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## Qualitative study of challenges of caring for a person with heart failure

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## ABSTRACT

Heart failure (HF) is a chronic health condition that causes significant morbidity among older adults, many of whom receive support and care from an informal caregiver. Caregiving is a difficult role with many responsibilities and challenges. An in-depth understanding of these challenges is necessary to develop services, resources, and interventions for HF caregivers. The goal of this study was to qualitatively ascertain the most significant challenges facing HF caregivers. We conducted semi-structured interviews with 16 caregivers of a person with HF (PHF). Content analysis revealed challenges rooted within the *PHF* (negative affect, resistant behavior, independence, and illness) *Caregiver* (balancing employment, lack of support, time, and caregiver health) and *Relational* level (PHF/caregiver dyadic relationship and other relationships). These findings can be used to inform interventions and support services for HF caregivers.

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## Introduction

Heart Failure (HF) is a chronic life-limiting condition that affects over six million Americans.<sup>1</sup> The risk of HF is clearly age-related, with a prevalence of <1% in those <50 years, but as high as 10% in those 65 and older.<sup>2</sup> Furthermore, HF is the single most frequent cause of hospitalization in persons over age 65.<sup>3,4</sup> Thus, optimizing strategies for the treatment and management of HF has important implications for the Medicare population. Elderly persons with HF (PHF) often have a high burden of comorbidities which further complicates HF self-management and disease progression.<sup>5,6</sup> Due to the complexities of self-management and comorbidities of HF, many PHF require the help of an informal caregiver to manage their illness.

Caregiving situations vary widely, and caregivers help with a vast range of care tasks for PHF to help facilitate self-care, psychological health and relationships, and quality of life.<sup>7</sup> Caregivers' spend a significant amount of time contributing to PHF self-care, which involves monitoring weight gain, managing adherence to medication, diet, alcohol, and exercise recommendations.<sup>8</sup> Caregivers often intensely and carefully monitor of the health status and decline of the PHF, drawing upon a nuanced understanding of the PHF, and are able to read changes in health status quickly and accurately.<sup>9</sup>

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In addition to helping with self-care, caregivers also spend their time interfacing with the health care team, managing information, arranging clinical appointments, and motivating the PHF to perform better self-care.<sup>10</sup> Caregivers are also involved in more objective aspects of decision making with the PHF and the healthcare team, and take on full responsibility for healthcare decisions when a PHF is cognitively impaired, by serving as a proxy.<sup>11,12</sup> Finally, caregivers provide immense emotional support to PHF in the form of showing understanding, keeping the PHF company, talking about worries, and providing comfort.<sup>13</sup>

While caregivers are critical to HF management, they often experience high burden, emotional distress, and depressive symptoms associated with care demands.<sup>14–16</sup> One study found that greater perceived difficulty with HF care tasks has been associated with poorer perceived mental health.<sup>17</sup> Caregivers may also experience social isolation and curtailed daily activities linked to the physical limitations associated with HF.<sup>15,18</sup> Caregivers have a range of unmet needs that fluctuate with PHF medical status, and are ineffectively addressed or ignored by the formal healthcare system, and relatively few interventions effectively support HF caregivers.<sup>7,19</sup> It is critical to develop interventions that support these caregivers so that care can be provided in effective and sustainable ways. Moreover, supporting HF caregivers also has important implications for PHF. When caregivers' health and well-being are compromised the health and outcomes of the PHF may be negatively affected.<sup>15,20</sup> A recent meta-analysis examining the associations of caregiver well-being and PHF outcomes found higher caregiver strain to be associated with greater PHF symptoms and worse quality of life.<sup>21</sup> As such, the prospect of alleviating caregiver stress through

services, resources, and interventions holds promise in improving outcomes for both caregivers and PHF. However, in order to develop effective interventions, research is needed to delineate the challenges that HF caregivers face.

Substantial research has found qualitative and theoretical support for the notion that caregivers contribute to PHF safety, health and well-being, however, less qualitative inquiry has explored challenges of caring for PHF.<sup>10</sup> Thus, there is a need to explore the specific aspects and nuances of caregiving that are most challenging and burdensome. This knowledge can be used to guide and develop programs, resources and interventions to address caregiver distress. The present study seeks to contribute an in-depth understanding of caregiver challenges using qualitative methodology.

## Material and methods

### Design

The present study uses a qualitative descriptive design. This work was conducted as part of a larger study examining the experiences of PHF and their caregivers in Olmsted County, Minnesota.<sup>22-24</sup> The findings presented in this article are specific to the qualitative analysis of participants' responses to the question: "Can you describe to me what have been the most challenging components of being a caregiver for your loved one?" This question was part of a larger qualitative interview guide. This study was approved by the Mayo Clinic Institutional Review Board and data were collected from August 2015- January 2017.

### Participants

PHF were approached to participate in the hospital and administered a face-to-face questionnaire by a study coordinator. Upon completing the survey, PHF were asked to provide the contact information of their caregiver, defined as "The person who is most likely to help or take care of you if you needed it". Caregivers were eligible if they were serving as the primary caregiver of a PHF, over age 18, able to consent for themselves, and able to complete the survey on their own. Caregivers were sent a survey in the mail, which sought to assess caregiver demographic information, measures of burden, health, and well-being. At the end of the survey, caregivers were asked to indicate whether or not the research team could contact them for future research.

Of the 60 caregivers who completed and returned the quantitative survey, 49 (81%) agreed to be contacted for future research, and were subsequently invited via telephone or electronic mail (three contact attempts maximum) to participate in a phone interview. Of the 49 caregivers who agreed to be contacted, 10 (20%) declined to participate in the phone interview, 23 (46%) could not be reached, and 16 (32%) caregivers completed the phone interview.

### Measures

We collected basic demographic information on caregivers through the quantitative survey including age, gender, race, years of education, marital status, relationship to the patient, duration of care, and hours providing care per day (Table 1). We utilized a qualitative interview guide designed by two researchers with expertise in qualitative and caregiver research, and a cardiologist with expertise in HF. Interview questions were initially developed and then refined during team meetings, with the intention of providing depth of understanding to compliment the breadth of knowledge elicited from the quantitative survey, and to ultimately identify concerns not addressed by the quantitative questionnaires.

**Table 1**

Demographic characteristics of patients and caregivers.

Characteristic	Caregiver (N = 16)	Patient (N = 16)
Age, years, median (IQR)	63 (59, 68.5)	83.5 (69, 88)
Female, N	14	5
White, Non-Hispanic, N	16	16
Education		
Less than high school	0	1
High school graduate	2	6
Some college or 2-year degree	9	4
4-year college degree	3	2
Masters, doctoral or professional degree	2	3
Marital Status		
Married	15	9
Widowed	0	6
Single	1	1
Duration of Care		
<6 months	3	—
6–11 months	3	
1–5 years	3	
>5 years	6	
Unsure	1	
Hours per day providing care, median (IQR)	2 (1, 2)	—
Relationship to Patient (N)		
Spouse	7	
Child	7	
Sibling	1	
Friend	1	

IQR = interquartile range.

### Procedures

One-time phone interviews were conducted by a researcher trained in qualitative methods. Telephone interviews ranged in length from 27–52 minutes and were digitally recorded and transcribed for content analysis.

### Analysis

Qualitative content analysis was completed using a multi-step approach<sup>25</sup> As an initial step, interview transcriptions were read as a whole. Next, codes were derived by reviewing transcripts word-by-word. During weekly meetings, discrepancies in coding were discussed until consensus was reached. Codes were then organized into themes. Next, categories were generated to group codes into meaningful clusters. During weekly meetings, analysis and results were discussed in order to verify findings and maintain study progress. Interviews were conducted until repetition of content indicated that theoretical saturation had been reached.

## Results

Content analysis revealed 36 codes (e.g., *Other illness besides HF, Medication management, Pain of my loved one, I need time away, I don't have time*) that were then organized into three themes, each theme contained different categories of challenges that fit within the larger themes (Table 2). Themes included 1) *PHF challenges* focused around the PHF. Categories within this theme include negative affect, resistant behavior, independence, and illness; 2) *Caregiver challenges* including balancing care demands. Categories include employment, lack of support, time, and caregiver health. 3) *Relational challenges* encompassing the interpersonal difficulties of caregiving. Categories include challenges on the PHF/caregiver dyadic relationship and other relationships.

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