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## Family Caregiver Outcomes in Heart Failure

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## Abstract

**Background**—Family caregivers of patients with heart failure (HF) report high stress, burden, and poor emotional and physical health, but less is known about predictors of health among these caregivers.

**Objectives**—To determine predictors of family caregiving outcomes among caregivers of patients with HF and to identify the tasks reported as most difficult and the most negative outcomes.

**Methods**—A total of 63 patients with heart failure and their 63 family caregivers were enrolled in this prospective study. Data were collected from medical records and from interviews conducted at baseline and 4 and 8 months later.

**Results**—Caregivers reported moderately poor physical and emotional health-related quality of life. Those with more depressive symptoms at baseline were more likely to report their lives had changed for the worse at 4 months ( $P = .03$ ). The caregivers' medical health condition ( $P < .001$ ) and perceived difficulty of caregiving tasks ( $P = .04$ ) were predictors of physical health-related quality of life at 4 months; at 8 months, medical health condition was the only predictor ( $P = 0.004$ ). At 4 and 8 months, depressive symptoms were predictors of emotional health-related quality of life ( $P < .$

001 and  $P = .001$ , respectively). The most difficult caregiving tasks were those dealing with patients' behavior problems; the most negative outcome was having less time for activities with friends.

**Conclusions**—Studies are needed in larger samples to identify needs of vulnerable populations of caregivers of patients with heart failure and to develop and test interventions for improving caregivers' outcomes.

### Keywords

heart failure; family caregiving; caregiving; caregiver health; caregiver outcomes; health-related quality of life

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Heart failure continues to be a major public health problem in the United States, with more than 5 million diagnoses of heart failure and nearly 500,000 new cases reported annually.<sup>1</sup> The 12-month mortality rate is 10% to 20% for all patients with heart failure and 50% for patients with advanced, or New York Heart Association class IV, heart failure.<sup>1</sup> Heart failure is a leading cause of hospitalization for elderly patients and costs millions of dollars in health care annually.<sup>1</sup> Importantly, the health-related quality of life (HRQL) of these patients is poor because of the many troublesome signs and symptoms they experience.<sup>2–6</sup> To improve survival, enhance HRQL, and reduce costly hospitalizations, patients with heart failure must adhere to complex medication, dietary, and self-care regimens; this adherence often requires the assistance of the patients' family caregivers.<sup>7,8</sup>

Most of the care provided to patients with major chronic illnesses such as heart failure is performed by family caregivers. Farran<sup>9</sup> estimates that 90% of care of patients with chronic illness care in the United States is delivered by family caregivers. Indeed, supporting family caregivers in order to provide ongoing quality care for chronically ill individuals is a national health priority.<sup>10</sup> In the landmark Caregiver Health Effects Study,<sup>11</sup> after 4 years, with controls for demographic and common clinical diseases, 392 elderly caregivers (66–96 years old) of patients with disability had a significantly higher mortality rate than did the 427 noncaregivers. Furthermore, caregivers who reported having emotional strain as a result of caregiving were 63% more likely to die compared with the noncaregivers.<sup>11</sup> In other studies,<sup>11–14</sup> caregivers of chronically ill patients have reported stress, burden, depression, anxiety, and poor physical and emotional health.

Caregivers of patients with heart failure have reported problems similar to those of caregivers of patients with other chronic illnesses, although some differences within the context of heart failure may present unique challenges.<sup>15</sup> For example, the frequent periods of exacerbation leading to hospitalizations may contribute to caregivers' stressors among those who care for patients with heart failure. The need to monitor signs and symptoms to prevent decompensation may be a challenge to caregivers of heart failure patients that does not occur with other disorders. The cognitive impairments that occur in 25% to 50% of patients with heart failure may also increase caregivers' stress.<sup>16</sup> Recent advances in medical therapies, such as the implantation of defibrillators and ventricular assist devices, may further contribute to caregivers' stressors and burden because of increased needs for care of these devices and increased health care visits. Overall, caregivers of patients with heart failure report high stress, burden (defined as the overall demands of caregiving), depressive symptoms, and poor emotional and physical health.<sup>15, 17–21</sup>

Guided by the theoretical and empirical literature on family caregiving stress, burden, and other outcomes<sup>11,15,17–25</sup> we conducted this study to investigate predictors of family caregiving outcomes in heart failure. Our primary purpose was to determine predictors of family caregiving outcomes among caregivers of patients with heart failure. We hypothesized that caregivers' medical health condition, age, family functioning, perceived control, depressive

symptoms, anxiety, and perceived caregiving stress at baseline would be predictive of self-reported caregiving outcomes and physical and emotional HRQL at 4 and 8 months after collection of baseline data. Our secondary purposes were to identify the tasks caregivers report as most difficult and most negative self-reported caregiving outcomes.

## Methods

### Procedure

The study was approved by the institutional review board at Indiana University in Indianapolis. Data were collected from December 2005 through June 2007. The patients and their caregivers were recruited from a multidisciplinary heart failure clinic affiliated with the university medical center. The clinic staff provides care to more than 700 patients with heart failure. Potentially eligible patients and caregivers were invited to participate in the study by clinic staff during a regularly scheduled clinic visit. The names of patients and their family caregivers who agreed to participate were provided to members of the research team by clinic personnel. Members of the research team contacted the patients and the caregivers to obtain signed informed consent and schedule caregiver interviews. For their convenience, at baseline, caregivers were offered the choice of completing the questionnaires face-to-face with an interviewer or by telephone; interviews 4 and 8 months after baseline were by telephone. Three graduate nursing students read all questions to the caregivers during the interviews in order to standardize data collection. The rationale for collecting data at 4 and 8 months after baseline was to provide a sufficient length of time for the caregiving experience to unfold and to allow sufficient time for change to occur. In previous studies,<sup>3,26</sup> one third of the patients with heart failure had a change in condition or were hospitalized within 6 months after baseline collection of data. The data were entered into the study database and verified. All data on the patients were retrieved from the patients' medical records at baseline by the graduate nursing students by using a standardized data abstraction form and were entered into the database.

### Sample

A convenience sample of 63 patients with heart failure and their family caregivers were enrolled in the study. Patients who were the care recipients were eligible for the study if they had a documented medical diagnosis of heart failure and were receiving care at the specialty clinic. Selected vulnerable populations of patients (terminal cancer patients, prisoners) were excluded. Caregivers were eligible if they were a family caregiver, defined in this study as a family member or friend of a patient with heart failure who helps the patient at home with self-care activities and is not paid to do so; were able to speak English and hear at a conversational tone; were alert and oriented as determined by clinic staff; and had access to a working telephone. A total of 25 caregivers or their family members who were heart failure patients declined to participate in the study for the following reasons: too busy (n = 6), too sick (n = 4), consent too long (n = 4), not interested (n = 3), and no reason given (n = 8).

### Data Collection

**Family Caregivers**—The caregivers' perceptions of changes in their lives as a result of caregiving were measured by using the Bakas Caregiving Outcomes Scale,<sup>27,28</sup> a 15-item questionnaire with 7-point response scales (from -3, changed for the worst to +3, changed for the best) on which caregivers rate how their lives have changed since they began providing care for the family member. The item scores are transformed from scores of -3 to +3 to scores of 1 to 7 and summed: Scores higher than 4 indicate perceptions that the caregiver's life has changed for the better since becoming a caregiver. Scores lower than 4 indicate negative perceptions of the caregiving experience. Validity and reliability have been documented among family caregivers of stroke survivors<sup>27,28</sup> and heart failure patients.<sup>15</sup> Among 147 caregivers of stroke survivors, the Cronbach  $\alpha$  reliability was 0.90; among 21 caregivers of heart failure

patients, it was 0.88.<sup>15,28</sup> In the study reported here, the Cronbach  $\alpha$  coefficients were 0.88, 0.72, and 0.82 at baseline, 4 months, and 8 months, respectively.

HRQL was conceptually defined as overall well-being in health domains. Physical and emotional HRQL were assessed by using the Physical and Mental Component Summary scores of the Medical Outcomes Study Short-Form-12 (SF-12).<sup>29</sup> These scales have been widely used in health outcomes research, and their validity and reliability have been documented.<sup>15,29</sup>

The medical health condition of the caregivers was assessed by using the Charlson Comorbidity Index, on which participants are asked to indicate whether or not they have a history of medical problems in 12 areas, with responses of yes or no.<sup>30</sup> The medical problems on the index are weighted by severity of the condition; each rating is worth 1, 3, or 6 points. A summary score is obtained; higher scores indicate more and/or more severe comorbid conditions. The index is predictive of 1-year mortality and health care costs.<sup>30–32</sup>

The Family Assessment Device<sup>33</sup> (brief version) is a 27-item scale with 4-point response scales on which persons rate aspects of their family functioning, including general function, problem solving, and communication. Possible scores range from 1 to 4; a score of 1 indicates healthy family functioning and a score of 4, unhealthy family functioning. Validity and reliability have been reported among healthy persons and psychiatric patients<sup>34</sup> and in caregivers of stroke survivors.<sup>35</sup> Among caregivers of stroke survivors (baseline,  $n = 239$ ; 2 years later,  $n = 53$ ), the Cronbach  $\alpha$  values of the 12-item General Functioning Subscale at 4 time points ranged from 0.88 to 0.92.<sup>35</sup> In our sample, the Cronbach  $\alpha$  for the total scale was 0.84.

Perceived control, defined as a person's perceptions of control over cardiovascular-related health, was assessed by using the Control Attitudes Scale (Family version).<sup>36,37</sup> This instrument is a 4-item scale with 7-point response scales (1, not at all helpless, to 7, very helpless). Higher scores indicate perceptions of greater control. Validity and reliability have been documented.<sup>15,20,36,37</sup> The Cronbach  $\alpha$  value was 0.75 among 21 caregivers of heart failure patients and 0.90 among 69 spouses of heart failure patients.<sup>15,20</sup> In our study, the Cronbach  $\alpha$  for the 4 items was low, at 0.44. Therefore, after consultation with the author of the scale (D. K. Moser, personal communication, June, 2007) only the first two items, which focus on control in managing a family member's heart disease, were used. The Cronbach  $\alpha$  of the 2-item scale remained somewhat low: 0.54.

Depressive symptoms of caregivers were measured by using the Patient Health Questionnaire-8 (PHQ-8).<sup>38,39</sup> The PHQ-8 is the first 8 items of the PHQ-9,<sup>39</sup> which was based on the 9 criteria for depression of the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition. The ninth item requires participants to respond to whether they have had suicidal thoughts; this item may not be necessary when working with nonpsychiatric populations.<sup>39</sup> The PHQ-8 has psychometric properties comparable to those of the PHQ-9.<sup>39</sup> Possible scores for the PHQ-8 range from 0 to 24. Scores of 1 to 4 indicate no depressive symptoms; 5 to 9 mild; 10 to 14, moderate; 15 to 19, moderately severe; and 20 to 24, severe. Scores of 10 or higher indicate the need for clinical assessment and management. Validity and reliability of the PHQ-9 and the PHQ-8 have been documented.<sup>38,39</sup> The reliability estimate of the PHQ-9 was 0.89 among 3000 primary care patients and 0.86 among 3000 obstetrical and gynecological patients.<sup>40</sup> The Cronbach  $\alpha$  in our sample was 0.79.

The Anxiety Subscale of the Brief Symptom Inventory<sup>41</sup> was administered to assess caregivers' level of anxiety. The subscale is a 6-item measure on which participants rate how distressing symptoms of anxiety are for them on 5-point response scales (0, not at all, to 4, extremely). The subscale yields an item mean score ranging from 0 to 4; higher scores indicate higher anxiety levels. The mean score in healthy populations is 0.35.<sup>41</sup> Validity and reliability

have been documented.<sup>41–43</sup> The Cronbach  $\alpha$  was 0.74 among 87 patients with heart failure.<sup>43</sup> In our sample, it was 0.75.

The Oberst Caregiving Burden Scale<sup>44</sup> was developed to measure the perceived stress and burden associated with the performance of the physical and emotional tasks of caregiving. It has 2 subscales, 18 items each, that are used to assess the time spent on tasks performed daily by the caregiver and the perceived difficulty of the tasks. The original scale had 15 items<sup>44</sup>; 3 items were added for this study to assess activities associated with helping patients with cognitive and behavioral needs. Item responses for the time and difficulty subscales are on 5-point response scales (time subscale: 1, none, to 5, a great amount; difficulty subscale: 1, not difficult, to 5, extremely difficult). Higher scores indicate perceptions of more time spent or greater difficulty of the tasks. Scores greater than 2 on the difficulty subscale items indicate moderate, very, or extreme difficulty with caregiving tasks.<sup>15,44</sup> Validity and reliability have been reported among caregivers of patients with heart failure and other chronic illnesses.<sup>15, 44</sup> In 2 studies<sup>28,44</sup> among caregivers of stroke patients, the Cronbach  $\alpha$  values were 0.93 (n = 147) and 0.90 (n = 116) for the time subscale and 0.90 and 0.94 for the difficulty subscale. Among 21 caregivers of heart failure patients,<sup>15</sup> the Cronbach  $\alpha$  was 0.92 for the difficulty subscale. The Cronbach  $\alpha$  values in our sample were 0.82 for both the time subscale and the difficulty subscale.

**Patients with Heart failure**—Demographic and clinical variables of heart failure severity were obtained from the medical records. The severity of heart failure was measured by using the New York Heart Association classifications<sup>45</sup> and the left ventricular ejection fraction. The chart review version of the Charlson Comorbidity Index was used to measure comorbid conditions.<sup>30</sup>

## Statistical Analyses

Descriptive statistics were computed for all study variables. Cronbach  $\alpha$  coefficients were calculated for multi-item scales to evaluate internal consistency reliability. Pearson product moment correlation coefficients were computed to measure the degree of linear relationship between the baseline variables and the 4- and 8-month dependent variable scores. Univariate linear regression was performed to identify independent predictors of the 4- and 8-month dependent variable scores. The dependent variables were the 4- and 8-month perceptions of caregiving-related life changes, as indicated by scores on the Bakas Caregiving Outcomes Scale, and HRQL, as indicated by scores on the SF-12 Physical and Mental Component Summary Scales. The baseline variables of caregivers' medical health condition, age, family functioning, perceived control, depressive symptoms, anxiety, and perceived time and difficulty of caregiving tasks were entered separately into the equations as independent predictor variables. On the basis of the univariate analyses, variables that were significantly predictive of caregiving-related life changes and HRQL at a significance level of 0.10 or less were entered into the stepwise regression models to identify the combination of variables with the most predictive power. The significance level was set at  $P \leq .05$  for the stepwise regression analyses. Frequencies were computed to determine the tasks that caregivers perceived to be most difficult and the outcomes they perceived to be most negative.

## Results

### Characteristics of the Sample

The caregiver recipient sample at baseline consisted of 34 men (54%) and 29 women (46%) who had heart failure. The mean age was 69.0 years (SD, 12.6; range, 30 to 91). As indicated by the medical records, 51 were white (81%), and 12 were African American (19%). The mean left ventricular ejection fraction was 0.43 (SD, 0.16); 4 patients (6%) had New York Heart



Association class I heart failure, 15 (24%) had class II, 33 (53%) had class III, 10 (16%) had class IV, and 1 missing. Comorbid conditions were moderate overall (mean, 4.1 comorbid conditions; SD, 2.8; range, 1 – 16). More than half of the patients were married at the time of the first interview.

The characteristics of the caregivers are presented in Table 1. A total of 63 family caregivers completed baseline interviews, 59 completed 4-month interviews, and 54 completed 8-month interviews. Among 63 caregivers, 9 (14%) did not complete the 8-month interviews because of the following reasons: the patient died ( $n = 5$ ), the patient was too ill ( $n = 1$ ), the caregiver could not be contacted ( $n = 2$ ), and no reason was provided ( $n = 1$ ). Compared with the caregivers who completed the study, the caregivers who did not complete the study were significantly older (independent  $t$  test, 2.16;  $P = .03$ ) and had more or more severe depressive symptoms (independent  $t$  test, 2.56;  $P = .01$ ) and poorer physical HRQL at baseline (independent  $t$  test, 2.22;  $P = .03$ ).

### Caregivers' Scores

Descriptive statistics for the dependent variables at baseline and at 4 and 8 months after baseline are presented in Table 2. The caregivers' perceptions of how their lives had changed as a result of caregiving became significantly more positive from baseline to 4 months (paired  $t$  test, 2.1;  $P = .04$ ) and from baseline to 8 months (paired  $t$  test, 2.23;  $P = .03$ ). However, both the physical and emotional HRQL scores were moderately poor for the caregivers at baseline and remained similar over time (paired  $t$  tests not significant).

At baseline, the caregivers' mean score was 1.4 for self-reported medical health condition as assessed by using the Charlson Comorbidity Index, a low score (Table 3). However, the range was 0 to 13, indicating that some caregivers had multiple or severe comorbid health conditions. Family functioning, according to scores on the Family Assessment Device, was moderately healthy on average. Mean perceived control was moderate overall. The caregivers' PHQ-8 scores indicated that, on average, they were not experiencing high levels of depressive symptoms. However, 11 (17%) of the caregivers had PHQ-8 scores of 10 or higher, which suggests the need for clinical assessment and possible treatment.<sup>39</sup> Mean anxiety, measured by using the Brief Symptom Inventory Anxiety Subscale, was high at 0.5 compared with the mean score of 0.35 for healthy individuals.<sup>41</sup> On average, the perceived amount of time spent on caregiving tasks was small to moderate, and the perceived difficulty of the tasks was slight to moderate.

### Predictors of Caregivers' Perceived Life Changes

Baseline depressive symptoms were significant predictors of caregiving outcomes of life changes at 4 months and accounted for 6% of the variance ( $F = 4.84$ ; Table 4). Caregivers with more depressive symptoms were more likely than those with fewer symptoms to report that their lives had changed for the worse over time. At 8 months after baseline, none of the baseline variables were significant predictors of the caregiving outcomes as measured by using the Bakas Caregiving Outcomes Scale.

### Predictors of Caregivers Physical and Emotional HRQL

Baseline medical health condition of the caregivers and perceived difficulty of caregiving tasks were significant predictors of physical HRQL at 4 months, accounting for 24% of the variance ( $F = 9.68$ ) (Table 4). At 8 months, the only predictor of physical HRQL was caregivers' medical health condition, accounting for 13% of the variance ( $F = 8.89$ ). Caregivers with more medical conditions or more severe medical conditions at baseline had significantly worse physical HRQL at 4 and 8 months. At 4 months, the perceived difficulty of the caregiving tasks contributed significantly to worse physical HRQL.

Depressive symptoms were significant predictors of emotional HRQL at 4 months, accounting for 21% of the variance ( $F = 15.85$ ; Table 4). Similar results were obtained for the 8-month emotional HRQL, with depressive symptoms accounting for 19% of the variance ( $F = 13.54$ ). Other independent variables were not significant in the models. Caregivers with more depressive symptoms at baseline had poorer emotional HRQL 8 months later.

### Most Difficult Caregiving Tasks and Most Negatively Perceived Caregiving Outcomes

Caregivers' most difficult tasks were dealing with the patient's behavior problems such as moodiness, providing emotional support to the patients, managing dietary needs, monitoring signs and symptoms, managing personal finances, and obtaining information from health care providers (Table 5). A total of 44% of the caregivers perceived behavior problems such as moodiness as difficult to manage, 41% perceived providing emotional support as difficult, and 38% reported that managing dietary needs was difficult.

The changes that caregivers perceived in their lives as most negative as a result of caregiving were having time for activities with friends, being able to cope with stress, and financial well-being (Table 6). Other negative changes were reported in emotional, physical, and general health; energy level; time for activities with family members; and relationships with friends. A total of 43% of the caregivers reported that their time for social activities had been reduced because of caregiving. Approximately one third perceived negative changes in their emotional health (34%) and in their ability to cope with stressful situations (32%).

## Discussion

The results of this prospective study are important because significant predictors were determined for physical and emotional HRQL over time among family caregivers of patients with heart failure. Our results support the multidimensionality of HRQL and suggest the need for separate models to predict physical and emotional HRQL.

Significant predictors of the caregivers' physical HRQL were the caregivers' medical health condition and their perceptions of the difficulty of caregiving tasks at baseline. These 2 variables accounted for 24% of the variance in physical HRQL over 4 months. However, at 8 months, the caregivers' medical health condition was the only significant predictor of physical HRQL, accounting for 13% of the variance. The mean score for physical HRQL was moderate (49 to 51 on the SF-12 Physical Component Summary scale), but low compared with the norm (54.3) for healthy persons with no chronic conditions.<sup>29</sup> Furthermore, the range of physical HRQL scores supports the notion that some caregivers had poor physical HRQL. These results are consistent with findings of poor physical health in the Caregiver Health Effects Study,<sup>11</sup> in which elderly caregivers with emotional strain had higher mortality rates. Caregivers in that study neglected their own health (e.g., inadequate sleep, forgetting to take medications), a situation that may have contributed to poorer physical health and mortality.<sup>46</sup> In a meta-analysis<sup>47</sup> of 176 studies, perceptions of difficulty managing patients' behaviors were significantly associated with poorer physical health of caregivers, particularly among caregivers who were psychologically distressed. The caregivers in our study had better physical HRQL scores than did 48 caregivers of heart failure patients in a study by Martensson et al,<sup>18</sup> who reported a mean score of 40.2 for physical HRQL as assessed by using the SF-12 Physical Component Summary Scale. A limitation of our study was that physical health was measured by using self-reports and perceived HRQL. Studies are needed to thoroughly assess the actual physical health status of family caregivers of patients with heart failure in order to design interventions for maintaining or improving the caregivers' physical health. Importantly, poor physical health among caregivers may directly influence their ability to provide safe or high quality patient care and thereby influence patients' outcomes; this area warrants further

study. Other variables predictive of physical HRQL among caregivers of heart failure patients must be identified.

Baseline depressive symptoms were the only significant predictor of caregivers' emotional HRQL, accounting for 21% and 19% of the variance at 4 and 8 months, respectively. Conceptually, depressive symptoms should be related to emotional HRQL but the two are distinct concepts. Emotional HRQL is a broader concept of well-being than is depressive symptoms and integrates positively and negatively toned emotions, symptoms, functional status, and health perceptions.<sup>48</sup> Importantly, the caregivers' mean emotional HRQL scores (48.7 – 50.6) were similar to the mean emotional HRQL scores of 45.5 (n = 48 heart failure caregivers) reported by Martensson et al<sup>18</sup> and 50.9 (n = 103 heart failure caregivers) reported by Evangelista et al.<sup>17</sup> The mean score for healthy individuals with no chronic conditions is 52.29.<sup>29</sup> The finding that caregivers' depressive symptoms are associated with and/or predictive of outcomes is consistent with the results of previous studies of caregivers of patients with heart failure,<sup>15,18,19</sup> stroke survivors,<sup>12</sup> and persons with other major chronic disorders.<sup>23–25</sup> Notably, 17% of the caregivers in our sample had scores on the PHQ-8 that suggested the need for clinical evaluation and possible treatment. In a meta-analysis<sup>23</sup> that integrated results from 228 studies, behavior problems among care recipients were consistently related to burden and depression among caregivers. Our results are consistent with those of a meta-analysis<sup>24</sup> of 60 studies on subjective well-being among caregivers in which significant and negative associations were found between caregivers' depression and subjective well-being.

The depressive symptoms that occur among caregivers may have physiological and psychological detrimental effects. In addition to the known psychological effects, depressive symptoms may increase the susceptibility to infectious agents and alter sympathetic arousal and cardiovascular reactivity, increasing the risk for cardiovascular disorders.<sup>47</sup> Depressive symptoms among caregivers of heart failure patients may diminish the caregivers' ability to provide care and thereby contribute to negative outcomes for the patients.

Although our results are consistent with previously reported findings in several aspects, other variables (other than depressive symptoms) hypothesized to be predictive of 4- and 8-month caregiving outcomes and HRQL were not significant. Our lack of significant correlates of caregiver life changes over time differs from the results of a study<sup>15</sup> in which the investigators used a smaller sample of patients with heart failure and cross-sectional data collection and from the results of a study<sup>12</sup> of caregivers of stroke survivors. In our study, caregivers had a long duration of caregiving (more than 9 years on average) and this characteristic may have influenced their perceptions of changes in their lives due to caregiving. Another explanation for the lack of significant predictors of perceived change in caregiving outcomes may be the number of caregivers who declined participation (25) or the number who did not complete the study (9). Compared with caregivers who completed the study, those who did not were significantly older, had more or more severe depressive symptoms and poorer HRQL at baseline. Furthermore, the prospective design of our study may have contributed to results that differ from those of a previous study<sup>15</sup> in which a cross-sectional approach and a smaller sample were used. Recently, Nauser<sup>49</sup> reported development and psychometric evaluation of an instrument designed specifically to measure quality of life among caregivers of heart failure patients. Such specificity can improve the measurement of quality of life among persons with heart failure<sup>3</sup> and this type of condition-specific measure may have greater precision than do generic measures for caregivers' quality of life.

Older age has been associated with more difficulty in providing care, but some researchers<sup>15,20</sup> found that younger caregivers had more difficulty than older caregivers did in providing care. In our study, age was not a predictor of outcomes over time, possibly because of the larger influence of the medical health condition and depressive symptoms. The



longitudinal nature of the study might be another explanation for the lack of significance of age, because in many previous studies,<sup>15,17–21</sup> a cross-sectional approach was used. Furthermore, the caregivers in our study who did not complete the study were significantly older, a characteristic that may have limited our ability to detect relationships with age.

Perceived control, anxiety, family functioning, and time spent in caregiving were hypothesized as predictors of the study outcomes on the basis of previous studies.<sup>15,16–21,23,24,49</sup> The sample size of 54 at 8 months may have influenced our results. However, with a sample size of 54 participants at 8 months after baseline, we had 80% power to detect an  $R^2$  of 0.20 in HRQL and in caregivers' perceived life changes by using a multiple regression model at the 5% significance level (2-sided) and after adjusting for 4 variables in the model. Another explanation for the lack of significant findings for these variables could be the severity and complexity of the heart failure condition in the patients receiving care. Alternatively, the physical and emotional health of the caregivers may be most influential for outcome caregiving variables regardless of individual factors such as perceived control. We did not include duration of time in the caregiving role as a predictor variable because of the sample size in our study, but previous investigators<sup>24,25</sup> found that longer durations were associated with increased burden. Future studies are needed to investigate the transitions that occur over time as the caregiving experience in HF unfolds; such studies could provide information for the design of interventions tailored to the unique needs of these patients and families at different times.

Identification of the most difficult caregiving tasks and the most negative changes as a result of caregiving provides information that can be used in clinical assessment and in the design of future interventions for testing. The most difficult tasks were managing behavior problems, providing emotional support, adhering to dietary restrictions, and monitoring signs and symptoms; these tasks are similar to the tasks reported in other studies<sup>15,25</sup> by caregivers of patients with heart failure. Among caregivers of patients with stroke and Alzheimer's disease, managing behavior problems and providing emotional support were commonly perceived as difficult.<sup>12,23,34</sup> However, the dietary sodium restrictions and the monitoring of signs and symptoms required in heart failure were not common problems identified in these other populations. More than one-fourth of the caregivers in our study reported difficulty with these tasks, suggesting the need for educational and/or counseling interventions to assist them in accomplishing the tasks. In our study, the most negative changes experienced as a result of caregiving were having less time for activities with friends, coping with stress, less financial well-being, worse emotional well-being, and less energy, findings consistent with those of past studies.<sup>15,44</sup> Strategies need to be designed and tested for identifying caregivers who have the greatest difficulty with tasks and improving their outcomes in order to facilitate caregivers' health.

In summary, the physical HRQL and the emotional HRQL were moderately poor in this sample of caregivers. The medical health condition of caregivers and their perceptions of difficulty in performing the tasks of caregiving at baseline were predictive of physical HRQL at 4 months, whereas only the medical health condition was predictive of physical HRQL at 8 months. Depressive symptoms and difficulty in performing caregiving tasks were predictive of emotional HRQL at 4 months, but only depressive symptoms were predictive at 8 months. Prospective studies with larger samples of caregivers are needed to understand caregivers' health over time in order to design and test efficacious interventions. Clinicians caring for heart failure patients need to assess the ability of the patients' families to meet the time and financial demands of providing care.<sup>50</sup>

## Summary of key points

Among family caregivers of patients with heart failure, medical health condition and perceived difficulty of caregiving tasks were predictors of physical health-related quality of life at 4 months after collection of baseline data; at 8 months, medical health condition was the only predictor. At 4 and 8 months, depressive symptoms were a predictor of emotional health-related quality of life. Clinicians caring for patients with heart failure need to assess the ability of the patients' families to meet the time and financial demands of providing care for the patients.

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**Table 1**  
Demographic and clinical characteristics of family caregivers (baseline, n = 63)

Characteristics	
Age, y	
Mean (SD)	59.7 (15.0)
Range	24.0 – 86.0
Sex, No. (%) of caregivers	
Men	15 (24)
Women	48 (76)
Race, No. (%) of caregivers	
African American	10 (16)
White	53 (84)
Relationship to patient, No. (%) of caregivers	
Spouse	43 (68)
Adult Child	13 (21)
Other relative/friend/other	7 (11)
Caregiver lives with patient who has heart failure, No. (%) of caregivers	
Yes	52 (83)
No	11 (17)
Education, y	
Mean, (SD)	12.9 (2.8)
Range	4.0 – 22.0
Economic status, No. (%) of caregivers	
Comfortable	29 (46)
Just enough to make ends meet	24 (38)
Not enough to make ends meet	10 (16)
Duration of caregiving, y	
Mean (SD)	9.3 (8.4)
Range	0.3 – 45



**Table 2** Descriptive statistics and internal consistency reliability for dependent variables at baseline and 4 and 8 months after baseline<sup>a</sup>.

Variable	Score				Cronbach $\alpha$
	Mean	Median	SD	Range	
Perceived caregiving-related life changes					
Baseline (n = 63)	54.1	57.0	11.8	23 – 91	0.88
4 month (n = 59) <sup>b</sup>	57.5	58.0	7.4	41 – 81	0.72
8 month (n = 53) <sup>c</sup>	59.6	60.0	8.9	28 – 82	0.82
Physical health-related quality of life					
Baseline (n = 62)	47.4	51.1	10.8	17 – 61	-
4 month (n = 57) <sup>d</sup>	48.2	51.5	10.3	18 – 63	-
8 month (n = 54) <sup>d</sup>	49.4	52.5	9.8	21 – 64	-
Emotional health-related quality of life					
Baseline (n = 62)	48.7	51.9	10.5	20 – 65	-
4 month (n = 57) <sup>d</sup>	50.6	54.1	9.5	24 – 63	-
8 month (n = 54) <sup>d</sup>	49.7	52.7	10.9	19 – 64	-

<sup>a</sup>Sample sizes vary due to missing data for 2 participants.

<sup>b</sup>Baseline to 4 months paired t test = 2.1, P = 0.04.

<sup>c</sup>Baseline to 8 months paired t test = 2.23, P = 0.03.

<sup>d</sup>Baseline to 4 months and 8 months paired t tests nonsignificant.

**Table 3** Descriptive statistics and internal consistency reliability coefficients for independent variables, multi-item scales, at baseline (n = 63)

Variable	Score					Cronbach $\alpha$
	Mean	Median	SD	Actual Range		
Medical health condition	1.4	0	2.5	0 – 13	-	-
Family functioning	2.1	2.1	0.33	1.2 – 2.7	0.84	0.84
Caregiver's perceived time with tasks	40.0	39.2	9.0	25 – 60	0.82	0.82
Caregiver's perceived difficulty with tasks	29.7	28.0	9.0	18 – 54	0.82	0.82
Depressive symptoms	4.8	4.4	4.1	0 – 18	0.79	0.79
Perceived control	3.5	3.5	1.5	1 – 7	0.54	0.54
Anxiety	0.5	0.54	0.17	0 – 1.83	0.75	0.75

**Table 4**

Stepwise multiple regression for perceived caregiving outcomes and health-related quality of life in caregivers of patients with heart failure (n = 63)

Variables	Adjusted R <sup>2</sup>	P	F <sup>a</sup>	df
Perceived caregiving related life changes, 4 months <sup>b,c</sup> Depressive symptoms	0.06	0.03	4.84	1, 57
Physical health-related quality of life, 4 months <sup>b,d</sup>	0.24	<.001	9.68	2, 54
Medical health condition	0.19	<.001		
Perceived caregiving stress, task difficulty	0.24	.04		
Physical health-related quality of life, 8 months <sup>b,e</sup> Medical health condition	0.13	.004	8.89	1, 52
Emotional health-related quality of life, 4 months <sup>b,d</sup> Depressive symptoms	0.21	<.001	15.85	1, 55
Emotional health-related quality of life, 8 months <sup>b,e</sup> Depressive symptoms	0.19	.001	13.54	1, 52

<sup>a</sup> Overall F-Statistic.

<sup>b</sup> Dependent variable

<sup>c</sup> n = 59

<sup>d</sup> n = 57

<sup>e</sup> n = 54

**Table 5**

Caregiver perceived difficulty with task (Oberst Caregiving Burden Scale) item means and caregiver percentage ratings of moderate, very, or extreme difficulty with tasks (Item scores > 2) (n = 63)

Caregiver-perceived difficulty with task item	Mean	Score		Item Scores > 2, No. (%)
		SD	Range	
1. Treatments (medications, etc.)	1.5	0.8	1 – 5	9 (14)
2. Personal care	1.2	0.6	1 – 3	6 (10)
3. Dietary needs	2.2	1.2	1 – 5	24 (38)
4. Mobility	1.3	0.8	1 – 4	5 (8)
5. Emotional support	2.2	1.1	1 – 5	26 (41)
6. Symptom monitoring	2.0	1.0	1 – 5	17 (27)
7. Transportation	1.7	0.9	1 – 4	12 (19)
8. Managing finances	1.8	1.1	1 – 5	14 (22)
9. Household tasks (laundry, etc.)	1.7	0.8	1 – 4	10 (16)
10. Tasks outside home (grocery shopping, etc.)	1.5	0.8	1 – 4	9 (14)
11. Planning activities	1.3	0.6	1 – 4	3 (5)
12. Behavior problems (moodiness, etc.)	2.4	1.4	1 – 5	28 (44)
13. Behavior problems (memory loss, etc.)	1.7	1.1	1 – 5	13 (21)
14. Behavior problems (confusion, etc.)	1.3	0.8	1 – 4	6 (10)
15. Finding caregiver to help	1.4	0.8	1 – 4	7 (11)
16. Communication	1.5	0.9	1 – 4	8 (13)
17. Resources	1.4	0.8	1 – 5	7 (11)
18. Seeking information from doctors, nurses	1.8	1.1	1 – 5	13 (21)

**Table 6**

Bakas Caregiving Outcome Scale item means and percentages ratings of negative outcomes at 8 months after baseline (item scores < 4) (n = 53)

Item	Mean	Score		Item scores < 4 No. (%)
		SD	Range	
1. My self esteem	4.3	0.9	2 – 7	3 (6)
2. My physical health	3.9	0.9	1 – 7	8 (15)
3. My time for family activities	3.9	1.3	1 – 7	15 (28)
4. My ability to cope with stress	3.7	1.1	1 – 7	17 (32)
5. My relationship with friends	3.9	0.9	1 – 7	9 (17)
6. My future outlook	4.4	1.3	1 – 7	9 (17)
7. My level of energy	3.8	1.1	1 – 7	13 (25)
8. My emotional well-being	3.8	1.1	1 – 7	18 (34)
9. My roles in life	4.1	1.1	1 – 7	9 (17)
10. My time for social activities with friends	3.4	1.1	1 – 7	23 (43)
11. My relationship with my family	4.3	1.0	1 – 7	4 (8)
12. My financial well-being	3.7	1.1	1 – 6	12 (23)
13. My relationship with the patient	4.6	1.6	1 – 7	9 (17)
14. My physical functioning	4.0	0.8	1 – 7	6 (11)
15. My general health	3.9	1.0	1 – 7	11 (21)