especially those delivering primary care, that include both the patient and family caregivers, are critical for patients with advanced HF. These iterative goals of care discussions should include description of realistic expectations based on current evidence. Early referrals to palliative care services for advanced HF patients are warranted and evidence based guidelines are needed to effectively transition palliative care services with patients and their caregivers as they traverse the various levels of care during their illness. Frequent and ongoing discussions of the advanced heart failure trajectory for patients with Stage D HF may lead to more realistic expectations in the caregiver.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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- Caregivers do not comprehend the severity of the patient's heart failure or recognize heart failure as a terminal disease.
- Patients are more likely to receive services if their caregivers express an understanding of illness severity.