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Caregiving for Patients with Heart Failure: The Impact on Family Members

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Caregiving for Patients with Heart Failure: The Impact on Family Members

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Caregiving for Patients with Heart Failure: The Impact on Family Members

Boyoung Hwang, RN, PhD

Abstract

Heart failure (HF) is a chronic progressive condition, with debilitating symptoms. Despite the pivotal role family caregivers play in the care of HF patients, family caregiving has received little attention in HF research.

The primary aims of this dissertation were to describe the nature of family caregiving in the context of heart failure (HF) and to identify factors associated with the impact of caregiving. A particular focus was on the positive aspect of caregiving and the role of social support on the impact of caregiving. This dissertation includes a review of the literature and findings from three research studies.

The first study is a secondary analysis of data from 338 partners of HF patients and 1202 partners of healthy individuals. Care tasks performed by partners were compared between the two groups. Partners of HF patients were more likely to provide personal care and emotional care than partners of healthy individuals, even when only non-HF-specific care tasks were investigated.

In the second study, data were obtained from 76 HF patient-family caregiver dyads. Caregiving had both positive and negative impact on family caregivers. The level of caregiver perceived control and social support were important factors in the impact of caregiving measured with the Caregiver Reaction Assessment. The severity of HF and patients' clinical events were also associated with the impact of caregiving.

In the third study, family caregiving was examined in the context of a specific etiology of HF, pulmonary arterial hypertension (PAH). Among the 35 family caregivers of PAH patients in the study, 14% were identified as having moderate to severe depressive symptoms. Most caregivers were involved in managing care for the patient and helped the patient with self-management activities. Lower level of social support was significantly associated with more severe depressive symptoms in caregivers.

The role of family caregivers becomes increasingly important with the rising prevalence of HF and increased emphasis on self-management. The needs of family caregivers should not be overlooked in clinical practice. Social support and information to meet the demands of caregiving need to be provided to family caregivers in order to optimize the caregiving experience.

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Chapter 1

Introduction

Background

The Burden of Heart Failure

Cardiovascular disease (CVD) is a serious problem affecting 81 million people in the United States, with more than one in three American adults having one or more types of CVD (Lloyd-Jones, et al., 2010). While CVD accounts for 34% of all deaths and has been the number one cause of death in the United States since 1900, mortality rates for CVD, especially for coronary heart disease, have decreased as a result of advances in treatment, including secondary prevention after myocardial infarction and revascularization (Ford, et al., 2007; Lloyd-Jones, et al., 2010). The decline in CVD mortality in combination with the aging of the US population has consequently led to increases in the incidence and prevalence of heart failure (HF) (Mosterd & Hoes, 2007). Recent statistics provided by the American Heart Association indicate that each year 10 per 1000 persons over 65 years of age are newly diagnosed with HF, and HF currently affects a total of 5.8 million Americans (Lloyd-Jones, et al., 2010).

HF is a chronic progressive condition characterized by a constellation of signs and symptoms caused by cardiac dysfunction, including dyspnea, reduced exercise tolerance, and fatigue. Despite the advances in treatment for HF, the prognosis remains poor and is even referred to as being more malignant than cancer (Mosterd & Hoes, 2007). In addition, serious complications accompany the frequent acute exacerbations of HF. Therefore, the trajectory of HF is summarized as an overall gradual decline in function punctuated by episodes of acute deterioration requiring increased support and utilization of hospital care, eventually resulting in a seemingly unexpected death (Goldstein & Lynn, 2006; Jaarsma, et al., 2009). The devastating symptoms, poor prognosis, and unpredictable trajectory make assistance from family members essential in the care of patients with HF. Furthermore, support from family caregivers contributes to better outcomes for HF patients, such as better physical and emotional well-being and quality of life as well as to lower hospitalization and mortality rates (Bennett, et al., 2001; Coyne, et al., 2001; Krumholz, et al., 1998; Luttik, Jaarsma, Veeger, & van Veldhuisen, 2006).

The Impact of Caregiving on Families

Unfortunately, however, caring for a chronically ill family member can be challenging. As shown in the meta-analysis of studies comparing physical and mental health between caregivers and non-caregivers, there is sufficient evidence that caregivers experience stress related to their responsibilities, have low physical and emotional well-being, and suffer from chronic illnesses including depression (Pinquart & Sorensen, 2003). Moreover, in a four-year follow-up study, caregivers experiencing stress had higher mortality rates than non-caregivers (Schulz & Beach, 1999). Consequently, a great deal of attention has been paid to the levels of stress and burden on caregivers of patients with dementia, Alzheimer’s disease and stroke and to the development of interventions to prevent detrimental outcomes in these caregivers (Brodaty & Donkin, 2009; Rigby, Gubitz, & Phillips, 2009; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007).

Unlike in other chronic diseases, only a limited number of studies examining the impact of caregiving on individuals caring for patients with HF have been reported, with no intervention studies aimed to ease burden in this caregiver population conducted to date (Molloy, Johnston, & Witham, 2005). The findings from previous studies are consistent in that many caregivers of patients with HF have difficulties in performing caregiving tasks (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006; Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007; Pressler, et al., 2009; Scott, 2000) and experience anxiety and depression (Barnes, et al., 2006; Boyd, et al., 2004; Hooley, Butler, & Howlett, 2005; Luttik, Lesman-Leegte, & Jaarsma, 2009; Martensson, Dracup, Canary, & Fridlund, 2003; Molloy, et al., 2006; Pihl, Jacobsson, Fridlund, Stromberg, & Martensson, 2005; Pressler, et al., 2009; Saunders, 2008; Scott, 2000). However, inconsistent results regarding the health status of caregivers of patients with HF in comparison with the general population warrant further investigation (Bakas, et al., 2006; Dracup, et al., 2004; Martensson, et al., 2003; Pihl, et al., 2005). In addition, more research is needed to identify factors associated with the levels of burden and emotional well-being in this population because of inconsistent findings from previous studies, including those regarding the association of caregiver burden (Barnes, et al., 2006; Karmilovich, 1994) and caregiver depression (Martensson, et al., 2003; Saunders, 2008) with patient NYHA class and the association between emotional well-being and caregiver age (Bakas, et al., 2006; Dracup, et al., 2004; Pihl, et al., 2005).

Lastly, although caregiving is often stressful and exhausting, it is important to note that caregiving has positive aspects. The positive aspects are conceptualized as caregiver esteem, uplifts, and satisfaction (Hunt, 2003; Kramer, 1997). Most previous studies of caregivers of HF patients focused on the burden or stress of these caregivers. However, an increasing number of studies show that caregivers of HF patients report that their relationship with the patient was enhanced as a result of caregiving and that they felt rewarded to be able to do things for their loved one (Luttik, et al., 2007; Saunders, 2008; Scott, 2000, 2001). Therefore, the positive aspects of caregiving should not be neglected in research.

Theoretical Framework

While frameworks within the stress and coping paradigm are considered to be dominant in caregiving research (Biegel, et al., 1991; Schulz & Sherwood, 2008), there in fact remains no consensus about the most appropriate theoretical approach to use to guide practice and research on family caregiving. The caregiver stress-coping model proposed by Biegel and colleagues (1991) was chosen as the theoretical framework for this dissertation (Figure 1). One of the strengths of the caregiver stress-coping model is that it incorporates important concepts omitted in other theoretical frameworks, such as structural variables, while keeping its structure relatively simple and clear so that the relationships contained in the model can be empirically tested. The model, based on the stress and coping paradigm, has been elaborated upon and used as a theoretical guide in many caregiving research studies with various samples of caregivers, including caregivers of patients with spinal cord injury, stroke, Alzheimer's disease, and mental illness (Biegel, Milligan, Putnam, & Song, 1994; Biegel, et al., 1991; MacMaster, 2006; Schulz, Tompkins, & Rau, 1988; Schulz, Tompkins, Wood, & Decker, 1987; Song, et al., 1997).

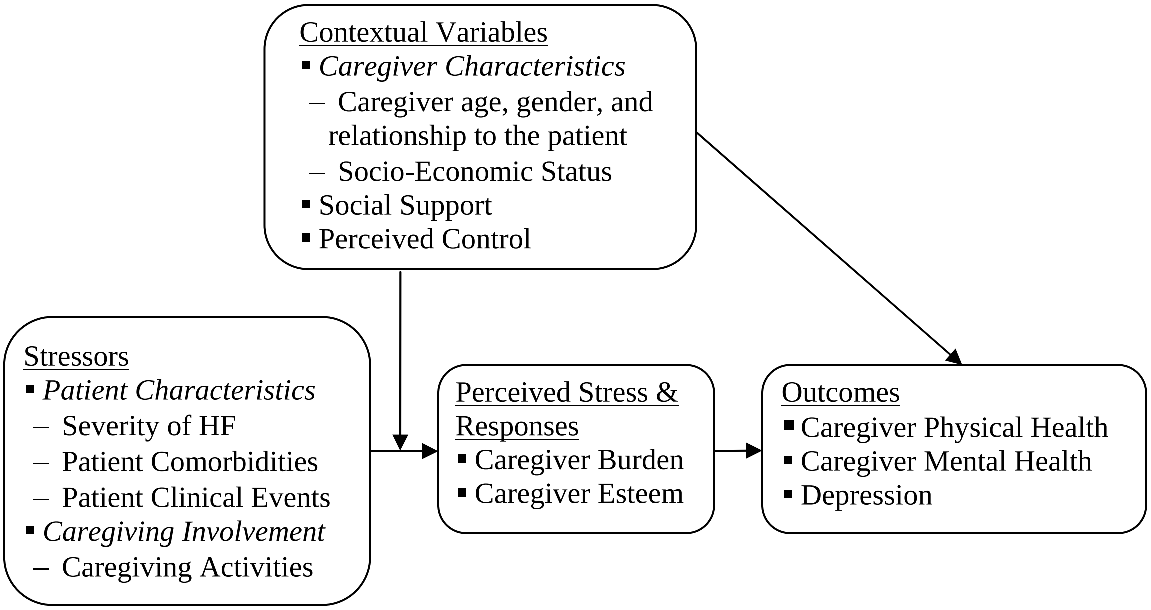

Figure 1

Caregiver Stress-Coping Model (Biegel, Sales, & Schulz, 1991; MacMaster, 2006; Song, Biegel, & Milligan, 1997)

The variables in the caregiver stress-coping model are summarized into four categories: (a) stressors, (b) contextual variables, (c) caregiver burden/stress, and (d) enduring outcomes (Song, et al., 1997). In general, stressors are defined as any environmental, social, or internal demands which exceed an individual’s abilities and require the individual to readjust his or her usual behavior pattern (House, 1974; Thoits, 1995). In caregiving situations, the illness or patient characteristics and caregiving involvement represent objective stressors to family members. The illness can be characterized by a wide range of dimensions including patients’ functional limitations, cognitive impairment, behavioral problems, and symptomatology (Biegel, et al., 1991; Schulz, et al., 1987; Song, et al., 1997). Care activities performed and time spent on providing care represent the degree of the patient’s disability and are viewed as stressors to family caregivers (Schulz, et al., 1987).

Many factors, besides the stressors discussed above, can contribute to caregiver outcomes. In the caregiver stress-coping model, these are called contextual or conditioning variables and are defined broadly to include characteristics of caregivers, social support systems of caregivers, as well as personality attributes such as orientation toward control (Biegel, et al., 1991; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000; Schulz, et al., 1988). These variables can have direct effects on caregiver burden and enduring outcomes, and some of these contextual variables, such as social support, can be treated as interactive conditioning factors that moderate the relationships between stressors and their impact on caregivers (Biegel, et al., 1991).

Caregiver stress or burden is the central feature of caregiving research. It is often treated as the primary outcome or as a mediator between stressors and other outcomes such as caregiver depression or well-being (Biegel, et al., 1991; Sales, Greeno, Shear, & Anderson, 2004). Caregiver burden is defined as the physical, psychological, emotional, social, and financial problems experienced by individuals caring for their family members with chronic illness (Biegel, et al., 1991; George & Gwyther, 1986; Given & Given, 1991; Zarit, Reever, & Bach-Peterson, 1980). That is, caregiver burden refers to not only an individual’s subjective perception of overload but also personal reactions to caregiving (Chou, 2000).

Lastly, enduring outcomes are the cumulative consequences of being exposed to the stresses of caregiving, which include physical health, mental health, and depression. These outcomes are distinguished from caregiver burden in that they are affected by both caregiver burden and many other factors (Biegel, et al., 1991).

Dissertation Aims

The goal of this dissertation is to describe the nature of family caregiving in the context of HF with a focus on identifying factors associated with the impact of caregiving among family caregivers of patients with HF. This dissertation is divided into six chapters.

Chapter 1 provides an introduction to the dissertation and presents a brief background, the theoretical framework, and an overview of the dissertation.

Chapter 2 is a comprehensive review of the current research related to issues in HF family caregiving. Important gaps in current knowledge are identified with a particular focus on caregivers' perspectives.

Chapter 3 presents the findings of a research study comparing care activities performed by spouses of HF patients with care activities performed by spouses of healthy older individuals. The kind and amount of care are compared between the two groups and gender differences in the performance of care tasks are also examined.

Chapter 4 presents the research findings of a cross-sectional study, describing the levels of perceived physical and mental health status and depression, types of performed care tasks, social support, and impact of caregiving among family caregivers of HF patients. The research findings highlight factors associated with the impact of caregiving and the moderating effects of social support on the impact of caregiving.

Chapter 5 presents the results of a subgroup analysis focusing on caregiving in pulmonary arterial hypertension (PAH) which is one etiology of right-sided HF. The chapter provides information on the characteristics of family caregivers of patients with PAH and the impact of caregiving on these caregivers. Care tasks that these family caregivers frequently perform and the association between caregiver depression and social support are also discussed.

Chapter 6 summarizes the findings of the research studies on family caregiving in HF. The chapter also presents clinical and social implications and recommendations for future research.

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Chapter 2

Family Caregivers of Patients with Heart Failure: A Review of the Literature

ABSTRACT

Family caregivers play a significant role in the care of patients with heart failure (HF). Although assistance and support from family caregivers contributes to better outcomes for HF patients, providing care for a family member influences the caregiver's life. Thirty three studies (published between 1994 and 2009) on family caregiving in the context of HF were reviewed. Many caregivers of HF patients were distressed and socially isolated, had poor physical and emotional well-being, and experienced anxiety and depression. Factors related to caregiver burden, poor emotional well-being, and depression included lack of family support, low income, caregivers' poor physical health, and patients' and caregivers' own poor emotional well-being. Important gaps in current knowledge are presented and suggestions for future research are made. The information from this review will provide a guide for future research as well as for clinicians working with HF patients.

Introduction and Significance

Currently, 5.8 million people have heart failure (HF) in the United States and the incidence and prevalence of HF increase each year.[1] Patients with HF often need assistance from family members in their activities of daily living due to their symptoms such as dyspnea, reduced exercise tolerance, and fatigue.[2, 3] Support from family caregivers is related to better outcomes for patients with HF, including lower hospitalization and mortality rates, better physical and emotional well-being, and improved quality of life.[4-7] Yet, the caregiver role places a significant burden on caregivers. Family caregivers of patients with chronic diseases experience dramatic changes in their everyday life because of their caretaking role. Their physical and mental health status is often compromised.[8] Stress related to caregiving also contributes to mortality among older spousal caregivers.[9]

Unlike other chronic diseases such as dementia, stroke, and cancer, little attention has been given to issues surrounding family caregiving in the context of HF. The importance of the family’s role in caregiving has recently become increasingly recognized in HF patient care. However, most studies have focused on the benefit of caregiving in terms of outcomes of HF patients as reflected in two comprehensive reviews.[10, 11] Surprisingly, few studies have focused on the experience and needs of HF family caregivers. In addition, family caregivers’ emotional needs have been neglected in relationships with health care professionals. Caregivers feel that they do not have adequate support for their caring role or for their added responsibilities in the care of their family member with HF.[12-15]

The aims of this paper are to provide a comprehensive review of the current research related to issues in HF family caregiving and to identify important gaps in current knowledge with a particular focus on caregivers' perspectives. Recommendations for future research are also discussed. Ultimately, it is hoped that the knowledge obtained through this review will guide research on HF family caregiving and contribute to the development of diverse services for patients with HF and their family caregivers.

Search Strategies

Three databases were utilized in the literature search, including PubMed, CINAHL Plus, and PsycINFO. Due to the relatively new emphasis on this topic in the literature, the publication dates were not limited. All literature published prior to the search being undertaken (October 2009) was included. Combinations of the following keywords and subheadings were used: *caregiving, caregiver, carer, spouse, partner, and heart failure.* The search yielded 353 potentially relevant articles, excluding duplicates. The abstracts of these 353 articles were reviewed. Forty-four potentially relevant articles were selected based on the following criteria: (a) published in peer-reviewed journals, (b) published in English, (c) involved family caregivers, and (d) focused on HF rather than chronic diseases, palliative care, or transplants. Studies of general social support rather than family caregiving were excluded. Abstracts, reviews, and editorials were also excluded. Because two groups of researchers recently reviewed studies that examined the benefit of family support on outcomes of HF patients,[10, 11] 11 studies with a focus only on HF patient outcomes were excluded in the current review. The references for the articles selected were also reviewed, but no additional articles were identified. Therefore, the final review included 33 articles. The characteristics of the study samples are summarized in Table 1. In the literature search, it was noted that no studies of HF family caregiving were published until 2000 after the first study was published in 1994. This clearly illustrates that HF family caregiving has attracted growing attention in the last decade.

Review of Current Research

Impact of Caregiving on Family Caregivers of HF Patients

Providing care for a loved one with HF has multiple consequences on the caregiver's life. Caregivers of HF patients were distressed,[16] had low emotional well-being compared to the general population,[17, 18] and often experienced anxiety and depression.[12, 15, 19]

Depression

Instruments with cut-off points for depression were used to identify the prevalence of depression in family caregivers of HF patients in nine studies, which excluded studies based on the same data set as another study in the review. The percentage of HF family caregivers identified as depressed ranged between 14% and 64% of the study samples. This wide range seems to be related to instruments used and the varying samples. Study samples differed in terms of characteristics that might be related to depression, such as the caregivers' age and gender as well as the severity of the patients' HF. In six studies, approximately 15% to 20% of the caregivers were depressed.[20-25] A much higher prevalence of depression in caregivers was reported in three other studies.[18, 26, 27] In one study, 50% and 45% of the caregivers had anxiety and depression respectively.[18] The high prevalence of anxiety and depression can be explained by the fact that these caregivers were providing care for end-stage HF patients. However, the severity of patients' HF may not explain the high prevalence of depression in a second study. Pihl et al.[26] reported that 60% of patients with HF and 47% of their spouses were mild to severely depressed, when 51% of the patients had New York Heart Association (NYHA) class II symptoms.[26] The depression prevalence in HF patients was much higher in this study compared with the 22% that was calculated in a meta-analysis of 27 studies on depression in HF patients.[28] The prevalence of depression among patients with HF varied by study depending on the method used to assess depression (clinician assessment vs. self-report), the instrument used to diagnose depression, the severity of HF, and the patient's hospitalization status.[28] These factors may explain the higher prevalence of depression among HF patients and their caregivers in the study by Pihl and colleagues.[26] Interestingly, a higher percentage (64%) of depressed family caregivers was reported in a study with a higher proportion of adult child caregivers in the sample[27]compared with other studies whose samples consisted mainly of spousal caregivers. However, any conclusion is premature for the reasons addressed above and because the samples of these studies were non-representative.

Physical Health

Caring for a family member with chronic disease can also affect the physical health of family caregivers.[8, 9] In six studies, the perceived health status of HF family caregivers was measured by instruments whose scores can be compared with norms from the general population.[17, 22, 26, 29-31] HF family caregivers' perceived health status was much lower than that of the general population in three studies,[17, 22, 29] but did not differ from that of the general population in the other three studies.[26, 30, 31] Interestingly, Luttik et al.[25] found no difference in the perceived physical health status between spousal caregivers of HF patients and individuals living with a healthy partner, but they found a difference by gender. The health status of male caregivers did not differ from that of men living with a healthy partner, whereas female caregivers perceived their physical health to be worse than women living with a healthy partner. Changes in caregivers' health status were examined in two recent studies.[24, 32] The health status of family caregivers of HF patients was poor at baseline and remained unchanged[24] or declined slightly[32] over time. In other studies, the physical health status of HF family caregivers was assessed by asking caregivers whether they had any health problems. One third of family caregivers of HF patients reported having two or more medical conditions,[14, 18, 20] and many caregivers were hospitalized or visited an emergency care setting for their own medical problems.[21, 27]

Physical symptoms experienced by HF family caregivers were examined in several studies. In a study by Scott,[18] 39% of caregivers for end-stage HF patients reported constant fatigue. Thirty six percent of family caregivers for HF patients reported ongoing sleep disturbances.[27] Changes in sleep and dietary patterns[19] as well as physical exhaustion[33] were also reported in qualitative studies.

Social Isolation

Social isolation was repeatedly identified as one of the problems experienced by family caregivers of HF patients. Due to the fear of symptom exacerbation and the unpredictability of its onset, both HF patients and their caregivers restricted their social activities, and therefore became socially isolated.[13, 15, 20, 33] Isolation was also caused by caregivers not having enough time for family or social activities due to their care responsibilities.[19, 29]

Relationship Change

Changes in the relationship between patients and their family caregivers were described in several qualitative studies, with changes being more prominent in marital relationships. Roles within the relationship between patients and their spouses changed due to HF. Because of the patient's HF symptoms, spouses had to assume responsibilities for tasks to which they were not accustomed, and patients felt guilty for not being able to assume their former roles in the relationship.[12, 13, 15, 19, 20, 33] Spousal caregivers also expressed difficulties in communicating with their spouse with HF and in their sex lives.[15] While the negative influences of HF on the relationship between patients and their spouses were emphasized in many studies, positive changes were also noted.[15, 16]

Changes in Quality of Life

Caring for a family member with HF compromises the physical, mental, and social health of the family caregiver and imposes relational and financial burdens on the family. All of this can be summed up as changes in the quality of life for family caregivers. The overall quality of life of spouses of HF patients was poorer compared to the norms in the general population.[34] Family caregivers reported better quality of life than did patients when patients were at home.[18, 34] But, the quality of life of the spouse was lower than the patient's when the patient was hospitalized.[34] This suggests the need for supporting family caregivers while patients are receiving hospital care.

Factors Associated with HF Caregiver Outcomes

Various aspects of caregiver outcomes have been studied in caregiver research, including physical health, emotional well-being, depression, quality of life, caregiver burden, health care utilization, coping styles, and relationship strain between caregivers and patients. The current review focused on the three most often studied caregiver outcomes: caregiver burden, caregiver emotional well-being, and depression. Table 2 is a summary of the factors related to these caregiver outcomes.

Factors Associated with Caregiver Burden

In order to identify the most vulnerable populations among caregivers, many researchers have examined caregiver characteristics in relation to caregiver burden. In several studies, caregiver burden was associated with caregiver depression[20, 21, 27] and poor mental health.[30] However, the direction of the association between these factors and caregiver burden cannot be discerned due to the cross-sectional design of the studies. Caregivers' financial status was another factor associated with caregiver burden. Higher caregiver burden was related to caregivers' low income status.[21] Results were inconsistent regarding the association between caregiver gender and caregiver burden. While Molloy et al.[35] reported that female caregivers had higher levels of caregiver burden than male caregivers, Saunders[27] found no significant relationship between caregiver gender and caregiver burden.

Characteristics of patients with HF were also explored in relation to caregiver burden. The patient's lower perceived functional status was related to higher caregiver burden.[30] However, the associations of patients' comorbidity and NYHA class to caregiver burden are inconsistent. HF patients' higher comorbidity was related to higher caregiver burden in one study,[27] but not in another.[30] While higher NYHA class was related to higher caregiver burden in one study,[20] no significant relationship was found between them in the other study.[14] A difference between these two study samples is that the patients in the former study had NYHA class I through IV HF (56% class I or II),[20] whereas the latter study only included patients with NYHA class III or IV HF.[14]

Associations between caregiver burden and various factors related to caregiving itself were examined. More caregiving hours and lack of a respite caregiver were associated with higher caregiver burden.[27] High caregiver burden was also related to providing personal care to the patient.[30] These results suggest that providing assistance with caregiving tasks could reduce the burden for family caregivers of HF patients.

Factors Associated with Caregiver Emotional Well-being

Caregiver emotional well-being was closely related to the emotional well-being of the patient[16, 36] and the caregiver's own health problems.[20] Two groups of researchers reported that female caregivers were more distressed than male caregivers,[16, 25] while no difference in the level of caregiver emotional well-being was found by gender in a third study.[36] Among female caregivers, caregivers who provided personal care for their family member with HF reported lower emotional well-being than those who did not. However, this difference was not documented in male caregivers.[37]

In addition, caregivers' poor emotional well-being was associated with a poor marital relationship[16] and lower perceived control over the family member's heart problems.[17, 29] Studies showed inconsistent results regarding the association between caregiver age and emotional well-being. In two studies with relatively young caregivers, younger caregiver age was associated with worse emotional well-being,[17, 29] while there was no association in a third study with older caregivers.[26]

Factors Associated with Caregiver Depression

Depression is prevalent in family caregivers of HF patients. Caregivers were more depressed when they perceived little family support and their family member with HF had more comorbidities.[38] Although, in general, the prevalence of depression is higher in women than in men,[39] results are inconsistent regarding the relationship between caregiver gender and depression. While female caregivers had higher anxiety and depression scores than male caregivers in one study,[16] the level of depressive symptoms in caregivers did not differ by gender in others.[21, 40]

Inconsistent results were also found in the associations between caregiver depression and characteristics of patients, such as patient age, depression, and NYHA class. Among young couples, younger patient age was a significant predictor of spousal depression,[22] whereas it was associated with higher patient age in older HF patients.[26] Further research is warranted to confirm the relationship between caregiver depression and patient age, controlling for other factors, such as patients' functional status and caregiver gender. The association of patient depression with caregiver depression also needs further investigation. While a significant relationship between patients' and caregivers' depression was reported in one study,[26] no significant relationship was found in others.[21, 22]

The relationship between patients' NYHA class and caregiver depression is another factor which has yielded conflicting results. While patients' NYHA class did not have a significant relationship with caregiver depression in one study,[26] caregiver depression was associated with higher NYHA class in a second study.[27] The contradictory results may be due to the differences in the study samples. In the first, all of the caregivers were spouses with an average age of 75 years, whereas in the second, half were adult children with an average age of 58 years.

The Nature of Family Caregiving in HF

In the first study of its kind, Karmilovich[14] examined the burden and stress related to spousal caregiving for HF patients and demonstrated that physical caregiving was eclipsed by emotional caregiving. Luttik et al.[30] also reported that caregiving had less impact on the caregiver's own daily activities and physical health in the context of HF compared to caregivers of patients with stroke or rheumatoid arthritis. Caregivers of stroke patients performed more tasks related to personal care, such as bathing and dressing, whereas household tasks, treatment related tasks, and emotional support were prominent in the care of HF patients. It was also noted that while the tasks differed, the burdens faced by spouses of HF patients were comparable to the burdens of spouses of cancer patients.

The findings of a recent qualitative study by Clark et al.[41] are in line with the results from the previous studies. The investigators identified two types of caring activities performed by HF family caregivers: visible and invisible caring. Visible caring refers to the observable activities that family caregivers perform, including meeting the patient's personal needs and medication management. Invisible caring includes surveillance, monitoring, and assessment of signs and symptoms. Future research that explores the unique demands of HF caregiving, especially as related to emotional support for patients and invisible caregiving activities, is needed.

Needs of Family Caregivers of HF Patients

Family caregivers face a multitude of challenges in providing care for their family member with HF, but they do not receive enough support from other family members or from health care professionals.[14] Although caregivers were aware of the importance of their own self-care, they could not meet their own needs because of the challenges of meeting the needs of the patient, performing complex tasks, and dealing with psychological and financial burdens.[19] They also had difficulties in performing caregiving tasks such as: changes in the daily schedule, financial problems, household tasks, tasks related to the patient's treatment, and managing the patient's emotional distress.[15, 18, 24, 29]

Lack of support from health care professionals was repeatedly discussed in qualitative studies. HF patients and their family caregivers felt that they did not have adequate professional support.[13] While family caregivers felt positive about their caregiving experiences when they were included in patient care,[42] they did not always feel involved in patient care in health care settings.[15] Family caregivers felt that they did not receive adequate educational preparation for the care they provided[19] and expressed the need for individualized information about the prognosis and management of HF.[12, 13, 15, 41]

Limitations of Current Research and Suggestions for Future Research

Limited View of the Caregiving Experience

The majority of previous studies in HF caregiving have explored only certain aspects of the caregiving experience, including the caregiver's emotional well-being, burdens, stress, and demands, which are all based on the assumption that caregiving has only a negative impact on caregivers. However, several studies revealed positive aspects of caregiving. Family caregivers of HF patients felt privileged to be the patient's caregiver. They felt satisfied and rewarded by being able to care for their loved one.[19, 27] Some spousal caregivers felt that their marital relationship had improved during the course of the illness.[15, 16] In a study of caregivers for end-stage HF patients, all of the caregivers expressed a desire to provide care, and most of them felt positive about their role as a caregiver despite the complicated care required for their loved one.[18] Therefore, research is needed to address not only the negative impact of caregiving on caregivers' lives but also the positive aspects of the experience in order to have a comprehensive understanding of HF caregiving.

Measurement of the Caregiving Experience

A few problems were evident in the current review regarding measurement. The caregiving experience has been defined in positive ways such as caregiver esteem and satisfaction as well as negative ways such as burden, stress, strain, and demands. The term "caregiver appraisal" has been used as a neutral term to incorporate both positive and negative aspects.[43] In addition, caregiver burden is considered to have two aspects, subjective and objective burden. Subjective burden refers to the feelings aroused in caregivers as they fulfilled their caregiving functions, whereas objective burden refers to the events and activities associated with the caregiving experience.[44, 45] Therefore, depending on its definition, various instruments have been used to measure the caregiving experience.[46, 47] In the current review of 33 studies, the caregiving experience was measured in 17 studies using 10 different instruments: the Bakas Caregiving Outcome Scale,[29] the Caregiver Appraisal Scale,[17, 48] the Caregiver Reaction Assessment,[18, 27, 30, 38, 49, 50] the Caregiver Response Scale,[51, 52] the Caregiving Demands Scale,[14] the Carer Strain Index,[20] the Care Work Strain Scale of the Impact of Informal Caring Scale,[23, 35] the Dutch Objective Burden Inventory,[30] the Oberst Caregiving Burden Scale,[24, 29] and the Zarit Caregiver Burden Interview.[21]

In addition, most of the measurements were developed for caregivers of patients with chronic diseases other than HF, such as Alzheimer’s disease, dementia, stroke, and cancer.[53] Several researchers have tackled this problem. In a study of caregivers of HF patients, Bakas et al.[29] revised some items of the Oberst Caregiving Burden Scale to increase its sensitivity for caregivers of HF patients. Luttik et al.[49] developed the Dutch Objective Burden Inventory to represent aspects specific to HF. Although the Caregiver Reaction Assessment has been used most often in research of HF caregiving, there still remains no consensus about the most appropriate instrument to measure the caregiving experience in the context of HF. Researchers will continue to test and refine the existing instruments.

Study Design and Sample

The majority of the studies reviewed are descriptive or correlational studies with cross-sectional designs. This type of study design makes it impossible to discern causality among the variables studied. Therefore, more longitudinal studies are needed to identify predictors of caregiver outcomes.

Most studies on caregivers of HF patients have included only patients’ spouses. While this approach enables researchers to focus on the marital relationship, it raises a concern. According to the results of the national telephone survey of caregiving,[54] among 260 caregivers who participated in the survey, only 17% were providing care for their spouses or partners. Forty-five percent of the respondents were taking care of their parents or parents-in-law, and 28% were caring for grandparents, other relatives, or friends. The proportion of spousal caregivers among family caregivers of HF patients is not known since none of the studies of HF caregiving used a probability sample.

However, it could be inferred that a significant proportion of family caregivers of HF patients are non-spousal caregivers. Among 572 patients who participated in a multi-center HF trial, only 61% of the patients were living with a partner or spouse.[55] Therefore, more caregivers of HF patients can benefit from the findings of studies when extended family caregivers as well as spouses are included.

Conclusion

HF family caregiving is a relatively new research area that has been actively explored only in the last decade. In spite of the benefits of caregiving on patients' quality of life and well-being, family caregivers of HF patients experience various challenges in their lives due to their role as a caregiver. The physical and emotional well-being of family caregivers can be compromised. Many caregivers are depressed, burdened, and socially isolated due to their care responsibilities and have a poor quality of life. Researchers have tried to identify factors related to these problems in order to find ways to support caregivers and to improve outcomes of HF patients. Lack of family support, low income, caregivers' poor physical health, and patients' and caregivers' own poor emotional well-being have been identified as factors related to caregiver burden, poor emotional well-being, and depression. Although the functional status of the patient is known to be a factor related to caregiver burden and depression, inconsistent results have been reported. Similarly, the associations of caregiver age and gender with caregiver burden and emotional well-being reported in studies are inconsistent. Many previous studies included mostly female spousal caregivers of HF patients. In order to draw a definite conclusion about these relationships, future studies need to include various factors and test the effect of each factor after controlling for possible confounding factors.

To achieve this, the samples in future studies must be large as well as diverse in regard to caregiver’s age, gender, and relationship to the patient.

Despite the number of difficulties that family caregivers experience, the current health care system does not provide adequate support for individuals caring for HF patients. Family caregivers need information about the prognosis and management of HF and want to be involved in patient care. Clinicians working with HF patients must address the needs of not only patients but also family caregivers.

Caring for a loved one with HF is burdensome for family caregivers. Therefore, the negative influence of caregiving on the lives of caregivers has been the focus of most studies up to now. However, many family caregivers of HF patients find caregiving to be a positive and rewarding experience. Even when HF patients and their caregivers are having a difficult time, some caregivers still find positive meaning in their experience. Unfortunately, little is known about the positive aspects of caregiving. Therefore, future research on HF family caregiving should include the positive aspects of caregiving.

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Table 1

Characteristics of Studies on Heart Failure Family Caregiving

Authors, year & country	Design	Sample 1) Sample size 2) Demographics of patients (pts) / caregivers (CGs) 3) NYHA class of pts 4) CG relationship to the pt
Aldred, et al., 2005[13] UK	Qualitative	1) 10 dyads 2) Age range 60-77, 70% male / 60% female 3) Class II-IV 4) 100% spouse/partner
Bakas, et al., 2006[29] US	Descriptive Cross-sectional	1) 21 dyads 2) Mean age 63, 96% male / Mean age 60 (±9), 95% female 3) Class II-IV (62% class III or IV) 4) 95% spouse
Barnes et al., 2006[20] UK	Mixed Methods: Quantitative (Correlational Cross-sectional) & Qualitative	1) 213 dyads (quantitative) 16 dyads (qualitative) 2) 74% 70 years or older, 64% male / 70% 60 years or older, 76% female 3) Class I-IV (56% class I or II) 4) 73% spouse/partner, 20% adult child
Boyd et al., 2004[12] UK	Qualitative	1) 20 dyads 2) Mean age 74, 55% male / Not provided 3) Class IV 4) Not provided
Bull, et al., 2000[31] & Bull, et al., 2000[52] US	Comparative Longitudinal	1) 130 dyads[31] & 134 dyads[52] 2) Mean age 73 (±9), 51% male / Mean age 59 (±14), 73% female 3) Not provided 4) 55% spouse, 40% adult child
Bull, et al., 2000[51] US	Quasi-experimental	1) 140 dyads (71 dyads in the control group) 2) Mean age 74 (±9) / Mean age 59 (±15), 73% female 3) Not provided 4) 50% spouse, 38% adult child
Chung et al., 2009[40] US	Descriptive Cross-sectional	1) 58 dyads 2) Mean age 62 (±13), 74% male / Mean age 58 (±12) 3) 43% class III or IV 4) 100% spouse/partner

Clark et al., 2008[41] UK	Qualitative	1) 30 dyads 2) Not provided / 77% female 3) Class II or III 4) 80% spouse/partner, 13% adult child
Dracup et al., 2004[17] US	Correlational Cross-sectional	1) 69 dyads 2) Not provided / Mean age 54 (±12), 75% female 3) Class III or IV 4) 100% spouse
Evangelista et al., 2002[36] US	Comparative Correlational Cross-sectional	1) 103 dyads 2) Mean age 58 (±12), 67% male / Mean age 60 (±18), 71% female 3) Class I-IV (40% class III) 4) 83% spouse
Hooley, et al., 2005[21] Canada	Descriptive Cohort study	1) 50 dyads 2) Mean age 72 (±11), 72% male / Mean age 61 (±14), 80% female 3) Class I-IV (72% class III or IV) 4) 66% spouse
Karmilovich, 1994[14] US	Descriptive Cross-sectional	1) 41 dyads 2) 44% between 51 and 60 years old, 68% male / Mean age 57, 68% female 3) Class III or IV 4) 100% spouse
Luttik, et al., 2007[15] Netherlands	Qualitative	1) 13 dyads 2) Not provided / Mean age 66 (range 47-80), 77% female 3) Class II or III 4) 100% spouse/partner
Luttik, 2007[30] Netherlands	Correlational Cross-sectional	1) 357 dyads 2) Mean age 68 (±11), 75% male / Mean age 67 (±12), 75% female 3) Class II-IV 4) 100% spouse/partner
Luttik, et al., 2005[34] Netherlands	Descriptive Comparative Cross-sectional	1) 38 dyads 2) Mean age 68 (±8), 82% male / Mean age 64 (±9), 84% female 3) Class III or IV (50% class IV) 4) 100% spouse/partner
Luttik, 2009[37] Netherlands	Comparative Cross-sectional	1) 303 partners of HF pts and an age-gender matched sample of partners of healthy individuals 2) Not provided / Mean age 69, 73% female 3) Not provided 4) 100% spouse/partner

Luttik, et al., 2009[25] Netherlands	Comparative Cross-sectional	1) 393 dyads 2) Mean age 68 (±11), 76% male / Mean age 67(±12), 76% female 3) Class II-IV (67% class II) 4) 100% spouse/partner
Martensson, et al., 2003[22] US	Comparative Correlational Cross-sectional	1) 48 dyads 2) Mean age 61 (±9), 100% male / Mean age 57 (±10), 100% female 3) Class I-IV (58% class III) 4) 100% wife
Martensson, et al., 2001[42] Sweden	Qualitative	1) 23 dyads 2) Not provided / Mean age 74, 65% female 3) Class III or IV 4) 100% spouse
Molloy, et al., 2006[23] & Molloy et al., 2008[35] UK	Randomized Controlled Trial[23] Theory-testing Cross-sectional[35]	1) 60 dyads 2) Mean age 80 (±5), 67% male / Mean age 63 (±15), 65% female 3) Class II or III (50% class III) 4) 40% spouse, 43% adult child
Pattenden, et al., 2007[33] UK	Qualitative	1) 36 pts and 20 CGs 2) Age range 36-89, 64% male / 90% female 3) Class I-IV (69% class II or III) 4) 95% spouse
Pihl, et al., 2005[26] Sweden	Comparative Correlational Cross-sectional	1) 47 dyads 2) Mean age 78 (±5), 72% male / Mean age 75 (±7), 72% female 3) Class II-IV (51% class II) 4) 100% spouse
Pressler, et al., 2009[24] US	Descriptive Prospective	1) 63 dyads 2) Mean age 69 (±13), 54% male / Mean age 60 (±15), 76% female 3) Class I-IV (53% class III) 4) 68% spouse, 21% adult child
Rohrbaugh, et al., 2002[16] US	Comparative Correlational Cross-sectional	1) 181 dyads 2) Mean age 53 (±10), 73% male / Mean age 52 (±11), 73% female 3) Class I-IV (42% class II) 4) 100% spouse
Rohrbaugh, et al., 2009[32] US	Comparative Correlational Prospective	1) 60 dyads 2) Mean age 67 (±12), 72% male / Mean age 66 (±11), 72% female 3) Class I-IV (55% class II) 4) 100% spouse

Saunders, 2008[27] & Saunders, 2009[50] US	Correlational Cross-sectional	1) 41 pts and 50 CGs 2) Mean age 78 (±10), 49% male / Mean age 58 (±15), 84% female 3) Class I-IV (47% class III) 4) 38% spouse, 50% adult child
Saunders, 2008[38] US	Correlational Cross-sectional	1) 41 dyads 2) Mean age 78 (±10), 49% male / Mean age 59 (±15), 85% female 3) Class I-IV (46% class III) 4) 46% spouse, 46% adult child
Schwarz, et al., 2008[48] US	Pilot Randomized Controlled Trial	1) 102 dyads (51 dyads in each group) 2) Mean age 78 (range 65-94), 48% male / Mean age 65 3) Class II-IV (48% class III) 4) 53% spouse, 28% adult child
Scott, 2000[18] US	Descriptive Cross-sectional	1) 20 pts and 18 CGs 2) Mean age 69 (±9), 90% male / Mean age 63 (±12), 89% female 3) Not provided (End-stage HF pts) 4) 90% spouse
Scott, 2001[19] US	Qualitative	1) 4 dyads 2) Mean age 73 (±5) / Mean age 71 (±8), 75% female 3) Class I-IV 4) 100% spouse

NYHA class, New York Heart Association Class

Table 2

Factors Related to Outcomes of Family Caregivers of Heart Failure Patients

Caregiver outcomes	Risk factors
Caregiver burden	Caregiver’s poor mental health[30] Caregiver depression[20, 21, 27] Low income[21] Patient’s low functional status[30] Caregiving hours[27] Lack of a respite caregiver[27] Providing personal care to the patient[30]
Poor emotional well-being	Patient’s poor emotional well-being[16, 36] Caregiver’s health problems[20] Caregiver’s low perceived control over managing patient’s heart problems[17, 29] Poor marital quality[16]
Depression	Patient’s comorbidity[38] Lack of family support[38]

Chapter 3

Family Caregiving for Patients with Heart Failure:

Types of Care Provided and Gender Differences

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ABSTRACT

Background: Knowledge about the potential burden for family caregivers related to the care of patients with heart failure (HF) is limited. The aims of the study were to compare the kind and amount of care provided by partners of HF patients and partners of healthy individuals and to examine the associations between gender and the performance of caregiving tasks.

Methods and Results: Caregiving tasks performed by 338 partners of HF patients were compared with those performed by 1202 partners of healthy individuals. Partners (age 70 ± 9, 76% female) of HF patients were more likely to provide personal care compared with partners (age 65 ± 7, 66% female) of healthy individuals after controlling for their age. However, the magnitude of the odds ratios (OR) differed by gender of partners (OR for male 6.7; 95% confidence interval [CI] 3.9 - 11.4; OR for female 3.7; 95% CI 2.7 - 5.1). Partners of HF patients were more likely to provide emotional care than partners of healthy individuals, controlling for age and gender (OR 2.4; 95% CI 1.5 - 3.6). Male partners of HF patients were more likely to provide personal care compared to female partners of HF patients (OR 1.9; 95% CI 1.1 - 3.2).

Conclusions: The care performed by partners of HF patients is above and beyond normal spousal assistance. The study underscores the crucial role of family caregivers in the care of HF patients and encourages health care providers to address the needs of both HF patients and their caregivers.

Keywords: *Caregiving task, heart failure, partner, spouse, gender difference.*

Introduction

Heart failure (HF) is a chronic debilitating disease, with an increasing incidence each year. It is estimated that 5.7 million people in the United States and more than 15 million people in Europe have HF.[1, 2] Patients with HF often need assistance in their daily lives due to their symptoms and poor functional status.[3] Family members, including partners, most often assume the caregiver role at home. The availability of family caregivers has been shown to be an important factor in HF patients' outcomes such as readmission and mortality.[4] Caregiving, however, can be very demanding and stressful for the individuals providing care. Nevertheless, scant attention has been given to family caregiving in the context of HF. Studies have focused primarily on the benefits of caregiving for HF patients,[5] and only a limited number of studies have explored the actual content of HF caregiving.[6-9] More importantly, these studies did not address the fundamental question of whether the care activities provided by partners of HF patients differ from those that healthy older couples normally provide each other.

In general, couples help each other with performing household work and provide emotional support to each other. Particularly, in the older adult population, it can be expected that the need for helping and supporting each other increases due to alterations in physical abilities related to normal aging. Caregiving, by definition, is providing assistance which is more than the aid provided for a physically and psychologically healthy person.[10] HF caregiving, therefore, needs to be distinguished from care activities normally exchanged in healthy older couples. Identifying the kind and amount of care activities that partners of HF patients perform that is above and beyond normal spousal assistance will help health care professionals anticipate the needs of partners of HF patients and counsel them more appropriately.

Within a traditional gender framework, caregiving is a female role, while men are primarily responsible for providing financial resources.[11] In a meta-analysis of 229 caregiving studies in diverse populations, Pinquart and Sorensen[12] concluded that female caregivers performed more caregiving tasks and spent more time on caregiving than males. Given that the prevalence of HF is similar in men and women,[1]gender is an important factor that needs to be taken into consideration in research on family caregiving in HF. Only one researcher has examined gender differences in the amount of care tasks performed by spouses of HF patients, and results similar to those of Pinquart and Sorensen[12] were reported.[7] Nevertheless, given the paucity of research, no definitive conclusions can be drawn about the gender difference in HF caregiving. More information on gender difference in HF spousal caregiving will provide the basis for developing interventions for both HF patients and their partners.

The aim of the current study was to compare the kind and amount of care provided by partners of HF patients and partners of healthy individuals. A secondary aim was to investigate the associations between gender and the performance of caregiving tasks. The following research questions were formulated:

1. Do partners of HF patients perform more and different caregiving tasks compared to partners of healthy individuals?
2. Does the performance of caregiving tasks differ by partner's gender?

Methods

Participants and Procedure

A cross-sectional, comparative design was used to answer the research questions. Caregiving data obtained from a sample of partners of HF patients were compared with ones from a reference group of individuals living with a healthy partner drawn from the general population in the Netherlands. The study was approved by the Central Ethics Committee and the investigation conformed to the principles outlined in the Declaration of Helsinki.

Partners of Heart Failure Patients. Data were collected from partners of HF patients who participated in the COACH trial. The COACH trial was a randomized clinical trial conducted in 17 centers in the Netherlands during the period from 2002 to 2005. The trial studied the effects of education and counseling on patients with HF.[13, 14] Patients were recruited when hospitalized for symptomatic HF (New York Heart Association [NYHA] class II - IV) with evidence of structural underlying heart disease. Patients who were unable to fill out the questionnaire, had an invasive intervention (cardiac surgery) within 6 months prior to the study, or had one planned for the following 3 months were excluded. All patients were approached by a cardiologist and a research nurse and written informed consent was obtained.

Clinical data and demographics of HF patients were collected through chart review and patient interview. Twelve months after the patient’s initial hospitalization, partners received a self-report questionnaire by mail and were asked to complete it independently from the patient. Research assistants visited patients and their partners at home and collected the questionnaires. There were no specific inclusion or exclusion criteria for partners except that they had to be able and willing to complete the questionnaire.

Partners Living with a Healthy Individual. Data from the Dutch national survey of partners living with a healthy individual were used as the comparison group. In the national survey, random samples of addresses of 500 to 1000 individuals, who were at least 55 years old and not living at the same address, were collected from nine local district council offices in different areas in the Netherlands. Between July and August 2005, 5500 questionnaires and a pre-stamped envelope for return of the questionnaire were mailed to these random addresses along with a letter inviting respondents to participate in the study. Anonymity and confidentiality were assured.

Measurements

Caregiving Tasks; Dutch Objective Burden Inventory. The kind and amount of care activities performed by partners of HF patients and partners of healthy individuals were measured with two domains of the Dutch Objective Burden Inventory: personal care and emotional care. The Dutch Objective Burden Inventory was developed to assess caregiving tasks performed by partners of HF patients. Each item is scored with a 3-point Likert scale ranging from never (1) to always (3). Each domain score is computed as the average of the subsequent items' scores with a range between 1.0 (providing no care) and 3.0 (providing much care). The reliability and validity of the instrument were tested and reported previously.[15] Cronbach's alphas of the personal care and emotional care domains in the current study were 0.83 and 0.85 respectively.

Severity of HF; NYHA Class. The severity of HF in patients was assessed with the NYHA functional classification system. This system classifies patients into one of four classes based on limitations in physical activities caused by cardiac symptoms, with

IV being the most severely limited.[16] The NYHA Classification is widely used to measure the functional status of HF patients.[17]

Perceived Physical Health; RAND-36. The RAND 36 Item Health Survey (RAND-36) was administered to measure the perceived general health and physical health of partners of HF patients and partners of healthy individuals. Among eight subscales of the RAND-36, two subscales, physical functioning and general health perceptions, were used for the current study. Each subscale score has a range from 0 to 100, and a higher score represents a more favorable health status. The reliability and validity of the RAND-36 have been tested in a wide variety of populations.[18, 19]

Statistical Analysis

Data were entered into SPSS 15.0. The characteristics of the groups were compared using descriptive statistics, frequencies, independent t-tests, and chi-square tests. Chi-square tests were used to compare percentages of people providing care for their partner between the groups. Logistic regression analyses were performed to examine the association of HF and gender with providing care for partners. Each domain score was recoded using a cutoff point at 1.0 (providing no care versus providing care) for the logistic regression analyses. All two-way interactions were tested in multiple logistic regression analysis. The statistical significance level was set at $p < .05$.

Results

Response Rate

Among 1023 HF patients enrolled in the COACH trial, 605 patients (59%) were married or living with a partner. At 12 months after the initial hospitalization, 441 questionnaires were sent out because 112 patients had died before 12 months and 52 partners were unable or refused to complete the questionnaires. Four hundred and seven partners (92%) returned the questionnaire. In order to make a comparison to the reference group, which consisted of community dwelling older adults aged above 55 years, 44 partners of HF patients who were less than 55 years old were excluded from the analyses. Therefore, the final analyses included 338 cases, excluding 25 cases with incomplete data.

Out of the 5500 questionnaires distributed among community dwelling older adults, 2497 (45%) were returned. Of these, 1712 respondents (69%) were married or living with a partner, and 1288 respondents reported their partner's health status to be good to excellent. After excluding 86 cases with incomplete data, 1202 cases were used for the final analyses.

Study Population

The demographic characteristics of both partners of HF patients and partners of healthy individuals are summarized in Table 1. The majority of partners were female, although there were significantly more females among partners of HF patients than among partners of healthy individuals (76% and 66% respectively, $p < .001$). All but one couple (male HF patient and male partner) were heterosexual. The average ages of partners of HF patients and partners of healthy individuals were 70 (± 9) years and 65 (± 7) years respectively. On average, partners of HF patients were significantly older compared to partners of healthy persons ($p < .001$). To examine differences in age, each group was divided into two age groups using the median age of all study participants (65 years) as a cutoff point. While 67% of partners of HF patients were 65 years old and older, 47% of partners of healthy individuals were in the same age group ($p < .001$).

Partners of healthy individuals perceived their physical health to be better than partners of HF patients (*p* < .001).

Sociodemographic data were not available for the sample of healthy individuals. However, the characteristics of HF patients were as follows: the majority were male (76%) with a mean age of 70 (± 8) years. Most of the HF patients were classified as NYHA class II (59%) or class III (29%). There was no significant difference in HF patient's age (*p* = .16) or NYHA class (*p* = 1.00) by gender.

Heart Failure and Caregiving Tasks

While respectively 172 (51%) and 305 (92%) respondents living with a HF patient (n = 338) provided personal care and emotional care for their partner, 221 (19%) and 949 (81%) respondents living with a healthy individual (n = 1202) provided personal care and emotional care respectively. Significant differences were found in the percentage of partners providing care between partners of HF patients and partners of healthy individuals (Personal Care $\chi^2(1) = 141.714$, $p < .001$; Emotional Care $\chi^2(1) = 21.481$, $p < .001$).

In order to control for the differences in age and gender of partners between the two groups, the effect of HF on providing care was examined by logistic regression analyses. The final models are presented in Table 2. In the logistic regression model for personal care, there was a significant interaction between gender and group. That is, the effect of HF on providing personal care depended on the partner's gender. Therefore, an additional logistic regression model was built for each gender. While both male and female partners of HF patients were more likely to provide personal care compared to partners of healthy individuals after controlling for their age, the magnitude of the odds ratios differed by their gender. Specifically, among male partners, the odds for partners of HF patients providing personal care were 6.7 times higher than for partners of healthy individuals, holding age constant (95% confidence interval [CI], 3.9 - 11.4). Among female partners, the odds for partners of HF patients providing personal care were 3.7 times higher than for partners of healthy individuals, holding age constant (95% CI, 2.7 - 5.1). No other interaction terms (age by group or age by gender) were significant in the model.

After controlling for age and gender, partners of HF patients were more likely to provide emotional care than partners of healthy individuals (adjusted odds ratio [adj. OR], 2.4; 95% CI, 1.5 - 3.6). None of the interaction terms (gender by group, age by group, or age by gender) were significant in the model.

Personal and Emotional Caregiving

Table 3 and Table 4 present the numbers and percentages of respondents performing each caregiving task measured with the Dutch Objective Burden Inventory. Among the 11 personal care items, the item ‘being available for 24 hours’ was most frequently performed in both groups. While 41% of partners of HF patients reported that they felt they had to be available for 24 hours for their partner, only 9% of partners of healthy individuals responded positively to this item (Table 3). More than 30% of partners of healthy individuals and more than 40% of partners of HF patients performed at least one emotional care task (Table 4).

Gender Differences in Performing Caregiving Tasks

In order to answer the second research question, the effect of gender was examined for each personal care and emotional care domain.

Personal Care. As shown in Table 2, gender was not significant in the logistic regression model for personal care; however, there was a significant interaction between gender and group. A significant gender difference was found in providing personal care among partners of HF patients. Specifically, male partners of HF patients were more likely to provide personal care compared to female partners of HF patients after controlling for age (adj. OR, 1.9; 95% CI, 1.1 - 3.2). No difference in providing personal care was noted by gender in partners of healthy individuals. The gender difference for each group is depicted in Figure 1.

Emotional Care. Holding age and group constant, female partners were more likely to provide emotional care compared to male partners (adj. OR, 1.5; 95% CI, 1.1 - 1.9). The gender difference in providing emotional care was present whether the respondents were partners of HF patients or of healthy individuals.

Discussion

This is the first study conducted to compare the kind and amount of caregiving tasks performed by partners of HF patients with those of healthy individuals from the general population. Compared to partners of healthy individuals, partners of HF patients were significantly more likely to perform caregiving tasks to help their partner physically and emotionally. Partners of HF patients were more likely to provide personal care and emotional care compared to partners of healthy individuals even after correcting for differences in age and gender between the two groups.

It is important to state that in the current study, we only measured non-HF-specific care tasks–personal care and emotional care–performed by partners of HF patients. Based on data from a national survey of 1002 family caregivers for chronically ill, disabled, or older persons who need assistance, Donelan et al.[20] reported that 43% of these caregivers performed at least one medical task such as helping their family member with medical equipment, medication administration, and wound care. More than one fourth of caregivers in this survey helped to give five or more different medications to their family member. Similarly, previous studies show that caregivers of HF patients perform care tasks related to HF management, such as fluid restriction, managing sodium intake, weight monitoring, and medication management.[15, 21, 22] Clark et al.[22] further stressed the complexity of care that family caregivers of HF patients performed by addressing ‘invisible care’ which includes constant observation and monitoring of signs and symptoms. This indicates that HF places a great amount of caregiving demands on partners of HF patients. Until now, most studies of HF caregiving have focused on HF-specific caregiving tasks. We suggest that future research include general care activities performed by partners of HF patients in addition to HF-specific caregiving tasks in order to assess the actual burden of care.

In our study, more than 40% of partners of HF patients felt that they had to be available for their partner 24 hours a day. This sense of responsibility might be associated with feelings of social isolation in partners of HF patients, a phenomenon that has been identified as a significant problem for spousal caregivers of HF patients in previous studies.[21, 23-25] In addition, over 40% of partners in the current study reported that they had to talk to their partner to reduce his or her anxiety or depression. Depression and anxiety are prevalent among patients with HF,[26, 27] and it is not surprising that caregivers identified a need to intervene to reduce these negative emotions. Interestingly, managing a patient's negative affect was identified as one of the most difficult tasks HF caregivers experienced.[9]

In the current study, caregiving tasks were different for male and female caregivers. Women were more likely to provide emotional care for their partner than their male counterpart, which is consistent with previous findings that women in general do more emotional caregiving than men.[28]

There was a difference in physical caregiving between male and female partners of HF patients. In our study, more men reported performing personal care tasks than women. As there was no significant difference in patient age or NYHA class by gender, the difference in performing personal care tasks cannot be explained by the patient's age or the severity of HF. In a meta-analysis of caregiving studies in various disease populations, Pinquart and Sorenson[12] found that female caregivers performed more personal care than male caregivers with a small difference in magnitude. However, the samples in this meta-analysis consisted of heterogeneous caregivers including spouses, adult children, and other informal caregivers caring for dementia patients or physically frail older adults. Only one other investigator has examined the influence of gender on caregiving tasks in the context of HF. Contrary to our findings, Karmilovich[7] reported that wives of HF patients performed more personal caregiving tasks and had more difficulty in performing them than did husbands of HF patients. In this study, the sample size was small and the patient's disease severity was not considered, which may explain the difference in findings between the two studies. In addition, other factors, such as reporting bias and baseline differences in the samples that were not measured in our study, could have contributed to this finding. The data used in our study include only limited information on HF patients. Therefore, future research is warranted to determine gender differences in caregiving among caregivers of HF patients.

The present study has several limitations. First, the reference group sample may not be representative of the population of partners living with a "healthy" individual. Participants in the reference group were selected based on self-report of their partner's health status; no objective measure was used to confirm that their partners were healthy. Second, the higher response rate for women than men in partners of healthy individuals might also suggest self-selection bias. Third, our data on the severity of HF are limited to NYHA class. Therefore, the difference in providing personal care found between male and female caregivers could have been due to confounders not measured in the study. Fourth, data on caregiving tasks were obtained by self-report. Walker, Pratt, and Eddy[10] noted that self-report on caregiving activities can be affected by the subject's gender in such a way that male caregivers report performing more caregiving activities because these are not their ordinary responsibilities. Women may not report some caregiving activities because they consider them to be an expected part of their role. It is therefore possible that the observed differences in the present analysis may have been somewhat overestimated.

In conclusion, partners of HF patients performed more caregiving tasks than did people living with a healthy partner, even when only non-HF-specific caregiving tasks were investigated. Therefore, as underlined by Stewart,[29] future research and services for patients with HF must acknowledge the crucial role of partners and address needs of both HF patients and their partners. Interventions targeted at supporting partners caring for their loved ones with HF can in turn improve the care for people with HF. More male partners of HF patients reported performing personal care tasks than women, and more female caregivers reported performing emotional care than men regardless of the presence of HF. Hence, gender specific interventions need to be considered not only for patients but also their partners. Finally, understanding perceived burden related to performing care tasks in addition to our findings will help health care providers and policy makers to prioritize the areas where HF patients and their partners need assistance.

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Table 1

Demographic Characteristics of Respondents

	Partners of HF patients (n = 338)	Partners of Healthy Individuals (n = 1202)	*p*-value
Gender			
Female Gender, n (%)	257 (76)	786 (66)	< .001
Age			
Mean Age ± SD (year)	70 ± 9	65 ± 7	< .001
65 years and above, n (%)	227 (67)	560 (47)	< .001
Health Status			
Respondent's Perceived General Health (RAND-36), Mean ± SD	59 ± 21	65 ± 19	< .001
Respondent's Perceived Physical Health (RAND-36), Mean ± SD	68 ± 27	77 ± 24	< .001

Table 2

Logistic Regression Analyses

	Personal Care (n = 1501)			Emotional Care (n = 1498)		
	B (SE)	adj. OR[†]	95% CI[§]	B (SE)	adj. OR	95% CI
Included						
Constant	-1.68 (0.28)	0.19		0.73 (0.25)	2.07	
Group: HF	2.61 (0.56)	13.53	4.53 - 40.41	0.86 (0.22)	2.36	1.54 - 3.62
Gender: Female	0.03 (0.16)	1.03	0.75 - 1.40	0.37 (0.15)	1.45	1.09 - 1.93
Age: 65 or older	0.36 (0.13)	1.43	1.12 - 1.84	0.29 (0.14)	1.34	1.01 - 1.77
Gender X Group	-0.65 (0.31)	0.52	0.28 - 0.96	NS[*]	-	-

Personal Care: R^2 = .085 (Hosmer & Lemeshow), .093 (Cox & Snell), .136 (Nagelkerke).

Model $\chi^2(4) = 145.902$, $p < .001$.

Emotional Care: R^2 = .029 (Hosmer & Lemeshow), .023 (Cox & Snell), .039 (Nagelkerke).

Model $\chi^2(3) = 35.402$, $p < .001$.

[†] adj. OR: adjusted odds ratio

[§] CI: confidence interval

[*] NS: not significant (Only significant interaction terms were included in the model.)

Table 3

Number of Respondents Providing Personal Care by Group

	Partners of HF Patients (n = 335) n (%)	Partners of Healthy Individuals (n = 1168) n (%)
Eating and Drinking	27 (8)	68 (6)
Washing and Bathing*	48 (14)	60 (5)
Dressing and Undressing*	56 (17)	49 (4)
Going to the Toilet	9 (3)	17 (2)
Assistance with Appearance*	38 (11)	46 (4)
Walking in and around the House*	57 (17)	45 (4)
Coming in and out of Bed or Chair*	20 (6)	39 (3)
Walking Stairs*	21 (6)	31 (3)
Helping to Find a Comfortable Position in Bed	16 (5)	43 (4)
Being Available for 24 hours*	136 (41)	108 (9)
Providing Care at Night*	54 (16)	32 (3)

Each item score was recoded using a cutoff point at 1.0.

*Items significantly different at α = .05, using chi-square tests.

Table 4

Number of Respondents Providing Emotional Care by Group

	Partners of HF Patients (n = 332) n (%)	Partners of Healthy Individuals (n = 1169) n (%)
Providing Comfort*	194 (58)	549 (47)
Talking to Reduce Anxiety*	137 (41)	381 (33)
Talking to Reduce Depressive Feelings*	140 (42)	378 (32)
Talking about Worries	199 (60)	678 (58)
Showing Understanding*	279 (84)	880 (75)
Keeping Company*	276 (83)	869 (74)

Each item score was recoded using a cutoff point at 1.0.

*Items significantly different at α = .05, using chi-square tests.

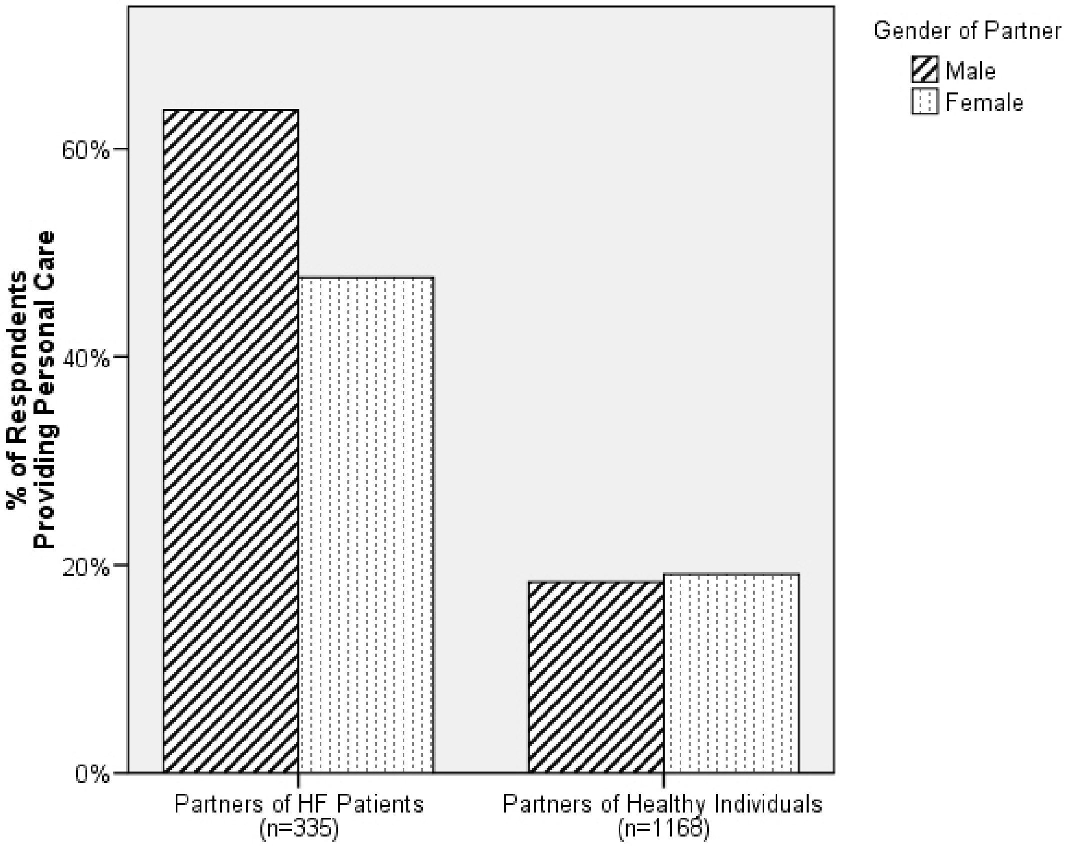

Figure 1

Percentage of Respondents Providing Personal Care by Group and Gender

Chapter 4

Caregiving for Patients with Heart Failure: The Impact on Family Members

ABSTRACT

Background: Little is known about the factors associated with the impact of caregiving on caregivers of heart failure (HF) patients. Moreover, social support and positive aspects of caregiving have been neglected in previous studies of HF caregiving. The study was aimed to identify factors associated with the impact of caregiving, including both positive and negative aspects.

Methods and Results: Self-report data were collected from 76 dyads of HF patients (mean 54 ± 14 years, 55% male, 55% New York Heart Association class III) and their family caregivers (mean 53 ± 16 years, 71% female, 74% spouse). Clinical data were obtained from medical records. The sense of less family support for caregiving was associated with higher patient NYHA class, being a non-spousal caregiver, lower caregiver perceived control, and lower social support. Higher financial strain was related to lower caregiver perceived control and social support, after controlling for economic status. More disruption of caregivers' schedules was associated with higher patient NYHA class, performing more care tasks, and lower perceived social support. Greater impact of caregiving on caregivers' health was related to more recent patient hospitalization, lower caregiver perceived control and social support. Non-white caregivers and caregivers whose family member had fewer emergency department visits felt more positive about caregiving than did others. Social support had a moderating effect on the relationship between patient co-morbidities and positive aspects of caregiving.

Conclusions: Caregiving had both positive and negative impact on family caregivers of HF patients. The findings suggest the need for interventions aimed at increasing caregivers’ sense of control and social support. Clinicians should assess caregivers’ needs and the resources available to them. To minimize the negative impact of caregiving on their health, caregivers may need additional support during the period immediately following patient hospitalizations.

Keywords: *Heart failure, family caregiver, impact of caregiving, caregiver burden, social support, perceived control*

Introduction

With rising prevalence, heart failure (HF) currently affects over 5.8 million Americans.[1] Consequently, the number of family caregivers providing care at home for patients with HF is increasing. Moreover, greater emphasis on self-management in the care of HF requires more time and energy from family caregivers to ensure adherence to complex therapeutic regimens.[2] While the role of family caregivers is pivotal in the care of HF patients, caregiving, unfortunately, can negatively impact various aspects of life of the person providing care. The negative impact of caregiving includes physical, emotional, social, and financial problems that often result in stress, health problems, and depression in caregivers.[3, 4]

The issues surrounding family caregiving in HF have not been adequately addressed in research and practice.[2, 5] Furthermore, the inconsistent findings in the existing literature warrant the need for further investigation. In a few studies, the perceived physical and mental health status of caregivers was poorer compared to the general population,[6, 7] while others found no difference in mental health[8, 9] or both physical and mental health.[10] Knowledge about factors contributing to the negative impact of caregiving is critical for identifying caregivers at risk so that early intervention and support can be provided. In previous studies, caregivers' lower income status[11], more hours of caregiving,[12] and patients' lower functional status[13] were identified as associated with higher burden in caregivers. However, some potential factors that may be important in the impact of caregiving have been overlooked in research on caregiving in HF. Over the course of the disease, patients with HF experience repeated episodes of acute exacerbation which require emergency treatment or hospitalization.[14] It is not known how these clinical events affect caregivers. In addition, despite its important role in reducing stress, particularly the stress related to family caregiving, the relationship of social support to the impact of caregiving has never been examined in the context of HF. In caregiving research, social support is also conceptualized as a moderator that buffers the effects of caregiving stressors on perceived stress by changing caregivers' appraisal of stressors or enhancing their ability to cope.[15] Therefore, the examination of social support in the context of caregiving in HF can add critical information to the current knowledge base.

Taking care of a loved one can be demanding but can also provide rewards and satisfaction.[4] Although many caregivers of HF patients described the positive impact of caregiving on their lives,[7, 12] the negative aspects, often referred to as caregiver stress or burden, have been a focus of most previous studies. Therefore, the factors related to the positive impact of caregiving remain unclear.

Given the important role that family caregivers play in the care of patients with HF and the gaps in knowledge identified above, further work is needed to elucidate the factors related to the impact of caregiving with a focus on the potential positive aspects and the role of social support. The current study was conducted to identify factors associated with the impact of caregiving, including both positive and negative aspects, among family caregivers of patients with HF. Specific aims of the study were to: 1) describe the levels of perceived physical and mental health status and the impact of caregiving among family caregivers of HF patients, 2) identify factors associated with the impact of caregiving, and 3) determine moderating effects of social support on the impact of caregiving.

Methods

Study Design and Sample

A cross-sectional descriptive design was used. After receiving approval from the Institutional Review Board, a convenience sample of 76 patients with HF and their primary family caregivers was recruited from clinics at a university affiliated hospital between October 2009 and February 2010. Potential subjects received information about the study from their health care providers and were screened for their eligibility to participate in the study. The inclusion criteria for patients were: 1) 18 years or older, 2) diagnosed with HF, 3) community-dwelling (i.e., not receiving care in an institution), 4) having a family member or friend providing care for them at home, and 5) able to read and write English. Eligible patients were asked to name a person who helps them the most at home in order to identify a primary family caregiver. The inclusion criteria for family caregivers were: 1) 18 years or older, 2) a person identified by the patient as being primarily involved in the patient’s care at home, 3) able to read and write English, and 4) not a person hired for the care of the patient (a paid caregiver).

Procedures

When both patient and caregiver met the inclusion criteria and agreed to participate, written informed consent was obtained from each of them. Subjects were given the option to complete the questionnaire either alone or by interview (via telephone or in-person). The patients and caregivers who chose to complete the questionnaire by themselves at home were instructed to do so without discussing it with each other. A stamped addressed envelope was provided for return of the completed questionnaire. On average, questionnaire completion took 10 minutes for patients and 45 minutes for family caregivers. Clinical data on HF patients were collected through medical record review.

Measurements

Severity of HF. The severity of symptoms in HF patients was assessed by the NYHA class collected from medical records. It is based on the extent to which symptoms limit the patient's level of physical activity and is widely used in clinical practice and in research.[16, 17]

Comorbidity. Data on patients' comorbid diseases were abstracted from medical records using the Charlson Comorbidity Index.[18] The measure generates a weighted index based on 17 indicators of coexisting conditions, which takes into account the number and the severity of comorbid conditions. A value of 0 for the index indicates that there is no serious comorbid condition. The Charlson index is a valid predictor of mortality from comorbid disease.[18]

Impact of caregiving. The impact of caregiving on caregivers' lives was measured with the Caregiver Reaction Assessment (CRA).[3] The CRA is one of the few instruments which measures both positive and negative aspects of the caregiving experience.[19] It is composed of 24 items, each of which is answered with a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The items are categorized into five subscales: lack of family support, impact on finances, impact on schedule, impact on health, and caregiver esteem. The caregiver esteem subscale measures a positive aspect of caregiving, whereas the other four measure negative aspects.[3] Each subscale score is the average of the subsequent items' scores and ranges from 1 to 5. A higher score represents stronger impact. Adequate psychometric properties were reported in previous studies, including studies of caregivers of HF patients.[3, 7, 12]

Caregiver health status. Caregivers' perceived physical and mental health status were measured by the Physical and Mental Component Summary scores of the Health Survey Short Form 36 Items version 2 (SF-36v2).[20] The SF-36 is widely used, and its psychometrics have been extensively tested in a wide variety of populations, including the general population and patients with chronic conditions. The second version introduced in 1996 has better internal consistency than the original version.[20, 21]

Caregiver depression. Caregiver depressive symptoms were measured with the 8 item depression scale of the Patient Health Questionnaire (PHQ-8).[22] PHQ-8 is a brief tool for depression screening.[23] The PHQ-8 contains the first 8 items of the PHQ-9, excluding the item regarding suicidal thoughts. It can be used when the risk of suicidal ideation is considered to be low, when depression is assessed as a secondary outcome, or when data are collected by self-administration rather than by interview.[24] Each item can be scored from 0 (not at all) to 3 (nearly every day). Possible scores for the PHQ-8 range from 0 to 24, and a score greater than or equal to 10 suggests clinical depression.[22, 24] The psychometrics of the PHQ-8 are well-established.[22] Its sensitivity and specificity are comparable to a structured psychiatric interview.[24]

Care activities performed. The care activities that family caregivers performed for their family member with HF were measured with the English version of the Dutch Objective Burden Inventory designed to measure a full range of care activities specific to HF caregiving.[25] It is comprised of 38 items divided into four subscales: personal care, motivational care, emotional care, and practical/treatment-related care. Each item is scored with a Likert scale ranging between never (1) and always (3). Each subscale score is computed as the mean of the subsequent items' scores.[13, 25] The instrument demonstrated good psychometric properties in a sample of spousal caregivers of HF patients.[25]

Perceived social support. The perceived availability of social support was measured with the Medical Outcome Study Social Support Survey. Social support is defined as the degree to which interpersonal relationships serve particular functions, such as emotional support, information or guidance for problem-solving, tangible support, affectionate support that involves expressions of love and affection, and social companionship.[26] The Social Support Survey contains 19 items, each of which is scored from none of the time (1) to all of the time (5). Eighteen items are used to form four subscales: emotional/informational support, tangible support, affectionate support, and positive social interaction. Each subscale score is the average of the scores for each item in it. An overall support index is the average of the scores for all 19 items. Its validity and reliability are well established.[26, 27]

Caregiver perceived control. Caregivers' perceived control over family member's heart disease was measured with the family version of the Control Attitude Scale-Revised.[28] The Control Attitude Scale was originally developed with four items and recently revised to improve its psychometrics.[28, 29] The revised version consists of eight items, each of which is rated on a 5-point Likert scale. The total score ranges from 8 to 40, with higher scores indicating greater perceived control. Although no psychometric information is available for the family version, the psychometric properties of the revised Control Attitude Scale was reported to be satisfactory in patients with cardiac disease.[28]

Statistical Analysis

Data were analyzed using SPSS 15.0. Descriptive statistics including means, standard deviations, frequencies, and ranges were used to describe characteristics of HF patients and family caregivers and other study variables. Demographic characteristics of patients who participated in the study and those who did not were compared using the t-test and chi-square test.

To identify variables associated with the impact of caregiving, a correlation matrix was constructed to test the relationships among variables. Multiple regression analyses were then conducted to identify the optimum combination of variables explaining the maximum total variance in each aspect of the impact of caregiving as measured with subscales of the CRA. The assumptions of multiple linear regression analysis were checked. Candidate variables were selected for inclusion in each regression model based on their significance in univariate analyses ($p < .10$) or their theoretical relevance. When there is a strong correlation (above .70) between two candidate variables, only one of them was selected for regression analysis based on its theoretical relevance to avoid multicollinearity. After constructing multiple regression models with selected variables, the significance level of each independent variable was assessed. To construct a parsimonious model, only variables significant at .10 in each model were included in each regression model.

To determine the moderating effects of social support on the impact of caregiving, all two-way interactions involving social support were tested in each regression model. Only significant interaction terms were included in final regression models. The statistical significance level was set at $p < .05$.

Results

Response Rate

Of the 116 eligible patients who were approached about possible participation, 20 patients declined. Among the remaining 96 patients who agreed to participate, 16 patients were excluded because their caregivers did not want to participate. Four patients were hospitalized before data collection was completed. Therefore, the analysis includes data from 76 patient-caregiver dyads. The average age of the patients who did not participate in the study (n = 36) was 58 (± 16) years, and 58% of them were female. There were no statistically significant differences between the patients who did not participate and the study subjects in regard to age and gender (p's > .10).

Sample Characteristics

The demographic and clinical characteristics of patients with HF and their caregivers are presented in Table 1. Most patients were male (55%) and currently married (61%). The average age of patients was 54 (± 14) years. The majority of patients were white (66%), followed by Hispanic/Latino (11%), African-American (11%), and Asian/Pacific Islander (9%). Most patients had NYHA class II (38%) or III (55%) HF symptoms and had a Charlson Comorbidity Index score of 1 or 2 (55%). In the 12 months prior to the study, on average, the patients were hospitalized twice (mean 2.0 ± 2.0, median 2, range 0 - 10) and visited the emergency department more than once (mean 1.7 ± 1.9, median 1, range 0 - 10). Thirty two patients (42%) had a hospitalization within 3 months of study recruitment.

The majority of primary caregivers were the spouse or partner (74%) of the patient. The mean age of caregivers was 53 (± 16) years. Most caregivers were female

(71%) and currently married (71%). The majority of caregivers were white (63%), followed by Hispanic/Latino (16%), African-American (9%), and Asian/Pacific Islander (9%). More than half of the caregivers (54%) were currently employed full-time or part-time, and about a fourth had to quit their job or reduce work hours to provide care for their family member. Most caregivers (87%) lived in the same household with the patient. On average, caregivers had cared for the patient for 4.5 (± 1.3) years, and the duration of caregiving ranged from 2 months to 24 years (median 2.8 years). The mean hours per week spent taking care of the patient was 52 (± 64) hours. The caregiving hours ranged from 1 hour per week to 24 hours a day, with a median of 20 hours per week.

Descriptive Statistics for Variables

Table 2 lists the descriptive statistics for the variables studied and the internal consistency of each instrument. Family caregivers reported the highest scores for the impact on the daily schedule subscale and the impact on finances, among the four negative subscales of the CRA. The mean score for the caregiver esteem subscale that measures a positive aspect was also high. The mean Physical and Mental Component Summary scores for the caregivers were 49.1 (± 10.3) and 51.1 (± 9.7), respectively. The family caregivers' perceived physical and mental health status were not significantly different from the general population norms ($t = -0.77$, $p > .05$; $t = 1.08$, $p > .05$). The mean score for the PHQ-8 for our caregiver sample was 3.5 (± 4.6). Eight caregivers (11%) had a PHQ-8 score of 10 or higher, suggesting clinical depression. Among the four subscales of the Dutch Objective Burden Inventory, the highest scores were obtained in emotional care and practical/treatment-related care. On average, caregivers perceived emotional/informational support to be least available for them among the four types of social support measured with the Social Support Survey.

Factors Related to the Impact of Caregiving on Caregivers of HF Patients

Final multiple linear regression models for the impact of caregiving are presented in Table 3. Lack of family support for caregivers was associated with patient NYHA class, caregivers' relationship to the patient, caregivers' perceived control, and social support. Patient NYHA class ($\beta = .17$, $p = .04$) was the only patient characteristic variable that contributed to lack of family support; higher NYHA class was associated with the sense of less support for caregiving. Non-spousal caregivers reported that they received less support from other family members compared to spousal caregivers ($\beta = .26$, $p < .01$). Of the caregiver psychosocial variables, lower perceived control ($\beta = -.19$, $p = .04$) and social support ($\beta = -.49$, $p < .001$) were related to a greater sense of lack of family support.

Financial strain resulting from caregiving was related to caregivers' economic status, perceived control, and social support. While caregivers' economic status ($\beta = -.43$, $p < .001$) explained a considerable amount of variance in the financial strain (16%), caregivers' perceived control ($\beta = -.24$, $p = .01$) and the availability of social support ($\beta = -.26$, $p = .01$) accounted for 5% of the variance, respectively.

Factors associated with disruption of caregivers' usual activities included patient NYHA class, amount of caregiving tasks performed, and caregivers' perceived social support. Even when the amount of care tasks that caregivers performed was controlled for ($\beta = .43$, $p < .001$), patient NYHA class ($\beta = .27$, $p < .01$) and the amount of social support available for caregivers ($\beta = -.37$, $p < .001$) respectively explained 7% and 14%

of the variance in disruption of the caregivers' usual activities. Higher NYHA class and less available social support were related to more disruption of caregivers' usual activities.

The impact of caregiving on caregivers' health was associated with time since patients' last hospital discharge, caregivers' perceived control, and social support. Caregivers' health was more affected by caregiving responsibilities for those whose family member's last hospitalization was more recent than for others ($\beta = -.26$, $p < .01$). Lower caregivers' perceived control ($\beta = -.21$, $p = .03$) and less social support ($\beta = -.45$, $p < .001$) were also related to a greater impact of caregiving on caregivers' health.

Although the main effect of social support was significant in all four models presented above, none of the interactions between social support and variables in these models was significant. However, the interaction between caregiver perceived social support and patient co-morbidities ($\beta = 1.57$, $p = .01$) was significant in the model for the positive impact of caregiving, caregiver esteem. For those caregivers who perceived their social support to be low, there was an inverse relationship between the co-morbidity score and the positive aspects of caregiving; namely, higher levels of patient co-morbidities were associated with family members feeling less positive about caregiving. However, no such relationship existed in those caregivers who perceived their social support to be high, meaning that patient co-morbidities did not decrease caregivers' positive feelings about caregiving. Caregiver race/ethnicity and the number of patient emergency department visits were also significantly associated with caregiver esteem. Non-white caregivers felt more positive about their role as a caregiver compared to white caregivers ($\beta = 0.29$, $p < .01$). The more often patients visited the emergency department in the past 12 months, the less positive their caregivers felt about their role as a caregiver (β = -.25, p = .02).

Discussion

Caregiver Perceived Health Status and the Impact of Caregiving

To date, no definite conclusion has been reached about the physical and mental health status of family caregivers of HF patients due to the inconsistent results from previous studies. In the present study, family caregivers' perceived physical and mental health status was comparable to the general population norms. While the perceived health status of the caregivers was not compromised, many family caregivers in our study reported that caregiving had negatively affected their health. Therefore, future research should use objective measures of caregivers' health status as well as a longitudinal design that would enable researchers to assess the actual changes in caregivers' health due to caregiving.

Overall, the impact of caregiving on family caregivers of HF patients was comparable to that of caregivers for patients with colorectal cancer.[30] In our sample, the negative impact of caregiving was most prominent with the caregivers' daily schedules. Interestingly, the mean score for the "impact on schedule" subscale in our sample was higher than that reported among caregivers of cancer patients[30] and of patients with multiple sclerosis.[31] The score was comparable to that reported among stroke caregivers.[32] That is, family caregivers of patients with HF felt that their daily activities were centered around care for the patient. This finding is consistent with previous studies that identified social isolation as one of the problems that caregivers experience. Many caregivers of HF patients felt they had to be available 24 hours a day,[33] and therefore gave up their social activities.[34, 35]

Factors Associated with the Negative Impact of Caregiving

The present study adds to the knowledge about family caregiving in HF by identifying the factors related to various aspects of the impact of caregiving. We found that caregivers' perceived availability of social support, which has never been reported in the context of HF, was associated with all four negative subscales of the CRA. Caregivers with lower social support perceived their caregiver role as more burdensome and less enjoyable or rewarding than others with higher social support. Family caregivers of HF patients had the lowest score on the emotional/informational support among the four subscales of the Social Support Survey. This suggests that the caregivers perceived resources related to emotional support, information, and advice were not sufficiently available for them. Our findings are consistent with previous reports that general information and emotional support were identified as priority needs for family caregivers of patients with chronic illness.[36] Therefore, interventions for family caregivers should include careful attention to increasing social support, particularly emotional support, as well as providing information that helps caregivers deal with difficult situations.

In line with the previous studies that showed a relationship between caregivers' low perceived control and poor emotional well-being,[6, 8] caregivers' perceived control over their family member's heart problem was an important factor in the impact of caregiving in the current study. On average, the level of perceived control among the caregivers in our study was low, and lower perceived control was associated with a greater negative impact of caregiving. The finding suggests that improving perceived control may reduce the negative impact of caregiving on these caregivers. Therefore, interventions for family caregivers of HF patients need to include strategies such as education and counseling to enhance their level of perceived control.

Consistent with previous studies, higher patient NYHA class,[37] the amount of care tasks performed,[13] and lower caregiver economic status[11] were associated with a more negative impact of caregiving. This information can be useful for clinicians working with HF patients and their families. Extra attention is needed for family caregivers of patients with severe HF, who receive no assistance with caregiving and are of low socioeconomic status.

Our findings also add new information about caregivers at high risk. In the current study, non-spousal caregivers, including adult children, parents, and siblings of the patient, felt they did not receive adequate support for caregiving from other family members. While spouses may be more distressed by patients' physical impairments than adult children due to their age-related health problems, adult children may be more vulnerable to distress because of conflicting demands, such as the demands of caregiving and those from work and their own families.[38] To date, the majority of studies of caregiving in HF have focused on the marital relationship, and only a limited number of studies included non-spousal caregivers. Therefore, future research is warranted to further examine differences in the impact of caregiving between spousal and non-spousal caregivers. In addition, caregivers perceived that their health was compromised more by caregiving demands when their family member's hospitalization was more recent. This finding underscores the importance of assessing caregivers' needs during the period immediately following the patient's discharge from hospital.

Factors Associated with the Positive Impact of Caregiving and the Moderating Effect of Social Support

Caregiving is stressful, but can also be a source of positive feelings, such as feeling good, confident, and satisfied about oneself.[4] Many caregivers of HF patients report that they felt rewarded by being able to provide care for their family member.[7, 39] Nevertheless, factors associated with the positive aspects of caregiving in the context of HF have remained unclear until now. In the present study, non-white caregivers and caregivers whose family member had fewer emergency department visits tended to perceive their caregiver role as more enjoyable and rewarding. The results reinforce the importance of preventing unnecessary emergency department visits and re-hospitalization through proper management of HF. Fewer patient emergency department visits was associated with higher caregiver esteem, even when patient co-morbidities were accounted for. A possible explanation for this relationship is that caregivers may view their family member's adverse outcomes such as emergency department visits as a failure of caregiving. Future research is needed to further explore the relationship.

Many HF patients have severe co-morbidities that decrease the family caregivers' positive feelings about providing care. However, the present study provides evidence that social support moderates the relationship between patient co-morbidities and positive aspects of caregiving. This finding reinforces the importance of social support for family caregivers. As clinicians assess the families' experiences with caregiving, it is important to also assess the amount of social support available to them.

Limitations

Several limitations of the present study need to be noted. First, the sample was small, non-random, and from outpatient clinics at a single university medical center. Although there was no difference in patient characteristics (i.e., age and gender) between study participants and patients who did not participate in the study, the possibility of selection bias cannot be completely ruled out because no information was available on other patient or caregiver characteristics for those who refused to participate. Patients and caregivers in this study were relatively young compared with those in most previous studies. Therefore, the generalizability of the findings is limited. However, it may increase the significance of the findings because most caregiving research has focused on the older population and less is known about caregiving for young and middle-aged adults with HF. Second, like many other studies of HF caregiving, the results of this study have to be interpreted with caution because of the cross-sectional design of the study. While we were able to identify the factors associated with the impact of caregiving, the causality of the relationships cannot be determined. Future longitudinal research is needed to confirm causal relationships.

Conclusion

Family caregivers of HF patients experience considerable burden from their caregiving responsibilities, although at the same time many feel positive about their role as a caregiver. The findings from our study reinforce the importance of assessing the needs of family members providing care for patients with HF. The assessment should be initiated during the patient's hospitalization to minimize the negative impact of caregiving on caregivers' health. In addition, clinicians should provide extra support for family caregivers during the period immediately following the patient's hospitalization.

Caregivers of patients with severe HF, non-spousal caregivers, and caregivers with low socioeconomic status and no assistance from others are more likely to feel burdened in the caregiving role. Interventions for family caregivers should be aimed at increasing caregivers’ sense of control and social support. Moreover, providing social support can increase positive feelings about providing care among family caregivers.

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Table 1

Characteristics of Patients with Heart Failure (HF) and Their Caregivers

	Patients with HF (n = 76)	Family Caregivers (n = 76)
Age (year)		
Mean ± SD (range)	53.8 ± 14.3 (20 - 78)	53.4 ± 15.7 (18 - 92)
Gender, n (%)		
Female	34 (45)	54 (71)
Race/Ethnicity, n (%)		
White	50 (66)	48 (63)
Education, n (%)		
≤ High school	37 (49)	33 (43)
Annual household income, n (%)		
< $20,000	20 (27)	16 (21)
$20,000 - 75,000	26 (34)	29 (38)
> $75,000	23 (30)	24 (32)
Missing	7 (9)	7 (9)
Marital status, n (%)		
Currently married	46 (61)	54 (71)
NYHA class, n (%)		
I	2 (3)	
II	29 (38)	
III	42 (55)	
IV	3 (4)	
Charlson Comorbidity Index, n (%)		
1 - 2	42 (55)	
3 - 4	24 (32)	
> 5	10 (13)	
Clinical events within 12 months		
Mean ± SD (range)		
Number of hospital admissions	2.0 ± 2.0 (0 - 10)	
Number of emergency department visits	1.7 ± 1.9 (0 - 10)	
Days since last hospital discharge, n (%)		
< 3 months	32 (42)	
3 months - 12 months	24 (32)	
> 12 months	20 (26)	
Relationship to patient, n (%)		
Spouse/Partner		56 (74)
Adult child		7 (9)
Parent		7 (9)
Other relative/friend		6 (8)
Employment, n (%)		
Employed		41 (54)

Quit a job or reduced work hours to provide care, n (%)		18 (24)
Living with patient, n (%)		66 (87)
Duration of caregiving (months) Mean ± SD (range)		53.4 ± 15.7 (2 - 282)
Caregiving hours per week Mean ± SD (range)		52.4 ± 64.0 (1 - 168)

Table 2

Descriptive Statistics for Measures (n = 76)

	Mean ± SD	**Actual range**	**Internal consistency**
Impact of caregiving (CRA)			
Lack of family support	2.1 ± 0.8	1.0 – 4.6	.77
Impact on finances	2.7 ± 1.1	1.0 – 5.0	.84
Impact on schedule	2.8 ± 0.9	1.0 – 4.8	.82
Impact on health	2.1 ± 0.8	1.0 – 4.3	.73
Caregiver esteem	4.2 ± 0.5	2.7 – 5.0	.71
Caregiver health status (SF-36v2)			
Physical health (PCS)	49.1 ± 10.3	18.4 – 66.4	.94
Mental health (MCS)	51.1 ± 9.7	26.5 – 66.7	.92
Caregiver depression (PHQ-8)	3.5 ± 4.6	0 – 20	.87
Care activities performed (DOBI)			
Personal care	1.3 ± 0.4	1.0 – 2.9	.88
Practical/treatment-related care	2.0 ± 0.5	1.0 – 3.0	.88
Motivational care	1.6 ± 0.5	1.0 – 3.0	.83
Emotional care	2.4 ± 0.5	1.0 – 3.0	.87
Caregiver social support (MOS SSS)			
Emotional/informational support	3.7 ± 1.0	1.0 – 5.0	.95
Tangible support	3.8 ± 1.1	1.0 – 5.0	.96
Affectionate support	4.3 ± 1.0	2.0 – 5.0	.94
Positive social interaction	4.1 ± 1.0	1.0 – 5.0	.97
Overall support index	3.9 ± 0.9	1.3 – 5.0	.96
Caregiver perceived control (CAS-R Family version)	27.9 ± 5.1	18.0 – 40.0	.80

CRA, Caregiver Reaction Assessment; SF-36v2, Health Survey Short Form 36 Items version 2; PCS, Physical Component Summary; MCS, Mental Component Summary; PHQ-8, Patient Health Questionnaire 8 items; DOBI, Dutch Objective Burden Inventory; MOS SSS, Medical Outcome Study Social Support Survey; CAS-R, Control Attitude Scale-Revised

Table 3

Multiple Regression Analyses for Impact of Caregiving

CRA subscales	***Beta***	***t***	***sr^2***	***p*-value**
Lack of family support				
Patient NYHA class	0.17	2.05	.03	.044
Non-spousal caregiver	0.26	3.04	.06	.003
Caregiver perceived control	-0.19	-2.15	.03	.035
Caregiver perceived social support	-0.49	-5.55	.22	< .001
R^2 = .50, *adj.* R^2= .48, *F*(4, 71) = 17.99				< .001
Impact on finances				
Caregivers' economic status	-0.43	-4.59	.16	< .001
Caregiver perceived control	-0.24	-2.63	.05	.010
Caregiver perceived social support	-0.26	-2.66	.05	.010
R^2 = .45, *adj.* R^2 = .42, *F*(3, 72) = 19.38				< .001
Impact on schedule				
Patient NYHA class	0.27	3.08	.07	.003
Amount of care tasks performed	0.43	4.77	.18	< .001
Caregiver perceived social support	-0.37	-4.25	.14	< .001
R^2 = .44, *adj.* R^2 = .42, *F*(3, 72) = 19.14				< .001
Impact on health				
Days since last hospital discharge	-0.26	-2.74	.07	.008
Caregiver perceived control	-0.21	-2.17	.04	.034
Caregiver perceived social support	-0.45	-4.58	.19	< .001
R^2 = .36, *adj.* R^2 = .34, *F*(3, 72) = 13.61				< .001
Caregiver esteem				
Number of patients' emergency department visits	-0.25	-2.43	.06	.018
Patient co-morbidities	-1.58	-2.81	.08	.006
Caregiver race/ethnicity: non-white	0.29	2.86	.08	.006
Caregiver perceived social support	-0.24	-0.94	.01	.352
Patient co-morbidities * social support	1.57	2.53	.06	.014
R^2 = .32, *adj.* R^2 = .27, *F*(5, 70) = 6.63				< .001

CRA, Caregiver Reaction Assessment; NYHA class, New York Heart Association class;

sr^2, Squared semi-partial correlation coefficient = R^2 change

Chapter 5

Family Caregiving in Pulmonary Arterial Hypertension

ABSTRACT

Background: Pulmonary arterial hypertension (PAH) is a devastating disease that places a significant burden on patients and their families. However, family caregiving has never been described in this population. The purpose of the study was to describe depressive symptoms, types of performed care tasks, social support, and impact of caregiving among family caregivers of PAH patients.

Methods and Results: Data were obtained from 35 dyads of patients with PAH (mean age 51 ± 12 years, 63% female, 54% World Health Organization functional class III) and their family caregivers (mean age 52 ± 13 years, 60% female, 68% spouse). Five caregivers (14%) were identified as having moderate to severe depressive symptoms. The majority of caregivers reported their daily activities as being centered around caregiving responsibilities. More than 85% of the caregivers were involved in managing care for the patient, and more than half helped the patient with self-management activities. The level of caregivers' perceived social support was low, especially for emotional/informational support. Lower level of social support was significantly associated with more severe depressive symptoms in caregivers ($r = -.50$, $p = .002$).

Conclusions: Caregivers of PAH patients play a significant role in patients' medical care and self-management, yet they lack sufficient emotional support or information to meet the demands of caregiving. The findings underscore the importance of supporting family caregivers of PAH patients.

Keywords: *Pulmonary arterial hypertension, family caregiver, impact of caregiving, care tasks, social support, depressive symptoms*

Introduction

Pulmonary arterial hypertension (PAH) is a poorly understood chronic disease characterized by severe elevation in pulmonary arterial pressure that ultimately leads to right ventricular heart failure.[1] According to recent reports in Europe, the prevalence of PAH is estimated to be 15-50 people per million population.[2] Although this estimate suggests a relatively low prevalence, this may be a low estimate because of the lack of awareness of the disease.[3] As the prognosis and survival of PAH patients improve with the development of new treatments, patients face new challenges in dealing with the unpredictable course of the disease and managing complex treatments that often require adjustment in their daily lives.[4] Subsequently, increasing attention is being paid to the impact of PAH on the psychosocial well-being and quality of life of these patients.[4, 5]

Patients with PAH often require assistance from family or friends because of their symptoms and functional limitations. Due to the complexity of the disease and its management, education and care plans for PAH patients need to include family caregivers.[6] As patients' symptoms progress, family caregivers encounter the same challenges patients face, which can affect their psychosocial well-being and quality of life. Caregiving can be stressful and affect various aspects of caregivers' lives, including physical and mental health, social life, and financial status.[7, 8] Prior studies showed that depression was prevalent in family caregivers and that the physical and mental health of caregivers was compromised.[8-10] To date, no study has examined family caregiving in the context of PAH. Research is needed specifically targeted to this caregiver population to identify the problems that family caregivers of PAH patients experience and to find the best way to assist them with their caregiving responsibilities.

Family caregivers perform a variety of care tasks for their family member with chronic illness, including assisting with activities of daily living, managing symptoms, carrying out treatment regimens, and communicating with providers.[10] Nevertheless, family caregivers often lack sufficient information and appropriate support from health care professionals.[8, 10] Clinicians who know the type of tasks that family caregivers of PAH patients are called upon to perform are better able to prepare them for their caregiver role. Education and support can be provided to family caregivers for the tasks that they perform.

Social support is another area that requires priority in this population. Social support buffers the effects of stress on an individual's health.[9] Current studies demonstrate that insufficient social support is associated with caregiver depression, which is one of the frequently reported problems related to caregiving.[8, 9] Social support has been an important element in interventions for caregivers of patients with chronic illness.[11] Assessing the level of social support for caregivers of PAH patients is needed to identify the areas where caregivers need further support and to identify the association between social support and caregiver depression in this population. The present study was conducted to: 1) describe the characteristics, depressive symptoms, and impact of caregiving in family caregivers of PAH patients, 2) identify care tasks that family caregivers perform, and 3) examine the association between caregiver depression and social support.

Methods

Study Design and Sample

This is a cross-sectional descriptive study. Thirty-five patient-family caregiver dyads were recruited from outpatient clinics at a university affiliated hospital with a pulmonary hypertension specialty center. All patients met the standard criteria for the diagnosis of PAH, namely a mean pulmonary arterial pressure (PAP) greater than 25 mm Hg at rest and the absence of significant left heart disease and other causes of pre-capillary pulmonary hypertension.[1, 2] In those cases where a mean PAP had not been recently obtained by cardiac catheterization, results of echocardiography were used combined with treatment for PAH with prostanoids or phosphodiesterase type-5 inhibitors. All patients were 18 years or older, community-dwelling (i.e., not receiving care in an institution), had a family member or friend providing care for them at home, and were able to read and write English. Eligible patients were asked to name a person who helped them the most at home. Then, the person was approached and screened for eligibility. Family caregivers were recruited if they were 18 years or older, able to read and write English, and were not hired for the care of the patient (a paid caregiver). The study was approved by the Institutional Review Board.

Procedures

Written informed consent was obtained from each subject. Data were collected using questionnaires and medical record review. Subjects were offered the option to complete the questionnaire themselves or to have an interview (via telephone or in-person). If subjects chose to complete the questionnaire themselves at home, they were instructed not to discuss their answers with each other. The completed questionnaire was returned in a stamped self-addressed envelope. The average questionnaire completion time was 10 minutes for patients and 45 minutes for family caregivers.

Measurements

Severity of PAH. The severity of PAH was assessed by the World Health Organization (WHO) functional class collected from medical records. The WHO functional class is an adaptation of the New York Heart Association functional class, which categorizes patients into one of four classes with class IV being the most severe.[1, 2]

Comorbidity. Patients' co-morbid conditions were identified from medical records using the Charlson Comorbidity Index, which is based on assessment of 17 co-morbid conditions. The index score is a sum of the weights of each condition, which takes into account both the number and the severity of conditions. The Charlson index is widely used in research and is a valid predictor of mortality from co-morbid disease.[12]

Caregiver health status. Two summary scores from the Health Survey Short Form 36 Items version 2 (SF-36v2) were used to measure the perceived physical and mental health status of caregivers. The SF-36v2 is the second version of the SF-36, and both have been used in a variety of populations, including the general population and individuals with chronic illness.[13] The validity and reliability of the SF-36 v2 were confirmed in many studies.[13, 14]

Caregiver depression. The nine-item Patient Health Questionnaire (PHQ-9) is a measure recommended for depression screening.[15] We used the eight-item version (PHQ-8), excluding the item regarding suicidal or self-injurious thoughts, to measure depression in family caregivers. The eight-item version can be used when the risk of suicide is considered to be low, when depression is a secondary outcome in the study, or when the instrument is administered by self-completion rather than by interview.[16] Each item is related to a particular depressive symptom, and responses to each range from 0 (not at all) to 3 (nearly every day). Total scores can range between 0 and 24. A score of 10 or greater suggests clinically significant depression.[16, 17] The psychometrics of the PHQ-8 are well-established.[17]

Impact of caregiving. The Caregiver Reaction Assessment was used to measure the impact of caregiving on various dimensions of the lives of caregivers. This instrument is a 24-item 5-point Likert scale with five subscales: lack of family support, impact on finances, impact on schedule, impact on health, and caregiver esteem. Each subscale score is the mean of the subsequent items' scores.[7] It measures both positive and negative aspects of the impact of caregiving. While four subscales measure negative aspects, the caregiver esteem subscale assesses whether caregiving is enjoyable and rewarding.[7] A higher score represents stronger impact. Acceptable psychometrics have been reported in studies of caregivers of patients with various chronic illnesses.[7, 18-20]

Care tasks performed. The type and amount of care that family caregivers performed for patients with PAH was measured with the English version of the Dutch Objective Burden Inventory. It contains 38 items, each of which is scored on a 3-point Likert scale ranging from never (1) to always (3). The items are categorized into four subscales based on the type of tasks: personal care, practical/treatment-related care, motivational care, and emotional care. Each subscale score is computed by averaging the scores of the subsequent items.[21, 22] Good psychometrics were reported previously in spousal caregivers of HF patients.[22]

Perceived social support. The extent of social support available to family caregivers was assessed with the Medical Outcome Study Social Support Survey. The instrument consists of 19 items with four subscales: emotional/informational support, tangible support, affectionate support, and positive social interaction. Each subscale score is an average of the scores on the subscale items. The overall support index is calculated by averaging the scores for all items. The scores can be transformed into a 0 - 100 scale so that the availability of different types of support can be compared with each other or with published means.[23] Satisfactory psychometrics were reported previously in patients with chronic disease and in family caregivers.[23, 24]

All instruments used in the current study demonstrated adequate internal consistency in our sample, with Cronbach's alphas above .70.

Statistical Analysis

SPSS 15.0 was used to analyze the data. Characteristics of patients with PAH and their family caregivers along with other study variables were analyzed using descriptive statistics, including means, standard deviations, frequencies, and ranges. Using one-sample t-test, the data were compared with normative or previously published data, if available. Data on tasks performed by family caregivers of PAH patients were presented with the percentage of caregivers scoring above one on each item of the Dutch Objective Burden Inventory. The Pearson correlation coefficient was used to examine the association between caregiver depression and social support. The statistical significance level was set at $p < .05$.

Results

Characteristics of Patients

Table 1 presents the characteristics of patients with PAH and their family caregivers. On average, patients were 51 (± 12) years old, with a wide age range (20 – 72 years). Half of the patients were currently married. The majority of patients were female

(63%) and white (60%). Hispanic/Latino was the second largest ethnic group in the patient sample (20%). Asians/Pacific Islanders and African-Americans consisted of 11% and 9% of the patient sample, respectively. Eight patients had idiopathic PAH (23%), and one had heritable PAH (3%). Other patients had PAH associated with drugs or toxins (37%), connective tissue disease (14%), congenital heart disease (8%), human immunodeficiency virus infection (6%), portal hypertension (6%), or chronic hemolytic anemia (3%). All patients had World Health Organization (WHO) functional class II (46%) or III (54%) symptoms. About one third of the patients were receiving continuous intravenous PAH therapy, and eight patients (23%) were on continuous oxygen therapy. While 57% of the patients had a Charlson Comorbidity Index of 1 or 2, 14% had an index of 5 or higher. The patients had an average of more than one hospitalization in the previous year (mean 1.7 ± 1.6, median 1, range 0 - 5). For 40% of the patients, their previous hospital discharge was within the past 3 months. The mean number of emergency department visits in the past 12 months was 1.5 (SD 2.0, median 1, range 0 - 10).

Characteristics of Family Caregivers

Almost two thirds of the family caregivers were female. The mean age of the caregivers was 52 (± 13) years. The caregiver sample consisted of spouses or partners (68%), adult children (9%), parents (9%), and other relatives or friends (14%) of patients. More than 60% of the caregivers were currently married. Most of the caregivers were white (66%), with 20% Hispanic/Latino, 8% African-American, and 6% Asian/Pacific Islander. More than half of the caregivers were currently working. Five caregivers (14%) reported that they had to quit their jobs or reduce work hours to provide care for the patient. About 80% of the caregivers were living with the patient. The caregivers had provided care for the patient for an average of 4.3 (± 5) years and provided 61 (± 69) hours per week of caregiving. The median duration of caregiving was 2 years. The number of hours providing care varied from 1 hour per week (6%) to 24 hours a day (26%), with a median of 23 hours per week.

Caregiver Health Status, Depression, and Impact of Caregiving

The descriptive statistics of the caregiver variables are summarized in Table 2. The mean SF-36v2 Physical Component Summary score in the caregiver sample was 50.0 (± 9.6), and the mean Mental Component Summary score was 49.1 (± 10.5). These mean scores were not significantly different from the general population norms ($t < .001$, $p > .05$; $t = -0.43$, $p > .05$). The caregivers scored an average of 4.6 (± 5.0) points on the PHQ-8. Five caregivers (14%) had a PHQ-8 score of equal to or greater than 10, suggesting moderate to severe depression. The average subscale scores for the Caregiver Reaction Assessment were highest on impact on daily schedule and impact on finances, among the four negative subscales. The average score for the positive subscale, caregiver esteem, was also high.

Caregiving Tasks Performed

Emotional care was the most frequently performed type of task among the four types measured with the Dutch Objective Burden Inventory (Table 2). At the item level, most caregivers reported they perceived the need to talk to the patient to reduce his or her anxiety (83%) or depressive feelings (71%). Caregivers of PAH patients also reported that they often provided practical/treatment-related care (Figure 1). Almost 90% of the caregivers helped the patient with household work. The family caregivers were also often involved in managing care for the patient by attending appointments and meetings with health care professionals (91%) and obtaining medications for the patient (86%). Items in the motivational care subscale showed that half of the caregivers assisted patients in adhering to diet (69%), exercise (60%), and fluid restrictions (49%) as well as medications (49%). While personal care was less frequently performed than other types of care, more than half of the caregivers felt they had to be available for 24 hours a day for the care of the patient (Figure 2). Helping at night (40%) and assisting with walking stairs (40%) were the next most frequently performed care tasks. Few caregivers assisted patients with appearance or going to the toilet.

Caregivers’ Perceived Availability of Social Support and Depressive Symptoms

Among the four subscales of the Social Support Survey, the availability of affectionate support was rated the highest and emotional/informational support was rated the lowest. Lower scores were reported on the items related to having “someone to share your worries and fears with,” “someone to give you information,” “someone to give you advice,” and “someone to turn to for suggestions.” The association between the availability of social support and the severity of depressive symptoms measured with the PHQ-8 was moderate to strong (r = -.50, p = .002), according to Cohen’s criteria.[25] Among the four subscales of the Social Support Survey, emotional/informational support (r = -.58, p < .001) and positive social interaction (r = -.34, p = .043) had significant inverse associations with the severity of depressive symptoms.

Discussion

To our knowledge, this is the first study on family caregiving in the context of PAH. As the life expectancy of PAH patients has increased with the development of new treatment strategies,[4] the issues related to family caregiving have become more important in this population. The findings of the current study provide a significant basis for understanding these important issues and will support the design and testing of appropriate education and counseling strategies for caregivers of patients with PAH.

Consistent with previous studies of PAH patients,[4] the majority of patients in the study were middle-aged women. Most caregivers were also middle-aged females. Specifically, all non-spousal caregivers, except a brother of one patient, were female relatives of patients. This high proportion of female caregivers is consistent with the gender proportion reported in studies of caregivers for patients with chronic illness and may reflect that caregiving is commonly considered to be women's work.[8, 10] Half of the caregivers in the sample were currently working, which suggests that many caregivers may experience conflicts between their work and caregiving demands.

In the current study, caregivers' perceived physical and mental health status was not significantly different from general population norms. However, 14% of the caregivers had a PHQ-8 score of 10 or greater, suggesting clinical depression. This number is higher than the prevalence of depression in the general population, which was reported to be 8.6% using the same criteria.[17] Caregivers of PAH patients reported that the negative impact of caregiving was greatest on their daily schedules and finances. That is, caregivers of PAH patients perceived that their usual activities were interrupted by care responsibilities and they experienced considerable financial burden related to caregiving. These levels were comparable to those reported in caregivers of stroke patients.[20] However, it must be noted that despite the negative impact of caregiving, caregivers of PAH patients viewed caregiving as a source of self-esteem. The mean score for “caregiver esteem,” the positive subscale of the Caregiver Reaction Assessment, was higher in this study than in caregivers of stroke patients. Overall, findings indicate that while providing care for a family member with PAH is burdensome for caregivers and the burden was comparable to that of caregivers of stroke victims, these caregivers also viewed their caregiving responsibilities as positive and rewarding.

Caregiving tasks that family caregivers perform for patients with PAH were examined in the current study. While personal care was not dominant in this population, caregivers of PAH patients reported frequently providing emotional care for the patient. A large number of caregivers in this study reported that they perceived the need to talk to the patient regarding his or her feelings of depression and anxiety. Emotional problems including depression and anxiety are prevalent in patients with PAH;[4] therefore, family caregivers need to be prepared for the emotional problems that patients may experience and be informed about resources available. Caregivers of PAH patients also played a significant role in patient care management. They were involved in patient care by attending appointments and meetings with health care professionals, obtaining patient medications, assisting the patient in adhering to prescribed self-care regimens. A third of the patients in this study were receiving continuous intravenous prostanoids, which often requires additional caregiver involvement, such as managing and administering medication, ensuring sufficient supplies, monitoring signs and symptoms of side effects, and caring for the central venous catheter.[26]

The data on social support reflect the areas in which caregivers of PAH patients need further support. Compared with the Social Support Survey scores reported in patients with chronic illness,[23] caregivers of PAH patients had a significantly lower score on emotional/informational support. This finding is consistent with previous reports on areas identified as the greatest needs by caregivers in general, which included general information and emotional support.[8] It is important to note that the caregivers in the current study were recruited from a hospital with a pulmonary hypertension specialty center. Even though the patients and caregivers received specialized care for the disease, including a specialized support group, these caregivers perceived that they did not have sufficient emotional support or information available. Similar issues were also reported in patients with PAH in a qualitative study.[5] PAH patients reported having difficulties dealing with the uncertainty of the disease and its progression. Strategies that these patients used to cope with the uncertainty included seeking information through the internet and seeking out support from support groups. Therefore, providing information and emotional support may be the key element in interventions for both patients with PAH and their family caregivers. In addition, support group interventions need to provide evidence-based content and thus to address the specific concerns and needs of these caregivers.

Caregivers' perceived availability of social support was further examined in relation to the severity of depressive symptoms of caregivers. Consistent with findings from previous studies of caregivers for persons with chronic illness,[9] the level of social support was associated with depressive symptoms of caregivers for PAH patients. Specifically, the availability of emotional and informational support as well as positive social interactions were related to depressive symptoms in these caregivers. These findings suggest that providing social support for caregivers of PAH patients in conjunction with proper therapeutic approaches such as counseling and medications may decrease their depressive symptoms.

Several limitations of this study warrant discussion. Generalizability of the study findings is limited by the small sample size and use of a convenience sample. The sample was from a single university affiliated hospital with a specialized pulmonary hypertension center. Therefore, our findings may not be applicable to caregivers of patients who do not have access to a specialty center and its associated resources. The findings need to be confirmed in larger studies, preferably multicenter studies. In addition, the use of structured questionnaires in the current study may have limited the depth of information collected. Because the knowledge about family caregiving in PAH is scarce, adding qualitative components to future research may provide more in-depth information. Lastly, the reliance on self-report measures, except for patients' clinical data, may limit the conclusions drawn from our study. Objective measures of caregiver health status and depression, such as number of co-morbidities, physiologic measures, and clinician-rated depression, in combination with the self-report measures may provide additional information about caregiver health and well-being.

Conclusion

The current study findings highlight the importance of assessing the impact of caregiving and depressive symptoms in family caregivers of PAH patients. Providing care for a loved one with PAH impacts various aspects of caregivers' lives. Family caregivers of PAH patients reported considerable negative impact of caregiving, especially on their daily activities and finances. But, at the same time, they viewed caregiving as a source of self-esteem.

Family caregivers often provided emotional support for the patient with PAH and were involved in the patient's medical care and self-management. Nevertheless, these caregivers did not have sufficient emotional support or information, and low social support was related to depressive symptoms. These findings provide information for clinicians to help family caregivers of PAH patients be prepared for the care tasks that they are likely to perform and to better understand the areas in which caregivers need support. Clinicians should assess the level of resources available to PAH patients and their families and focus on providing sufficient information and emotional support for them so that they can effectively manage the disease and issues related to care.

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Table 1

Characteristics of Patients with Pulmonary Arterial Hypertension (PAH) and Their Caregivers

	Patients with PAH (n = 35)	Family Caregivers (n = 35)
Age (year)		
Mean ± SD (range)	50.5 ± 12.2 (20 - 72)	51.7 ± 12.9 (18 - 72)
Gender, n (%)		
Female	22 (63)	21 (60)
Race/Ethnicity, n (%)		
White	21 (60)	23 (66)
Education, n (%)		
≤ High school	23 (66)	18 (51)
Annual household income, n (%)		
< $20,000	13 (37)	9 (26)
$20,000 - 75,000	11 (32)	12 (34)
> $75,000	7 (20)	10 (29)
Missing	4 (11)	4 (11)
Marital status, n (%)		
Currently married	16 (46)	22 (63)
WHO clinical classification, n (%)		
Idiopathic PAH	8 (23)	
Heritable PAH	1 (3)	
Associated PAH	26 (74)	
WHO functional class, n (%)		
II	16 (46)	
III	19 (54)	
Continuous intravenous PAH therapy		
Epoprostenol or Treprostinil, n (%)	11 (31)	
Continuous oxygen therapy, n (%)	8 (23)	
Charlson Comorbidity Index, n (%)		
1 - 2	20 (57)	
3 - 4	10 (29)	
> 5	5 (14)	
Clinical events within 12 months		
Mean ± SD (range)		
Number of hospital admissions	1.7 ± 1.6 (0 – 5)	
Number of emergency department visits	1.5 ± 2.0 (0 – 10)	
Days since last hospital discharge, n (%)		
< 3 months	14 (40)	
3 months - 12 months	11 (31)	
> 12 months	10 (29)	

Relationship to patient, n (%)		
Spouse/Partner		24 (68)
Adult child		3 (9)
Parent		3 (9)
Other relative/friend		5 (14)
Employment, n (%)		
Employed		20 (57)
Quit a job or reduced work hours to provide care, n (%)		5 (14)
Living with patient, n (%)		28 (80)
Duration of caregiving (months) Mean ± SD (range)		51.7 ± 62.0 (2 – 240)
Caregiving hours per week Mean ± SD (range)		60.9 ± 69.4 (1 – 168)

WHO, World Health Organization

Table 2

Caregiver Health Status, Depression, Impact of Caregiving, Performed Care Activities, and Social Support (n = 35)

	Mean ± SD	**Actual range**
Caregiver health status (SF-36v2)		
Physical health (PCS)	50.0 ± 9.6	22.4 – 64.3
Mental health (MCS)	49.1 ± 10.5	26.5 – 66.7
Caregiver depression (PHQ-8)	4.6 ± 5.0	0 – 20
Impact of caregiving (CRA)		
Lack of family support	2.3 ± 0.9	1.0 – 4.6
Impact on finances	2.9 ± 1.1	1.0 – 5.0
Impact on schedule	2.9 ± 0.8	1.6 – 4.2
Impact on health	2.2 ± 0.8	1.0 – 3.5
Caregiver esteem	4.0 ± 0.6	2.7 – 4.9
Care activities performed (DOBI)		
Personal care	1.4 ± 0.4	1.0 – 2.5
Practical/treatment-related care	2.0 ± 0.5	1.0 – 3.0
Motivational care	1.6 ± 0.5	1.0 – 3.0
Emotional care	2.4 ± 0.5	1.3 – 3.0
Caregiver social support (MOS SSS)		
Emotional/informational support	59.1 ± 29.0	0.0 – 100
Tangible support	65.5 ± 30.7	6.3 – 100
Affectionate support	76.7 ± 25.9	25.0 – 100
Positive social interaction	71.2 ± 27.4	0.0 – 100

SF-36v2, Health Survey Short Form 36 Items version 2; PCS, Physical Component Summary; MCS, Mental Component Summary; PHQ-8, Patient Health Questionnaire 8 items; CRA, Caregiver Reaction Assessment; DOBI, Dutch Objective Burden Inventory; MOS SSS, Medical Outcome Study Social Support Survey

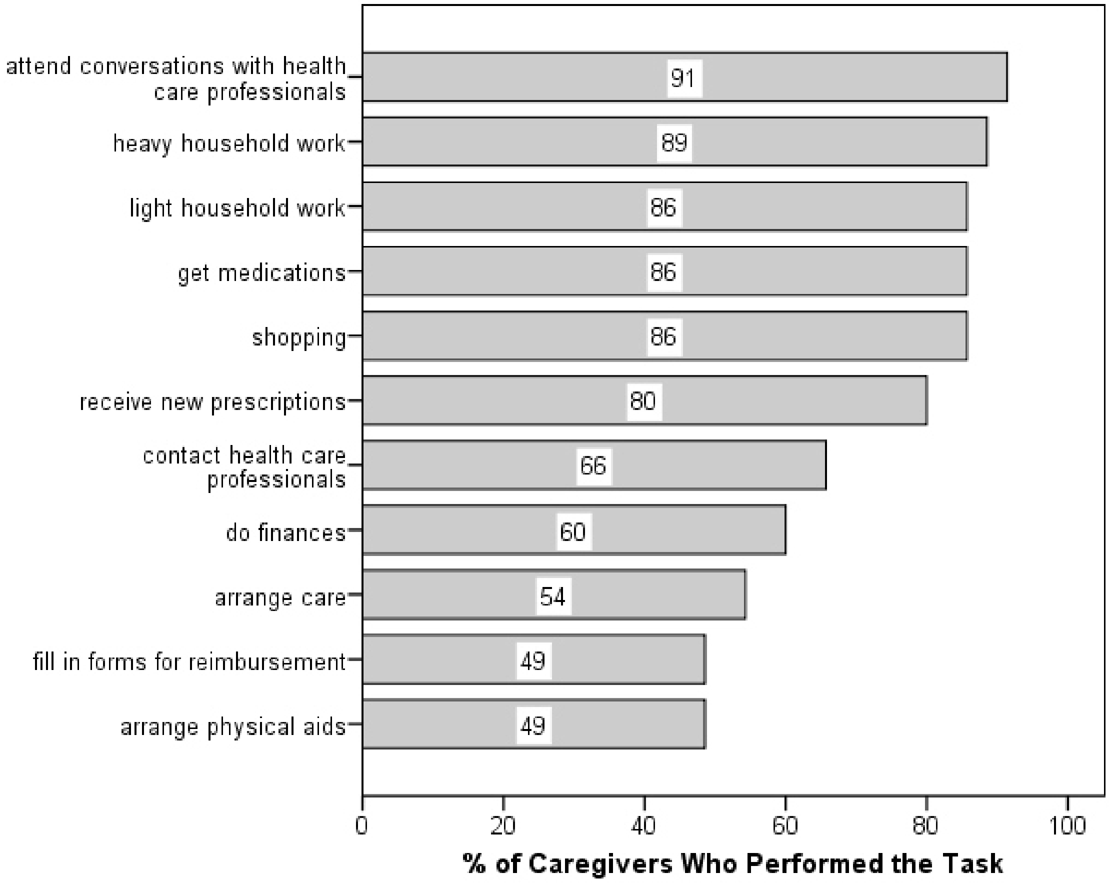

Figure 1

Percentage of Family Caregivers Performing Practical and Treatment-related Care for Patients with Pulmonary Hypertension (n = 35)

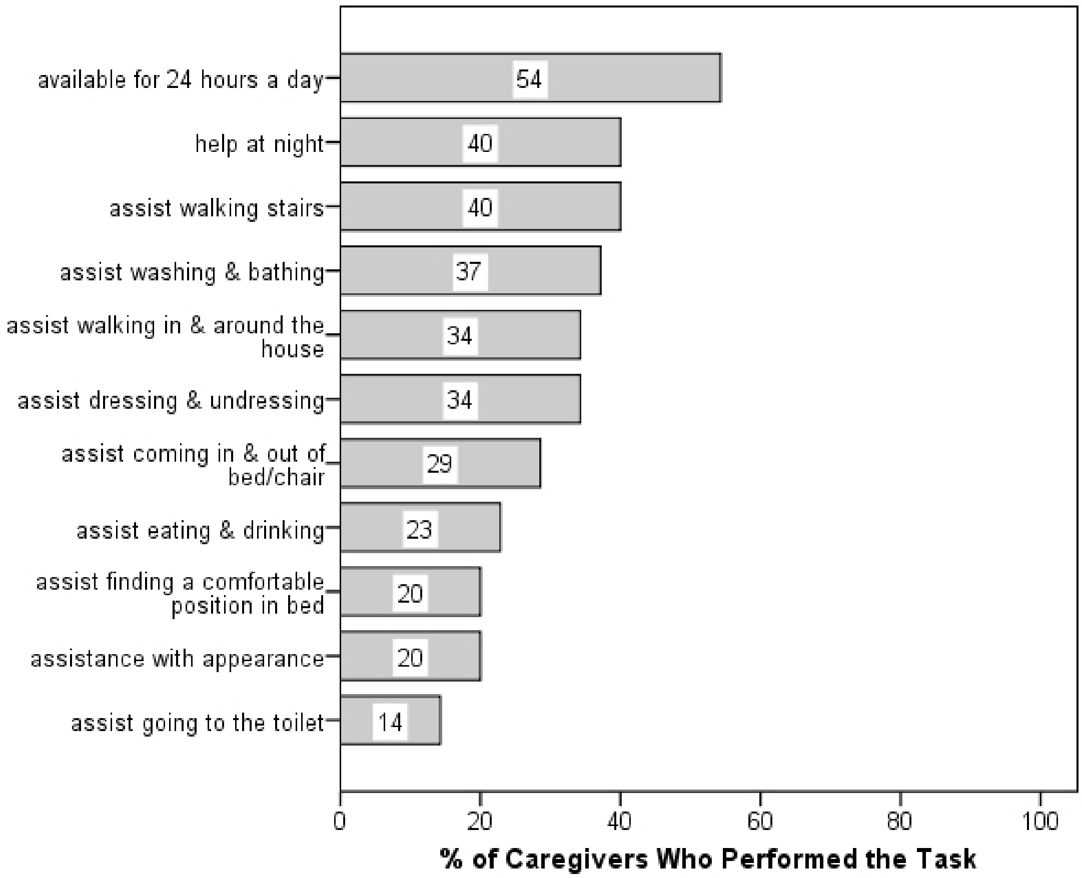

Figure 2

Percentage of Family Caregivers Performing Personal Care for Patients with Pulmonary Hypertension (n = 35)

Chapter 6

Summary and Conclusions

The overall purpose of this dissertation was to describe the nature of family caregiving in the context of heart failure (HF) with a focus on identifying factors associated with the impact of caregiving. Despite the important role that family caregivers play in the care of patients with HF, family caregiving is an area that has received little attention in HF research until recently. The role of family caregivers becomes even more important with the continuous rise in the prevalence of HF (Lloyd-Jones, et al., 2010) and the increased emphasis on adherence to complex therapeutic regimens in HF care (Stewart, 2005).

The findings from the three studies presented in this dissertation provide a significant addition to our current understanding of family caregiving in HF. The first research study (chapter 3) provides evidence that the care that spouses provide for patients with HF is above and beyond care normally exchanged in healthy older couples, even when HF-specific care tasks were not considered. The findings also provide information about gender differences in performing care tasks and suggest the need for gender-specific interventions for spousal caregivers of HF patients. The second research study (chapter 4) presented in this dissertation provides a description of the levels of perceived physical and mental health status and depression, types of performed care tasks, social support, and impact of caregiving among family caregivers of HF patients. The focus of the study was on identifying factors associated with the impact of caregiving and examining the moderating effects of social support on the impact of caregiving. This is the first study that examined the role of social support on the impact of caregiving in the context of HF. Family caregiving in the context of a specific etiology of HF, pulmonary arterial hypertension (PAH), was examined in the third research study (chapter 5) presented in this dissertation. The purposes of the study were to describe the characteristics of family caregivers of patients with PAH and the impact of caregiving on these caregivers. Care tasks that family caregivers of PAH patients frequently perform and the association between caregiver depression and social support were also examined. The findings from this research study are particularly important given the fact that family caregiving has never been described in this population prior to this.

The findings from this dissertation have pertinent clinical implications for the care of patients with HF and their families. The results also have theoretical implications that warrant further exploration and provide an impetus for policy development to support families caring for loved ones with HF. In addition, the findings from this dissertation may be used as a basis for future research regarding issues related to family caregiving in HF, where many questions remain to be answered before appropriate interventions can be designed and tested.

Clinical Implications

The dissertation findings have several important implications for clinicians caring for patients with HF. First, the results from this dissertation highlight the importance of assessing the impact of caregiving on the lives of families caring for HF patients. This dissertation research showed that caregiving had a great impact on caregivers' lives, including their daily activities, financial status, and health. Family caregivers of HF patients experienced substantial stress and burden related to caregiving responsibilities. Many caregivers felt that their daily activities were centered around the care for the patient and that they had to be available for the patient 24 hours a day. This may be one reason that caregivers of HF patients become socially isolated (Aldred, Gott, & Gariballa, 2005; Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007; Scott, 2001). In addition, consistent with findings from previous studies, family caregivers in this dissertation research perceived that their health was affected by caregiving. Family caregivers of HF patients also often report physical symptoms, such as constant fatigue, physical exhaustion, and sleep disturbance (Pattenden, Roberts, & Lewin, 2007; Saunders, 2008; Scott, 2000). Nevertheless, caregivers are not likely to receive medical attention unless they initiate a visit to their primary care provider. Even worse, it is common for caregivers to prioritize the needs of the patient while ignoring their own needs and health problems. Therefore, clinicians caring for patients with HF should be aware of the potential problems that family caregivers may experience and assess the level of burden and health problems in these caregivers.

Social support was identified as an important factor in the impact of caregiving on various aspects of caregivers' lives. Caregivers with lower social support perceived that caregiving had a more negative impact on their lives than did others with higher social support. The importance of social support appears to be even more prominent in caregivers of PAH patients, who reported having little information or emotional support. Therefore, providing social support for caregivers of HF patients may optimize the caregiving experience. Health care providers should assess the resources available to family caregivers and provide information that helps them deal with the many difficult situations and challenges inherent in caring for a loved one with a difficult chronic illness like HF.

The findings from this dissertation showed that caregiving had a greater impact on caregiver health when the patient's hospitalization was more recent. HF accounts for over

1.1 million hospital discharges in the United States a year (Lloyd-Jones, et al., 2010). Despite the advancement in treatments for HF, a recent report of Medicare patients indicated that over 20% of patients hospitalized for HF were readmitted to hospital within 30 days after discharge (Ross, et al., 2010). Given the high rehospitalization rate for patients with HF, the relationship between patient hospitalization and the impact of caregiving on caregiver health underscores the need for assessing the capacity of the caregiver to provide the support that is needed following discharge. Appropriate patient discharge planning and follow-up might decrease the level of burden experienced by caregivers. In addition, preventing rehospitalization in patients with HF would benefit both patients and their families.

Theoretical Implications

Caregiving is a complex phenomenon that affects many aspects of the lives of people providing care for their loved ones. Many factors play an important role in the caregiving experience. Therefore, a theoretical framework, which is clear and at the same time comprehensive, is needed for research on this phenomenon.

The caregiver stress-coping model used to guide this dissertation provides a comprehensive description of caregiving within a stress and coping paradigm. Although data from the studies presented in this dissertation support the model, it is important to note a limitation of this model. Traditionally, most stress and coping paradigms have focused on appraisal of a stressful event and coping processes that help manage or reduce distress (Folkman, 1997; Folkman, Lazarus, Gruen, & DeLongis, 1986), and have paid little or no attention to the positive aspect of caregiving (Kramer, 1997). Likewise, the positive aspect of caregiving is not explicitly described in the caregiver stress-coping model. Therefore, in this dissertation, the positive aspect of caregiving was viewed as part of perceived stress and responses among the four categories of variables included in the model (stressors, contextual variables, perceived stress and responses, and enduring outcomes). This view was supported by the data showing that caregiving is stressful but is also a source of positive feelings. However, because knowledge about the positive aspect of caregiving is limited, further investigation is needed in regard to its effect on stress responses and health.

Social Implications

The growing geriatric population and increase in numbers of patients with chronic illnesses as well as the growing evidence of the detrimental effects of caregiving on caregiver health have drawn increased attention to family caregiving. As a result, the Family Caregiver Support Act passed by Congress in 2000 includes funding for states to provide various support services for family caregivers, such as information, referral, training, counseling, and respite care (Donelan, et al., 2002). However, relatively little attention has been paid to family caregiving in the context of HF. Although the increasing emphasis on self-care and adherence to complex therapeutic regimens has increased the demands on the family, family caregivers of HF patients often do not receive sufficient support from health care providers (Aldred, et al., 2005; Stewart, 2005). To adequately address the problems faced by these family caregivers, much needs to be done. Research and clinical guidelines for HF care need to provide information about effective ways to support family caregivers. For this, more funding sources need to be made available for research on caregivers of HF patients. In addition, changes are necessary in our health care payment system which currently provides no financial incentives for providing care for family caregivers. Raising public awareness of the issues surrounding family caregiving in HF will encourage these caregivers to pay attention to their own health and to reach out to family, friends, and health care professionals for support.

Future Studies

While the positive aspect of caregiving has been overshadowed by the detrimental effects of caregiving described in previous studies, this dissertation research showed that many family caregivers felt rewarded for being able to help their loved one with HF. The data also suggest that adverse outcomes of patients may decrease caregivers' positive feelings toward caregiving. Because little is known about factors associated with the positive aspects of caregiving, more studies are needed in this area.

To date, there has been no intervention study designed to relieve caregiver burden or to improve outcomes in family caregivers of HF patients. The findings from this dissertation research suggest that improving caregivers' perceived control and providing social support may reduce the negative impact of caregiving. Therefore, future research needs to focus on developing interventions aimed to enhance the level of perceived control in family caregivers, such as by providing education and counseling. Research is also needed to test the effectiveness of different methods of providing social support for these caregivers, such as support groups, online resources, and individual counseling sessions.

The cross-sectional design of the studies limits interpretation of the results. To elucidate causal effects of caregiving on caregiver burden and health, longitudinal studies with repeated measures would be optimal. Use of physiological measures of caregiver health and stress, such as a standardized health status inventory and markers of neuroendocrine and immune function, should also be considered in future research.

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