

## Clinical Investigation

# Comparing Perspectives of Patients, Caregivers, and Clinicians on Heart Failure Management

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## ABSTRACT

**Background:** Although substantial effort has been devoted to reducing readmissions among heart failure (HF) patients, little is known about factors identified by patients and caregivers that may contribute to readmissions. The goal of this study was to compare the perspectives of HF patients, their caregivers, and their care team on HF management and hospital admissions. Understanding these perspectives may lead to better strategies for improving care during the post-hospital transition and for reducing preventable readmissions.

**Methods and Results:** We performed freelist, an anthropologic technique in which participants list items in response to a question, with hospitalized HF patients (n = 58), their caregivers (n = 32), and clinicians (n = 67). We asked about home HF management tasks, difficulties in managing HF, and perceived reasons for hospital admission. Results were analyzed with the use of Anthropic. Saliency indices (measures of the most important words for defining the domain of interest) were calculated. Patients and clinicians described similar home HF management tasks, whereas caregivers described tasks related to activities of daily living. Clinicians cited socioeconomic factors as challenges to HF management, whereas patients and caregivers cited limited functional status and daily activities. When asked about reasons for hospitalization, patients and caregivers listed distressing symptoms and illness, whereas clinicians viewed patient behaviors to be primarily responsible for admission.

**Conclusions:** These findings highlight that although some similarities exist, there are important differences among patients, caregivers, and clinicians in how they perceive the challenges of HF management and reasons for readmission. Understanding these differences may be critical to developing strategies to reduce readmissions. (*J Cardiac Fail* 2016;22:210–217)

**Key Words:** Heart failure, readmissions, patient-centered care, transitional care, qualitative research.

## Introduction

Heart failure (HF) has an enormous impact on health and the health care system in the United States of America. It afflicts ~5.1 million Americans and is the primary diagnosis in >1 million admissions yearly.<sup>1</sup> In 2012, the estimated total cost of HF was \$30.7 billion, with projected growth to \$69.7 billion by 2030.<sup>1</sup> Readmissions also contribute substantially to the high costs of HF care. The estimated cost of 30-day readmissions is approximately \$17.4 billion.<sup>2</sup> Among Medicare patients who are admitted for various conditions, HF patients have the highest 30-day readmission rate: 27%.<sup>2</sup>

Because of the high prevalence and costs of HF, substantial resources and research have been devoted to improving outpatient HF care and reducing hospitalizations. In

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particular, efforts directed toward reducing readmissions by improving transitional care have accelerated owing to financial penalties enacted by the Centers for Medicare and Medicaid Services for institutions with higher readmission rates.<sup>3,4</sup>

Several interventions have been shown to reduce HF readmissions.<sup>5-7</sup> However, a better understanding of the perspectives among patients, caregivers, and clinicians and the etiologies of hospital admissions may inform improvements in interventions. Although numerous qualitative and quantitative studies have examined barriers to HF care from the patient and caregiver perspectives, relatively few studies have used qualitative methods to triangulate perspectives of patients, caregivers, and clinicians on HF management and factors for hospital admission.<sup>8-13</sup> Comparing perspectives is crucial because the ways that patients and their families experience illness is often very different from the ways that their health care providers understand that experience.<sup>14,15</sup> Therefore, we hypothesized that qualitative interviews would better inform our understanding of HF management after hospital discharge and across the continuum of care. Qualitative interviews provide a medium through which patients and caregivers can describe their experiences from their own perspectives, unconstrained by expert points of view. These voices become particularly important after hospitalization during the transitional period, which appears to be a time of increased risk for various adverse health events.<sup>4,16</sup> Identifying areas of concordance and discordance in perspectives may be helpful in improving communication among patients, caregivers, and clinicians. In addition, this knowledge could be used to inform the design of HF interventions by ensuring that barriers identified by each stakeholder are addressed.

To evaluate similarities and discrepancies among the patient and caregiver experiences and perceptions of experienced care teams, we used freelist, a qualitative research strategy that elicits participants' ideas about concepts that belong in a particular domain.<sup>17-19</sup> With the use of freelist, wherein participants generate a list of words in response to a prompt, we sought to characterize the patient and caregiver experience of managing HF at home by interviewing admitted patients and their caregivers. We also interviewed physicians, registered nurses (RNs), nurse practitioners (NPs), physician assistants (PAs), social workers, and care coordinators with expertise in managing HF patients.

## Methods

### Study Overview

We designed a qualitative study with the use of a purposive sample<sup>20</sup> of HF patients, their caregivers, and clinicians. The study sites were the Hospital of the University of Pennsylvania (a large, urban academic health center) and Penn Presbyterian Medical Center (an urban community teaching hospital affiliated with the University of Pennsylvania Health System). The Institutional Review Board of the University of Pennsylvania approved this study, and every participant provided informed consent.

### Patient and Caregiver Samples

Patients were eligible for this study if they were admitted to a cardiology or general medicine service at either site with a primary diagnosis related to HF. The exclusion criteria were 1) current long-term facility residents or prisoners, 2) non-English speaking, 3) unable or unwilling to provide consent, 4) severe cognitive impairment, and 5) patients with or scheduled for left ventricular assist device, cardiac transplantation, or home inotrope therapy. HF patients were identified by means of a combination of an electronic health record query that generated a daily census of patients admitted with a HF or HF-related diagnosis, chart review by research assistants, and direct contact with floor nurses. Cognitive impairment was screened by means of chart review, and patients with documented cognitive impairment were excluded. Caregivers were identified by the patient and asked if they were able to participate. We purposively sampled to achieve a mix of patients from cardiology and medicine floors and patients with and without recent hospital admission. Patients were consented and interviewed in person. Caregivers were contacted, consented, and interviewed separately either via telephone or in person during a hospital visit.

### Clinician Sample

Clinician participants were those working on interdisciplinary teams caring for HF patients at the two hospitals. These included physicians, NPs, RNs, PAs, social workers, and care coordinators (nurses who provide case management and discharge planning services). Multiple mechanisms were used to identify clinicians. We obtained lists of all of the general cardiology, HF, and hospital medicine interdisciplinary teams. We contacted these individuals either via e-mail or in person, and then scheduled an interview time, either in person or over the telephone. We identified inpatient RNs while on the inpatient floors with admitted HF patients. We purposively sampled to create a mix of clinicians from different training disciplines.

### Data Collection

The research team developed freelist interview guides based on their expertise, review of the literature, and input from a patient with HF. The guides consisted of an initial description of the study, instructions for freelist, and a warm-up exercise. To enhance consistency across interviews, the guide included a written script for the interviewer. The participants were asked to generate a list of words or short phrases in response to 3 separate questions as presented in [Supplemental Table 1](#). The questions were designed to identify perceptions of 1) how patients manage their HF at home, 2) barriers to effective management, and 3) reasons for hospitalization.

Interviews were conducted from October 2012 to April 2013. All interviews were performed by either a research assistant or one of the study authors (F.S.A. or B.P.) and typically lasted 30 minutes. All interviewers underwent training in conducting freelist interviews by a medical anthropologist (F.K.B.). The interviewers met regularly with the medical an-

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