



ELSEVIER

Contents lists available at ScienceDirect

## Heart &amp; Lung

journal homepage: [www.heartandlung.org](http://www.heartandlung.org)

## Caregivers' perceptions of illness severity and end of life service utilization in advanced heart failure

Windy Alonso, MS, RN<sup>a,\*</sup>, Judith E. Hupcey, EdD, CRNP, FAAN<sup>a</sup>,  
Lisa Kitko, PhD, RN, FAHA<sup>b</sup>

<sup>a</sup> Pennsylvania State University College of Nursing, 1300ASB/A110 90 Hope Drive, Hershey, PA 17033, USA

<sup>b</sup> Penn State College of Nursing, 307H Nursing Sciences Building, University Park, PA 16802 USA

### ARTICLE INFO

#### Article history:

Received 29 March 2016

Received in revised form

2 September 2016

Accepted 26 September 2016

Available online xxx

#### Keywords:

Advanced heart failure

Palliative care

End-of-life services

Caregiver perceptions of illness severity

Service utilization

### ABSTRACT

**Objectives:** To assess perceptions of illness severity and terminality in caregivers of advanced heart failure (HF) patients and how these perceptions influence utilization of palliative care and end-of-life services. **Background:** HF is a terminal disease; yet patients and caregivers do not understand the severity of HF or acknowledge disease terminality.

**Methods:** This study was conducted using a qualitative design with in-depth interviews and content analysis.

**Results:** Most caregivers did not understand the severity of HF (68%) or disease terminality (67%). Patients were more likely to receive services when their caregivers expressed an understanding of illness severity and/or terminality.

**Conclusions:** Inclusion of caregivers in discussions of goals of care, advance care planning, and palliative care and end-of-life services with patients and providers is imperative.

© 2016 Elsevier Inc. All rights reserved.

### Introduction

Heart failure impacts nearly 6 million Americans and 5% of those have reached an advanced stage of illness, Stage D.<sup>1</sup> 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.<sup>2,3</sup> It is projected that by 2030 the United States will have upwards of 8 million HF patients.<sup>4</sup> 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 colleagues<sup>3</sup> 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.<sup>5</sup> 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.

### 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<sup>2</sup>; however, these services are not frequently offered or when offered, refused by the patients and caregivers.<sup>5,6</sup> 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.<sup>7</sup> 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

\* Corresponding author.

E-mail address: [wwa103@psu.edu](mailto:wwa103@psu.edu) (W. Alonso).

provider difficulties in beginning the conversation, disease-specific unpredictability and organizational issues.<sup>8</sup> 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.<sup>2,9,10</sup>

A widespread lack of understanding of supportive care by clinicians exists, including the care of HF patients.<sup>11</sup> 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.<sup>5,12</sup> 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.”<sup>13</sup> 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<sup>3</sup>; 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.<sup>3</sup> 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.<sup>14</sup> 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 acknowledgment 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 Krippendorff<sup>15</sup> 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).<sup>16</sup> The SHFM has been previously described and validated.<sup>16,17</sup> 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 PI in qualitative interview techniques. The initial interview was the lengthiest at 45–60 min, followed by monthly interviews ranging in length from 15 to 30 min. Post-death interview lengths varied based caregiver wishes and ranged from 10 to 60 min. 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 analysis<sup>15</sup> 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 PIs of the parent study, four PhD students, and the project director.

Download English Version:

<https://daneshyari.com/en/article/5568102>

Download Persian Version:

<https://daneshyari.com/article/5568102>

[Daneshyari.com](https://daneshyari.com)