

University of Arkansas, Fayetteville
ScholarWorks@UARK

The Eleanor Mann School of Nursing
Undergraduate Honors Theses


The Eleanor Mann School of Nursing

5-2017

Exploring the Effects of Caring for Congestive Heart Failure Patients on Caregiver Well-Being: A Descriptive Study

Hanna S. Curtis
University of Arkansas

Follow this and additional works at: <http://scholarworks.uark.edu/nursuht>

 Part of the [Cardiology Commons](#), [Geriatric Nursing Commons](#), and the [Public Health and Community Nursing Commons](#)

Recommended Citation

Curtis, Hanna S., "Exploring the Effects of Caring for Congestive Heart Failure Patients on Caregiver Well-Being: A Descriptive Study" (2017). *The Eleanor Mann School of Nursing Undergraduate Honors Theses*. 54.
<http://scholarworks.uark.edu/nursuht/54>

This Thesis is brought to you for free and open access by the The Eleanor Mann School of Nursing at ScholarWorks@UARK. It has been accepted for inclusion in The Eleanor Mann School of Nursing Undergraduate Honors Theses by an authorized administrator of ScholarWorks@UARK. For more information, please contact scholar@uark.edu, ccmiddle@uark.edu.

**Exploring the Effects of Caring for Heart Failure
Patients on Caregiver Well-Being: A Descriptive Study**

An honors thesis/project in partial fulfillment of the requirements
for the degree of Honors Baccalaureate in Nursing

By

Hanna Curtis
Honors Nursing Student

May 1, 2017
University of Arkansas

This honors undergraduate thesis/project is approved for recommendation
to the College of Education and Health Professions Honors Council.

Nan Smith-Blair

Name of Thesis Mentor

Honors Thesis/Project Director

Stephanie Seef

Name of Committee Member

Committee Member

Cathy Hale

Name of Committee Member

Committee Member

*Funding for this project made possible through a University of Arkansas
Honors College Student Undergraduate Research Grant.*

With 1-2% of the general population in developed countries developing heart failure (HF), it is quickly becoming the leading cause of disability among older adults and an ever-increasing drain on health services (American Heart Association, 2016). As the incidence of heart failure increases, it is anticipated that that the number of patients being cared for in the home by non-professional caregivers will also increase (Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011). In addition, in 2011, over 130,000 patients with heart failure over the age of 65 were readmitted within 30 days of their previous hospital discharge, costing Medicare more than \$1.7 billion (Hines, Barrett, Jiang, & Steiner, 2014). As national government initiatives attempt to lessen the cost of hospital stays by reducing the length of stay for heart failure patients, more patients will be discharged into the care of non-professional caregivers (Collins & Swartz, 2011). Heart failure patients being discharged home following hospitalization are often reliant on family or friends for assistance in activities of daily living (e.g. bathing, dressing, shopping, and housekeeping). These patients may depend on caregivers to attend to problems like limitations in physical activity, complex medication regimens, fluid and sodium restrictions, frequent rehospitalizations, and heart failure-related depression. Furthermore, there is growing evidence that social support, provided by a caregiver, positively impacts outcomes of patients with cardiovascular disease (Chin & Goldman 1997). However, the benefit provided by a caregiver may be offset by the negative impact on the caregiver's own physical and emotional health. Schulz and Beach (1999) have demonstrated that informal caregiving is an independent risk factor for mortality in caregivers. Few studies have examined the physical and emotional impact caregiving has on the informal caregiver's familial and social relationships and lifestyles. The purpose of this study is to explore how the stress factors of being a caregiver

impact the physical health, emotional health, social activity, relationships, and lifestyle of the caregiver for a patient with HF.

Literature Review

An informal caregiver may be defined as a person who provides the majority of non-professional care for someone with a chronic condition who is unable to perform all activities of daily living on their own. In 2009, almost one third of American households reported one or more members providing unpaid care to a relative (Collins & Swartz, 2011). The informal caregiver may be a friend or family member who is unpaid for their services, though most caregivers in a study by Hwang et al. (2011) were the spouse or partner of a patient. The informal caregiver is an extremely important role. Collins & Swartz (2011) report that caregivers save approximately \$375 billion dollars nationally. Moreover, the value of improving quality of life for the patients is immeasurable.

Benefit to the Heart Failure Patient

Having a family member or friend is beneficial for the HF patient because the presence of a caregiver, and their assistance with the medical management of the disease, leads to an improvement in their overall quality of life (D'alto, Pacileo, & Calbro, 2003). Several studies have demonstrated the positive impact on mortality of heart failure patients with a spouse or family member acting as caregiver. Murberg, Bru, Aarsland, & Svebak (1998) found that even when controlling for depressive symptoms, HF severity, functional status, and age, the degree of social isolation experienced by the patient was a significant predictor of patient mortality. Another study, by Krumholz et al (1998), demonstrated that among hospitalized elderly female patients with heart failure, the absence of emotional support by a spouse was a strong,

independent predictor of the occurrence of both fatal and nonfatal cardiovascular events during the year following hospitalization. Although the benefit of caregiver social support is well documented for the HF patient, it is less clear how caregiving impacts physical and emotional costs to the caregiver providing the support.

Detriment to the Informal Caregiver

The added role of caring for a patient with heart failure often leaves the caregiver under considerable strain. Several studies have demonstrated in a variety of clinical conditions that providing care to a functionally dependent member or friend can contribute to emotional and physical morbidity in the informal caregiver (Pinquart & Sorenson, 2003; Vialiano, Zhang, & Scanlan, 2003). A study by Schulz and Beach (1999) demonstrated higher mortality risks for caregivers than non-caregiver controls (relative risk [RR], 1.63; 95% confidence interval [CI], 1.00-2.65) following adjustment for socioeconomic and demographic factors, subclinical cardiovascular disease, and prevalent disease. Personal stress for the caregiver is influenced on all sides by elements such as these, as well as interpersonal relationship strain, which have been collectively referred to as "caregiver stress factors" (Kim, Chang, Rose, & Kim, 2011).

The duties of a caregiver are diverse, depending on the severity of the patient's condition and their ability to perform activities of daily living (ADLs). Necessary activities, such as buying or preparing food, basic hygiene, and home maintenance may not be within the capability of someone with a chronic illness. It may be left up to the caregiver to perform these duties along with more complex duties such as instrumental activities of daily living (e.g. managing complicated medication regimens, and transporting the HF patient to and from doctor's appointments) (Kim et al., 2011). According to Kim et al. (2011), as the need for a

caregiver to perform these more involved tasks increases, the burden on the caregiver does also. Caregivers who live with the patient experience a higher level of caregiver burden, as well as other negative determinants such as an increased sense of responsibility for the welfare of the patient and more hours spent caregiving (Kim et al., 2011). A common type of caregiver strain is scheduling adequate time for themselves as they try to balance the needs of the patient against the caregiver's own (Sautter et al., 2014). Lack of free time that contributed greatly to negative caregiver outcomes was a recurring theme in the literature (Hwang et al, 2011; Kim et al, 2011; Liljeroos, Ågren, Jaarsma, & Strömberg, 2014). For example, most participants in the Collins and Swartz (2011) study were actively caring for a patient between 20 and 39 hours a week. Many caregivers are forced to reduce their work hours or to quit their job altogether as the needs of the patient begin to grow and take precedence (Hwang et al., 2011). Financial strain can also add to caregiver burden due to the increased expense of heart failure treatment and care, often requiring caregivers to spend as much as 10% of their annual income to cover related expenses (Collins & Swartz, 2011). As these stressors compound with the patient's progressive disease, caregivers' health and mortality rate may be impacted significantly (Collins & Swartz, 2011; Kim et al., 2011).

Social isolation, defined by Hwang et al. (2011) as a lack of free time combined with little support from others, increases feelings of helplessness, which not only reduce the quality of life for the caregiver, but can subsequently lead to the patient receiving inferior care. Many caregivers report feeling "cut off" from the rest of the world or being abandoned by friends and family, putting them at greater risk for deterioration in their own health (Kim et al., 2011). One study, done by Liljeroos et al. (2014), took a qualitative approach to determine what heart

failure patients and their caregivers thought were aspects of burden. Liljeroos et al. (2014) found that many wanted relationships not only with others who experienced similar situations, but also with a provider to whom they felt personally connected. The relationship between the patient and the caregiver is also of vital importance. Stress and chronic illness can create a rift that leads to increased depression and mortality in caregivers (Liljeroos et al., 2014). As many as 70% of caregivers exhibit signs of depression, 25-50% warranting a diagnosis of major depression, and Zarit reports that many “become demoralized and exhausted” (Family Caregiver Alliance, 2006). According to a study by Lee et al. (2014), the category of caregivers with the highest levels of satisfaction are those that have a good relationship with the patient. Therefore, social support may have the ability to temper the negative effects, including anger and anxiety that being a caregiver can have (Family Caregiver Alliance, 2006; Hwang et al., 2011).

The treatment of the HF patient and their caregiver as a dyad is vitally important in the practice of healthcare professionals because the health of the patient is directly influenced by the health of the caregiver (Collins & Swartz, 2011). An essential part of this is homogenous education delivered to both patient and caregiver across the disease process and patient’s life (Liljeroos et al., 2014). This delivery of information involves the development of a relationship between the dyad and the healthcare provider, offering benefit both through social support and by decreasing the feeling of helplessness in caregivers (Hwang et al., 2011; Liljeroos et al., 2014).

To put so much emphasis on the stressors facing caregivers and interventions that can be implemented to lessen them, is not to say that burden is all that a caregiver experiences.

Caregivers report positive aspects to caregiving, including feelings of self-satisfaction, confidence, personal fulfillment, and reward for caring for someone else (Collins & Swartz, 2011; Hwang et al., 2011). Sautter et al. (2014) reported very high levels of caregiver esteem, calling it “almost universal” among participants. It is the hope of the healthcare professional that these positive aspects of caregiving might be amplified while attempts are made to reduce the negatives – to ensure good quality of life for the individual and thereby increase the effectiveness of one of the best tools available in the fight against heart failure.

Study Aims

The aim of this study was to explore how the stress factors of being a caregiver impact the emotional health, physical health, social activity, relationships, and lifestyle of the caregiver for a patient with HF.

The following research question was used in this study:

1. What is the impact of providing care to a patient with HF on the caregiver’s emotional health, physical health, social activity, relationships, and lifestyle?

Methodology

This study was conducted following approval by the University of Arkansas and Washington Regional Medical Center Institutional Review Boards (IRBs).

This project was designed as a descriptive study to explore the stress factors of caregivers caring for individuals with HF. For the purposes of this study, “stress factors” refers to the caregiver’s socio-demographic status, relationship to the patient, and the progressive nature of HF. Caregiver burden, for the purposes of this study, includes negative states in the caregiver’s emotional health, physical health, social activity, relationships, and lifestyle.

Caregiver Burden Questionnaire- Heart Failure Version 3.0

The Caregiver Burden Questionnaire – Heart Failure Version 3.0 (CBQ-HF), a quantitative survey of 26 questions covering the past four weeks of the caregiver’s experience was used to evaluate caregiver burden (Appendix A). The survey was based on previously conducted qualitative interviews of HF caregivers and uses a 5-point Likert severity scale assessing 4 domains of physical, emotional/psychological, social and lifestyle burdens using a 4-week recall period (Humphrey, Kulich, Deschaseaux, Blackburn, Maguire and Strömberg, 2013). A study by Humphrey et al. (2013) found this version to be a comprehensive and valid assessment of the factors affecting burden.

Sample

The study sample consisted of 29 individuals identified as friends or family members of a patient with HF, who provide the majority of care and did not receive financial compensation for such care. The study population was obtained through a HF clinic in Northwest Arkansas. Heart failure patients were screened by the Advanced Nurse Practitioner to determine if they met the study criteria of having an unpaid caregiver as defined in the study. If the individuals met the criteria, the patient was approached to provide consent to talk with their caregiver. The HF patient was asked to sign a patient informed consent to enter the study and a HIPAA waiver to approach their caregiver to complete the survey. Once the informed consent was obtained, the HF patient’s caregiver was approached to participate in the study. Both the HF patient and caregiver were informed of the study’s purpose, potential risks and benefits, and their ability to withdraw at any time. Informed consent was obtained from the caregiver prior to participation in the study. The caregiver burden survey was administered in paper format at

a designated, private area. The information was gathered by the researcher and transcribed to a spreadsheet that was kept in a password protected format. The hardcopies of the consent forms and surveys were kept in the principal researcher's office in a locked cabinet. All study participant information was de-identified according to the Health Insurance Portability and Accountability (HIPAA). HF patient consents, caregiver consents, and surveys were given randomized numbers which correlated with a designation in the spreadsheet so that data could be organized without impingement on participant privacy.

Statistical Analysis

Descriptive statistics of sociodemographic variables and age were calculated for HF patients using means and SE for quantitative data, and frequencies and percentages for categorical variables including sex, race, and HF classification. The caregiver relationship to the HF patient was also calculated for frequency and percentage. The Spearman's rank-order correlation was used to measure the strength and direction of the association between ordinal variables of the Caregiver Burden Questionnaire – Heart Failure Version 3.0 (CBQ-HF).

Results

Sample

Of the 31 dyads of patients and caregivers who were approached to be in the study, 28 participated. Of the 28 dyads who participated, 25 surveys were administered in the HF clinic, and 3 were given in the patient's home. In 3 instances, surveys were given to multiple caregivers of the same patient when it was determined that more than one person met the criteria for inclusion. The study included equal numbers of male and female HF patients. Of the 28 HF patients consenting to participate in the study, 26 were Caucasian (93%), 1 Hispanic (4%)

with 1 non-disclosed race. The most frequent of American Heart Association Classification of HF within the study was Class III (64%) (Table 1).

Table 1

Descriptive Statistics of Sociodemographic Variables of HF Patients

Variable	Frequency	Percent
Sex		
Male	14	50
Female	14	50
Race		
Caucasian	26	93
Hispanic	1	4
Missing Data	1	
Heart Failure Class		
I	2	7
II	4	14
III	18	64
IV	2	7

Analysis of Demographics

A Spearman's correlation determined that a statistically significant correlation existed between caregiver sex and their relationship to the patient. There was no statistically significant correlation between patient age or heart failure class and any other category.

Analysis of Individual Domains

Questions on the survey tool were broken down based on which caregiver well-being domain was measured. Domain scores were averaged to determine overall wellness in each area, with 0 being the best possible score (indicating responses of "not at all") and 4 the worst (indicating responses of "a lot"). The participants' scores by domain were then pooled, and the average scores for Total Physical Well-Being, Total Emotional Well-Being, Total Social Life and

Relationships, and Total Lifestyle were compiled. Participant's answers were compiled by domain, and then used to find the overall average score for said domain. Based on the average scores in each domain, Total Emotional Well-Being was the area most affected by being a caregiver, with an average score of 1.80 out of 4. The area least affected by being a caregiver was Total Social Life and Relationships, with an average score of 0.96. Total Physical Well-Being had an average score of 1.51, indicating less impact than Total Emotional Well-Being. Overall, the average score of all answers was 1.46 out of 4, indicating the overall health of our sample population.

Analysis of Domains

Each domain was analyzed to determine if correlations existed between them (Appendix B). There was a strong positive correlation between Total Physical Well-Being and Total Emotional Well-Being in our participants, $r_s(28) = .802, p < .01$. Other strong positive relationships existed between Total Physical Well-Being and Total Lifestyle, $r_s(28) = .637, p < .01$; Total Emotional Well-Being and Total Lifestyle, $r_s(28) = .602, p < .01$; and Total Emotional Well-Being and Total Social Life and Relationships, $r_s(28) = .401, p < .05$.

Analysis of Individual Questions

An analysis of individual questions was performed to determine the percentage of participants who answered "Somewhat" or lower or "Quite a lot" or higher, as well as the frequencies of answers. Analysis of the physical well-being domain revealed study participants demonstrated that 39% of caregivers felt that caregiving made them feel physically tired.

Analysis of the domain questions related to emotional well-being revealed that 71.4% of caregivers worried about the person for whom they cared. Every participant said that they

worried about their loved one at least a little. In contrast, 46.4% of participants said they felt neither that the patient asked too much of them as a caregiver, nor that caregiving had limited their time spent doing things for others.

The questions related to the concepts of social life and relationships had the strongest positive responses. Of the participants, 96.4% indicated that caregiving had caused few problems in their relationship with the HF patient. No participants reported their relationship had been greatly affected. Most participants (82.1%) said caregiving had limited their free time only somewhat or less, and many participants said that it had not affected it at all (9 out of 28).

The final domain looked at lifestyle changes for the caregiver. In this section, caregivers were asked how often they felt they could not be away from the patient, to which 46.4% of participants said either quite a lot or a lot of the time. On the other hand, 15 of the 28 participants (53.6%) said that caregiving had not affected their ability to do paid work.

Discussion

Domains

Upon analysis of the average total score for each category, it was clear that some areas were affected by caregiving more than others. Total Emotional Well-Being was most greatly affected by caregiving. This may be largely explained by the fact that the caregivers interviewed had a close personal connection to the patient – most caregivers were the spouse or adult child of the patient. In the case of a spouse, an individual that had shared a lifetime of mutual caring had become dependent, and the loss of autonomy was emotionally demanding for both parties. In the case of a parent, the child must see one who was once a symbol of safety and protection be forced into a role of submission and uncertainty. Every day holds the potential for

catastrophic decline in function, and the knowledge that this disease process may eventually progress to consume everything the individual once was is an excruciating burden.

Our study concluded that total social life and relationships were least affected by caregiving. One explanation for this finding was that questions in this section either asked specifically about the relationship with the patient or did not ask the respondent to think of other relationships apart from the relationship with the patient. For example, one question asked if caregiving had forced the caregiver to limit time spent with their partner, friends, or family. It could not be determined if participants distinguished between their relationship with the patient and relationships with others, as the caregiver's relationship with the patient would have fit into one of these categories. It is also possible that questions about problems in the caregiver's relationship with the patient elicited guilt. Caregivers presented to the clinic with a HF patient with the intent of talking about the patient's condition and ailments, which, in comparison, might make the caregiver's burden appear somewhat smaller. In addition, the caregiver was the one who took the effort to bring the patient to the clinic, and therefore our sample could have consisted of individuals more willing to engage in caregiving or more resilient against caregiver burden. This could be due to an intrinsic sociality in many people who are willing to be a caregiver, a large medical and nonmedical support network, or simply good planning and coping skills in our sample. Additionally, the length of time as a caregiver was not measured, which may impact the patient-caregiver relationship.

One category that showed little impact of caregiving was Total Physical Well-Being. It was initially anticipated this area would be perceived by the caregivers as a burden to the same degree or more than Total Emotional Well-Being, yet total scores for Total Physical Well-Being

were less frequently negative than Total Emotional Well-Being. One explanation might be that while a decline in physical ability is evident in many patients with heart failure, perhaps the level of physical care needed is dependent more upon the individual and their baseline functioning and comorbidities. An example of this was one participant who was 96 years old and successfully lived alone, while another in their 40s was almost totally dependent because of other comorbid conditions. Another theory is that the duties of a caregiver are sometimes more management-based (e.g. handling medications or scheduling appointments) than physical labor. The physical decline that occurs in heart failure may also be seen as a natural life occurrence common in old age, so that the caregiver does not think of it as an unexpected burden. For example, when asked if they felt the patient “asks too much of them,” one caregiver noted, “It’s not a request, it’s what needs to be done.” Finally, our sample may have consisted of individuals who had not declined physically in the disease process and required little assistance with normal activities of living and physical care.

Domain Correlations

A strong positive correlation (0.767) between emotional well-being and physical well-being was noted. As the physical demands of caregiving increase (more time needed to care for the patient, increased dependence upon caregiver for activities of daily living such as bathing and dressing), the emotional impact is also greater. When the patient reaches a point that more caregiver intervention is necessary for day-to-day activities or an increase in severity of symptoms, the caregiver is forced to acknowledge that their loved one is deteriorating.

Physical and emotional well-being demonstrated positive correlations with lifestyle (0.646 and 0.589 respectively). As physical demands increase for the caregiver, less time is

available for the caregiver's work or personal activities. As emotional burden increases, the caregiver's perception of available free time may decrease, especially if the burden is so great that the individual becomes fixated on their duties and the struggle of the patient.

Likewise, as the caregiver's emotional burden increases, their perception of personal relationships with the patient and with others may become more negative, which may explain the correlation between Total Emotional Well-Being and Total Social Life and Relationships. The caregiver may begin to feel alienated and that no one is trying to help them or the patient. As more time is required in caring for the HF patient, the caregiver may increasingly withdraw from social life or show a decreased willingness to participate in activities with friends and loved ones because of the emotional weight they carry. Alternatively, a caregiver's emotional well-being may begin to deteriorate if they receive no support from outside the patient-caregiver dyad or if their relationship with the patient becomes strained.

Total Emotional Well-Being correlated with every other category to varying degrees. This is understandable because when an individual's emotional outlook becomes more negative, their perception of every aspect of life becomes more pessimistic. A person with low emotional health may view physical requirements as more demanding, free time as more infrequent, and personal relationships as less fulfilling.

ANALYSIS OF INDIVIDUAL QUESTIONS

Total Physical Well-Being. Examining physical well-being revealed that many participants said they were physically tired quite a lot. While it would make sense that they might experience interrupted sleep or physically demanding activities to contribute to physical

tiredness, questions specifically asking about these factors returned comparatively low scores (only 17.9% responded “Quite a lot” or higher). Another potential explanation is that many stressors present themselves as fatigue, so while there was low reported burden in other areas, it could be that this indicator is a sentry for other forms of caregiver strain. This number could also be dependent upon the number of hours spent with the patient, if the caregiver lives with the patient, and if the caregiver also has a full or part time job on top of their caregiving duties.

The relatively high reports of physical tiredness caused by caregiving contrasted with other measured indicators of physical well-being. In fact, no respondents reported a high frequency of aches and pains. Part of this could be from the caregivers’ self-reporting. The survey tool specifically asks the participant to think of their condition in relation to caregiving, and when the caregiver’s own state is put in contrast to the patient’s, it is possible that their responses could be impacted.

Total Emotional Well-Being. When asked if the caregiver was worried about the patient, most caregivers answered quite a lot or a lot. The caregivers surveyed were all of close personal relation to the patient, so concern for their wellbeing and a desire to be of help are natural. Depending on the length of time that the individual had spent as a caregiver, they could have been witness to various tests and procedures, numerous hospitalizations, and physical decline that can be difficult for the patient as well as the caregiver. With the knowledge that their loved one is in a precarious health situation comes an inherent level of concern.

Only 32% of caregivers responded they felt stressed quite a lot or a lot of the time, yet all caregivers reported that they felt some stress. While few participants said that their stress was on the extreme high end of the spectrum, every caregiver felt enough stress to report it.

Forty-six per cent of respondents reported feeling emotionally drained, which could be due in part to the caregiver being close to the patient and witnessing their decline. Other contributing factors could include how long the individual has been acting as caregiver and if there was a recent history of hospitalization or medical emergency, which were not measured by this study. Many participants also reported feeling mentally tired or overwhelmed. The workload of the caregiver was not measured, but these questions gave insight into how our sample population perceived their duties. HF is a complex disease process that involves many organ systems and affects many parts of daily life. A caregiver's duties often involve management of complicated diets and medication regimens as well as maintaining contact and appointments with many different physicians, all of which contribute to the feeling of being overwhelmed and mentally fatigued.

The caregivers surveyed did not report feeling lonely or that the patient asked too much of them (89% stating somewhat or not at all). One participant wrote that while they felt their duties were numerous and demanding, the patient did not *ask* them to be a caregiver, but that they felt required by their relationship to do so. The low reports of these negative feelings also connect with the low physical demand reported by caregivers. While their duties are undoubtedly great, the absence of much physically hard work may make it feel less. Caregivers reported feeling that they received little support from family, but the amount of time spent with the patient may act as a mediating factor against loneliness in these situations. Most caregivers said that they felt caregiving caused very few problems in their relationship with the HF patient.

Total Social Life and Relationships. Based on the responses to questions related to the social life and relationship concept, the majority (96%) of respondents did not believe caring for the HF patient had caused problems with their relationship with the patient. It may be assumed that the relationship between the patient and the caregiver had strong resilience based on the nature of a person willing to hold the demanding position of caregiver. Many caregivers had known the patient for many years, and had time to build a strong relationship. Although a number of respondents said they sometimes felt lonely, the majority (89%) noted this was not an issue. The respondents also denied they received support from family or friends to any great extent (71% noted somewhat or less). These combined questions suggest the relationship between the patient and caregiver acts as a stronger buffer against loneliness and social isolation than outside support.

Total Lifestyle. Forty-six per cent of caregivers reported feeling as if they could not get away. The nature of HF makes it a disease of mountains and plateaus, meaning that a patient is often stable for a period of time followed by exacerbations and worsening of the disease. As one participant stated, "A lot can happen in congestive heart failure." Another stated it was not just the heart that is affected by this disease, but also the mind and the ability to sleep – which in turn affect every other part of life. The survey tool asked respondents to consider the past four weeks of caregiving only, which could have been during either a plateau of the disease or an exacerbation period. As one participant wrote, "He just went thru [sic] a really bad flare up of CHF – it's better now." The caregivers seemed to view their loved ones as always on the brink of decline, relating to the reported high levels of stress and worry about the patient.

The majority of caregivers did not feel their ability to do paid work was impacted by their role as a caregiver. These responses were in agreement with previous questions that determined caregivers did not feel their role as caregiver limited what they could do for others, or caused them to have limited time with friends or family or for themselves. However, another factor to consider may be that many of the caregivers surveyed were spouses of the HF patients, and so many were retired. Some who were retired were confused by the question and simply put "Not at all," writing in "Retired" in the margins.

Demographic

The only significant correlation between demographic data was between the patient's sex and their relationship to their caregiver. If the patient was female, the caregiver was most often an adult child. If the patient was male, the caregiver was most often a spouse. In general, wives outlive their husbands and are forced to rely on their children or friends for caregiving needs. In these cases, the children are at risk for role overload. The adult child of a patient usually has many other duties including a job or being a spouse, parent, or grandparent. When the caregiver is a spouse, they are usually of approximately the same age as the patient and experience their own health problems, which can be amplified by caregiving. In one instance, a HF patient expressed guilt that the responsibility of caring for him had made his wife's condition deteriorate more rapidly than it should. He also voiced concern about what would happen to him if she were to die before he did.

Interestingly, there was no correlation between the American Heart Association's heart failure classification and the patient's age or sex. Severity of heart failure, as described by heart failure class, and an increasing patient age would be expected to positively correlate with most

other determinants of caregiver well-being. As the class or age increased, we presumed that the average score for each category would also increase, indicating a greater negative effect on the caregiver. Yet this was not the case in our study. The discrepancy in age as a predictor of caregiver well-being may be explained by the common adage “age is but a number.” *Aging* is an individual process that doesn’t always correlate with a numeric scale. For example, a 96-year-old HF patient in this study was living a full and independent life. However, the class scale should be more uniformly accurate, with Class III patients (69.2% of our sample population) starting to exhibit marked limitations in physical ability. One explanation may be that by the time the patient has advanced to Class III, their caregiver has had time to adjust to the process of heart failure treatments and appointments, and has developed new life norms and coping strategies that allow them well-being comparable to caregivers of patients with lower classes of heart failure.

Overall Caregiver Burden Score

Overall, the average score of all categories combined was low, suggesting that our sample was of “healthy” caregivers with little demonstrated burden. Patients and caregivers used in this study were all located in or near a healthcare-dense area, and had access to general and specialized care that is not available to every caregiver or patient. Some participants in this study were involved in a program run by the local university where student nurses visit patients in their home once a week, providing the patient and caregiver with more support, both medical and emotional, than might be normal. These caregivers were also approached in clinic, suggesting that our sample was of patients receiving current treatment and caregivers who could be greatly involved in care. The patients approached were not hospitalized or in rapidly

deteriorating condition at the time of the survey, and could have been in a plateau phase of heart failure, a time when their caregivers' outlooks would be more optimistic. This was also a convenience sample in which those who had negative perceptions of their caregiver burden could have chosen not to participate.

Limitations

There were several limitations to our study. Our population was a very homogenous group of small sample size; of our 28 total participants, 26 were white. Eighteen of the 28 HF patients had Class III heart failure. In addition, the survey tool used asks for the participant to consider the last four weeks only. HF may be a rapidly changing condition or a slow, progressive one. The length of time since the patient's last hospitalization was not ascertained. Other aspects of caregiving that were not measured include length of time spent as a caregiver and average hours spent caregiving per week. A final limitation to the study may be the use of self-report rather than objective measures to measure self-care burden. Caregiver personality characteristics and overall outlook at the time of survey could influence reports of their own impairment when compared to objective assessment methods. Thus, self-report and objective measures should be used when measuring self-care burden and stressors.

Implications for Future Research

Previous studies have indicated that caregiving causes increased mortality in caregivers which was not addressed in our study (Schulz & Beach, 1999). While the overall average score for caregiver physical well-being was low when compared to other areas, many caregivers reported "somewhat" neglecting their own health. Future studies should include an objective measures of caregiver physical health as our study relied on caregivers to self-report, which

could have introduced biased responses. A longitudinal study of patients and caregivers over an extended period could help to determine if morbidity and mortality rates do indeed increase. The health of the caregiver is of vital importance to the outcomes of the patient. As practitioners see patients who have an informal caregiver, it is important to assess their well-being and needs as well as the patient's. One patient understood the connection between the health of the patient and caregiver, and expressed concern that his condition had caused a deterioration in his wife's health, and worried that neither would survive long without the other.

Studies indicate that most caregivers tend to be the patient's spouse (Hwang et al., 2011). Based on our sample, spouses do make up a considerable portion of caregivers, especially in the case of male patients. Another demographic to consider, however, are the adult children of female patients who frequently act as caregivers. Larger sample sizes with patients of varying ages and classes of heart failure would serve to see if this trend holds true. While the health of a caregiver should always be assessed, these two groups may have different needs and require different interventions. The spouse of a patient is typically of older age and has their own health problems to consider. An adult child is at risk for role overload and caregiver burnout because of the added responsibility of caregiving on top of their numerous other duties.

The drain on a caregiver has also been linked to the number of hours spent caregiving during the week. Kim et al. (2011) predict that as the need for a caregiver increases, the caregiver's burden does as well. The results of our study could potentially reflect this finding as many caregivers did respond that they felt "overwhelmed." However, we did not measure

hours spent caregiving per week. The measure of patient decline we used was class of heart failure, which proved to be a poor indicator of patient reliance on caregiver help. Future studies should include a caregiver estimation of the number of hours that caregiving is performed, and could also ask caregivers the nature of their duties to better gauge the caregiver's perception. Caregivers can suffer from burnout when their duties become too much to bear, and it is important that providers gauge caregiver burden and refer to sources of support like home health or respite care.

Lee et al. (2014) suggest the best outcomes for caregivers are when there is a good relationship between the caregiver and the patient. Our results concluded this may be the case because the overall health of our caregiver population was high, as was their perception of their relationships with the patients. Future studies should include questions of satisfaction with medical professionals and care received by the patient to determine if it is the patient-caregiver, medical professional-caregiver, or outside acquaintance-caregiver relationship that does the most to fight feelings of social isolation. It may be important for providers to give information to both the caregiver and patient so the translation of medical information from one party to the other does not cause strain on the relationship. Additionally, providers may make referrals to counseling services to protect this valuable relationship.

The responsibilities for providing care to the HF patient can be overwhelming, and may lead to exhaustion, depression and affect the health of the caregiver. Though the economic value of informal care-giving in the management of HF patients may be determined by the amount of money saved through avoiding rehospitalization, the overall worth of a caregiver cannot be quantified. Additional emphasis needs to be given to the preservation of these

invaluable individuals, because supporting and empowering the caregiver may improve not only their outcomes, but also the outcomes of the HF patient.

References

- American Heart Association. (2016). *Executive summary: Heart disease and stroke statistics – 2016 update: A report from the American Heart Association*. Dallas, TX: American Heart Association.
- Chin, M., & Goldman, L. (1997). Correlates of early hospital readmission or death in patients with congestive heart failure. *American Journal of Cardiology*, 79(12), 1640-1644.
- Collins, L., & Swartz, K. (2011). Caregiver care. *American Family Physician*, 83(11), 1309-1315.
- D'Alto, M., Pacileo, G., & Calabro, R. (2003). Nonpharmacologic care of heart failure: Patient, family, and hospital organization. *American Journal of Cardiology*, 91(9), 51-54.
- Family Caregiver Alliance. (2006). *Caregiver assessment: Voices and views from the field*. (Vol. 2). San Francisco, CA: Author
- Hines, A., Barrett, M., Jiang, J., & Steiner, C. (2014). *Conditions with the largest number of adult hospital readmissions by payer, 2011* (Statistical Brief # 172). Retrieved from Healthcare Cost and Utilization Project website: <https://www.hcup-us.ahrq.gov/reports/statbriefs/sb172-Conditions-Readmissions-Payer.jsp>
- Humphrey, L., Kulich, K., Deschaseaux, C., Blackburn, S., Maguire, L., & Strömberg, A. (2013). The Caregiver Burden Questionnaire for Heart Failure (CBQ-HF): Face and content validity. *Health and Quality of Life Outcomes*, 11(84). Retrieved from <http://www.hqlo.com/content/11/1/84>

- Hwang, B., Fleischmann, K., Howie-Esquivel, J., Stotts, N., & Dracup, K. (2011). Caregiving for patients with heart failure: Impact on patients' families. *American Journal of Critical Care, 20*(6), 431-440.
- Kim, H., Chang, M., Rose, K., & Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing, 84*6-854.
- Krumholz, H., Butler, J., Miller, J., Vaccarino, V., Williams, C., de Leon, C., Seeman, T., Kasl, S., & Berkman, L. (1998). Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation, 97*, 958-964.
- Lee, C., Vellone, E., Lyons, K., Cocchieri, A., Bidwell, J., D'Agostino, F., ... Riegel, B. (2014). Patterns and predictors of patient and caregiver engagement in heart failure care: A multi-level dyadic study. *International Journal of Nursing Studies, 52*, 588-597.
- Liljeroos, M., Ågren, S., Jaarsma, T., & Strömberg, A. (2014). Perceived caring needs in patient-partner dyads affected by heart failure: A qualitative study. *Journal of Clinical Nursing, 23*, 2928-2938.
- Luttik, M., Jaarsma, T., Veeger, N., Tijssen, J., Sanderman, R., & van Veldhuisen, D. (2007). Caregiver burden in partners of heart failure patients: Limited influence of disease severity. *The European Journal of Heart Failure, 9*, 695-700.
- Murberg, T., Bru, E., Aarsland, T., & Svebak, S. (1998). Functional status and depression among men and women with congestive heart failure. *International Journal of Psychiatry in Medicine, 28*(3).

Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in

psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267.

Sautter, J., Tulskey, J., Johnson, K., Olsen, M., Burton-Chase, A., Lindquist, J., ... Steinhauser, K.

(2014). Caregiver experience during advanced chronic illness and last year of life. *Journal of the American Geriatrics Society, 62*, 1082-1090.

Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The Caregiver Health

Effects Study. *Journal of the American Medical Association, 282*(23), 2215-2219.

Stewart, S., MacIntyre, K., Hole, D., Capewell, S., & McMurray, J. (2001). More 'malignant' than

cancer? Five-year survival following a first admission for heart failure. *The European Journal of Heart Failure, 3*, 315-322.

Vitlsaliano, P., Zhang, J., & Scanlan, J. (2003). Is caregiving hazardous to one's physical health? A

meta-analysis. *Psychological Bulletin, 129*(6), 946-972.

Appendix A
The Caregiver Burden Questionnaire- Heart Failure 3.0 (CBQ-HF)

Questions by Domain During the past 4 weeks.....	Frequency (percent)				
	Not at all	A little	Somewhat	Quite a lot	A lot
Physical Well-Being					
How much has caregiving made you feel <i>physically tired</i> ?	3 (10.7)	7 (25)	7 (25)	8 (28.6)	3 (10.7)
How much as caregiving made you <i>neglect your own health</i> ?	8(28.6)	6 (21.4)	10(35.7)	3(10.7)	1(3.6)
How much as caregiving been <i>physically hard work</i> ?	5(17.9)	11(39.3)	7(25)	2(7.1)	3(10.7)
How much as caregiving made it <i>difficult to sleep</i> ?	9(32.1)	8(28.6)	6(21.4)	2(7.1)	3(10.7)
How much as caregiving caused you <i>aches and pains</i> ?	11(39.3)	6(21.4)	4(14.3)	7(25)	0 (0)
Emotional Well-Being					
How much have you felt like you <i>need to do more</i> for the person you care for?	1(3.)	9(32.1)	7(25)	7(25)	4(14.3)
How much have you felt the person you care for <i>asks too much</i> of you?	13(46.4)	5(17.9)	7(25)	1(3.6)	2(7.1)
How <i>guilty</i> have you felt because the time you spent caregiving <i>limited</i> what you can <i>do for others</i> ?	13(46.4)	7(25)	4(14.3)	3(10.7)	1(3.6)
How <i>guilty</i> have you felt because you <i>cannot do enough</i> for the person you care for?	8(28.6)	6(21.4)	4(14.3)	4(14.3)	6(21.4)
How much as caregiving made you feel <i>frustrated</i> ?	4(14.3)	10(35.7)	7(25)	4(14.3)	5(17.9)
How much has caregiving made you feel <i>stressed</i> ?	1(3.6)	11(39.3)	7(25)	4(14.3)	5(17.9)
How much has caregiving made you feel <i>sad</i> ?	8(28.6)	8(28.6)	6(21.4)	5(17.9)	1(3.6)
How much has caregiving made it <i>difficult to focus or concentrate on other things</i> ?	2(7.1)	10(35.7)	8(28.6)	7(25)	1(3.6)
How much has caregiving made you <i>worry</i> about the person you care for?	4(14.3)	4(14.3)	10(35.7)	10(35.7)	0(0)*
How much has caregiving made you feel <i>mentally tired</i> ?	3(10.7)	8(28.6)	5(17.9)	8(28.6)	3(10.7)*
How much as caregiving made you feel <i>emotionally drained</i> ?	4(14.3)	6(21.4)	5(17.9)	11(39.3)	2(7.1)
How much has caregiving made you feel <i>overwhelmed</i> ?	2(7.1)	11(39.3)	2(7.1)	11(39.3)	2(7.1)
How much has caregiving made you feel <i>lonely</i> ?	13(46.4)	7(25)	5(17.9)	2(7.1)	1(3.6)

Questions by Domain During the past 4 weeks.....	Frequency				
	Not at all	A little	Somewhat	Quite a lot	A lot
How much <i>support</i> have you had from family or friends?	5(17.9)	11(39.3)	4(14.3)	5(17.9)	3(10.7)
How much have you <i>enjoyed</i> caregiving?	1(3.6)	3(10.7)	11(39.3)	6(21.4)	7(25)
Social Life & Relationships					
How much has caregiving caused problems in your relationship with the person you care for?	16(57.1)	7(25)	4(14.3)	1(3.6)	0(0)
How much has caregiving limited the time you spend with partner, family, or friends?	9(32.1)	8(28.6)	6(21.4)	4(14.3)	1(3.6)
Lifestyle					
How much have you felt like you have no time for yourself?	5(17.9)	9(32.1)	9(32.1)	3(10.7)	2(7.1)
How much has caregiving caused you to change your plans or make you avoid making plans?	4(14.3)	9(32.1)	8(28.6)	6(21.4)	1(3.6)
How much have you felt you cannot be away?	4(14.3)	5(17.9)	6(21.4)	7(25)	6(21.4)
How much has caregiving made it difficult to do paid work?	15(53.6)	7(25)	2(7.1)	4(14.3)	0(0)

*One missing response

Appendix B
Spearman's Correlation by Well-Being Domain

Correlations

			Total Physical Well-Being	Total Emotional Well-Being	Total Social Life and Relationships	Total Lifestyle
Spearman's rho	Total Physical Well-Being	Correlation Coefficient Sig. (2-tailed) N	1.00 . 28	.767** .000 28	.270 .164 28	.646** .000 28
	Total Emotional Well-Being	Correlation Coefficient Sig. (2-tailed) N	.767** .000 28	1.000 . 28	.423* .025 28	.589** .001 28
	Total Social Life and Relationships	Correlation Coefficient Sig. (2-tailed) N	.270 .164 28	.423* .025 28	1.000 . 28	.173 .377 28
	Total Lifestyle	Correlation Coefficient Sig. (2-tailed) N	.646** .000 28	.589** .001 28	.173 .377 28	1.000 . 28

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).