



## 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.

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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

Abbreviations: HF, Heart failure; NYHA, New York Heart Association.

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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 interchangeably.<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 caregiving, 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.”

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