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## Caregiving in heart failure: Relationship quality is associated with caregiver benefit finding and caregiver burden

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### Abstract

**Objective**—To determine whether relationship quality is associated with caregiver benefit or burden and how depression influences these associations.

**Background**—Caregivers influence outcomes of patients with heart failure (HF). Relationship quality, caregiver benefit and burden are key factors in the caregiving experience.

**Methods**—Nineteen caregivers of HF outpatients completed measures of relationship quality, caregiver benefit, burden and depression. Associations were assessed using Pearson's correlations.

**Results**—Relationship quality was positively associated with caregiver benefit ( $r = 0.45$ ,  $P = 0.05$ ) and negatively associated with burden ( $r = -0.80$ ,  $P < 0.0001$ ) and depression ( $r = -0.77$ ,  $P = 0.0001$ ). Relationship quality and burden remained associated after controlling for depression.

**Conclusions**—In this exploratory study, relationship quality was positively associated with caregiver benefit and negatively associated with burden. Future studies are needed to further understand these key caregiving factors, which may lead to opportunities to help caregivers see benefits and reduce burden.

### Keywords

Heart failure; Caregivers; Relationship quality; Mutuality; Burden

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## Introduction

Chronic heart failure (HF) is an increasingly common chronic illness with unique caregiving needs related to disease-specific physical and psychosocial effects, significant functional limitations, a variable disease trajectory and complex advanced cardiac therapies.<sup>1,2</sup> Social support has been increasingly identified as an important contributor to positive and negative outcomes for patients with HF.<sup>3-5</sup> Informal caregivers play a unique HF-specific role that includes assisting with symptom control, self-care, care transitions and decision making. At home, caregivers also engage in a range of emotional, cognitive, physical function and advocacy roles.<sup>6</sup> Lack of available support from spousal caregivers has been associated with increased risk of death and hospital readmission for patients with HF.<sup>7</sup> The impact of caregiving on caregiver outcomes can also be substantial, including an increased risk of mortality for elderly spousal caregivers who experienced significant caregiver burden.<sup>8</sup> Among HF caregivers, caregiving has been associated with increased caregiver burden, depression and reduced quality of life.<sup>3,9</sup>

Because caregivers play a central role in health outcomes of patients with HF, and caregiving affects caregiver health, there is a need to improve the understanding of key factors that influence the caregiver experience in HF. Caregivers of patients with HF who are homebound and receiving home health nursing have identified multiple aspects of the caregiving experience including an emphasis on family support and obstacles in caregiving that might benefit from targeted support from nurses.<sup>10</sup> As family caregiving research in HF advances, we and others have begun to examine patients with HF and their informal caregiver as a unit in a relationship, or a dyad, and to identify factors present in those relationships such as relationship quality.<sup>3,11</sup> Trivedi et al have proposed that caregivers and patients affect each other reciprocally and that the interplay between this dyad will influence disease management.<sup>3</sup> They hypothesize that relationship quality may be an important mediating or moderating factor on outcomes of the dyadic relationship such as caregiver burden. Currently, most nursing HF interventions focus primarily on patients to improve outpatient self-care. Sebern emphasized that future nursing interventions should recognize the importance of family care relationships and involve both members of the dyad to achieve optimal outcomes.<sup>12</sup> An improved understanding of relationship quality in HF, as a key aspect of complex dyadic relationships, is needed to guide novel supportive care programs facilitated by HF nurses and other members of the health care team.

In family caregiving literature, relationship quality and mutuality represent the same concept and are frequently used inter-changeably.<sup>13</sup> Mutuality can be defined as ‘the positive quality of the relationship between caregiver and care receiver’ and consists of the following four dimensions: love and affection, shared pleasurable activities, shared values and reciprocity.<sup>14</sup> In the present investigation, mutuality is used synonymously with relationship quality. To our knowledge, relationship quality, defined as mutuality, has not been assessed in caregivers of patients with HF.<sup>14-16</sup> While a recent systematic review reported that relationship quality was often strongly associated with indicators of mental health and emotional well-being like depression, none of these studies included patients with HF.<sup>13</sup> Conceptually, relationship quality has been proposed to be a key factor in caregiver burden from care-giving, and caregiver depressive symptoms may significantly confound this relationship.<sup>3,17</sup> Caregiver

burden in HF includes physical, emotional or psychological, social and lifestyle burdens of providing care and support.<sup>18</sup> In HF, caregiver burden is common and related to higher levels of depression in both HF patients and their caregivers.<sup>19–21</sup> Another key factor in the caregiving experience is caregiver perception of benefit finding. Caregiver benefit is the experience of positive aspects of the caregiver role, in spite of caregiving challenges.<sup>22,23</sup> Domains of caregiver benefit include acceptance, empathy, appreciation, family, positive self-view, and reprioritization. Among qualitative studies of HF caregivers, experiences of caregiver benefit have been associated with increased life satisfaction.<sup>24</sup> While the presence and relevance of caregiver benefit has been shown in the cancer caregiving experience,<sup>23</sup> caregiver benefit in HF has not been explicitly quantified, nor has it been examined for its potential association with other key factors of the HF caregiving experience such as relationship quality or caregiver burden.

Given the importance of caregiving in HF and the role nurses play in identifying the dynamic characteristics of supportive relationships on the care of patients with HF,<sup>25</sup> there is a need to examine relationship quality, caregiver benefit and caregiver burden as potential key factors that may mediate patient and caregiver health outcomes. Moreover, given the potential confounding associations of caregiver depression with relationship quality, perceived caregiver burden, and benefit finding,<sup>3,17</sup> we included depressive symptoms as a potential confounder in this study. Thus, the specific objectives of this hypothesis-generating study are to 1) measure relationship quality and caregiver benefit in caregivers of patients with HF, 2) determine whether relationship quality is associated with caregiver benefit or caregiver burden, and 3) determine how depressive symptoms influence these associations. The findings of this exploratory study may emphasize the relevance of these potential key caregiver factors for nurses who support the patient–caregiver relationship in HF.

## Methods

### Participants and study design

In this hypothesis-generating, cross-sectional analysis of potential associations among key factors in the caregiving experience, data from nineteen caregivers of patients with HF were drawn from a study that was designed to examine major concerns and unmet care needs with the intent of developing a program to support patients with HF and their family caregivers.<sup>2</sup> Purposive sampling was used to identify patients with symptomatic HF and their caregivers from a single academic medical center, as previously described.<sup>11</sup> Eligible patients had an HF diagnosis from their doctor and NYHA functional class II–IV. Patients were asked to identify a caregiver when asked, “Can you think of the one person besides a health care provider who helps you the most with your heart condition?” This method is modeled after the “Shared Care” construct and nursing intervention where a caregiver is defined as whomever the patient identifies as providing them with assistance and support, such as a relative or a friend.<sup>12</sup> Of 33 patients involved in the study, 20 patients provided names of their caregivers for the research team to contact. Thirteen patients did not have a caregiver, opted not to provide caregiver information or had a caregiver who (according to the patient) was unavailable for interview because of illness, scheduling difficulties, or other family circumstances. All caregivers gave informed consent and participated. Caregivers completed

quantitative surveys and provided demographic information specific to their caregiving relationship. Surveys were completed apart from the patient, either at home or in the clinic. The study was approved by the Colorado Multiple Institutional Review Board.

### Study measures

As introduced earlier, in the nursing caregiver literature, relationship quality and mutuality represent the same concept and are frequently used interchangeably.<sup>13</sup> Relationship quality was assessed in caregivers using the Mutuality Scale of the Family Caregiving Inventory, with higher scores indicating better quality of the dyadic relationship.<sup>14</sup> There are 15 items measured with a 5-point Likert-type scale (0 = not at all; 4 = a great deal) and examples include, “*How close do you feel to him or her?*” and “*How much do you confide in him or her?*” The Mutuality Scale is scored by calculating the mean across all items. Previous investigations have shown that the internal consistency reliability of this measure is very high ( $\alpha = 0.91$ ) and the items on the scale demonstrate strong face validity.<sup>14</sup> Furthermore, the scale has been used in a variety of different populations and settings and has demonstrated criterion validity with a variety of caregiving-related outcomes.<sup>13</sup> Caregiver burden was measured using the 21-item Zarit Burden Inventory.<sup>26</sup> Questions are rated on a 5-point Likert-type scale (0 = strongly disagree; 4 = strongly agree) and examples include “*I feel angry when I am around [the patient]*” and “*I feel that I have lost control of my life since [the patient]’s illness.*” Scores are summed and higher scores represent greater burden. The Zarit Burden Inventory has demonstrated excellent internal consistency ( $\alpha$  ranges from 0.83 to 0.87).<sup>27,28</sup> Caregiver benefit was measured using the Benefit Finding Scale, a 17-item questionnaire that uses a 5-point Likert-type scale (0 = not at all; 4 = extremely) to assess the degree to which caregivers experience personal growth and positive aspects of life through caregiving.<sup>23</sup> Caregivers were prompted with “Individuals sometimes feel that going through a difficult situation can make a contribution to their lives, as well as causing problems,” and asked items including, “*Being a caregiver has brought my family closer together*” and “*led me to deal better with stress and problems.*” The Benefit Finding Scale is scored by calculating the mean across all items with higher scores indicating greater caregiver benefit finding. Evidence indicates that the Benefit Finding scale demonstrates very high internal consistency reliability ( $\alpha = 0.95$ ), and evidence for criterion validity suggests that benefit finding is positively related to life satisfaction after controlling for several confounders.<sup>22</sup> Caregivers also completed the Patient Health Questionnaire-9 (PHQ-9), a 9-item screen for depressive symptoms.<sup>29</sup> Participants rated how often they were bothered by each depressive symptom over the past 2 weeks on a scale from 0 (*not at all*) to 3 (*nearly every day*). Items were summed for a total score. Evidence for validity for this scale indicates that higher scores on the PHQ-9 are related to greater likelihood of being diagnosed with any depressive disorder,<sup>30</sup> and a clinical cut-point of 10 or greater has been shown to have 88% sensitivity for major depressive disorder and 88% specificity. The data for each measure were normally distributed. All four scales had very high internal consistency in the present study (Mutuality Scale  $\alpha = 0.94$ ; Zarit Burden Inventory  $\alpha = 0.90$ ; Benefit Finding Scale  $\alpha = 0.94$ ; PHQ-9  $\alpha = 0.91$ ).

## Statistical analysis

The associations between relationship quality and caregiver benefit, caregiver burden, and depressive symptoms were calculated with Pearson's correlations and 95% confidence intervals. Partial correlations were used to examine the associations between relationship quality, caregiver benefit and caregiver burden controlling for depressive symptoms as a potential confounder. Because the sample size is small, we conducted a post-hoc power analysis to determine what correlation we would be able to detect in this study population. This informed which of our findings might be due to a small sample size. The study was powered to detect a correlation of 0.456 or greater with  $\alpha = 0.05$  given the sample size. All tests were two-tailed with significance determined by a  $P$ -value  $\leq 0.05$ . Analyses were performed using SAS 9.3 software.

## Results

Characteristics of patients and their self-identified caregivers are shown in Table 1. Patients were a mean age of 69 years old, predominantly male (63%) and white (63%). The study included patients who had New York Heart Association (NYHA) Class II–IV HF, of whom nearly one-half (47%) had moderate to severe functional limitations based on the presence of NYHA Class III or IV HF. Caregivers were a mean age of 59 years old, predominantly women (95%), and 79% had at least some college education. Within the caregiver sample, common characteristics included working full time, being a wife (42%) or daughter (32%) of the patient, and spending more than 8 h a week in caregiving-related activities (Table 1). The degree of relationship quality among this cohort of caregivers was rated on average between “quite a bit” and “a great deal” (3.07 out of 4). Average caregiver benefit was rated between “moderate” and “quite a bit” (2.64 out of 4). Average caregiver burden (cumulative score of 23.7) was considered in the “high” range, based on a definition of greater than 21 as high burden.<sup>26</sup> On the depression screen, three of 19 (16%) caregivers screened positive for at least “mild depression” with scores greater than or equal to 10 out of 27.

The associations between relationship quality and the key caregiver characteristics of caregiver burden, caregiver benefit, and caregiver depressive symptoms are shown in Table 2. Caregivers who reported higher relationship quality reported less caregiver burden and more caregiver benefit. Caregiver depressive symptoms were negatively correlated with relationship quality. After adjusting for depressive symptoms, the association between relationship quality and caregiver burden was reduced, although it remained significant ( $r = -0.54$ , 95% CI:  $[-0.81, -0.10]$ ,  $P = 0.02$ ).

## Discussion

To our knowledge, this is the first study to examine the association between relationship quality, caregiver burden and caregiver benefit in caregivers of patients with HF. Caregivers who perceived higher relationship quality with patients noted less caregiver burden, even after controlling for depressive symptoms. In this diverse group of caregivers of patients who had a range of HF-related functional status by NYHA classes, caregivers also reported experiencing benefit. Furthermore, the experience of care-giver benefit was positively associated with relationship quality.

While strong associations between relationship quality, care-giver burden and caregiver depression have been found in cancer and Parkinson's disease, these prior studies did not evaluate whether caregiver depression is a confounding factor on these associations as we have tested in this study.<sup>15,16</sup> Our findings indeed show that depression influences the association between relationship quality and caregiver benefit or burden. However, the small sample size limited the ability to determine whether relationship quality was still significantly associated with caregiver benefit after adjusting for depressive symptoms. One research implication of this study is the need for future larger studies among HF caregivers to quantify how caregiver depression impacts the identified associations between relationship quality and caregiver benefit or burden, while adjusting for other potentially influential characteristics of the patient, caregiver or dyadic relationship. If and when these associations are confirmed, next steps will include addressing whether the associations between these key caregiver factors are causal and/or modifiable in ways that impact patient or caregiver outcomes.

The findings contribute to the understanding of relationship quality in different types of dyadic relationships since 58% of the sample were non-spousal caregivers. Approximately half of studies involving relationship quality use mixed study populations, where the caregiver could be someone other than a spouse.<sup>13</sup> While some previous HF caregiver studies examined only spousal relationships,<sup>3,5</sup> our data show that other types of caregiver relationships such as those between adult children and their parents comprise a substantial portion of dyadic relationships and also experience a range of relationship quality, caregiver benefit and burden. Importantly, higher relationship quality was strongly associated with decreased caregiver burden in this diverse sample that included multiple types of caregivers. Future research should confirm these results by including substantial numbers of both spousal and non-spousal caregivers and analyzing the associations among these types of dyadic pairs to understand the determinants of relationship quality in different types of relationships. More generally, our study also supports the inclusion of non-spousal caregivers of HF patients in future nursing research that investigates the dyadic relationship and patient and caregiver outcomes.

This study has several limitations. The main limitation was the small sample size, which limited the ability to fully control for potential confounders of the identified associations such as age, caregiver hours and caregiver depressive symptoms, which has known associations with caregiver burden in HF.<sup>17</sup> Patients and caregivers were recruited from an academic medical center, which limits generalizability due to unique referral patterns (i.e. socio-economic status, race, education) or regional differences. This study was not able to address the intricacies of the dyadic relationship, including the relative importance of relationship quality to care-giver benefit finding or caregiver burden compared to other relationship factors (e.g., communication styles, disease severity, congruence or incongruence in the dyadic relationship regarding care plans<sup>11</sup>). Finally, given the observational, cross-sectional study design, the associations described here should not be interpreted to reflect causality. Taking these limitations into account, the findings from this study warrant future research using a longitudinal design and a diverse sample of HF caregivers that is large enough to account for potential confounders, as well as key mediators or moderators, of caregiving benefit and caregiver burden.



While the findings of this initial exploratory study cannot be used to recommend using a particular intervention to target relationship quality or other key factors of the HF caregiving experience, there are practical implications for the clinical practice of nurses who care for the patient-caregiver dyad in HF that warrant consideration. As caregivers have important roles in the care of people with HF, asking them about their specific roles and care-giving experiences could be useful. Given the presence of caregiver benefit among HF caregivers, nurses could initiate pro-active, supportive and open-ended questioning that explores the positive aspects of the caregiver's experience, as well as their perspective on the quality of the relationship with the patient. As depression influences the experience of caregiving, assessing caregiver mood and making appropriate referrals for further care could be useful.

From a caregiver research standpoint, these results suggest that positive or negative relationship quality can be meaningful in the patient-caregiver experience in HF and warrant further study. We could speculate that positive relationship quality might provide a bolstering or supportive effect for caregiver benefit or a reduction in caregiver burden, while negative relationship quality might lead a caregiver to be more susceptible to experience burden and less likely to find benefit. Addressing these hypotheses involves confirming the associations we found while accounting for other confounding factors. Once the nature of the association is fully explored, the next area of study is determining whether relationship quality is modifiable via dyadic interventions. A future goal might be to test interventions that aim to improve poor relationship quality as a means of decreasing or preventing caregiver burden, increasing caregiver benefit, and improving disease management and other patient outcomes. Because this is a hypothesis-generating study, multiple aspects of these associations need to be repeated and explored in greater detail.

In conclusion, this exploratory study builds upon the conceptual model suggested by Trivedi et al<sup>3</sup> and addresses our study objectives by finding that 1) HF caregivers can experience a range of benefits from caregiving, 2) relationship quality is positively associated with caregiver benefit and negatively associated with caregiver burden, and 3) depressive symptoms influence the association between relationship quality and caregiver burden. Moving forward, these findings raise the hypothesis that targeting relationship quality and depressive symptoms in order to help caregivers identify positive aspects of caregiving maybe novel ways to influence the caregiving experience and ultimately patient and caregiver outcomes.

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## Abbreviations

<b>HF</b>	Heart failure
<b>NYHA</b>	New York Heart Association

**Table 1**

Patient and caregiver characteristics.

Characteristics	Patient ( <i>n</i> = 19)	Caregiver ( <i>n</i> = 19)
Age: mean (range)	69 (34–over 89)	59 (30–89)
Female: <i>n</i> (%)	7 (37%)	18 (95%)
LVEF: mean (SD)	39.9 (16.5)	N/A
NYHA class: <i>n</i> (%)		
II	10 (53%)	N/A
III	8 (42%)	
IV	1 (5%)	
Race: <i>n</i> (%)		
White	12 (63%)	16 (84%)
Black	3 (15%)	2 (11%)
Hispanic or Latino	2 (11%)	1 (6%)
Other	2 (11%)	0 (0%)
Highest level education: <i>n</i> (%)		
Less than high school graduate	1 (5%)	0 (0%)
High school graduate, or equivalent	8 (42%)	4 (21%)
Some college	3 (16%)	6 (32%)
College graduate	4 (21%)	5 (26%)
Any post-graduate	3 (16%)	4 (21%)
Current work situation: <i>n</i> (%)		
Full time	3 (16%)	9 (47%)
Part time	0 (0%)	4 (21%)
Retired	9 (47%)	4 (21%)
On disability	6 (32%)	0 (0%)
Homemaker	0 (0%)	1 (5%)
Unemployed	0 (0%)	1 (5%)
Other	1 (5%)	0 (0%)
Current relationship status: <i>n</i> (%)		
Married	9 (47%)	11 (58%)
Divorced or separated	4 (21%)	5 (26%)
Widowed	4 (21%)	0 (0%)
Never married	1 (5%)	1 (5%)
Member of an unmarried couple	1 (5%)	2 (11%)
Total household income: <i>n</i> (%)		
Below \$40,000	8 (42%)	4 (21%)
\$40,000	8 (42%)	11 (58%)
Decline to answer	3 (16%)	4 (21%)
Relationship to patient: <i>n</i> (%)		
Spouse or significant other <sup>a†</sup>	N/A	11 (58%)
Daughter		6 (32%)

Characteristics	Patient ( <i>n</i> = 19)	Caregiver ( <i>n</i> = 19)
Son		1 (5%)
Other relative		1 (5%)
Relationship length <sup>b</sup> : mean (range)	45 (8–66)	Same
Living in same household: <i>n</i> (%)	12 (63%)	Same
Hours per week spent caregiving: <i>n</i> (%)		<i>n</i> = 18
<1 h	N/A	2 (11%)
1–2 h		1 (6%)
3–5 h		3 (17%)
6–8 h		3 (17%)
>8 h		9 (50%)
Survey measures		
Relationship quality <sup>c</sup> : mean (SD)	–	3.07 (0.78)
Caregiver benefit finding <sup>d</sup> : mean (SD)	–	2.64 (0.75)
Caregiver burden <sup>e</sup> : mean (SD)	–	23.7 (13.37)
Depressive symptoms <sup>f</sup> : mean (SD)	–	4.47 (5.40)

LVEF = left ventricular ejection fractions; NYHA = New York Heart Association.

<sup>a</sup>Includes one partner/significant other and two ex-wives.

<sup>b</sup>Response to the question, “About how many years have you known each other?”

<sup>c</sup>Mutuality Scale of the Family Caregiving Inventory, scale range 0–4; higher scores indicate better relationship quality.

<sup>d</sup>Benefit Finding Scale, scale range 0–4; higher scores indicate more perceived benefit.

<sup>e</sup>Zarit Burden Inventory, cumulative score, scale range 0–88; higher scores indicate more perceived burden.

<sup>f</sup>Patient Health Questionnaire-9, scale range 0–27; higher scores indicate greater frequency of depressive symptoms.

**Table 2**

Correlations among relationship quality and caregiver burden, benefit and depressive symptoms.

	Unadjusted correlation with relationship quality	Correlation with relationship quality, adjusted for depressive symptoms
Caregiver burden	-0.80 (-0.92,-0.54) $P < 0.0001$	-0.54 (-0.81,-0.10) $P = 0.02$
Caregiver benefit	0.45 (0.00,0.75) $P = 0.05$	0.29 (-0.21,0.66) $P = 0.25^a$
Depressive symptoms	-0.77 (-0.91,-0.49) $P = 0.0001$	N.A.

N.A. = not applicable.

<sup>a</sup>Insufficient power to determine whether this correlation is statistically significant.