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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.

Keywords

Heart Failure Caregivers; Qualitative Inquiry; Caregiver Burden

INTRODUCTION

Heart Failure (HF) is a chronic life-limiting condition that affects over six million Americans.¹ 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.² Furthermore, HF is the single most frequent cause of hospitalization in persons over age 65.^{3,4} 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.^{5,6} Due to the complexities of self-management and comorbidities of HF, many PHF require the help of an informal caregiver to manage their illness.

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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.⁷ 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.⁸ 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.⁹ 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.¹⁰ 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.^{11,12} Finally, caregivers provide immense emotional support to PHF in the form of showing understanding, keeping the PHF company, talking about worries, and providing comfort.¹³

While caregivers are critical to HF management, they often experience high burden, emotional distress, and depressive symptoms associated with care demands.^{14–16} One study found that greater perceived difficulty with HF care tasks has been associated with poorer perceived mental health.¹⁷ Caregivers may also experience social isolation and curtailed daily activities linked to the physical limitations associated with HF.^{15,18} 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.^{7,19} 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.^{15,20} 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.²¹ 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.¹⁰ 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.^{22–24} 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.

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 approach²⁵ 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.

PHF challenges

Negative Affect—Data reveal that caregivers are challenged by the negative affect of the PHF, including instances of negative mood, attitude, and undesirable changes in personality or temperament. Caregivers in our study described how the PHF's irritable temperament creates conflict: *"There are some days where it doesn't take much ... for him to start yelling at me, that I'm incompetent and I'm stupid and I'm clumsy."* One caregiver articulated that the PHF's negative affect served as the most significant challenge of caregiving: *"The only other real downside is what I call whining...it's 'oh I don't feel good this morning' and this and that and he has a tendency to not have a good outlook on anything."* Another caregiver described the toll that the PHF's attitude takes on her: *"I guess one of my biggest challenges is... his attitude. I don't know if part of this comes from all the other health issues that he has gone through with his heart... his personality has changed a little and I find him to be a little more childlike sometimes and not responsible as far as paying attention."*

Resistant Behavior—Analysis revealed that PHF engage in actions and behaviors to resist care, help, or support. Caregivers described specific actions or behaviors where the PHF was resistant to help from professional care services: *"My dad was getting worse and he was in the rehab unit, so he did have some care, but he would call me on the phone rather than push the nurse's button."* This notion was echoed by another caregiver who described the PHF's expectation that the caregiver would provide care even when the PHF was admitted to a residential care facility: *"When I was in the room with him, he expected me to do everything for him. I had to keep reminding him I was not employed there."* Another caregiver provided an example of how resistance to help placed the PHF in danger: *"He went into a skilled nursing care for two weeks of rehab. Into his second week, he decided he was getting along so well that he didn't need to press the call button for assistance... and ended up reaching a little too far for something and falling and cracking the back of his head open."* Caregivers also described challenges to PHFs' adherence to lifestyle changes necessary to manage HF: *"He promises to take his medications with his food and maintain the schedule that he has told people he will, then he doesn't take his medication. He doesn't."*

He has one excuse after another as to why he doesn't do it and he goes back into the same old problems. So, initially the honeymoon period, after he has a crisis, is good. I feel like we have accomplished a lot, but it doesn't last." Caregivers in our study often described resistant behavior in the context of the PHF wanting to maintain independence. Caregivers struggled to balance PHF autonomy and dependence: *"My husband is a very... independent person and doesn't like to be told what to do or how to do things, his word is 'mothering' him. So I try not to do that. I try to let him make his own decisions as best I can."* In other instances, a PHF may engage in resistant behavior in order to maintain their independence: *"When you have a fiercely independent person, they hide a lot of things from family. It took me a little too long (to figure out that the PHF had HF), even though my intuition was screaming at me that something was going on, she was denying it."*

Illness—Caregivers reported challenges rooted in HF symptoms and non-cardiac comorbidities. Several caregivers indicated that the PHF exhibited cognitive decline and memory loss. One caregiver articulated her frustration with cognitive decline: *"You need to be prepared for a little of the dementia, and yet (physicians) don't even mention it in their write ups when they talk to her. (The write up says) 'clear headed', '(PHF) understands', and yet when she reads she doesn't understand, but the doctors never note that."* In some cases, memory loss precipitated other problems, injuries, or conflicts: *"I can attribute him falling to his mild cognitive impairment, getting up on his own and thinking he could do it himself."* Another caregiver mentioned: *"When you have someone who is in their mid- 80's who doesn't remember conversations very well, doesn't remember, doesn't listen very well when the doctor is talking to her, so she gets stuff wrong a lot. It does create conflict."* Caregivers described difficulty behind coexisting health conditions: *"I mean he has other (health) issues than his heart failure. Heart failure is a part of the Parkinson's disease is a part of the aging process and all of that, so, I can't discern, I can't separate the heart failure from all the rest of it."* Other caregivers indicated that the PHF's mental health challenges increase the difficulty and complexity of caregiving for a PHF: *"The depression that goes along with having heart disease is a challenge."*

Caregiver challenges

Employment—Findings indicate that caregivers balance the demands of caregiving with part time or full time employment. Caregivers reported difficulty with balancing the demands of caregiving with professional responsibilities: *"I work two jobs... basically doing everything else as far as our home and things go, finding the time, or, making the time, not finding it, to do it, can be challenging. Sometimes by the time I get home after working two jobs, I don't want to do it."* Other caregivers explained that they could not balance caregiving with being employed full-time, and as a result, chose to leave their jobs or retire early. Another caregiver explained that caregiving contributed to her decision to retire: *"I just retired from my part time job because I couldn't be working... I couldn't do that and take care of him anymore."*

Lack of Support—Data reveal that caregivers do not have sufficient emotional, tangible, or social support. Many caregivers explained that they were the only available person to provide care to the PHF: *"I am an only child, so that takes on another factor. I am the only*

one; it falls on my shoulders." In other instances, caregivers' received some support, but did not get the support that they really needed: *"He doesn't have any children or close family here, I mean they support him emotionally, you know, he will call them and they will call him, that kind of thing, but when he's in the hospital and stuff, it's just me."* Often, caregivers sought formal support through respite care, but voiced concern over the substantial cost of these services: *"(Respite care) is 26 dollars an hour... you can easily be gone on a shopping trip or go somewhere for the day, and 10 hours are gone... you've gone out for the day, gone and done an activity, gone to dinner... there's \$250 to go have fun."* Another caregiver voiced frustration with the lack of formal support and social services available to help with self-management of HF: *"I have been an RN for 45 years, full time, no breaks, and I know the resources are out there...but nobody will take care of that."* Another caregiver explained that she did not receive any educational materials until well after the PHF had been diagnosed: *"I was never told of any programs until later on, even videos to watch, just to help me learn more about heart failure."*

Time—We found that caregivers experience great loss of their own personal time because of their care responsibilities. One caregiver shared: *"I don't mean to sound selfish, but I am selfish in that respect. I am quite a loner, and having so little time to myself it becomes irritating at times... having to stop everything...sometimes spending hours in the ER as well as the hospital."* Another caregiver explained the substantial time commitment of caregiving: *"The bad thing is that it's just particularly a thing that sucks time away, takes a horrendous amount of time that generally I could be doing stuff that I would like to be doing a whole lot more."* The demand on caregiver time also put a strain on the quality of caregiver/PHF interaction: *"(It is hard) finding the time to devote to her and not make it feel like it's a burden, or hiding it from her that it's a burden. The trickiest part is trying to be positive and not let her read into my words or my emotions or my tone of voice that, I need to be elsewhere, but you try to hide that from them. That kind of sucks sometimes because you just want to scream 'I don't want to do it! I am busy today!' But it doesn't work that way."*

Health—Findings indicated that caregivers are challenged by coping with their own health issues and mortality. One caregiver explained that her own recent health concerns added increased pressure to her caregiving role: *"I got a mammogram and they called yesterday and said, you need to come back in ... and it's like 'holy crap' you are trying to keep it all together... I can't handle this and my dad right now, I can't handle both things."* Others anticipated that normative age-related decline would eventually inhibit their ability to provide care: *"There's a thing inside of you too when you get older and close to like 70... there's not a whole hell of a lot of time left."* Another caregiver explained that her health issues did not take priority over the health of the PHF: *"I am a lot older than he is. I have a lot of aches and pains and chronic conditions, but if I mention anything about me, oh no, he's got it ten times worse."*

Relational challenges

Dyadic Relationship—Our study found that conflicts arise within the caregiver/PHF dyad. One caregiver indicated relational changes resulting from caring for her father with HF: *"It's a shift in roles I guess, and that is challenging. The other thing that's challenging is*

that he, I guess I would say that he didn't like me to tell him what to do and make sure he was following the rules, um, so that was challenging. I felt like I had to tell him, you know 'this is how you have to eat' and 'you can't be doing this' and 'you can't be doing that' and 'you can't drive' you know, a lot of those things that you never thought you would have to do for your parent." For those providing care to a spouse, changes in the spousal relationship were also distinct: *"It's changed a whole lot of physical activity. There's no ...sexual intimacy."*

Other Relationships—Caregivers explained that caregiving can impact family and social relationships in negative ways. One caregiver describes the strain of caring for her father on her marriage, *"My husband and I celebrated our 25th wedding anniversary and we weren't sure we were going to be able to do anything... that was a strain on my personal relationship."* Another caregiver explained how caring for her father changed her relationship with her spouse *"I think the biggest thing is the loss of privacy for my husband and I, because (PHF) is here all the time, and we don't get to go out."* Social relationships with friends also became jeopardized by the demands of caregiving: *"You are anchored with taking care of that person almost twenty-four seven, so the negative part of it is that you lose your social life."* Another caregiver explained that social relationships have changed as a function of the PHFs inability to engage in physical social activities: *"Some of our social life has diminished because we both were golfers and golfed together as couples a lot and haven't done that as much recently."* Another caregiver described the PHFs physical limitations as a barrier to engaging in social activities: *"We have friends that we go with one night a week for dinner, but he's kind of embarrassed that he can't get up from the chair, so he needs help."*

DISCUSSION

While a large body of literature has explored the burden and stress of caring for a PHF using survey data, our study contributes an in-depth, qualitative exploration of the most challenging aspects of this caregiving role. The findings are important because an in-depth understanding of the needs and concerns of HF caregivers is essential to improve services and educational interventions. Content analysis of interviews with HF caregivers revealed the interpersonal and intrapersonal complexities of caring for a PHF; these challenges were rooted within the PHF, the caregiver, as well as the PHF/caregiver dyadic relationship.

PHF Challenges

Our study found that the negative affect of PHF is a major challenge for caregivers who interact with the PHF on a routine basis. These findings are consistent with previous work that has identified managing PHF moodiness and irritability as one of the most frequent and difficult HF caregiving tasks.¹⁷ Recent literature reviews have identified negative affective dispositions, such as depression, anxiety, and anger-hostility, as acknowledged risk factors for coronary heart disease.^{26–28} Dyadic studies have highlighted the interdependent interactions of PHF and their caregivers, suggesting that PHF emotions, cognition, and behavior influence their own as well as their caregiver's outcomes.^{29,30} Caregiving for a PHF with negative affect and depressive mood poses unique challenges. One study found

that HF caregivers had greater difficulty in care responsibilities, worse quality of life, and spent more time providing care for PHF with depressive symptoms than did those caring for PHF without depressive symptoms.³¹ Our findings suggest further exploration of how negative affect of PHF can influence their own as well as their caregiver's outcomes. In order for such work to move forward, it is critical to include caregivers in patient-outcome research so that the links between patient and caregiver outcomes can be better understood. This work can also build a foundation for intervention and support services to help caregivers cope with PHF negative affect.

Findings show that PHFs engage in resistant behaviors that ultimately lead to rejecting help of their caregiver or formal services. Effectively addressing resistant behavior (e.g., nonadherence to medication, self-care, or lifestyle changes) is critical to ensuring optimal health outcomes of the PHF. Caregivers' in our study revealed several instances where a PHF's resistant behavior led to injury, illness, and hospital readmission. These findings provide further insight into previous research that has identified PHF nonadherence to a care plan as the most important contributor to hospital readmission.³² Readmission is increasingly being used as a quality metric, a basis for hospital reimbursement, and an outcome measure in clinical trials.³³ Thus, it is important to understand how resistant behavior in PHF is linked to readmission. Likewise, it is critical to identify strategies for caregivers to effectively cope with resistant behavior. Although caregivers may have increasing power in the relationship due to the PHF's declining functioning, caregivers in our study explained that PHFs engaged in resistant behavior as a mechanism to preserve autonomy and independence. Caregivers explained that a desire for independence led to resistant behaviors and withholding information; these results indicate the importance of promoting the autonomy of PHFs, while allowing their goals, values, and preferences to guide shared healthcare decisions.³⁴

Caregivers in our study were highly burdened by the illness of the PHF. These findings align with previous quantitative work that has linked physical health status of PHF to caregiver burden, disruption of daily schedule and decline in caregiver physical health.³⁵ However, our study differs from this work in that we highlight the challenges of comorbid conditions that often accompany HF. Comorbid conditions in HF may lead to greater healthcare utilization, and increase the risk of health complications and mortality.³⁶ While clinicians typically consider the impact of comorbidity on outcomes and management of HF, it is critical to acknowledge that HF caregivers provide care for comorbid conditions. Caregivers need support and resources to help them understand the complexity of care, management of diverse symptoms, and how different conditions manifest within the context of HF. While survey data may reveal what types of comorbidities commonly occur with HF, our study highlights some of the most stressful comorbid conditions from a caregiver perspective. Specifically, caregivers in our study mentioned age-related cognitive decline. Cognitive decline is common in HF, due to age-related risk of cognitive impairment in this primarily elderly HF population and pathophysiologic changes resulting from HF itself.¹⁵ For caregivers, cognitive impairment is problematic, frustrating, and threatens the PHF's safety. It is critical that research address cognitive decline when it coexists with HF, and test strategies to promote self-care among PHF with cognitive decline.³⁷ The high instances of

comorbidity in HF suggest the need to approach caregiver education in a more comprehensive manner.

Caregiver Challenges

Caregivers struggle to balance care demands with professional roles, highlighting the need for policy and infrastructure (e.g., flexible work policies) to support employed caregivers. As the nation's population ages, more employed individuals will become caregivers, and employers will need to adjust comprehensive work/life programs that incorporate address the needs of employees who are caregivers.^{38,39} Lack of support was a common theme among caregivers in our study; caregivers explained that they often do not receive adequate support or help from family members. These findings align with literature which documents inadequate emotional and social support as a prominent issue among dementia caregivers.⁴⁰ Moreover, caregivers in our study felt left out of the formal healthcare system. This finding are congruent with other work that shows HF caregivers receive little guidance and support from the health care team.⁴¹ However, caregivers in our study were not always successful in eliciting support from others, indicating that caregivers require skills to engage social support and formal services.⁴² Caregivers in our sample ranged from midlife to late-life, a time where age-related declines in health become more apparent. Thus, it is not surprising that many caregivers discussed the challenges of their own health. Our findings align with similar research that highlights HF caregivers' tendency to ignore their own health needs.⁴³ This issue is not unique to HF caregivers; research has shown that dementia caregivers experience greater comorbid risk, depression, and anxiety than their non-caregiving counterparts.⁴⁴ Given this knowledge, intervention efforts should take a dyadic approach, and explore strategies to maximize health outcomes for both PHF and caregivers.⁴⁵

Relational Challenges

Caregivers in our study provided many examples of how caring for a PHF depletes preexisting social networks, and limit social activities. Burden and barriers to caregivers' social participation following a HF diagnosis has been documented in cardiovascular nursing research.^{17,46} A critical target for intervention efforts should be enhancing and maintaining social connections within the context of HF. This is important for both the PHF and caregiver. Our study also found that the dyadic relationship between the caregiver and PHF is another critical relational challenge. Previous work has found that the dyadic management of HF is compromised when there are differences between the PHF and caregiver decisions, behaviors, and attitudes.⁴⁷ Our results further support this concept, and suggest that there may be significant incongruence in the way that PHF and their caregivers renegotiate relational roles. Spousal caregivers reported renegotiation of expectations for activities, companionship, and intimacy. Caregivers experienced challenges in restructuring parent/child roles and coping with the reality of their parent's mortality. Amidst the restructuring of the PHF/caregiver relationship, relational quality is critical: better relationship quality is related to a reduced PHF mortality, increased health status, and lower distress and burden for HF caregivers.^{48,49} Dyadic relational quality is of paramount importance in other caregiving settings, including dementia caregiving, where higher relationship quality has been linked to lower subjective care stressors, such as role captivity and role overload.⁵⁰ Thus, educational

and support services for caregivers should consider promoting positive relational functioning within the caregiver/care-recipient dyad.

CONCLUSIONS

The present study sought to understand key challenges, and contribute depth to our current understanding of caregiving for a PHF. Our study should be interpreted within the context of several limitations. First, our sample was obtained from one academic medical setting; participating caregivers more likely to be engaged as they took the time to complete the interview. It is possible that caregivers in other, more diverse medical and geographic contexts have unique challenges that need to be explored. Our sample consisted mostly of female caregivers. This is not unusual, as national estimates suggest that 85% of all caregivers are women. Male caregivers, however, have diverse experiences that warrant further exploration. Despite these limitations, our findings highlight the challenging interpersonal and intrapersonal aspects of the caregiving role, suggesting directions for future research and intervention aims that address HF caregiver health and well-being.

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Highlights

- Caring for a person with heart failure (PHF) is highly stressful and challenging; our study qualitatively examines the challenges of caring for a PHF.
- Caregivers experience challenges related to the PHFs health, mood, or personality.
- Age-related decline in memory and cognition are common challenges of caring for a PHF.
- Balancing caregiving with other aspects of life, such as employment, is particularly difficult for caregivers.

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	

Notes: IQR= interquartile range.

Table 2**Outcomes of Content Analysis**

Theme/Category	Challenge	Example
PHF challenges		
Negative Affect	The PHF has a negative mood, poor attitude, or irritable temperament.	<i>"He (PHF) has a tendency to not have a good outlook on anything."</i>
Resistant Behavior	The PHF engages in actions and behaviors to resist care, or maintain independence.	<i>"He (PHF) promises to take his medications with his food and maintain the schedule that he has told people he will, then he doesn't take his medication. He doesn't."</i>
Illness	The PHF has complex HF symptoms and non-cardiac comorbidities.	<i>"You need to be prepared for a little of the dementia."</i>
Caregiver challenges		
Employment	Caregivers balance the demands of caregiving with professional responsibilities.	<i>"If you're going to take care of someone with heart failure, you may lose your job, and that's a tough thing. I'm not asking for handouts or anything, but obviously we would have had to do something different if I were not at that age where I could quit (my job)."</i>
Lack of Support	Caregivers do not have sufficient emotional, tangible, or social support.	<i>"I am the only (caregiver) it falls on my shoulders."</i>
Time	Caregiving competes with personal time.	<i>"Having so little time to myself becomes irritating."</i>
Health	Caregivers must cope with their own health issues and mortality.	<i>"I am not getting any younger; I have health issues of my own that make caregiving even harder."</i>
Relational challenges		
Dyadic Relationship	Conflicts arise within the caregiver/PHF dyad.	<i>"It's a shift in roles...He (PHF) didn't like me to tell him what to do."</i>
Other Relationships	Caregiving impacts family and social relationships.	<i>"It (caregiving) changes your social life. When your friends say 'hey do you want to go out to dinner' you can't do it because you got to be here (for the PHF)."</i>

Notes. HF= heart failure; PHF= person with heart failure.