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Exploring the Challenges that Family Caregivers Faced When Caring for Hospice Patients with Heart Failure

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Abstract

Although patients with heart disease comprise the second largest diagnostic group in hospice care, the challenges faced by family caregivers of hospice patients with heart failure are poorly understood and often go unaddressed. This study explored the challenges and needs of family caregivers of adults with advanced heart failure receiving hospice care in the home. The baseline quantitative and qualitative data from 28 family caregivers' participation in a large-scale hospice clinical trial of a problem-solving therapy intervention were analyzed. The quantitative data showed that family caregivers were mildly anxious and had worse financial and physical quality of life than their social and emotional quality of life. The qualitative data showed that caregiver challenges were related to patient care and symptom management, inadequate social support, communication issues, and financial concerns. The results provide insight to hospice social workers and researchers to develop practical tools that can be used in routine care to evaluate family caregivers' needs comprehensively.

Keywords

heart failure; hospice; end-of-life care; family; caregiver; caregiving

Introduction

The Prevalence of Heart Failure

Heart failure is a major health issue in the United States (US). More than 5.8 million Americans live with heart failure, and roughly 550,000 patients are newly diagnosed each

year. Half of all patients with heart failure die within 5 years of being diagnosed (Roger, 2013). More than 300, 000 Americans live with end-stage heart failure (Whellan et al., 2014) and they may suffer serious physical symptoms such as dyspnea, edema, pain, cough, fatigue, anorexia, and constipation. Psychosocial symptoms include depression, worry, sadness, and irritability (Wilson & McMillan, 2013).

The Challenges of Caregiving for Patients with Heart Failure

Patients with heart failure experience various chronic symptoms throughout the disease trajectory. Their family caregivers play an essential role in supporting the patients' long-term care and self-management. However, most family caregivers do not have formal clinical training, and often have concurrent responsibilities, which make caregiving very difficult. A recent systematic review synthesized 37 studies exploring problems that family caregivers face when they take care of patients with heart failure. There were four main categories of issues: performing multifaceted activities and roles that evolve around daily heart failure demands; maintaining caregiver's physical, emotional, social, spiritual, and financial well-being; having insufficient caregiver support; and performing caregiving with uncertainty and inadequate knowledge (Grant, & Graven, 2018).

Approximately 1.43 million Americans received hospice care in 2016; a 200 % increase compared to the number in 2002. Nearly 20 % of the hospice patients were diagnosed with a cardiac disease (including heart failure) which is now the second largest diagnostic group in hospice care (National Hospice and Palliative Care Organization [NHPKO], 2018). Many patients with heart failure in their final months of life elect to receive hospice services, forgoing disease-directed procedures and interventions that may be perceived as overly burdensome (Whellan et al., 2014). Hence, family caregivers not only manage patients' care at home, but also deal with patients' end-of-life care issues, financial and legal issues, and their own anticipatory grief.

Family Caregivers of Patients with Heart Family in Hospice Care

About 55.6 % of hospice patients receive care at their home (NHPKO, 2018). Compared to traditional clinical settings, home hospice care is unique in that family caregivers take care of patients at home independently supported by hospice nurse visits as needed, typically once or twice every week. Family caregivers of patients with advanced heart failure often feel stressed, anxious, frustrated, isolated and unprepared because they are not equipped with necessary knowledge and skills to manage patients' care effectively, do not have sufficient information and communication on options and plans of end-of-life care, and a lack of adequate social resources to support their caregiving roles (Kang, Li, & Nolan, 2011; McIlpatrick et al., 2017; Nicholas Dionne-Odom et al., 2017; Strömberg, & Luttik, 2015). Family caregivers want to learn knowledge and skills for taking care of patients with heart failure and have access to more social support and resources to relieve stress from providing caregiving (Wingham et al., 2015).

The goal of hospice care is to provide patients and their family caregivers holistic and comfort care. Social workers on hospice interdisciplinary care teams serve an important role in coordinating care needs, facilitate decision-making and effective discussion among

stakeholders in goals of end-of-life care, and navigate essential resources in healthcare systems and community for patients and their family caregivers. However, the current assessment tools in most hospice agencies for social workers to evaluate patients' and caregivers' care needs (emotional care, long-term care options, financial plan, and others) are not comprehensive and consistent (Cagle, Osteen, Sacco, & Jacobson Frey, 2017b). Few studies have explored the challenges or needs of family caregivers of patients with advanced heart failure in home hospice care (Aziz, Miller, & Curtis, 2012). Therefore, this study was designed to further understand these particular caregiving challenges in home hospice care with the goal of providing insight for social workers to develop strategies and tools to better assess and support the needs for family caregivers of patients with advanced heart failure in home hospice care.

Methods

To understand caregiving challenges faced by patients with advanced heart failure in home hospice care, a secondary analysis was conducted to analyze the quantitative and qualitative data obtained from a recently completed five-year clinical trial of a problem-solving therapy intervention for family caregivers of hospice care. The parent study was funded by the National Institute for Nursing Research (Grant Nr. R01NR012213, Principal Investigator: Demiris) and approved by the Principal Investigator's academic Institutional Review Board. In the parent study, family caregivers of patients with a variety of diagnoses (e.g., cancer, heart disease, dementia, stroke, respiratory disease, and others) were recruited from two hospice agencies in Pacific Northwest region of the US. The inclusion criteria were as follows: (1) adult family caregivers (older than 18 years old) of patients receiving outpatient hospice services; (2) ability to understand and speak English; and (3) telephone access at home. Potential participants were excluded if they had cognitive impairment. The national median length of service for hospice patients is 24 days (NHPCO, 2018); thus, the family caregivers were interviewed at day 5 post admission to hospice (baseline), day 11, and day 16. All interviews were audiotaped. Literature has shown that family caregivers in end-of-life care felt anxious and experienced poor physical and psychological well-being and quality of life (Schulz, & Sherwood, 2008; Spatuzzi et al., 2017). Hence, in the original study, family caregivers were measured the changes in their level of anxiety and quality of life before (baseline) and after the study.

Of the 514 family caregivers enrolled in the original trial, 28 were caregivers of patients with a primary hospice diagnosis of heart failure. Family caregivers were enrolled in the trial and their baseline data were obtained around the first week of hospice enrollment. In the present study, only baseline (pre-intervention) data were analyzed to avoid capturing any intervention effects.

Quantitative Measures

In the original trial, the family caregivers' anxiety, quality of life, and problem-solving skills were measured at baseline. Caregiving may impact the well-being and quality of life of the family caregivers of patients with heart failure (Kang, Li, & Nolan, 2011; McIlpatrick et al., 2017; Strömberg, & Luttkik, 2015). Hence, in this secondary analysis study, family

caregivers' anxiety and quality of life (emotional, social, financial, and physical quality of life) were analyzed to understand caregivers' psychological well-being.

Family caregivers' anxiety was measured using the Generalized Anxiety Disorder 7-Item Scale (GAD-7) (Spitzer, Kroenke, Williams, & Lowe, 2006). The scale has well-established internal consistency (Cronbach $\alpha = .92$) and test-retest reliability (intra-class correlation = 0.83). The GAD-7 includes seven items describing various symptoms of anxiety. Respondents are asked to report the frequency with which they have experienced these symptoms in the prior 2 weeks. The GAD-7 total score ranges from 0 to 21 points, and a higher score indicates a higher level of anxiety. A score higher than 15 indicates severe anxiety, a score higher than 10 indicates moderate anxiety (and a need for further evaluation), and a score higher than five indicates mild anxiety (Spitzer et al., 2006). Quality of life was measured using the Caregiver Quality of Life Index-Revised (CQLI-R) (Courtney, Demirir, Oliver, & Porock, 2005). The scale has been tested with hospice family caregivers and showed acceptable internal consistency (Cronbach $\alpha = .769$) and test-retest reliability ($r_s = 0.912$, $p < 0.001$). It includes four domains: emotional, social, financial, and physical quality of life. The score for each domain ranges from 0 to 10. A higher score indicates a better quality of life (Courtney et al., 2005).

Given our limited sample size, quantitative analyses were limited to descriptive statistics (e.g. mean, standard deviation [SD]) for all study measures.

Qualitative Data

During their baseline interviews, the trained interventionist (who was a registered nurse and a social worker with hospice care experience and trained for the problem-solving therapy for 25 hours) first explained the steps and processes of the problem-solving therapy and asked family caregivers to identify and describe one of their most pressing life events or caregiving challenges that they want to work with the interventionist using the problem-solving techniques. The average length of each interview is 28 minutes and 4 seconds. All interviews were audio-recorded and transcribed verbatim, and the accuracy of all transcripts was verified prior to data analysis.

Two authors (NC, GD) were involved in the analysis of the interview data, following Braun and Clarke's thematic analysis method (2006). Two authors first listened to all the audio recordings and read the transcripts to become familiar with the data. Then, drawing on the initial reading of the transcripts and a comprehensive review of the pertinent literature, a codebook that listed specific codes and corresponding definitions related to caregivers' needs and challenges was created by two authors. Next, the first author coded all the transcripts line-by-line in the Microsoft word document to identify caregiving needs and challenges. The codebook was expanded and refined along the coding process. The coded data were organized into a table. While reviewing the table together, the two authors examined and discussed each coded data segment to ensure compatibility and consistency. The themes and definitions were identified after several rounds of discussion among all authors to reflect family caregivers' needs and challenges in home hospice care. The first author reviewed the final analysis and selected compelling examples to report in this paper.

Some strategies were used to protect the trustworthiness. The verification of transcripts, prolonged engagement in hospice research, established audit trail, and peer debriefing were used to enhance the trustworthiness. The transcripts were verified by the first author (NC) who was involved in the original data for four years. The second author (GD) had more than 15 years of hospice research experience to guide the analysis procedures. Two authors discussed the data analysis constantly, and asked for peer debriefing during weekly research team meetings (Guba, 1981).

Results

Demographics of Family Caregivers

The interviews of 28 family caregivers of home hospice patients with a primary hospice diagnosis of heart failure were analyzed. The mean age of this sample was 59.65 years. The majority of the caregivers were female (78.57%), White (92.59%), the patient's adult child (60.71%), had a college or more advanced degree (92.86%), provided caregiving more than 20 hours per week (64.29%), and took care of their loved one for more than three years (53.57%). Table 1 summarizes the demographic characteristics of the family caregivers and Table 2 lists individual family caregiver's profiles.

Quantitative Results.

In terms of anxiety, the mean score on the GAD-7 was 7.57 (± 6.41), which meant that the family caregivers experienced, on average, mild anxiety. For the quality of life measure, the mean total score on the CQLI-R was 31.14 (SD = 5.37) on a scale of 0 to 40, with higher scores indicating higher overall quality of life. Subscale scores ranged from 0 to 10. On average, family caregivers reported the highest scores for social quality of life (mean = 8.64, SD = 1.7), followed by emotional quality of life (mean = 7.75, SD = 2.03), financial quality of life (mean = 7.71, SD = 2.97), and physical quality of life (mean = 7.57, SD = 1.6) (See Table 3).

Qualitative Results.

Four themes that described family caregivers' needs and challenges were identified: difficulty in supporting patient care and activities of daily living, inadequate social support, communication issues, and financial concerns.

Theme 1: Difficulty in Supporting Patient Care and Activities of Daily Living

This theme included data describing challenges family caregivers encountered when providing patient care, managing patients' symptoms and medications, or assisting patients with activities of daily living. Seven caregivers indicated that they had assumed significant responsibilities related to their family member's activities of daily living such preparing meals, doing laundry, assisting with bathing, and helping their family member get in and out of bed and chairs. Some also completed clinical tasks including medication management and overseeing symptom control. The majority of family caregivers in this study provided caregiving for more than three years, often from diagnosis to the end-of-life stage of the disease. One caregiver commented on the challenge of identifying her mother's changing needs as the illness progressed: "It was a very gradual realization that she needed more

help.... She wasn't showering as often as she had been because she couldn't." (A 66-year-old adult child)

Over time, the declining condition and functional status of heart failure patients can increase the difficulty of caregiving. Some of the patients took medications such as diuretics or pain medications, which affected their consciousness and mobility and increased the risks of falling. The family caregivers had to closely monitor the patients' daily activities to ensure their safety. Some family caregivers had to manage the administration of multiple medications. One caregiver said that he was in charge of the patient's medications and had to provide medication reminders four times a day. (A 60-year-old adult child)

Most of the family caregivers who were managing medications did not have any formal medical or nursing training. Some patients were prescribed morphine to ease symptoms such as pain or shortness of breath. One caregiver felt uncomfortable administering narcotic medications, explaining, "I'm not looking forward to giving [the patient] morphine and things like that to make [the patient] more comfortable and dope [him] up to where he's too incoherent to talk." (A 54-year-old family caregiver)

In this study, more than 50 % of the family caregivers provided more than 20 hours of caregiving weekly for more than three years. Heart failure is a chronic condition which requires a lot of support and caregiving from family caregivers. The family caregivers found it difficult to carry out a variety of medical and nursing tasks for patients, manage symptom and medications, and support patients' activities of daily living.

Theme 2: Inadequate Social Support

This theme dealt with caregivers needing additional social support (instrumental and emotional support) from their family and friends and the healthcare system. Nine family caregivers felt that they did not receive adequate social support. The majority of family caregivers in the study were patients' adult children (60.71%), so several caregivers had other concurrent responsibilities such as a full-time job, taking care of their own children, or being a caregiver for another family member. As a result, some caregivers had to make significant accommodations to their work schedule to provide care. Lack of support and limited time for personal life and respite were consistently mentioned as challenges. The caregivers were often distressed and exhausted dealing with all the tasks. One caregiver felt it was difficult balancing caregiving with her other responsibilities and finding time to manage her own quality of life: "[I have] so many other household things and family events that [I] need to focus on and be good at time management...My goals are to be able to still maintain my own household and have a quality of life." (A 65-year-old adult child)

Another caregiver stated that because of caregiving for her husband, she had very limited time for her sick adult daughter:

I have to not only find someone to give me a ride [to the hospital to be with my daughter], but I have to find someone to stay with [my husband] because he just cannot be left alone [at home]. My daughter's having more surgery on Monday.... I feel so bad because I haven't been there for any of her surgeries. (A 76-year-old wife)

Many family caregivers in home hospice care struggle with managing multiple obligations simultaneously and do not have adequate social support to help them balance their personal life, work, and caregiving tasks.

Theme 3: Communication Issues

This theme dealt broadly with communication issues regarding patients' end-of-life care. Five family caregivers mentioned that they did not have open and clear discussions and decision making regarding the patient's prognosis and wishes for end-of-life care. One participant stated, "Well, it was a tremendous stress, despite the fact that we both agreed that [hospice care] is something that we were doing. We really had no idea what we were signing on for." (A 61-year-old adult child)

Another caregiver had a different opinion from her sister-in-law regarding her mother-in-law' end-of-life care: [My sister-in-law] makes all the financial decisions and the medical decisions for [my mother-in-law]. My thought is keeping medicine from someone is elder abuse. (A 63-year-old adult child)

Family caregivers described challenges related to communicating with other family members, particularly when given different expectations and goals for end-of-life care. One caregiver reported that her mother chose not to express her end-of-life wishes to her son, despite having shared them with others: "[My mother said], 'I don't want anything done.' But she never told my brother because she kind of knew [he] was having a hard time with that." This caregiver and her sister were both healthcare providers but they had different opinions regarding caregiving: [My sister] thinks she knows more than me...She would like to kind of dictate what to do, although she's a thousand miles away and trying to be involved but really not knowing how to be involved. (A 53-year-old adult child)

In end-of-life care, family caregivers advocate for patients to communicate with care providers and other family caregivers. Unclear and ineffective communication may prevent patients and caregivers from fully expressing their thoughts and honoring patients' end-of-life wishes.

Theme 4: Financial Concerns

Seven caregivers expressed financial concerns due to reduced work hours, necessary earlier retirement, long-term medical costs, and copayments for multiple medications. In addition, due to long-term caregiving and patients' longevity, a couple of the caregivers believed that they needed a thorough financial plan for themselves. One family caregiver shared her plan: "I did make an appointment with the financial adviser. He seems to think what I'm doing right now, that I'd be good until I'm 83, but we need to talk about it because this longevity in the family." (A 62-year-old family caregiver)

Another family caregiver expressed a similar point: I'm 65 and on Medicare now, but I have chosen not to start taking Social Security benefits, hoping to wait until I'm older so that the benefits are greater We don't know how long I'm going to live; therefore, we don't know how to allocate my resources. (A 65-year-old adult child)

Besides providing long-term caregiving, family caregivers managed household finances. Due to long-term caregiving, reduced working hours, and a greater longevity, some family caregivers believed that they needed a long-term financial plan.

Discussion

Although patients with heart disease comprise the second largest diagnostic group in hospice care (NHPCO, 2018), many patients' and family caregivers' needs are inadequately addressed. In this study, family caregivers of patients with heart failure in home hospice care discussed several caregiving challenges. They provided extensive assistance with patients' activities of daily living, medical and nursing care, and end-of-life decision making. In doing so, they struggled with other concurrent responsibilities and often had limited social support, long-term financial concerns, and ineffective communication in end-of-life care decision with healthcare providers and other family members. These qualitative themes reflected that family caregivers often felt mild anxiety and had a lower score of financial quality of life in their quantitative measures. While mean scores on quantitative measures reflected only mild levels of distress, measures of central tendency should be interpreted with caution in studies with small sample sizes. The depth of caregivers' concerns reflected in the qualitative interviews suggests the need for additional quantitative research using larger samples. Such an approach would also permit identification of risk and protective factors among family caregivers of patients with heart failure, which would be highly useful to social workers and other members of the hospice team when deciding how to allocate existing resources to best meet the needs of patients and their families.

In this study, most of the family caregivers were older adults who provided more than 20 hours of caregiving weekly for more than three years. The quantitative results showed that family caregivers were mildly anxious. They had better scores in their social quality of life and emotional quality of life than their financial quality of life and physical quality of life. The results are similar to the report of the national caregiving surveys (NAC & AARP, 2015) that older family caregivers usually experience less emotional stress than younger family caregivers; they tend to manage household finances, communicate with care providers, and advocate for their care recipient. The participants in this study suffered poor financial and physical quality of life.

Literature has identified that family caregivers of patients with heart failure do not have adequate knowledge and skills to meet the demands of daily heart failure care and symptom management (Grant, & Graven, 2018). In this study, even the family caregivers have served as caregivers for years, they still do not have structured training on disease management to support their caregiving tasks. Family caregivers need to be provided information and education materials to support heart failure caregiving tasks throughout the course of the illness. Presently, the educational material about caregiving and disease management vary from each hospice agency. Although there are some symptom management training programs for family caregivers (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Keefe et al., 2005; McMillan et al., 2006), few are able to be integrated into the typical design of home hospice care so that providers can teach and support family caregivers. More practical and accessible educational material or technology-enhanced educational interventions need to be

designed for hospice care providers to teach family caregivers regarding disease management and caregiving tasks during routine home visits.

Previous studies reported that family caregivers have difficulty meeting the caregiving demands and maintain their own physical, emotional, social, spiritual, and financial well-being (Grant, & Graven, 2018; Kang, Li, & Nolan, 2011). The caregivers in the study had long-term financial concerns for themselves and disagreement over patients' end-of-life plan with other family members. A comprehensive and regular assessment of the patients and family caregivers' knowledge of disease, care preferences, well-being, functions, social and financial resources, and communication issues at hospice enrollment has been advocated in literature and by several hospice and professional organizations (Cagle et al., 2017a; NHPCO, 2018; NAC & AARP, 2015). However, hospice clinical practice still has not developed structured and comprehensive evaluation tools to assess and support the needs of family caregivers and patients in hospice care. Future research should explore and assess the extent of the impact that caregiving has on family caregivers' overall health and life and develop comprehensive evaluation tools for hospice practitioners to provide a high quality of end-of-life care. Payment reform may be a means to motivate hospice clinicians to assess and support family caregivers' needs and well-being (Schulz, & Czaja, 2018).

Implications for Hospice Social Work Practice

These study findings have important implications for hospice social work. Family caregivers in this study reported challenges related to pain and symptom management. Hospice social workers are often called upon to address these issues as members of the interdisciplinary team (Parker Oliver, Wittenberg-Lyles, Washington, & Sehwat, 2009). Hospice social workers should assess family caregivers' comfort with both the practical and the emotional aspects of administering medications for terminal symptom relief. This may open the door to a deeper conversation about the progression of heart failure, what to look for as the disease advances, and how to maintain self-care in the midst of intensifying caregiving responsibilities.

Accessing needed social support is a well-documented challenge for hospice family caregivers (Albright, Washington, Parker Oliver, Lewis, Kruse, & Demiris, 2016; Wittenberg-Lyles, Washington, Demiris, Parker Oliver, & Shaunfield, 2014). It may be particularly difficult for individuals who have been needing or requesting help for years, as is likely the case for family caregivers of patients with heart failure. Social workers should assess the adequacy of family caregivers' existing support. If needed, they can help family caregivers grow their social support network or activate existing sources of support. They can provide education about the availability of hospice-specific resources such as volunteers, respite care, and face-to-face or online support groups. They can help caregivers resolve conflicts and communicate openly and effectively to more readily access needed practical and emotional support.

It has been found that hospice social workers do not use standardized assessment tools to determine families' long-term financial wellbeing. (Parker Oliver, Wittenberg-Lyles, Washington, & Sehwat, 2009; Washington et al., 2016). While there are existing assessment instruments that address families' financial wellbeing (Cagle et al., 2017b), they

often focus solely on the adequacy of existing resources to maintain safe and appropriate patient care. Family caregivers in this study discussed financial concerns more longitudinally, which makes sense in light of the chronic nature of heart failure. While their current financial needs may have been satisfied, caregivers were thinking ahead to the future and contemplating the long-term consequences of changes in employment made necessary by caregiving demands. This underscores the need for financial assessment tools that could help hospice social workers evaluate the families' long-term financial well-being.

Study Limitations

The data analyzed in this study were drawn from pre-intervention interviews and measures of family caregivers participating in a large clinical trial. Hence, the analysis was limited by secondary data previously obtained. In addition, since family caregivers entered the original trial around the first week of hospice enrollment, if and how these findings changed over the course of hospice is unknown. Future studies could follow family caregivers across their hospice trajectory to better capture their needs and challenges over time. In addition, the small size of a sample from one geographical area does not represent the entire population of hospice family caregivers of patients with heart disease. Future research should include more representative demographics of patients, caregivers, and healthcare providers to better understand the heart failure caregiving issues in home hospice care.

Conclusions

This paper highlighted the challenges encountered by family caregivers of patients with heart failure in home hospice care. They struggled with other concurrent responsibilities and had limited social support, long-term financial concerns, and ineffective communication with healthcare providers and other family members to make end-of life care decisions. Most of the time family caregivers managed patients' care independently and received support from nurses and social workers during the short encounters of home visits. Hence, this study indicated to hospice practitioners and researchers a need to develop more structured and accessible educational materials to train family caregivers to be competent providers at home. Comprehensive assessment tools to aid social workers in assessing caregivers' well-being, their needs in social support and long-term financial planning need to be developed.

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Table 1.

Demographics of Family Caregivers (N = 28)

Characteristic	Caregivers
Age, mean (<i>SD</i>)	59.65 (9.89)
Female	22(78.57%)
White	25 (92.59%)
Relationship to patient	
● Adult Child	17 (60.71%)
● Spouse or Partner	3 (10.71%)
● Other	8 (28.57%)
Married/partnered	19 (67.86%)
College Degree	26 (92.86%)
Lives with Patient	13 (46.43%)
Employed (full or part-time)	11 (39.29%)
Caregiving > 20 hours/week	18(64.29%)
Duration of Caregiving	
● Less than 1 month	1 (3.57%)
● 2–5 months	3 (10.71%)
● 6 months – < 1 year	5 (17.86%)
● 1 year – < 3 years	4 (14.29%)
● > 3 years	15 (53.57%)

Notes. n, (%) unless otherwise noted.

Table 2.

Individual Family Caregiver's Profiles Findings

Participant ID	Age	Relationship with patient
P1	53	Adult child
P2	63	Adult child
P3	61	Adult child
P4	65	Adult child
P5	65	Adult child
P6	54	Other
P7	44	Other
P8	61	Adult child
P9	76	Spouse/partner
P10	66	Adult child
P11	65	Adult child
P12	35	Other
P13	79	Spouse/partner
P14	48	Other
P15	58	Adult child
P16	50	Other
P17	67	Adult child
P18	51	Adult child
P19	56	Adult child
P20	65	Adult child
P21	66	Other
P22	53	Adult child
P23	60	Adult child
P24	58	Other
P25	74	Adult child
P26	68	Adult child
P27	47	Spouse/partner
P28	62	Other

Table 3.

Family Caregivers' Baseline Scores on Anxiety (GAD-7) and Quality of Life (CQLI-R) (N = 28)

Measures	Mean Scores (SD)	Minimum Score	Maximum Score
Generalized Anxiety Disorder-7 items (GAD-7)	7.57 (6.41)	0	21
Caregiver Quality of Life Index-Revised (CQLI-R)			
● Social	8.64 (1.70)	2	10
● Emotional	7.75 (2.03)	3	10
● Financial	7.71 (2.97)	0	10
● Physical	7.57 (1.60)	5	10
● Total	31.14 (5.37)	16	40