



Published in final edited form as:

J Cardiovasc Nurs. 2016 ; 31(3): 209–214. doi:10.1097/JCN.0000000000000241.

Competence, Compassion, and Care of the Self: Family Caregiving Needs and Concerns in Heart Failure

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Abstract

Background—Family caregivers are essential to the well-being of patients with chronic heart failure (HF) because they provide care in managing complex medication regimens, dietary sodium restrictions, and symptoms.

Objective—The purpose of this *qualitative* study was to gain a deeper understanding of the HF caregiving experience and describe the needs and concerns expressed by caregivers.

Methods—Qualitative *descriptive methodology* was conducted using data from responses to open-ended questions asked as part of a larger longitudinal study. The sample was 63 *patients with HF* and 63 family caregivers.

Results—Utilizing *basic content analysis*, the three main themes of *needs and concerns that emerged* were competence concerns, compassion maintenance, and care of the self. Sub-themes of competence concerns were doing things right, making a serious mistake, and uncertainty.

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Conflicts of Interest: Barbara Jean Sullivan, Linda Marcuccilli, Rebecca Sloan, Irmina Gradus-Pizlo, Tamilyn Bakas, Miyeon Jung, Susan J. Pressler – no personal or financial conflicts.

Conclusions—Family caregivers of HF patients had many needs and concerns about their competence in performing tasks, their compassion, and caring for themselves. Data can be used to design testable interventions to improve the HF caregiving experience for patients and caregivers.

Keywords

Caregivers; Heart failure; Adaptation; psychological

Introduction

Heart failure (HF) is a prevalent chronic syndrome that remains a leading cause of hospitalization and death among older adults.¹ Family caregivers are essential to the well-being of patients with chronic HF because they provide care and assistance in managing complex medication regimens, dietary sodium restrictions, and symptoms of dyspnea, fatigue, cognitive deficits, and depression.²⁻⁴

Family caregivers of HF patients experience depression,^{4,5} caregiver burden,⁶⁻¹¹ anxiety,¹¹⁻¹³ and poor quality of life as a result of providing care.^{5,7,8, 12,14-17} In past studies, HF family caregivers reported poor physical and emotional quality of life.^{6-11,13} In a landmark study by Schulz and colleagues,¹⁸ family caregivers of older adults with cardiovascular conditions who had increased caregiver strain had an increased risk of death compared with caregivers with no strain and non-caregiving individuals.

In past studies family caregivers of HF patients have reported limited understanding about patients' prognosis and medical treatments, inadequate support from health care providers, and insufficient resources to provide care.^{7,15,19} Caregivers have reported being concerned about providing physical care and emotional support to patients^{8,11,13,17} and the time spent performing caregiving tasks.^{7-9,11,17,20} Family caregivers spent a moderate to great deal of time completing instrumental care tasks such as managing finances, providing transportation, and managing the household.^{7,9,11,13} Changes in caregivers' lifestyle were reported, including sleep disturbances^{13,21} and less time for social activities.^{7,8,13,17} Family caregivers described the emotional cost of caring for a patient with HF as having lower perceived control,^{7,8} reduced ability to cope with stress,¹⁷ poorer mental health perceptions, a deteriorating future outlook, and decreased energy level.⁸ These negative caregiving outcomes persisted over time which is not surprising given the unpredictable trajectory of HF.

The purpose of the current study was to gain a deeper understanding of the HF caregiving experience and describe the needs and concerns expressed by caregivers. The data obtained provide essential knowledge that can be used to develop testable interventions for future studies to reduce negative outcomes and promote positive outcomes among family caregivers of patients with HF.

Methods

Design

This study was part of a longitudinal investigation designed to evaluate family caregiving in HF over eight months.¹⁷ Results of the quantitative component have been reported elsewhere. *Qualitative descriptive methodology was used in this study to better understand the needs and concerns expressed by family caregivers of patients with HF.* Institutional review board approval was obtained before initiation of the study, and written informed consent was provided *by patients and family caregivers.*

Participants

Patients were approached during a regularly scheduled clinic visit by a member of the research team. The team member asked patients if they would be willing to participate and if they had a family caregiver who could be invited to participate in the study. Eligibility criteria for HF patients were that they had a diagnosis of chronic HF and had a family caregiver. Eligibility criteria for caregivers were that they were: 1) a family caregiver (i.e., spouse, partner, adult child, or friend) of a person with chronic HF; 2) able to speak, read, and write English; 3) 21 years of age; and 4) able to hear at conversational tone. The final sample consisted of 63 patients with HF and their 63 family caregivers.

Data Collection

Data were collected from December 2005 through June 2007. *Data were collected from HF patients' medical records to describe their demographic and clinical characteristics.* Family caregivers were interviewed over the telephone or in-person according to their preference by research assistants who were graduate nursing students *who were trained by one of the investigators with expertise in qualitative research (RS).* After completion of structured questionnaires, *four open-ended questions were asked of caregivers in order to identify needs and concerns of caregivers that were not addressed by the structured questionnaires.* The open-ended questions were: 1) What are your three main needs and concerns related to being a caregiver; 2) What types of things do you do to prevent the patient from doing too much or getting into difficulty; 3) What are the things that you do that the patient is not aware of; and 4) What are the things that I did not ask you but should have. Responses were recorded in written format during the interviews. *Interviews lasted approximately 30 to 60 minutes. Caregivers were given the option to continue the interview during another call if fatigued. Data saturation was not assessed since the questions were asked of all caregivers in the parent study.*

Data Analysis

Qualitative content analysis was completed with a five step approach.^{22,23} First, data were read as a whole. Second, one member of the team (BJS) listed, reviewed, and categorized caregivers' responses according to similar content themes. Third, words and phrases were compared across caregivers' interviews and clustered topics were coded according to themes that emerged from the data. As the number of themes increased, team members discussed whether a response fit in an existing theme or whether the response was sufficiently distinct

to establish a new theme. Fourth, to ensure credibility a second member of the team (SJP) reviewed the data and verified categories and themes. Finally, through peer debriefing, all authors verified themes prior to finalization of main themes. *The team consisted of three nurse researchers with qualitative research expertise, a nurse researcher with expertise in caregiver research, a nurse researcher with expertise in cardiovascular research, a PhD nursing student, and a cardiologist with expertise in HF.*

Results

The sample consisted of 63 patients with chronic HF and their 63 family caregivers. The HF patients included 29 women and 34 men. Mean age was 69 years. The majority of patients were White (81%). Mean left ventricular ejection fraction was 43% and New York Heart Association class was: I - 4 (6%); II - 15 (24%); III - 33 (53%); IV - 10 (16%); and one missing.

Caregivers included 48 women and 15 men. Mean age of caregivers was 59.7 years. Most caregivers were spouses (68%) and reported race as White (84%). Fifty-two of the caregivers were living with the patients, and the mean duration of caregiving for the patients was 9.3 years.

Caregivers' three main needs and concerns clustered into three themes: 1) competence concerns about performance of caregiving tasks; 2) compassion maintenance, and 3) care of the self. Almost one-fourth (24%) of the responses were about competence concerns, 22% about compassion maintenance, and 13% about care of the self.

Competence concerns were the family caregivers' concerns about their own ability to perform caregiving tasks at home to the person with HF. Family caregivers wanted to be positively reassured by health care professionals that they were safely performing tasks of caregiving. Three sub-themes emerged within the competence concerns theme: 1) doing things right; 2) making a serious mistake; and 3) uncertainty about ability to be a family caregiver. For the sub-theme of doing things right, caregivers wondered if they were giving the right care such as recognizing and interpreting symptoms accurately and cooking properly. For example, one participant wondered when she could "push" the patient [to exercise] and when she could just say, "its ok, let's take a break." Caregivers wanted to do tasks well, but more importantly, wanted feedback about whether they were doing tasks correctly. For the sub-theme of making a serious mistake, caregivers were concerned that they could cause a serious mistake when performing caregiving tasks that would harm the patient. For example, they said "I'm afraid I'll give the wrong medications." Some said they needed a medical background in saying "I'm reading, researching, learning as much as I can...can't tell if a change is significant or if it's just nothing." For the sub-theme of uncertainty about being able to be a caregiver, they reported being uncertain in their ability. For example, caregivers said "I doubt myself a lot... I'm not sure I can do it."

Caregivers *described activities that* they did to prevent patients from doing too much. *Examples of these activities were* performing vigilance behaviors, regulating patient activities, and providing emotional support. Vigilance behaviors were mostly related to

activity and dietary restrictions. Family caregivers described “watching over” patients, “assuring she takes naps and vitamins, and following the patient,” “making sure she’s not doing too much,” “watching salt intake,” and “reading food labels.”

In regulating patients' activities, caregivers used words such as “limiting,” “preventing,” “refusing,” and “anticipatory helping.” Caregivers' limiting behaviors included limiting physical activity, encouraging rest, and making sure blood sugar is managed. Caregivers' prevention activities included preventing the patient from mowing the lawn, shoveling snow, vacuuming, or active painting. Caregivers' refusal behaviors included refusing to enable unhealthy behaviors such as not buying cigarettes or salty foods for the patient. Anticipatory helping behaviors by caregivers included paying bills, doing household chores or yard work, grooming a pet, doing errands, and driving to doctors' appointments before the patient did it him/herself.

Compassion maintenance was caregivers' compassion and desire to care with kindness as they struggled with the demands and strain of caregiving. This notion is best described in the statement, “I started this role with compassion and now I'm trying to maintain it.” Patience was the most frequent need in this theme. Phrases used by family caregivers such as “I need patience,” “patience in abundance,” “I need a softer tongue,” and “I make frequent short visits to limit contact and decrease frustration” articulated the need for patience.

Caregivers provided emotional support that prevented the patient from “getting into difficulty.” Caregivers described strategies such as “being there,” “trying to cheer her up,” “talking to her,” having a peaceful outlook, going to church, and finding a balance between “nagging and encouraging.” One caregiver succinctly described the emotional support as follows: “I do whatever I can to keep her spirits up, keep her mind engaged and keep her involved with church and friends to help her feel she has a purpose.”

The third theme, care of the self, captured caregivers' attempts to care for themselves. Multiple responsibilities included employment, childcare, and household chores. Caregivers described needs for personal care, time, energy, “escape,” “my own life,” fitness, self care, church, and shopping. Some caregivers were stressed by a multitude of responsibilities that made it difficult to balance in a single day, as poignantly described by this adult child caregiver:

“To be a good caregiver I consider empathy, addressing practical things like power of attorney and a will, counseling. You need a place for being selfish to keep myself healthy. It's difficult, especially emotionally. The strain is surprising.”

Discussion

The findings of this study are important because the common needs and concerns described by caregivers can be used to design testable interventions to improve caregivers' health and well-being. Delivering competent care, maintaining compassion despite the frustrations and challenges of caregiving, and taking care of one's self were primary concerns. Caregivers' expressed high levels of vigilance behaviors to perform tasks correctly and protect patients from doing too many activities or becoming more debilitated. Maintaining high levels of

vigilance over time could lead to fatigue and activate biological processes (e.g., hypothalamic-pituitary-adrenal axis) associated with poor physical health.²⁴ Past studies of HF caregiving have addressed physical and emotional burdens, but fewer studies have reported as many concerns about delivering competent care and performing caregiving tasks correctly. Given the increased pharmacological and technological advances that have occurred in HF in the past two decades, it is not surprising that caregivers are in need of more medical and nursing knowledge and skills to perform caregiving tasks. Future intervention studies are needed to teach the requisite knowledge and skills to perform caregiving tasks and evaluate their effect on caregivers' and patients' health outcomes.

These family caregivers wanted to be reassured by health care professionals that they were performing caregiving tasks correctly for their loved ones. These findings are consistent with findings from other studies of family caregivers of HF patients who perceived that resources for advice, information and emotional support were not adequately available to them.^{8,13} However, findings from the current study are unique in that family caregivers wanted a conversation with a knowledgeable “other” about whether they were performing tasks correctly, if they were making the appropriate decisions, and to validate their thinking about judgment calls such as *when to call an ambulance*. Answers to these questions and help with clinical decision-making processes could potentially reduce caregiver vulnerability, anxiety, as well as unnecessary emergency department visits. Since caregiver competence was noted as the most frequent need and concern of family caregivers in this study, this emerging concept has future research implications. Other than a small pilot study using a telephone coaching intervention with ten HF caregivers,²⁵ psychosocial and educational interventions for HF family caregivers are sparse.¹¹ A nurse-led telephone intervention may answer caregivers' specific questions related to HF caregiving tasks, provide an opportunity for exchange of knowledge and ideas, help ease stress, and build caregiver confidence.

Compassion maintenance, the second most frequent concern of family caregivers, represents a novel finding. Family caregivers repeatedly cited a need for patience, as well as compassionate ways to cope with frustration. Personal qualities such as compassion, thoughtfulness, and understanding were considered essential requirements for the caregiving role. The findings indicate that family caregivers in this study needed a considerable amount of patience in order to maintain the necessary compassion to deal with the numerous frustrations associated with caregiving. Family caregivers in this study may have accepted caregiving roles with the intention of providing care without full knowledge of the amount of information and experience necessary to address the complex medical, decisional, and interpersonal challenges ahead. If family caregivers are struggling with maintaining compassion, they may be at risk for the development of negative caregiver outcomes, such as negative physical and emotional outcomes, depression, decreased quality of life, and caregiver burden as reported in the literature.⁶⁻¹¹ It is unknown how the decision to become a caregiver was made among these caregivers. In this study, caregivers described how surprised they were about how much patience was required to care for a loved one with HF. Since family caregivers may have little to no support in their new caregiving roles,²⁶ research regarding decisional processes in becoming a caregiver might facilitate education and screening of potential family caregivers so that they are aware of the numerous tasks,

responsibilities, even emotional challenges and personal and social sacrifices associated with caregiving.

In the final needs and concerns theme of caring for the caregiver, caregivers' experiences mirrored those of past studies, including increased strain and burden and less time for socialization and their own health care.⁶⁻¹¹ Caregivers in this study stressed the importance of taking time out for one's self without bearing guilt for it. Although aware of the burden, they were willing to offer advice and be helpful to others for how to ease the burden. An interesting dynamic related to family caregivers care of self centered around their ability to verbalize the numerous stresses and strains while at the same time generously offering advice to future family caregivers about how they should take care of themselves. Future intervention studies should include teaching family caregivers specific strategies to better care for themselves. For example, interventions could include working with caregivers to design a manageable caregiving schedule that incorporates assistance from other family members and assistance from paid individuals to perform specific tasks (e.g., housekeeping, laundry) without feeling depleted by multiple responsibilities.

Family caregivers provided rich descriptions about the dynamics between interpersonal relationships with the patients as they transitioned from their previous roles such as husband and wife into new roles of patient and caregiver. A variety of emotions were expressed as interpersonal dynamics changed as patients progressed through the HF trajectory, including anger, frustration, even feeling overwhelmed by the challenges imposed by their new caregiving roles. Family caregivers expressed a loss of a familiar way of relating to one another as roles changed, even reversed. They described a change from their usual way of relating to one in which their functional role in relation to each other had become quite different than that to which they were accustomed. This study provided a window into the importance of the relationship complexities and dynamics between the caregiver and the patient.

Teo and colleagues²⁷ explored social relationships among 4,642 participants and reported that the quality of interpersonal relationships with spouses, family, and/or friends predicted a future major depressive disorder without regard to the number of social interactions. Findings suggested that by assisting couples to improve the quality of peer interpersonal relationships they may be able to deter a major depressive disorder. Chung and colleagues⁵ found that HF patients' poorer quality of life was associated with their own depressive symptoms and anxiety and with their family caregivers' depressive symptoms and anxiety. As suggested by previous studies,^{5,27} practitioners should consider engaging in therapeutic dialogue with patients about the quality of their interpersonal relationship with each other, not merely asking if they have a significant other. Interventions that incorporate dyadic therapy or coaching may be crucial to prepare both patients and family caregivers for their changing roles as HF progresses. Perhaps patients and their family caregivers could be better prepared for their roles if they received assistance throughout the HF trajectory. Future longitudinal studies exploring the quality of interpersonal dynamics in family caregiver and patient relationships across the HF trajectory may help to identify those at risk for depression as they transition into their new roles.²⁸

Family caregivers wanted their voices to be heard. The obvious giving nature of this group of family caregivers flourished with numerous suggestions about caregiving approaches when given the opportunity to tell us what we should have asked them. Incorporating the advice, knowledge, and experience of HF family caregivers into the design of testable interventions may better inform efficacious psychosocial and educational programs to improve quality of life for this growing population. Since evidence supports individualized interventions to meet the variety and often complex needs and concerns of family caregivers,^{29,30} involvement of experienced HF family caregivers in the design and development of tailored interventions may result in more effective ways of addressing family caregivers with their needs and concerns.

This study had limitations. First, some of the most stressed caregivers did not complete the study which may have resulted in important needs and concerns being missed. Second, the qualitative descriptive data were not analyzed in combination with the quantitative data as a mixed methods study because the intent was to identify needs and concerns not addressed by the structured questionnaires. Moreover, changes in needs and concerns were not analyzed over the three data collection time points because of the exploratory hypothesis-generating nature of the study. In future studies, investigators need to pre-specify mixed methods analysis and evaluation of trajectories of change over time to thoroughly understand the caregiving experience and design testable interventions. Third, the data were collected in 2005 to 2007 and may not be as informative about caregiving of HF patients today. However, the science of caregiving of persons with complex chronic conditions such as HF remains a national priority. In 2014, the National Nursing Research Roundtable met to discuss priorities for advancing the science of caregiving and will be forthcoming with specific recommendations.³¹ Importantly, unnecessary hospital readmissions of HF patients now result in penalties to hospitals. Data from this study can be integrated into programs that promote caregivers' well-being and thereby enable them to continue to provide safe, quality care to their loved one with HF. Data can be integrated into future studies of testable interventions.

Conclusion

This study adds to the body of knowledge about the needs and concerns of family caregivers of HF patients and supports the urgent need for intervention studies among them. Preparing both patients and family caregivers early and throughout the HF trajectory has potential to ease the role transition for both patients and family caregivers. Incorporating advice from HF family caregivers will assist in the development of efficacious interventions aimed at reducing overall caregiver burden by enhancing interpersonal relationships early in the HF trajectory. Caregivers may need referral to other health care professionals for emotional support. Clinicians can further assist caregivers to obtain resources needed to perform caregiving tasks for the persons with HF while maintaining the health of the family caregiver.

Acknowledgments

This research was supported by Research Investment Funds, Indiana University School of Nursing; the Barron Quality of Life Research Award, Center for Enhancing Quality of life in Chronic Illness, at Indiana University

School of Nursing; and in part by National Institute of Nursing Research grants R01 NR08147, R01 NR009280, and 2T32 NR007066.

Source of Funding: Supported by Research Investment Funds, Indiana University School of Nursing, and the Barron Quality of Life Research Award, Center for Enhancing Quality of Life in Chronic Illness, at Indiana University School of Nursing and in part by National Institute of Nursing Research R01 NR08147, R01 NR009280, and 2T32NR007066

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