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Caregiving experiences of Older Family Caregivers of Persons with Heart Failure: A Mixed Methods Study

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Abstract

Older family caregivers of persons with heart failure (HF-FCGs) are an understudied and vulnerable population, who are at heightened risk for age-related physical and cognitive declines. We explored caregiving experiences of older HF-FCGs and examined levels of their caregiver burden, psychological distress, caregiving self-efficacy and quality of life (QoL) using descriptive mixed methods. We conducted telephone-based surveys and semi-structured interviews (N=13). Low levels of caregiver burden, psychological distress, and high levels of caregiving self-efficacy and QoL were reported. Through qualitative interviews, three qualitative themes emerged: (1) Impact of Being a Caregiver, (2) Managing Caregiver Distress, and (3) Embracing the Caregiver Role. Psychological distress was the most frequently reported. Physical, psychological, and social distress experienced by older HF-FCGs might be offset by their coping strategies and willingness to accept their caregiver role. FCG-centered support programs that help older HF-FCGs develop and apply their own coping strategies should be considered.

Keywords

caregivers; aged; heart failure; caregiver burden

Introduction

Heart failure (HF) is the fastest growing chronic cardiovascular disease and disproportionately affects older adults.^{1,2} It affects about 40 million people globally³ and more than 6 million individuals in the United States.¹ Most older adults with HF receive informal home care, relying on unpaid help from their family caregivers (FCGs).^{1,4} Millions

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of FCGs provide informal care and support to family members with HF.⁵ FCGs of persons with HF (HF-FCGs) play a key role in managing HF-related health and engaging in medical decision-making for older adults with HF.^{6,7} As such, the caregiving role can place a considerable burden on HF-FCGs.

Caregiver burden can be described as the adverse effects of providing care.^{8,9} This burden can result in a multidimensional response to physical, psychological, social, and financial stressors.⁹ Along with caregiver burden, HF-FCGs often experience psychological distress related to their caregiving and support roles (e.g., stress, depression, anxiety), low caregiving self-efficacy,¹⁰ and a reduction in their quality of life (QoL).^{11,12} Moreover, it is known that due to caregiving responsibilities, many HF-FCGs neglect to manage their own physical and psychological health and are less likely to engage in health-promotion activities.¹¹⁻¹³ The reduction or absence of self-care places HF-FCGs at heightened risk for illness.^{1,11,13}

HF-FCGs are generally the spouse or partner of older adults with HF,^{1,12,14} thus, HF-FCGs are likely to be older adults, as well. Older adult FCGs are vulnerable to their own age-related health issues, while also needing to provide reliable in-home care for their family member with HF.^{15,16} In light of this, older HF-FCGs can face many challenges throughout the HF disease trajectory of their family member. Thus, supporting HF-FCGs' physical and psychological health is important to prevent them from becoming care recipients which would adversely impact the older adult with HF in their care.^{1,11}

Despite the vulnerability of older HF-FCGs with the dual impact of their age-related health issues and caregiving responsibilities, there is little research focused on caregiving experiences and perspectives of older FCGs caring for persons with HF. It is important to investigate how older HF-FCGs perceive their caregiver role, how caregiving duties affect their physical, psychological, and social health, and how they manage their caregiving-related distress. Therefore, the purpose of this study was to explore the experiences of older HF-FCGs and their perspective on providing care for older adults with HF. Additionally, we sought to examine levels of caregiver burden, psychological distress, caregiving self-efficacy and QoL experienced by older HF-FCGs.

Material and Methods

Study Design and Sample

This study is part of a larger study investigating the physical and psychological health of FCGs of persons with HF, and developing behavioral interventions to improve their health and QoL.¹⁷ In this analysis, we conducted a descriptive mixed methods design¹⁸ using in-depth interviews augmented with descriptive survey data (i.e., caregiver burden, psychological distress, self-efficacy, QoL). Both types of data collection were used to understand older HF-FCGs' experiences as unpaid care partners for their family member. This approach allows for in-depth insight through quantitative and qualitative investigations from older HF-FCGs' perspectives on a caregiving role.¹⁹ We used purposive sampling to obtain maximum variability in their perspectives.²⁰ We recruited HF-FCGs from January to April 2021 in the outpatient advanced heart failure clinic at an academic medical center in the United States. Due to the COVID-19 pandemic, all interviews were conducted via

telephone. The target sample size was 12 to 15 HF-FCGs based on the minimum sample size suggested to reach data saturation for qualitative data.^{21,22} The sample size was determined based on the qualitative section of the mixed methods because we centered predominantly on the qualitative approach. This was augmented with quantitative data that examines levels of caregiver burden, psychological distress, self-efficacy and QoL. Inclusion criteria for HF-FCGs were as follows: (1) 65 years or older, (2) living in the same household as a family member with HF, (3) providing at least 8 hours/week unpaid care for the past six months, (4) able to speak English, and (5) able to provide informed consent. Caregivers were excluded if they had mild cognitive impairment. To assess the participant's cognitive health, the RA asked questions using the Telephone Interview for Cognitive Status (TICS) form.²³ Participants who had a TICS score of less than 25 were excluded from participation. The study was approved by the institutional review board (#20-0353; exempt status and HIPAA waiver of written consent were received).

Recruitment and Data Collection

The principal investigator (PI) identified potential patients with HF (65 years or older) through an electronic health record (EHR) review. The primary cardiologist or advanced practice provider was approached to obtain approval for contacting the patients. A research assistant (RA) then contacted potential patients via telephone and/or email to explain the study purpose and procedures. If the FCG expressed an interest in participating in the study (via telephone or email), the RA screened the individual based on inclusion/exclusion criteria to verify study eligibility. If inclusion/exclusion criteria were met, the RA organized a convenient time to conduct the study visit via telephone. Participants received an electronic consent form via email prior to the study visit. At the beginning of the study visit, the RA explained the study purpose, procedures, and potential risks/benefits. Once the participant gave verbal consent, the PI or RA conducted semi-structured interviews and administered survey questionnaires. Each survey was completed on a separate day from the interview in response to participants developing fatigue. During the semi-structured interviews, HF-FCGs were asked about their caregiving experiences, caregiving-related physical, psychological and social health, and management of caregiving distress (e.g., "In caring for your loved one with heart failure, have you had any physical distress (e.g., fatigue)?" "What factors make you feel distressed in caring for the loved one?"). More detailed interview questions can be found in the Interview Guide (Appendix). The interviews lasted between 80 and 90 minutes. All participants were provided a \$50 gift card as a token of appreciation for their time.

Study Variables and Instruments

Demographic data, including age, gender, race, ethnicity, relationship to the person with HF, employment status and financial status, were collected.

Caregiving burden was measured using the Heart Failure Caregiver Questionnaire (HFCQ).²⁴ It consists of 21 items rated on a five-point Likert scale, with total scores ranging from 0 to 84 (higher scores = worse physical and psychological burden). The concurrent and construct validity were supported by correlations with other measures.²⁴ The Cronbach's alpha of the HFCQ in this study was 0.87.

Depression was measured using the Center for Epidemiological Studies Depression Scale (CES-D), a 20-item questionnaire rated on a four-point Likert scale, with total scores ranging from 0 to 60 (higher scores = worse depressive symptoms).²⁵ Scores greater than 16 is suggestive of clinical depression.²⁵ The CES-D has good sensitivity, specificity, and high internal consistency ($\alpha = 0.80$).²⁶ The Cronbach's alpha of the CES-D in this study was 0.69.

Anxiety was measured using the State Trait Anxiety Index (STAI), a 20-item questionnaire rated on a four-point Likert scale, with total scores ranging from 20 to 80 (higher scores = worse anxiety symptoms).²⁷ A cut-off score of 54–55 was suggested to detect clinically significant anxiety symptoms.²⁸ This instrument has high internal consistency ($\alpha = 0.85$), test-retest reliability, and validity.^{26,27} The Cronbach's alpha reliability of the STAI in this study was 0.88.

Stress was measured using the Perceived Stress Scale (PSS), a 10-item questionnaire rated on a five-point Likert scale, with total scores ranging from 0 to 40 (higher scores = higher stress).²⁹ The following values were considered to identify a level of stress; 0–13 (low stress), 14–26 (moderate stress), 27–40 (high stress).³⁰ In a similar population of HF-FCGs, the internal consistency of the PSS ranged from 0.84 to 0.86.²⁹ The construct, concurrent, and predictive validity were supported by correlations with other measures.²⁹ The Cronbach's alpha of the PSS in this study was 0.83.

Caregiving self-efficacy was measured using the Revised Scale for Caregiving Self-Efficacy (RSCSE),³¹ a 15-item questionnaire rated on an 11-point scale, with total scores of each subscale ranging from 0 to 100 (higher scores = better self-efficacy).³¹ The RSCSE consists of three subscales, including self-efficacy for obtaining respite, responding to disruptive patient behaviors, and controlling upsetting thoughts about caregiving. The RSCSE has good internal consistency ($\alpha = 0.8$), test-retest reliability, content validity, and construct validity.³¹ The Cronbach's alpha of the RSCSE in this study ranged from 0.91 to 0.96.

Quality of life (QoL) was measured using the Short Form 36 (SF-36) version 2, a 36-item questionnaire. SF-36 consists of eight subscales (i.e., physical functioning, role limitations due to physical health, bodily pain, mental health, role limitations due to emotional problem, social functioning, vitality, and general health) (higher scores = better QoL).³² SF-36 reports total scores for each subscale from 0 to 100. Scores ≥ 60 suggest a good QoL.³³ The internal consistency reliability for the summary measures of physical health and mental health ranged from 0.88–0.91.³⁴ The SF-36 (v2) has good internal consistency ($\alpha = 0.8$) and well-documented content and construct validity.²⁶ The Cronbach's alpha of the SF-36 in this study ranged from 0.53 to 0.91.

Data Analysis

For quantitative data, descriptive statistics (i.e., mean, standard deviation, frequency, and percentages) were conducted using SAS (v 9.4) to describe the sample characteristics and the levels of caregiving burden, depression, anxiety, stress, caregiving self-efficacy and QoL. Composite scores and composite subscale scores were calculated for each instrument. The internal consistency of the instruments was measured using Cronbach's alpha. To explore

the needs and experiences of older FCGs caring for persons with HF, thematic analysis³⁵ was conducted using qualitative data from the interviews to identify emerging themes. All interviews were audio-recorded and transcribed verbatim. In initial coding, three research team members coded the first three transcripts independently using Dedoose software (<https://www.dedoose.com>). Then, the research team developed a codebook which was continually revised through weekly discussions. Each of the three research team members coded the remainder of the transcripts independently based on the codebook. Codes were classified into categories and themes through the iterative process of merging, dividing, or removal. The research team had weekly meetings to discuss codes and themes and to reach consensus on differences in interpretation.

Trustworthiness

Qualitative trustworthiness—including credibility, confirmability, dependability and transferability—was established.^{18,36–39} Credibility was established through peer debriefing and investigator triangulation. Confirmability and dependability were established through codebook development. Transferability was established through a detailed description of participants and research procedures. Specifically, we provided a rich description of the context: study setting, sample, inclusion and exclusion criteria, data collection strategy, and interview procedure/questions.⁴⁰

Results

Characteristics of the sample

The mean age of 13 HF-FCGs participated was 70 (± 5.5) years, most were female (85%), White (92%), and 69% identified as non-Hispanic/Latino. Most were a spouse (92.3%) and retired (73.3%) (Table 1). The mean number of years the participant's family member had been diagnosed with HF was 9.5 (± 14.2) years. Most participants (84.6%) reported that they were comfortable financially, having more than enough to make ends meet.

Results from Quantitative Data

Table 2 shows the results related to the study aim that examines levels of caregiver burden, psychological distress, caregiving self-efficacy and QoL experienced by older HF-FCGs. Older HF-FCGs experienced low levels of stress (8.2 ± 5.7), depression (7.8 ± 4.5) and anxiety (24.8 ± 6.2), and reported a high level of QoL, ranging from 68.8 (± 14.6) to 90.8 (± 8.1) across the eight subscales. The HFCQ indicated a low level of caregiver burden (23.2 ± 11.6). The mean scores for caregiving self-efficacy on the RSCSE reflected a high level of caregiving self-efficacy with scores > 74 on a 0–100 scale.

Results from the Qualitative Data

Qualitative data were analyzed to explore caregiving experiences and perspectives of older HF-FCG. Themes that emerged from qualitative interviews were (1) *Impact of Being a Caregiver*, (2) *Managing Caregiver Distress* and (3) *Embracing the Caregiver Role*. Each of these themes is described below.

Theme 1. Impact of Being a Caregiver—The first theme had three categories: **physical, social, and psychological distress** (Table 3). *Physical* distress included sleep loss leading to sleep deprivation and a decrease in physical activity. Participants reported that physical distress impacted their health because they had less time to care for themselves such as “*can’t go to my exercise class.*” Being a caregiver produced *social* distress which included time restrictions due to the need to be a caregiver. Statements such as “*I’m not as free*” and “*just trying to keep up*” reflected their *social* distress. *Psychological* distress was the most frequently discussed distress. All participants discussed psychological distress during the interviews. *Psychological* distress included anxiety, feeling overwhelmed and frustrated, and worry, which linked to their family member’s HF trajectory and worsening physical health. However, participants mentioned that when their family member’s physical health improved, they had less psychological distress. Older HF-FCGs discussed that the interaction across physical, social and psychological distress had an impact on their lives. One participant said:

It was at that time that I was doing pretty much everything. Now, or in the last four months anyway since the heart issue is now paramount and the back issue is still there but not bad, I’m doing less caregiving. So I’m certainly not following the usually progression I presume where the caregiver gives everything upfront and then there’s a space where things are nice and calm for a long time. So I have to assume as he gets worse my symptoms will start showing because I will keep aging as well.

(P#11)

Additional quotes on the impact of being a caregiver are presented in Table 3.

Theme 2. Managing Caregiver Distress—Despite the distress associated with the caregiving role, older HF-FCGs described many ways that they managed to cope (Table 4). This coping came from **physical, psychological, and social activities**. One participant (P#4) best described this theme as, “*I’m coping with it.*” In *physical* coping, participants discussed many activities for physical coping, such as “*taking a walk,*” “*staying active,*” “*engaging in exercise,*” “*aromatherapy,*” “*doing crafts,*” and “*working in yard and lawn.*” *Psychosocial* coping consisted of many activities embedded in a support network. One participant (P#10) stated, “*I have three amazing daughters, and I got an amazing son too, when I need to unload on somebody or just talk something through, they’re all there.*” Participants also assessed that some of their psychosocial coping came through a “*team effort.*” In this team effort, older HF-FCGs did not believe they were doing the care by themselves. They described enjoyment from “*exercising together*” or “*gardening together,*” where this together-time was with a family member with HF. In this way, they would “*let*” their family member with HF “*do as much as they can,*” such as “*getting them to help with household chores.*” Activities they described for psychosocial coping included meditating, reflection, religious activities, and relying on peer support groups and family support such as “*having time outside with grandkids.*” Most participants reported that psychological and social support from family and friends who understood and empathized with participants’ situations was helpful in coping with caregiving distress.

Additional quotes on managing caregiver distress are presented in Table 4.

Theme 3. Embracing the Caregiver Role—As unpaid caregivers, the majority of the HF-FCGs stated that they fully embraced the caregiver role and found it difficult to differentiate between being a spouse (or partner) and caregiver (Table 5). Of note, 92% of these participants were husband or wife, with only one informal caregiver participant, who was a sister. Instead of saying the word, *caregiver burden*, the older HF-FCGs fully accepted their role, mentioning that it was “*not a problem to be a caregiver,*” or “*I don’t find it as a burden.*” One participant (#4) said,

... He helps make sure that I’m, if I’m tired, he will take over and do stuff. I mean like if I’m tired, I want to go to bed early. He would do his own batteries at night, I don’t have to go in and do that for him. So we work as a team. We’ve been married over 30 years... And I mean I can’t, it’s kind of hard to separate what I do as a caregiver and what I do as a wife... I do it as a wife... oh no, it’s hard, this one is a caregiver, you know it’s kind of hard to separate sometimes.

Additional quotes on embracing the caregiver role are presented in Table 5.

Discussion

Our findings extended and added to the limited body of literature on older adult FCGs caring for persons with HF. In particular, using a mixed methods study approach, this study provides a broader understanding of caregiving experiences and perspectives of older adults caring for persons with HF at home. While providing the overview and outline of levels of caregiving-related distress, self-efficacy and QoL through quantitative descriptive data, this study also provided detailed descriptions on how physical, psychological, and social distress experienced by older HF-FCGs have been offset by their coping strategies and then how they could embrace their caregiver role through qualitative interviews. That is, this study provides an integrated and comprehensive understanding on the process of the problem-solving-adaptation experienced by older FCGs caring for a family member with HF.

It appears that there is a discrepancy between findings from the survey scores and the interview data on caregiver burden and distress. This discrepancy likely relates to older HF-FCGs reporting low mean scores of caregiving burden and psychological distress (e.g., anxiety, depression, stress) reflecting low levels of caregiving burden and psychological distress in the survey, and they discussed several physical, psychological, and social distresses regarding caregiving in the interviews. However, perceptions of older HF-FCGs and related impacts need to be interpreted contextually and comprehensively rather than taking a snapshot of fragmented information. Although some older HF-FCGs discussed physical, psychological, and social distress in the interviews, the experiences of distress might be resolved through their own coping strategies and their willingness to embrace their caregiver role. For example, HF-FCGs’ process of *problem* (caregiving distress)-*solving* (coping strategies)-*adaptation* (embracing the caregiver role) identified in the interviews, might be reflected on the survey scores quantitatively. Thus, using a mixed methods approach that elicits older HF-FCGs’ perceptions is valuable in providing a more

comprehensive understanding of caregiving experiences and coping strategies of older HF-FCGs.

Older HF-FCGs in this study reported caregiving-related physical, psychological, and social distress in the interviews. The findings were supported by other previous qualitative studies.^{12,41,42} For example, Bahrami and colleagues' study found that FCGs caring for persons with HF experienced physical exhaustion (e.g., musculoskeletal disorder, fatigue, sleep disturbance), psychological exhaustion (e.g., loss of hope, anxiety, stress) and social isolation.⁴¹ Given that participants in this current study are older caregivers who provide care in the home, and typically lack emotional and social support, loneliness and social isolation they faced might be more challenging in managing their own health while at the same time, caring for their family members with HF. Thus, it is important to design and implement tailored, FCG-centered support programs that meet the older caregiver population's needs and requirements to support the physical and psychological wellbeing of HF-FCGs and their family members with HF.

We found that older HF-FCGs had coping strategies to manage their physical, psychological, and social distress, such as family support, team effort, and willingness to fully accept their caregiver role. Social and psychological support and acknowledgment of the caregiver role as coping strategies were supported by a meta-ethnographic review examining caring experiences of FCGs of persons with HF.⁴³ The *team effort* identified in this current study is one of the most important coping strategies because the participants valued spending time with the family member with HF. Caregiver research revealed that better quality of patient-caregiver relationship links to not only HF patients' reduced mortality and increased health status, but also FCGs' decreased caregiving burden and reduced distress.^{44,45} Therefore, the burden of care of older HF-FCGs in this current study might be offset by companionship and intimacy with their family member with HF, which contributes to their satisfaction with caregiving and increased resilience in adaptation and coping.^{42,43,46}

Similarly—and significantly—despite the interview questions explicitly using the word “burden” when seeking information about the caregiver role, participants never once mentioned that word in their responses. Instead, the HF-FCGs turned the discussion to coping with burden of care and embracing their caregiver role. They stated that it was “*not a problem to be a caregiver*” and fully accepted the role of caregiver through the *team effort* with their partner. Therefore, in light of these quotes and the lack of the word “burden,” although much literature has focused on the burden of caregiving, we should consider that older HF-FCGs may not see the caregiving role as burdensome. In alignment with the American Heart Association Heart Failure Caregiver Statement,¹ our findings also confirm that older HF-FCGs consider their role as a caregiver to have rewards such as feelings of satisfaction, accomplishment, and meaningfulness.

Limitations

There are several limitations to our study findings. First, older HF-FCG participants were recruited at a single academic medical center. Another limitation was the lack of diversity of the sample. Most participants of this study were non-Hispanic White and female. Future studies should focus on identifying caregiving distress and coping strategies in

a racially and ethnically diverse population of HF-FCGs, as well as male responses to caregiving. Moreover, we administered several survey questionnaires via telephone due to the COVID-19 pandemic. There might be response bias and social desirability bias (i.e., participants were likely to answer questions in a manner that was viewed favorably by the PI or RA). Finally, the small sample size of this study might be a limitation in using the mixed methods approach. However, we centered on a qualitative approach augmented with descriptive survey data and reached data saturation for the qualitative data.

Conclusions

HF-FCGs play a vital role in managing the physical, psychological, and social wellbeing of persons with HF. This study provides a comprehensive understanding of caregiving experiences of older HF-FCGs through a mixed methods approach. Physical, psychological, and social distress experienced by older HF-FCGs can be offset by their own coping strategies and willingness to fully accept their caregiver role. Therefore, FCG-centered support programs that help older HF-FCGs develop and apply their own coping strategies should be warranted to prevent older HF-FCGs from placing them at risk for illness as well as provide the best possible care to persons with HF.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

- Older family caregivers of persons with heart failure are an understudied and vulnerable population.
- A team effort was an important coping strategy for these older family caregivers.
- Family-centered support programs should be explored to help older family caregivers develop and apply their own coping strategies.

Table 1.

Characteristics of older HF-FCGs (N=13)

Characteristics	Mean (SD) or n (%) [*]
	Mean (SD)
Age (years)	70.0 (5.5)
Years lived one diagnosed with heart failure	9.5 (14.2)
	n (%)
Gender	
Male	2 (15.4)
Female	11 (84.6)
Race	
White	12 (92.3)
Asian	1 (7.7)
Ethnicity	
Non-Hispanic/Latino	9 (69.2)
Hispanic/Latino	4 (30.8)
Relationship to a person with heart failure	
Spouse	12 (92.3)
Sister	1 (7.7)
Employment status ^{**}	
Working part-time (including seasonal, work study, etc.)	3 (20)
Retired	11 (73.3)
Disabled	1 (6.7)
Financial status	
Comfortable; have more than enough to make ends meet	11 (84.6)
Have just enough to make ends meet	2 (15.4)
Do not have enough to make ends meet	0 (0)

^{*} Mean (SD [standard deviation]) were used for continuous variables and n (%) was used for categorical variables.

^{**} Two participants were counted twice due to them having more than one employment status.

Table 2.

Levels of caregiver burden, psychological distress, caregiver self-efficacy, and QoL

Variables	Mean (SD)	Range* (Min – Max)	Possible Scores**	Cronbach α	Cut-off scores or interpretations
Caregiving burden	23.2 (11.6)	6–47	0–84	0.87	Higher scores = worse physical and psychological caregiving burden
Depression	7.8 (4.5)	0–17	0–60	0.69	Higher scores = worse depressive symptom 16: considered clinically depressed
Anxiety	24.8 (6.2)	20–41	20–80	0.88	Higher scores = worse anxiety symptom A cut-off score of 54–55 suggested to detect clinically significant anxiety symptoms
Stress	8.2 (5.7)	2–17	0–40	0.83	Higher scores = higher perceived stress 0–13: low stress 14–26: moderate stress 27–40: high stress
Caregiving Self-Efficacy					Higher scores = better caregiving self-efficacy
<i>Obtaining Respite</i>	79.5 (30.2)	12–100	0–100	0.93	
<i>Controlling Upsetting Thoughts</i>	87.7 (13.2)	64–100	0–100	0.91	
<i>Responding to Disruptive Patient Behaviors</i>	74.5 (26.4)	32–100	0–100	0.96	
QoL					Higher scores = better QoL 60 suggested as good quality of life
<i>Physical Functioning</i>	74.6 (20.9)	40–95	0–100	0.87	
<i>Role Limitations due to Physical Problems</i>	76.9 (33.0)	25–100	0–100	0.77	
<i>Role Limitations due to Emotional Problems</i>	92.3 (14.6)	66.7–100	0–100	0.71	
<i>Vitality</i>	68.8 (14.6)	40–100	0–100	0.53	
<i>Emotional Well-Being</i>	90.8 (8.1)	73–100	0–100	0.70	
<i>Social Functioning</i>	89.4 (19.0)	50–100	0–100	0.77	
<i>Pain</i>	74.4 (23.4)	35–100	0–100	0.91	
<i>General Health</i>	81.5 (14.5)	50–100	0–100	0.64	

* The *Range* represents the minimum and maximum values in the data for the sample.

** The *Possible Scores* are the full range of possible results based on the instrument scoring.

Table 3.

Selected qualitative quotes on Theme 1. Impact of Being a Caregiver

Physical Distress	Psychological Distress	Social Distress
Decrease in my physical activity level. (P5)	It's just I would say anxiety just because I'm seeing her go through what she's gone through and just hoping that she'll come out of it sooner than later... I think sometimes the thing that becomes overwhelming with it is just that, although there are things she does try to do, there are a lot of things that I have to do and I am just trying to keep up with it. (P9)	It has stopped me from doing a lot of interaction with other people and being with family and friends, that has caused the problem that I'm having as a caregiver, that has caused some, you know, some problems, but that's an angry kind of -- you know, it's just --I don't like it. Like I like to travel, both he and I love to travel. You know we wanted to, you know, to the city where his family comes from. And one of his cousins are going to go and we really wanted to go, but he doesn't... he can't do it right now. (P8)
Sleep deprivation is, yeah, it's a huge thing, obviously. We got machines going and he just is restless and so yeah, we don't. We don't sleep long stretches at a time. (P6)	At the very beginning.... a lot of anxiety.... I don't have the anxiety as much anymore, but it is still there, it's always a constant....So there is always a very underlying sense of anxiety that goes on. (P1)	I'm not as free to be able to go off with a girlfriend. I'm not as free. I can't pick my own time sometimes to like when I want to go down to the swimming pool or go shoot pool. (P4)
Decrease in my other activities, some physical, some mental, some artistic, whatever are struggling to come back into my life. (P2)	But just a little bit of anxiety on my part, just because trying to help her get through it, worrying about her, so there is some, it's not uncontrollable anxiety, it's just I would say anxiety just because I'm seeing her go through what she's gone through and just hoping that she'll come out of it sooner than later. (P9)	
	It's just always an extra stressor... Well, it's always a worry because you don't know, you know, how much to let him do for himself and not trying to get in the way of him doing what he can do. Just trying to figure that out, it's been. (P4)	
	I guess it's just kind of worrying about when it's all going to come together for, when she can finally take a breath and relax and know that she's got many years to come with the LVAD. (P10)	

P=Participant number

Table 4.

Selected qualitative quotes on Theme 2. Managing Caregiver Distress

Physical coping	Psycho-Social coping
<p>I enjoy walking around. I find walking around outside is more relaxing and enjoyable... I like just like walking. (P14)</p>	<p>My younger daughter would come up and her and I would take off for lunch. So I have a lot of support with my children. (P17)</p>
<p>Another thing that I like doing is when the weather is really nice, I like to get out in the backyard and work in the yard or in the front. And then my husband would tease me because I like to sweep up all of the leaves, this is when I use the blower. And I tell him, this is therapy for me. (P17)</p>	<p>... having children and grandchildren in the house all of who love and adore me and don't add stress to my life whatsoever. If anything, they're taking it off; things that could be stressful. (P11)</p>
<p>It's, yeah, you've got to have exercise. I mean it's helps mentally without a doubt. (P1)</p>	<p>I've really good friend up in (name of town), that when I need anything if I need a stress relief, I'll call them and I just burn their ear and then I'm fine. (P4)</p>
<p>I personally, I believe in healthy eating and I believe in good quality exercise no matter whether it's going on with my caregiving or it's just by life. That's just the way I live. (P4)</p>	<p>I just need to talk to somebody that understands what I'm saying, rather than thinking. (P4)</p>
	<p>I have one friend who comes over and we take a walk, and usually just sit out on the porch when it's nice. (P2)</p>
	<p>In my mind I'm thinking well, I study scriptures daily. I play the piano and the organ. I'm writing a family history book... I have all these wonderful things happening in my life so I can cope. I don't feel overwhelmed because I have a good support system and activities to keep me mentally healthy and sharp... The most important things have emerged so I have time to read, more time to study, more time to write and more time to practice the piano which I never do or haven't done since many years ago. (P11)</p>
	<p>We both, you know, we work together. (P6)</p>
	<p>I think my coping mechanism is to stop and reflect and realize we are where we are and then make the best of what the situation is... I think my religion helps. (P5)</p>

P=Participant number

Table 5.

Selected qualitative quotes on Theme 3. Embracing the Caregiver Role

Embracing the Caregiver Role
It's almost like we're, I mean it's – if you're doing the vitals in the morning, once the vitals are done, it's like we are back to the husband and wife not patient and caregiver. The only time I'm the caregiver is when I'm doing vitals and he worked with me, because he could do his own stuff, I don't have to do it. (P5)
That's part of being the wife. Not the caregiver, that's part of being the wife... It's kind of hard to separate what I do as a caregiver and what I do as a wife. (P12)
No, not really, because I don't find it as a burden taking care of my husband. (P17)
I think caregiving is very hard to do, yes, but it's very rewarding. (P3)

P=Participant number