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Heart Failure Family Caregiver Sleep Quality and, Physical, Physiologic and Psychologic Outcome

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An abstract of
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Abstract

Heart Failure Family Caregiver Sleep Quality and, Physical, Physiologic and Psychologic Outcome

By Udia-Oghenetega Otuguor

Background: Over the next 20 years, the United States (U.S) will experience an increase in the number of people with chronic diseases as the baby boomer's population ages. Consequently, the demand for family caregivers (FCGs) is also expected to grow. Heart failure (HF) is a chronic condition and remains the number one cause of hospitalization of elders in the U.S. With hospital stays becoming shorter, family members are expected to provide continued care and manage their loved one's HF after initial hospital discharge. Family caregiving is demanding, stressful and FCGs often report poor sleep quality, which is detrimental to their overall health and well-being; yet, little is known about the sleep health of FCGs of persons with HF.

Purpose: To examine the prevalence of poor sleep quality and factors associated with poor sleep quality among FCGs of persons with HF.

Sample and Design: This was a correlational study of 127 FCGs of persons with HF (N=127, Mean age 55.3 ± 1.5 years) using baseline data from a family caregiver interventional study. Variables and measures included sociodemographic characteristics, comorbidity, sleep quality (PSQI), caregiving stress factors (Oberst Caregiving burden Scale; Bakas Caregiving Outcomes Scale), Anxiety (STAI), depressive symptoms (CES-D), and measures of health status (SF-36, IL-6, salivary cortisol). Analysis included descriptive statistics, correlations, and multiple regression**.**

Results: About 82% of FCGs of persons with HF report poor sleep. Poor sleep quality was associated with higher caregiving stress factors ($p<0.05$) but not with FCGs sociodemographic or comorbidity factors. In addition, an association between poor sleep quality and lower physical function ($p=.02$), as well as poorer psychological function including higher levels of anxiety ($p=.03$) and depressive symptoms ($p<.01$) was observed. No association was observed between poor sleep quality and physiologic outcomes of cortisol and interleukin 6.

Conclusion: These findings suggest that poor sleep quality is prevalent in FCGs of persons with HF, and that FCGs who experienced poor sleep had worse health outcomes. Caregiver stress factors are possible targets of intervention to reduce caregiver burden and possibly affect sleep quality. Future studies are needed to develop and test interventions that improve FCGs' health outcomes.

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CHAPTER I

Introduction

In 2014, about 6.5 million United States adults lived with heart failure (HF). This number is expected to rise by 46% by the year 2030. [1] The number of persons aged 65 years and above living with HF is also expected to rise by the year 2030 with the aging baby boomer population, consequently, the demand for family caregivers (FCGs) is expected to rise. [1, 2] HF progression is characterized by functional limitations, increased dependency, anxiety, depression and frequent exacerbations. [3] Managing these complexities places enormous physical and psychological burden on FCGs, [4] and evidence suggests that FCGs of persons with HF experience burden. [5-7] FCGs may not engage in their own self-care due to the demands of HF management which may affect their time and attention to health promotion behaviors including getting adequate sleep.

Poor sleep quality is linked with lower physical and psychological function such as depression, [8, 9] and other physiologic and metabolic disruptions including altered hypothalamic-pituitary-cortisol pathway, increased systemic inflammation and morbidity. [10-13] Thus, poor sleep quality has serious health consequences and ultimately may also impede the ability of FCGs to fully benefit from education and supportive interventions targeted at improving health outcomes for both FCGs and care recipients. Therefore, a greater understanding of the role of FCGs' sleep quality while managing a loved one's HF would elucidate the complexity of personal self-care needs of FCGs and guide the development of more effective interventions for them.

Characteristics associated with FCGs' sleep may vary by individual and caregiving characteristics. Older age, female gender and African American race are associated with poor sleep quality in the general population, [14-19] and many FCGS are women and some are elders. [20-22] For FCGs, factors relating to poor sleep quality in caregivers across chronic illnesses include patient disease severity, caregiver anxiety and depression, caregiver perceived burden and chronic stress. [23-26] However, caregiver sleep experience may vary with disease specific characteristics. In Alzheimer's disease, reduced mental function and nocturnal behavior of the care recipient have been identified as important predictors of poor sleep quality in FCGs. [25] Similarly, poor sleep quality of FCGs of persons with cancer has been linked to the care recipient's sleep activities, and the FCG's worries and grief. [8, 24] In studies of FCGs of persons with HF, poor sleep quality has been reported. [21, 27] Factors associated with poor sleep in FCGs of persons with HF include FCG issues (anxiety), and the burden of the care recipient's nocturia and sleep apnea. [28-30] However, studies of sleep behavior of HF FCGs are limited, lack rigor in terms of sample size, and have <u>not</u> 1) addressed the FCGs sociodemographic and health factors known to affect sleep, 2) used standardized sleep instruments to document sleep quality, or 3) examined associated health outcomes. No quantitative studies were found on factors associated with sleep in FCGs of persons with HF. These data are essential to identify modifiable factors that contribute to poor sleep quality and to determine protective factors to ultimately design and test interventions to reduce adverse outcomes in FCGs of persons with HF.

Purpose

The purpose of this study was to describe the overall sleep quality in FCGs of persons with HF and associated factors based upon the theory of allostatic load of stress which describes the pathway between chronic stress, failed adaptation and physiologic wear and tear of the body. [31] HF is a chronic condition, therefore, identifying factors that may lower FCGs sleep quality are necessary for developing targeted interventions to reduce overall burden and improve caregivers' outcomes. The study is a secondary analysis of baseline data from an intervention study of FCGs of persons with HF.

Specific Aims

Aim 1**:** Describe sleep quality (Pittsburgh Sleep Quality Index; PSQI) in FCGs of persons with HF and associated sociodemographic, clinical, and FCG stress factors (Bakas Caregiver Outcomes Scale; BCOS, and Oberst Caregiver Burden Scale-Difficulty subscale; OCBS-D).

H1a**:** Older age, African American race and caregiver comorbidities will be associated with worse sleep quality in FCGs.

H1b: Higher FCG stress factors will be related to worse sleep quality.

Aim 2**:** Examine the associations among FCG sleep quality and physical (SF-36 Physical Function Subscale) and psychological (depressive symptoms; CESD, and anxiety; STAI) functions.

H2a. Poor sleep quality will be associated with worse overall physical health status.

H2b. Poor sleep quality will be associated with worse psychological outcomes including greater depression and anxiety.

Aim 3: Examine the relationship between sleep quality and physiologic outcomes (salivary cortisol, Interleukin – 6 (IL-6)) in FCGs of persons of HF.

H3: Poor sleep quality will be associated with increased a.m. salivary cortisol and increased pro-inflammatory cytokines (IL-6).

Use of The Theory of Allostasis and Allostatic Load in Family Caregiving

The study was guided by the theory of allostasis and allostatic load. This theory provides a good understanding of human physiology and adaptation in stressful circumstances. Allostasis is the process by which the body responds to stressors in order to maintain stability, and allows for successful physiologic, emotional and behavioral coping within a stressful environment. [32, 33] While effective initially, as this process progresses over time, it can result in physiologic wear and tear that predisposes the individual to disease occurrence. These physiological changes can be seen through the activities of the hypothalamus-pituitary-adrenal (HPA) axis (glucocorcorticoids), and the immune system (inflammatory cytokine).

Family caregiving stress may trigger allostasis in FCGs who have been reported to have high caregiving burden, perceived stress, as well as poor sleep. Thus, over time, FCGs face the risk of building a high allostatic load that may be detrimental to their health and exposes them to early morbidity. This model outlines a proposed pathway by which sleep quality of FCGs of persons with HF may influence caregivers’ health outcomes. Therefore, this theory provides a robust depiction of caregiver stress, behavior and health outcomes illustrated in the study framework (Figure 1) and the variables of interest.

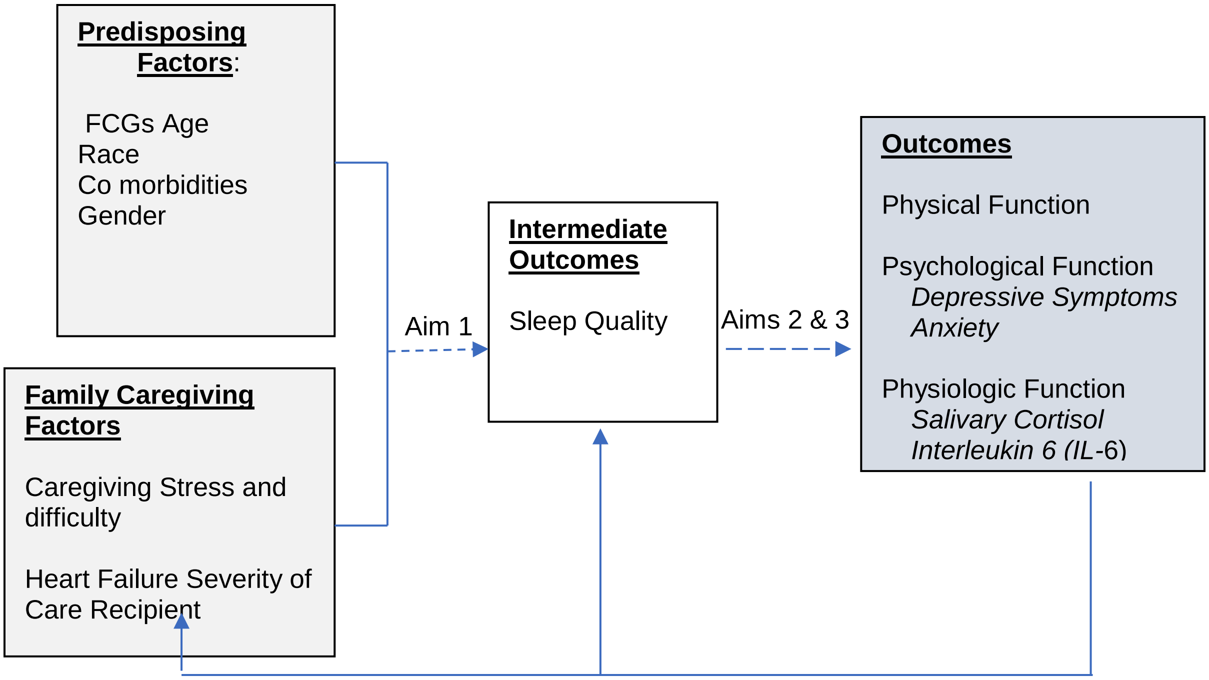

Figure 1. Conceptual framework of sleep quality in family caregivers of persons with heart failure

Significance

FCGs play an important role in the home-based management of HF after initial hospitalization.[34] Because caring for persons with HF is complex and difficult, FCGs often pay less attention to themselves, and do not engage in self-care behaviors that is essential for maintaining their optimal health. [14] When the health of FCGs is compromised, HF may be poorly managed, and several consequences may ensue including exacerbations requiring frequent emergency room visits, rise in direct medical cost of HF and early mortality. Sleep experience of FCGs of persons with HF has received sparse attention.

Clearly, there is a need to examine the sleep quality of FCGs in HF population. The issues that are responsible for high burden and poor health outcomes in FCGs are complex and multifaceted, and poor sleep quality may be an important contributor. This study examines factors that may be associated with sleep quality and outcomes in FCGs of person with HF.

BACKGROUND

Heart Failure Trajectory

Heart disease is a public health concern and remains the leading cause of death in the United States and around the world. The prevalence of HF among adults increased from 5.7 million in 2012 to 6.5 million in 2014. This number is expected to increase by 46 percent in 2030, accounting for a projected 8 million people living with HF by the year 2030. [1] This projected prevalence may be due in part to the aging U.S population, [35] and advances in medical science that has increased the survival rate of HF. [36] While this may be a positive step that decreases mortality from the disease, it is associated with high morbidity burden in persons with HF and high medical burden. [37]

The cost of care for persons 65 years and above suffering from HF have been projected to be 30.7 billion dollars in 2030 and does not include the services provided by family members which was estimated to be 3 billion dollars in 2010 and increases the indirect cost of HF by 35%. [1, 38] With shorter hospital stays and longer survival time, more emphasis is placed on the community-based management of HF. [39] Informal caregivers, usually family members, assume the task of continued care for their loved one at home. [34] This role is demanding, stressful and has been associated with poor health outcomes in FCGs. Also, the demand for FCGs is expected to surge with the growing aging U.S population. Thus, focusing on FCGs'' health is important for the successful management of HF.

Family Caregivers Heath Issues

Family members caring for persons with HF face many challenges. Although some report positive rewards from being a FCG, many perspectives are that caregiving is difficult, stressful and burdensome. [4] FCGs are expected to understand and monitor symptoms of HF, provide emotional support, facilitate lifestyle changes with diet modification, and support a complex medication regimen. [40] In addition, FCGs are involved in the day to day activities of the person with HF which may include collaborating with the healthcare professionals and scheduling of appointments, meal preparation and performing of activities of daily living as the person with HF becomes more physically dependent on FCGs. [40] In order to fulfill these demands, FCGs may alter their lives, health behaviors, and social activities. This alteration may increase burden and may result in FCGs not engaging in health promoting activities such as sleep in order to provide adequate care for their loved one.[30, 41] Caregivers need for sleep is paramount to their health and wellbeing. Further, HF requires long term management that is equated with chronic caregiving stress, and the cumulative effect of long term poor sleep quality may impede the ability of FCG to provide quality care, as well as increase their risk for adverse health outcomes. [42]

Sleep as a Health Factor

Poor sleep quality is a national concern that has been linked with poor health outcomes. About a third of the Unites States population experience poor sleep.[43] Improving the sleep quality of Americans has become one of the objectives of the healthy people 2020.[44] Poor sleep quality is associated with day to day stress, anxiety and poor health rating. Poor sleep quality is a risk factor for morbidity and mortality, as well as fatigue,[45] depression, inflammation,[46, 47] poor immune function, and cardiovascular disease.[48, 49]

The extent to which poor sleep quality occurs in FCGs may be proportional to the duration and severity of the stress, and many FCGs do not return to their pre-caregiving sleep habits after their loved one passes away.[50] With projected demands for FCGs , the multiple factors associated with caregiver burden and health outcomes, it is important to examine possible additional factors such as sleep that may be associated with caregiver burden and negative health outcomes.[51] In addition, sleep problems may be associated with caregiving challenges within specific disease population.[52, 53] Although this study is cross sectional, the findings from this study may be useful in informing interventions that target FCGs of persons with HF.

RESEARCH METHOD AND DESIGN

Design

This study uses a correlational, cross-sectional design in testing the hypotheses previously stated. A secondary data analysis was be performed using only baseline data from a prospective, randomized control trial. The parent study consisted of FCGs of person with HF (N=127) that were randomized to one of three groups: Psycho-education (PsychEd), Psycho-education plus exercise (PsychEd+Ex) and usual care. Participants were seen at baseline and 6-months later. Surveys, questionnaires, saliva samples and blood (venipuncture) were collected at each time point.

A cross sectional design provides a means of simultaneously obtaining information on both the predictor variables (caregiver stress and sleep quality) and the outcome variables (FCGs physical function, anxiety, depression and physiologic status) through the administration of surveys at a single point in time (see Figure 1 for a conceptual model that depicts the relationship among variables). Correlational studies are beneficial in estimating the prevalence of symptoms such as sleep quality in chronic conditions such as HF disease and are appropriate for this FCG study. In addition, this cross-sectional study design has helped in understanding the relationship between variables of interest and will inform future research that might include experimental HF FGCs studies.

Sample Recruitment and Informed Consent

In the parent study, FCG participants (n=127) were recruited through HF clinics at major metropolitan hospitals in Atlanta using a variety of direct recruitment, self-referral and convenience techniques. The non-random sampling method entails choosing participants based on availability and meeting of inclusion and exclusion criteria as noted below. These sampling methods are essential in recruiting FCGs because they are a difficult to reach population. Once written informed consent and baseline measures were obtained, participants were randomized into the intervention study.

*Rationale for sample size***:** For the purpose of this secondary analysis study, the 127 final sample from baseline was included. The overall minimum sample of 108 was determined through the Gpower analysis software for a multiple regression (power 90%, moderate effect size 0.15, significance 0.05) for four predictor variables (Aim 1). Thus, the sample size of 127 provides adequate power for this current study.

*Primary Eligibility***:** FCGs were required to be 21 years of ages and older, fluent in the English language, ambulatory and able to engage in structured low impact exercise (walking and upper body strength training) which was part of the intervention. FCG was defined as any relative who lives with the person with HF or in contact with a patient with HF in a caregiver relationship at least 4 times/week for at least one hour or more. The criteria for a family member were expanded to include family members who typically do not live with the person with HF (the ideal FCG) but assist persons with HF on a routine basis. This relationship was tracked in the parent study to determine if it altered the intervention outcome effects.

*Exclusion Criteria***:** Caregivers were excluded if they reported engaging in at least moderate exercise (30 minutes or more of moderately strenuous exercise 3 times or more a week); had medical, physical or psychiatric conditions that would interfere with study participation, were a current smoker, had cognitive difficulties as noted on the BLESSED screening instrument with a score ≥10 indicating impaired cognition, [54] on corticosteroids or other anti-inflammatory drugs. Several of these exclusion criteria were part of the design to avoid confounding of inflammatory markers in the parent study.

Potential Risk: This study bears no risk to participants as it uses deidentified data only. Data were handled in RedCap according to the Data Safety and Monitoring Plan (DSMP) which required deidentification at the conclusion of the parent study.

Predisposing Factors:

Demographic and clinical variables

FCG demographics were self-reported. Co morbidities were assessed using the Charlson comorbidity Index CMI). ADD ref number This instrument was developed to measure risk of death from co-morbid diseases and compares favorably with the more established Kaplan and Feinstein system, [55] and documents conditions which may account for other illnesses within family members. The CMI was developed empirically from 604 patients admitted to a hospital medical service to predict risk of death from comorbid conditions. [56] Reliability (0.74 – 0.95) and construct validity have been reported. [57] Heart failure severity of care recipients was collected using questions and ratings of symptoms by the FCG. Heart failure severity is Class I to IV with higher class reflecting greater severity..

Family Caregiving Factors

The Oberst Caregiving Burden Scale measures the time and perceived difficulty spent on caregiving tasks. [58] Items are rated on a 5-point response scale, with higher scores indicating greater time or difficulty (Cronbach alpha of .82).[59] The Oberst Caregiving Burden Scale was used to describe the HF FCGs perceptions and compare with historical or published norms. Evidence of internal consistency reliability and construct validity have been documented. [60]

The Bakas Caregiving Outcomes Scale (BCOS)[61] is a 15 item questionnaire with a 7-point response scale on which FCGs rate how their lives have changed since initiating care. Transformed and summed scores are interpreted with higher scores indicating perceptions for a better change and lower scores indicating negative perceptions of caregiving. Validity and reliability have been documented for FCGs of persons with HF with Cronbach's alpha of .72-.88. [59, 61] The BCOS was used for hypothesis testing.

<u>*Sleep Quality*</u>

The Pittsburgh Sleep Quality Index (PSQI) is a self-report questionnaire that provides a comprehensive assessment for sleep quality and disturbance over a 1-month time interval. [62] Nineteen individual items produce a global sleep quality score as well as seven component scores on sleep latency, sleep duration, habitual sleep efficiency, sleep disturbance, use of sleeping medications, and daytime sleepiness. The sum of scores for these seven components yields one global score. A global PSQI score equal to and greater than 5 yielded a diagnostic sensitivity of 89.6% and specificity of 86.5% (kappa = 0.75, p =.001) in discriminating poor versus good sleep. [63] Reliability and construct validity have been well documented. [64]

Health Outcomes

<u>*Physical function*</u> *(SF-36v2)* is defined as the ability to carry out activities that require physical capability, ranging from self-care (activities of daily living) to more vigorous activities that require increasing degrees of mobility, strength, or endurance. [65] The instrument includes 8 health elements that represent dimensions of quality of life (QOL): physical functioning; role-physical; bodily pain; general health perception; vitality; social

functioning; role-emotional; and mental health. Respondents are asked to rate on a 3-point scale the extent to which their health limited their ability to engage in the various activities over the past 4 weeks (1=limited a lot, 2=limited a little, and 3=not limited at all). Standard scoring algorithms transform raw scores to a 0 to 100 scale, with higher scores reflecting higher health related QOL. Various studies have supported the reliability and content validity of the SF-36 Physical function subscale with Cronbach alpha ranging from .8-.91. [66, 67] The physical function subscale (PFS) was used.

Anxiety. The State scale of the State-Trait Anxiety Inventory (STAI) consists of 20 items to which participants rate how they feel at the moment about that item on a 4 point scale with higher scores indicating higher levels of anxiety. STAI scores $\geq$ 40, indicate severe and clinically significant anxiety. The STAI has shown high degree of reliability and validity. [68-70]

Depressive symptoms was measured by the Center for Epidemiological Studies Depression Scale (CES-D), [71] a 20- item scale designed to assess depressive symptoms in the general population. Participants rate items according to how they have been feeling the past week. Higher scores indicate higher depressive symptoms with a cut off score $\geq$ 16 to indicate possible clinical depression. The CES-D has a reported alpha of .83, and substantial evidence of concurrent and construct validity [71] and has been used extensively with caregivers. [72]

Physiologic Function: Salivary cortisol represents the free fraction of circulating cortisol and is a reflection of the biologically active fraction of cortisol. Cortisol secretion surges immediately after awakening with decline during the day. [73] Participants were instructed on how to collect the saliva sample and store it frozen until the next clinic visit. Samples were analyzed using radioimmunoassay and assessed in triplicate for salivary cortisol levels.

Interleukin-6 (IL-6) is a pro-inflammatory cytokine that represents dysregulation of the immune system. Il-6 was measured using standard procedures. To control for circadian variations in immune biomarkers, blood was drawn preferably in the morning of the baseline treadmill test. Samples were obtained in chilled EDTA-coated tubes and spun at 1000g for 15 minutes at 4°C, and plasma was collected and stored at −80°C for later batched analysis of the inflammatory cytokine IL-6. Concentrations of IL-6 were assessed in duplicate using high sensitivity multiplex bead-based assays (R& D Systems) and analyzed on a MAGPIX CCD imager (Luminex). [74, 75] Mean inter- and intra-assay coefficients of variation (CV<10%) were acceptable.

Data Analysis

This project is a secondary data analysis of baseline data using a cross sectional study design. Since the study examines relationship between sleep quality and other variables of interest, correlation and regression analysis will be employed to test hypotheses, using SPSS v 25.

Bivariate analyses will be conducted to identify potential predictors for sleep as an intermediate outcome and the main outcomes of interest (physical, psychologic and physiologic functions). Pearson's and Spearman's rank correlations was used for parametric and non-parametric variables respectively. Variables that were significantly correlated with outcome variables were included in the building of the linear models. Model diagnostics were performed to ascertain whether or not the assumptions for linear regression model were satisfied. All variables in the model were examined for multi-collinearity and model adjustments were made if necessary. Stepwise variable selection method was used in building the final models.

Specific Aim 1: Describe sleep quality (Pittsburgh Sleep Quality Index; PSQI) in FCGs of persons with HF and associated sociodemographic, clinical, and FCG stress factors (Bakas FCG outcomes scale; BCOS, and Oberst Caregiver Burden Scale-Difficulty subscale; OCBS-D).

H1a**:** Older age, African American race and caregiver comorbidities will be associated with worse sleep quality in FCGs.

H1b: Higher FCG stress factors will be related to worse sleep quality.

Descriptive statistics was used to examine the proportion of demographics and clinical data of FCGs that report poor sleep quality, bivariate and multivariate regression analysis were used to examine the association between sleep quality and demographics, comorbidity, caregiver stress, family member NYHA class, caregiver difficulty and time.

Specific Aims 2 and 3:

Aim 2**:** Examine the associations among FCG sleep quality and physical (SF-36 Physical Function Subscale) and psychological (depressive symptoms; CESD and anxiety; STAI) functions.

H2a. Poor sleep quality will be associated with worse overall physical health status.

H2b. Poor sleep quality will be associated with worse psychological outcomes including greater depression and anxiety.

Aim 3: Examine the relationship between sleep quality and physiologic outcomes (cortisol, IL-6) in FCGs of persons of HF.

H3: Poor sleep quality will be associated with increased a.m. salivary cortisol and increased pro-inflammatory cytokines (IL-6).

Bivariate and linear regression analysis were used examine sleep quality association with each individual outcome variable (physical function, psychological function and physiologic function). Strength and direction of relationship between independent and outcome variables were examined

Summary

Heart failure (HF) is the leading cause of morbidity and mortality in the United States and worldwide.[76] The prevalence of HF disease is expected to rise as the number of older persons continues to rise in the United States. [1, 2] Family caregiving is the backbone of chronic disease management such as in HF disease. There is evidence that home based HF management is demanding and difficult and family FCGs experience adverse health outcomes related to their caregiving role that may jeopardize optimal care of the HF recipient, as well as increase their own risk for morbidity and mortality. [77]

The demands of caring for a loved one with HF may make it difficult for FCGs to engage in their own self-care and they may fall short on health promoting activities such as obtaining adequate sleep. Evidence suggests that FCGs of persons with HF experience sleep problems related to factors such as anxiety, and nocturia and sleep apnea in the person with HF. [21, 27, 30] In addition, social-demographic factors such as age, gender and race have been associated with poor sleep in FCGs. [20, 21] Adequate sleep is a fundamental process that is essential to a person's optimal functioning and plays an important role on how the body responds to daily stress. [9] FCGs of persons with HF may be at increased risk for poor sleep quality and consequently, poor physical and psychological function. Other effects include dysregulation of several biological systems (HPA, immune, circadian) that result in adverse health outcomes. Yet, to the best of our knowledge, no studies have been done to address these factors known to possibly affect FCGs' sleep.

The study was based on the theory of allostasis and allostatic load and focuses on overall sleep quality and associated factors in the growing population of FCGs of persons with HF. A secondary analysis of baseline data was used in a correlation study design to examine the proposed hypotheses. Furthermore, results from this study added to our knowledge of the science that may be used in developing and testing behavioral interventions to reduce adverse health outcomes of FCGs of persons with HF.

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CHAPTER II

Sleep Quality and Associated Factors Among Family Caregivers of Persons with Chronic Diseases: A Literature review.

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Abstract

Family caregiving for persons with chronic conditions can be complex, challenging and stressful. On average, family caregivers (FCGs) spend about 4 to 10 years in the role of caregiving. Evidence suggests that FCGs experience poor sleep that may continue throughout the trajectory of caregiving and beyond, which place caregivers at increased risk of developing adverse health outcomes. Maintaining good quality sleep is essential for caregivers' overall health and the successful management of their loved ones' chronic condition. This review discusses the prevalence of poor sleep quality in FCGs, and the multiple complex factors associated with poor sleep quality and outcomes in three major populations of chronic diseases: heart failure, Alzheimer's disease, and cancer. It also provides recommendations for research examining sleep quality and outcomes in FCGs.

Introduction

About 25% of adults in the United States (U.S) provide informal care to persons with chronic conditions. [1] This number is expected to grow with the demands of caregivers increasing in the coming years due to an increase in the aging population. Moreover, caregivers spend an average of 4 years in the role of caregiving, and this can span unto 10 years, [2, 3] making caregiving a long-term commitment. Caregiving tasks include assisting with activities of daily living (ADL), coordinating transportation and care with the healthcare team, managing complex medication regimen and supporting care recipient emotionally. [2, 4]

Caring for persons with chronic diseases can be challenging. On average, FCGs spend 24.4 hours a week on caregiving and FCGs who live with care recipient spend an average of 40.5 hours a week on caregiving. [2] FCGs often report overwhelming burden and chronic stress that can potentially alter caregivers' lives and increase caregivers' risk of developing adverse health outcomes.[1, 5-7] Further, caregiving has been associated with multiple factors that may affect the FCGs' ability to obtain good quality sleep. [8, 9] In addition to caregiving stress, the caregiving environment, disease severity, level of functioning and sleep habits of care recipients can also affect FCGs' sleep. [10] For example, factors associated with FCGs of persons with Alzheimer's disease (AD) include behavioral problems of care recipients and nocturnal activities. [11] These additional factors may be different for FCGs in other disease population (i.e. disease-specific associations) because caregivers' circumstances can vary markedly depending on the type and severity of the disease. Also, patient symptoms and distress may lead to alteration of FCG sleep habits.

Poor sleep quality has been associated with serious negative health consequences including depression, poor physical health and daily functioning, altered immune function, cardiovascular disease, increased morbidity, and premature mortality. [10, 12, 13] In addition, poor sleep quality not only puts FCGs at risk for poor health outcomes but can also lead to poor caregiving which has great implications for patient outcomes. [14]

Continued care at home for persons with chronic conditions is important. Chronic diseases are the leading cause of disability and death in the United States (U.S.). [15] They also place a high burden on the health care system and are associated with high medical and indirect cost. [16] In 2014, about 6.5 million United States adults lived with heart failure (HF). Similarly, 47 million adults in the United States lived with AD in 2015. Further, more than 1.5 million people are diagnosed with cancer each year.[17] The number of people living with chronic conditions is expected to grow by the year 2030. [18] Consequently, the number of FCGs is expected to increase. The successful management of these conditions often requires family members to be actively involved in the care of the patients. Thus, FCGs are relevant to and play an important role in patient outcomes throughout the trajectory of the disease.

Given this background, it is important to understand major gaps in the evidence regarding contributing factors associated with FCG sleep quality in order to develop and test targeted interventions to attenuate the effect of poor sleep on FCGs' health and its indirect effect on patient outcomes. The purpose of this literature review, therefore, was to examine existing evidence on factors contributing to poor sleep in FCGs of persons with chronic diseases and outcomes. Specifically, this review seeks to identify 1) the prevalence of sleep problems in FCGs, and 2) factors associated with poor sleep quality and outcome. This review focused on FCGs of persons with HF, Alzheimer's disease (AD) and cancer given their high prevalence in the United States, as well as their high dependence on FCGs.

Methods

A search strategy was performed to find literature related to sleep quality of FCGs of persons with chronic conditions. Three electronic databases, PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), and Web of Science were searched. The search terms used included: caregiver* AND sleep* AND (heart failure OR Alzheimer OR dementia OR cancer). The referenced lists from retrieved articles also were examined to identify other relevant studies. Studies were included if they were written in the English language, examined FCGs' sleep as a primary variable, the participants were primary FCGs aged 18 years or more, and were published as original data-based articles in peer-reviewed journals. The care recipient medical condition was limited to HF, AD and cancer populations. These three conditions rank top among the most common chronic condition in the United States incurring a high medical cost and requiring long-term care which is known to be very stressful and characterized by high caregiving burden. [3, 19] No limitation was placed on the date of publication, given the sparsity of sleep studies in some caregiving populations. Conference presentations, dissertation, and unpublished studies were excluded in this review.

About 184 articles were initially retrieved and screened by applying criteria mentioned above. Titles and abstracts of references, the overlap of references between databases, and reference accessibility were examined. Full texts of 49 peer-reviewed articles composed of 32 from cancer, 16 from AD and 4 from HF populations were further examined. Twenty-six articles were excluded due to reasons including unavailability of full text, the article focused on other disease populations, sleep was not a primary variable, focus on patients' sleep, and caregivers were not informal/FCGs. Overall, the final articles reviewed were 23 in total. No study was excluded on the grounds of quality (see figure 1).

Results

This review included research articles on FCGs from three chronic disease populations including AD, cancer, and HF (n=23). FCGs sleep problems were most frequently reported among FCGs of cancer patients (56.5%), AD (39.4%) and HF (0.04%) populations. Most of the studies were cross-sectional (65.2%). Two studies were longitudinal and two were randomized trials. The overall study results are summarized in Table 2.1.

Sleep Concept issues

Although sleep is an important process of health and well-being, researchers have not come to a consensus on one sleep terminology that best describes FCGs sleep. In this literature review, several terminologies used to describe FCGs' sleep were identified. The most common concept of sleep identified in this review was sleep disturbance, used to describe alterations in caregivers' sleep (14 studies). Other terminologies include sleep quality (4 studies), sleep loss (1 study), sleep-wake disturbance (1 study), insomnia (1 study), sleep problems (1 study) and impaired sleep (1 study). Sleep disturbance is an umbrella term used to describe several sleep disorders.[20] However, the National Sleep Foundation provides definitions for sleep quality, defined as a person's satisfaction with sleep experience, integrating aspects of initiation, sleep maintenance, sleep quantity and refreshment upon awakening. [21] Although this term does not have a clear definition, it is the second broadly used sleep terminology in this review. There is all together, a lack of consensus among researchers on the terminology used to describe FCGs sleep. Although these terms are similar and used interchangeably within the literature, they do not carry the same definition. This lack of consensus in sleep definitions among researchers indicates a lack of clarity on how sleep is conceptualized and measured.

Sleep Measurement Issues

Another challenge encountered in the review was the lack of consistency in how sleep was measured in FCGs. Because of the lack of clarity of the concept of sleep discussed above, FCGs and researchers may attribute different meaning to the term used to describe sleep, and this may pose some limitations on the accurate measurement of subjective sleep. Recommendations for sleep measurement included both subjective and objective measurements. [22] Among the studies identified in this review, 42.8% used subjective sleep measurement alone, 42.8% used both subjective and objective measurements of sleep, and 14.2% used objective sleep measurement only. The subjective instruments included the Pittsburgh Sleep Quality Index (PSQI), the General Sleep Disturbance Scale (GSDS), the Epworth Sleepiness Scale, sleep diaries, and investigator created surveys. The PSQI was the most commonly used, along with sleep diaries or sleep logs. Objective measures included polysomnography (PSG), and wrist/arm actigraphy. The gold standard recommended for measuring sleep is the PSG; the actigraphy is the most commonly used objective measure in the literature. [23]

The PSQI is a self-reported questionnaire and the most commonly used subjective sleep measure that assesses sleep quality in relation to 7 components including subjective sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, sleep quality from, use of sleep medication and daytime dysfunction. The total score of the PSQI range 0 to 21 with higher scores indicating worse sleep quality. To distinguish good sleepers from poor sleepers, a global cut off score equal to five or greater is indicated. [24] An important challenge identified in this review is lack of agreement on the exact cut off point used to identify poor sleep in the literature. About 56.5% of the studies reviewed used the PSQI as a subjective measure of caregiver sleep. The cut of point of greater than five was used to identify poor sleep by 61.5% of the studies in this review that included the PSQI as part of their measurement, and only 15% used a cutoff point equal or greater than five. Some studies did not establish a cutoff point but reported the mean PSQI score, and other focused on the PSQI subscales rather than the global score. This variability on the exact cut off point on the PSQI indicating clinical sleep problems poses a limitation in accurately estimating the prevalence of poor sleep among FCGs, and this could have important implications on how the results are interpreted.

Actigraphy measures sleep-wake status and allows for the calculation of total sleep time, total wake time, sleep latency, sleep efficiency, wake after sleep onset and time in bed based on a scoring algorithm. Due to its portability, it is deemed to be convenient for FCGs. In the studies reviewed, about 39% used wrist/arm actigraphy and FCGs wore the wrist actigraphy for 48 – 72 hours. However, the longer the actigraphy is worn, the better it has been shown to detect daily estimate of the sleep component. [25] Sleep data obtained from both the subjective and object measurement indicates that FCGs tend to overestimate their perception of sleep problems seen in the discrepancies between subjective measures and objective measures in predicting sleep correlates. [26]

These discrepancies validate the need to use subjective and objective measures simultaneously in caregiving populations. However, with family caregiving, caregivers' perception may be important to their daily function and outcomes, thus subjective measures of sleep quality may be important in evaluating sleep quality in this population. In addition, the authors of the three studies that measured sleep using an investigator-developed, structured questionnaire failed to provide reliability or validity.

Prevalence of Sleep Problems in Family Caregivers

Poor sleep quality is common with FCGs of chronic diseases. All the studies identified in this review indicate that a good proportion of caregivers experienced poor sleep, with the PSQI means score above five. While some of the studies provided the percentage of FCGs that suffer from poor sleep, others only provided that mean score of sleep measures indicating poor sleep in FCGs. For studies who indicated the proportion of FCGs with poor sleep, over 50% experienced poor sleep. Similarly, the lowest mean score for the PSQI was 6.4 ± 3.6 which is well above the cut point of $\geq$5. Sleep duration of FCGs estimated by objective measures indicates that caregivers sleep less than 7 hours during the night which is lower than the recommended range (7-9) for adults. [27]

Factors Associated with Sleep.

Several factors were identified as predictors of poor sleep quality in FCGs. These include sociodemographic, caregiving stress, psychosocial and physiologic factors. The major outcomes of poor sleep studied in FCGs include psychologic and physical function. One study found an association between poor sleep quality and physiologic outcomes in FCGs, but these results did not reach statistical significance.

Sociodemographic Factors

Studies varied in their finding on the association between FCG demographics and sleep quality. Among the studies that examined age, five studies found no association between caregiver age and sleep quality; [28-32] while two studies found a positive association between age and sleep quality, indicating that older caregivers are likely to experience poorer sleep than younger caregivers. [11, 33] Similarly, the association between gender and sleep quality had similar discrepant results among studies. Although most of the FCGs in the studies were female as expected, Mills et al. (2009) found that male caregivers caring for spouses with severe dementia experienced worse sleep than their female counterparts. These different results warrant more research in this area. Other sociodemographic factors associated with FCGs poor sleep quality include being unemployed, lack of social support, and caring for others. [28, 30]

Caregiving Stress Factor

Caregiving stress/burden was the most common factor identified to predict poor sleep quality in FCGs of persons with chronic diseases. Although the number of hours spent in caregiving or the length of caregiving varied among the studies reviewed, caregiving burden was reported among caregivers of persons with AD, cancer, and HF, as expected. Interestingly, no association was found between living in the same house or sharing the same bed with care recipient and caregiver sleep. [28, 29] Higher caregiver burden was significantly associated with higher sleep disturbances. Eight studies found significant associations between caregiving stress, including caregiver burden and difficulty, and poor sleep in FCGs. Caregiver depression was also linked with poor sleep; however, it was unclear if caregivers experienced depressive symptoms prior to becoming caregivers or if depressive symptoms began during the trajectory of the disease. [34]

In addition, the care recipient disease severity and behavior had a significant correlation with sleep quality. Lee et al (2015) and Simpson & Cater (2015) reported that sleep quality was significantly associated with the severity of cancer and AD diseases. Among AD caregivers, the most common predictors of poor sleep were disease severity, care recipient behavior and nocturnal activities of the care recipient. [11, 35] The most unique predictors of poor sleep among cancer caregivers identified in this review include recent patient diagnosis, worry, the severity of cancer, and care recipient undergoing several radiation therapies. [30, 36, 37] No quantitative studies examining predicting factors associated with poor sleep in FCGs of HF persons were found. However, in qualitative studies that have examined caregiver sleep in HF population, caregivers reported sleep disturbances resulting from the need to assist the care recipient to the bathroom, being vigilant, anxiety, care recipient mood, and sleep problems. [38, 39]

Health Outcomes of Poor Sleep

Good sleep quality is known to have a restorative effect on the body and thus is essential to health and wellbeing. FCGs who experience poor sleep are at increased risk for adverse health outcomes. Eleven studies in this review measured health outcomes related to FCGs sleep quality. Health outcomes explored include psychological distress (6 studies), emotional distress (3 studies), physical health (3 studies), and biomarkers of physiologic health (3 studies) (see table 2.2). Mcrae et al., (2016) found that poor subjective sleep was an important predictor of caregiver mood, specifically, negative affect. Al-Rawashdeh, Lennie & Chung (2016) examined dyads to determine if sleep disturbances of persons with HF and their spousal caregivers predicted their own and their spouse's quality of life. In this study, caregivers sleep disturbance was positively associated with caregivers own mental health. An interesting finding in this study was that FCGs' sleep disturbance was negatively associated with the care recipient's mental well-being, emphasizing the reciprocal impact of poor FCG sleep.

The most common psychological outcome associated with poor sleep was depressive symptoms. [40-42] Other poor outcomes of poor sleep quality included anxiety and body pains, [42, 43] emotional distress, [31] and reduced social and daytime function. [41] Three studies examined the relationship between FCG poor sleep and physiologic outcomes. Results from these studies were incongruent. Pawl et al (2013) found no associations among sleep loss and interleukin-6 of FCGs of persons with primary malignant brain tumor, although this study was done at the beginning of the caregiving trajectory which may have affected the results.   Further, Mills et al (2009) found increased levels of proinflammatory cytokines with 42% higher levels of circulating D-dimers and 28 to 38% higher levels of Interleukin-6 in FCGs providing care for persons with moderate to severe AD patients than those caring for persons with mild AD's and non-caregivers, although these numbers were not statistically significant. Further, Von Kanel et al (2010) found increased levels of proinflammatory cytokine, C-reactive proteins and Von Willebrand Factor (VWF), which suggests that FCGs with poor sleep quality may be at increased risk for developing cardiovascular problems.

Discussion

This review provides findings of current investigations on the sleep quality of FCGs of persons with chronic diseases and recommendations for future research (Table 2.3). Some important conceptual and methodological issues were identified. One major finding was the lack of consensus among researchers on the sleep terminology used when investigating FCGs' sleep. A clear definition and understanding of the important aspects of sleep relevant to FCGs is necessary to accurately address sleep issues in this population. Another important finding was the inconsistent use of concurrent subjective and objective sleep measurement among researchers. Gibbins et al (2009) reported some inconsistency between caregivers' subjective and objective sleep data. In this study, FCGs who reported normal sleep duration of 8 hours, were found to have poor objective sleep results. In addition, studies in this review used a slightly different cut off point for the PSQI score (≥ 5 Vs >5). This discrepancy may have large implications for the analysis and interpretation of the results. Al-Rawashdeh, Lennie, & Chung (2017) used an unstandardized sleep measurement in measuring sleep disturbance in persons with HF and their caregivers. Although the questionnaire was made up of questions taken from other validated instruments, validity and reliability were not reported.

This review shows a high prevalence of poor sleep among FCGs of persons with chronic diseases. Factors associated with FCGs' poor sleep were identified and categorized into sociodemographic and caregiving stress groups. Associations between FCGs sleep quality and sociodemographic including age and gender were inconclusive. Some studies found significant associations while others did not. Caregiver stress factors were important predictors of sleep quality. Factors identified to predict poor sleep in caregivers include caregivers' own mental state, caregiving burden and stress, disease severity and disease-specific characteristics such as nocturnal behavior in AD and HF patients, and cancer diagnosis in the cancer population. The association between caregivers' sleep quality and psychological outcomes were well investigated. Evidence suggests that FCGs who experienced poorer sleep were at higher risk of developing depression. [35, 44] A bidirectional relationship between sleep quality and depression was also observed among studies. [30] However, there was no indication whether caregivers had depressive symptoms prior to becoming caregivers that led to poor sleep or whether depressive symptoms were a result of the overwhelming stress of caregiving. The review also provides evidence on the associations between family caregiver sleep quality and physiologic outcomes. Results from these studies were inconsistent. Changes in physiologic responses to poor sleep may be observed over the caregiving trajectory, therefore, longitudinal studies in the future will be required to address these issues.

Most of the studies reviewed in this paper were observational and cross-sectional in design. Therefore, causal relationship between the predictor and outcome variables of poor sleep cannot be ascertained. This warrants further studies investigating these associations over a longer trajectory. Among the three population groups included in this review, more sleep studies have been conducted among cancer caregivers than in AD population. Only one quantitative study that used unstandardized sleep measures was found in the HF population. It is not known if caregiving factors majorly predict poor sleep quality for FCGs caring for persons with HF, or if HF disease-specific characteristics or a combination of both jointly contribute to FCGs poor sleep quality. More research is therefore needed in this vulnerable population of FCGs given the complexity of managing HF and the high caregiver burden reported in this population.

Conclusion

FCGs' sleep quality is being increasingly researched in various populations.. However, most studies have examined different parameters and have used different conceptual terms in describing sleep problems in caregiving studies. The literature reviewed here gives a basic understanding of the prevalence of poor sleep among family caregivers of persons with chronic illnesses and factors that predisposes FCGs to experience poor sleep quality as well as poor health outcomes that have been associated with poor sleep quality in FCGs. Issues that call for further investigation were identified. First, consensus on how sleep is conceptualized and what terminology should be used to guide research and sleep measures are needed in the family caregiving population. Second, methodological issues relating to tools used to measure sleep and cut off points on subjective sleep data need further consideration and consensus among researchers. Third, understanding factors that predispose FCGs to poor sleep and the potential detrimental effect of chronic poor sleep, especially in FCGs of persons with HF, is needed.

This review resulted in recommendations for nursing researchers to develop more rigorous studies that examine sleep quality in FCGs of persons with chronic diseases. These include exploring the true estimate of poor sleep prevalence in FCGs, addressing sleep terminologies that may mean different things to caregivers and clinicians/researchers, and addressing design and methodological issues to gain a better understanding of the contributing factors to poor FCG sleep quality, and testing innovative interventions that ameliorate poor health outcomes in FCGs. This literature review contributes to the evidence by validating the severity and importance of sleep quality to FCGs. It also identified specific vulnerable disease population that has been understudied and the need for more research in these populations.

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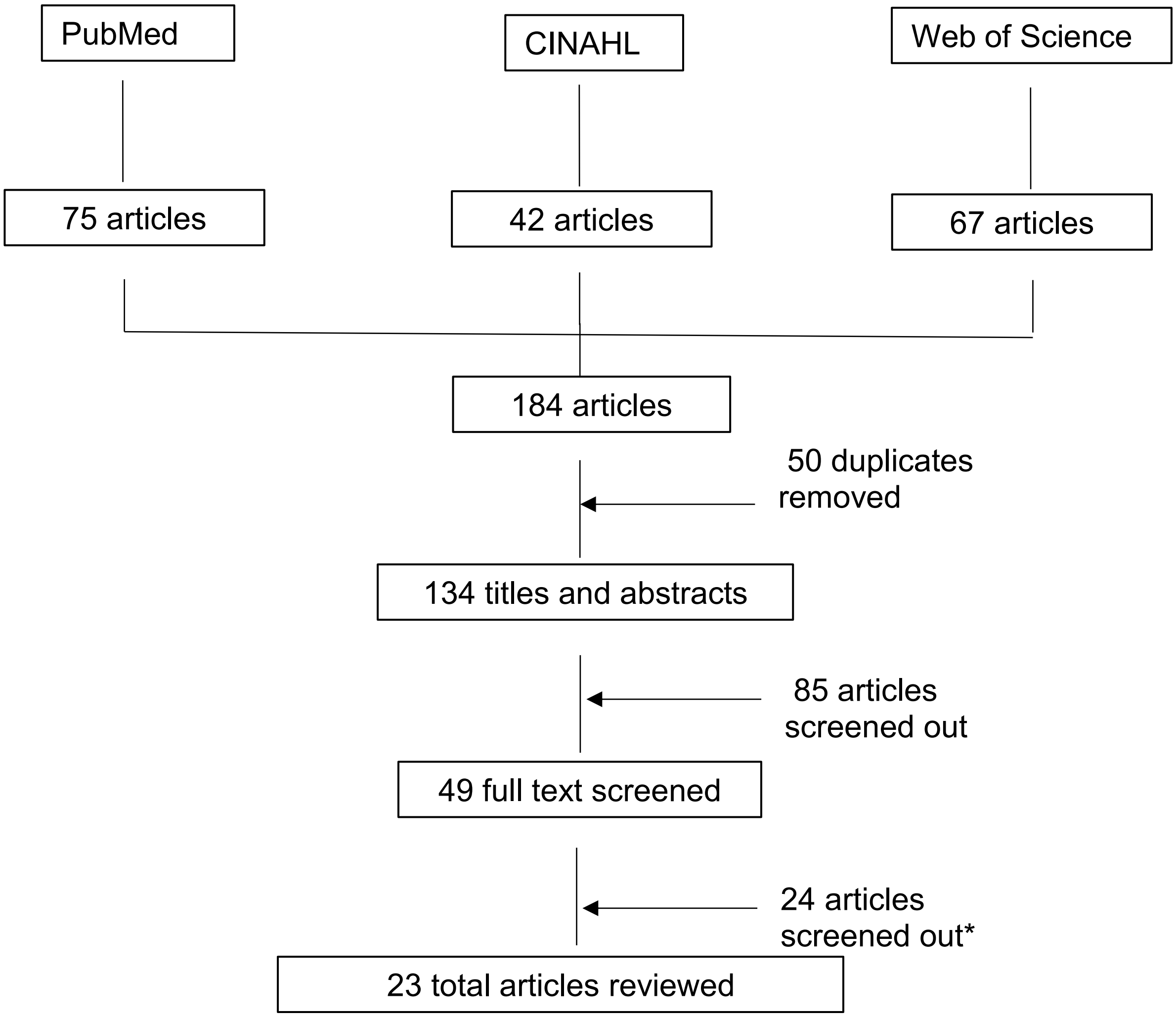
Figure 2.1

Flowchart of study literature review



*No full text available, not population of interest, not informal caregiver study, not chronic condition, focused on the patient, not family caregivers

Table 2.1

Sleep Studies on Family Caregivers of Persons with Chronic Diseases

				Poor Sleep Quality	
Study/Design	**Sleep Terminology/ Disease Population**	**Sample**	**Sleep Measures**	**Significant Associations**	**Non-significant Associations**
Lee, Hsieh, Lin, & Lin, 2018 Prospective Longitudinal Study	Sleep disturbance Cancer	N= 95 FCGs Mean age= 50.9 yrs Female= 68.4%	Subjective: PSQI (cut off score >5) Objective: Wrist actigraphy (48 hrs)	Older age (P) Female gender (P) Longer surviving period after diagnosis (P) Lower levels of caregiving tasks assistance (P) Higher depressive symptoms (P) Fatigue^{-}(P)	Coffee (P) Alcohol (P) Anxiety (P) Cancer disease-specific characteristics (P)

Al-Rawashdeh, Lennie, & Chung, 2017 Cross-sectional	Sleep disturbance Heart Failure	N=(78 FCGs 78, 78 patients) Mean age= 59.5yrs Female= 74.4%	Subjective: Survey • Changes in sleep pattern (taken from the Beck Depression Inventory II. • Sleep difficulty because of partner's HF (taken from the modified version of the Minnesota Living with HF Questionnaire) • Trouble falling asleep (taken from the Patient Health Questionnaire (PHQ-9) • Problems with restfulness (developed by the primary investigator)	Poor physical wellbeing (O) Poor mental wellbeing (O)	Patient sleep disturbance (P)
Ross, Yang, Klagholz, Wehrlen, & Bevans, 2016 Cross-sectional	Sleep disturbance Cancer	N= 78 FCGs Mean age= 52.4yrs Female = 70% College education= 43.6%	Subjective: PSQI (cut off score >5)	Avoidant stress management (P) Poor interpersonal relationship (P) Poor nutrition (P) Higher caregiver burden(P) Higher psychological distress (P)	Age (P) Gender (P) BMI (P)
McCrae et al., 2016 Observational, prospective	Sleep Quality Alzheimer	N= 55 FCGs Mean age= 62.8years Female= 77.8% College education= 83.3%	Subjective: Sleep Diary (Total Wake Time, Sleep Quality Rating) Objective: Actigraphy (actiwatch)	Lower negative affect (O) Higher positive affect (O)	

Morris et al., 2015	Insomnia Cancer	N = (234 FCGs, 500 patients) Mean age= 50yrs Female= 84.2% College education = 23.6% Moderate to severe clinical insomnia= 32.1%	Subjective: Insomnia Severity Index	Higher emotional distress (O)	Age (P) Gender (P) Education (P)
Lee, Yiin, Lu & Chao, 2015 Prospective, cross-sectional	Sleep disturbance Cancer	N=176 FCGs Mean age = 46.4yrs Female= 79.5% Sleep problems before caregiving= 40.9% Poor sleep= 72.2% .	Subjective: PSQI (cut off >5) Objective: Actigraphy (48 hours)	Female gender (P) Higher caregiver burden and difficulty (P) Care recipient disease severity (P) Unemployment (P). Patient recent diagnosis (P) Lack of social support (P) Higher self-esteem - caregiving reward (P)	Age (P) Caregiver comorbidity (P) Sleep problem history (P) Weekly exercise (P) Time spent on caregiving (P)
Lee, Yiin, Lin, & Lu, 2015 Descriptive, Cross-sectional	Sleep disturbance Cancer	N=172 FCGs Mean age= 46.1yrs Female= 79.1% Sleep problems before caregiving= 39.5% Poor sleep=76% .	Subjective: PSQI (cut off >5) Objective: Wrist Actigraphy (48hrs)	Female gender (P) More fatigue (P) Higher depressive symptoms (P) Greater caregiver burden (P) More caregiving time (>16/day) (P)	Anxiety (P) FCG physical status (P) Financial difficulty (P)

Simpson & Carter, 2015 Cross-sectional	Sleep disturbance Alzheimer	N = 80 FCGs Mean age= 61.6yrs Female= 87.8% Caregiving length = 80hrs/week Poor sleep=86.3%	Subjective: PSQI (cutoff >5)	More caregiving time (P) Problematic behavior of care recipient (P) Caring for others (P) Higher level of depression (P) Female gender (P)	Living away from care recipient (P) Age (P) Caregiving time (P) FCG health status (P) Alzheimer disease severity (P)
Cross-sectional Chiu et al., 2014	Sleep disturbance Alzheimer	N= 180 FCGs Mean age= 56 yrs Female= 65% Mean caregiving duration: 30 months Caregiving time: 66.2 hrs/week Poor sleep report = 99.4%	Subjective: General Sleep Disturbance Scale (GSDC)	Greater physical fatigue (P) Perceived caregiving stress (P) Higher depressive symptoms (P)	Age (P) Gender (P) Disease severity (P) Dementia diagnosis (P)
Von Kanel et al., 2014b Observational, longitudinal	Sleep Quality Alzheimer	N=126 FCGs Mean age = 74.2yrs Female = 70.6% Mean caregiving length= 4.3years Poor sleep=57.1%	Subjective: PSQI (cut off score >5) Objective: Wrist actigraphy (Night time TST, night time WASO, night time sleep percentage)	Female gender (P) Role overload (P) Care recipient behavioral problems (P) Alzheimer disease severity (P) Positive affect (P) Psychological distress (P) Use of antidepressant (P) BMI (P)	

Simpson & Carter, 2013 Cross-sectional	Sleep Quality Alzheimer	N=80 FCGs Mean age = 63.3 yrs Female = 88.8% Caregiving length = 2months to 12years Mean caregiving time= 80hrs/week. Poor Caregiving length < 5yrs = 56% sleep=76.3%	Subjective: PSQI (cut off score >5)	Higher depressive symptoms (P)	Age (P) Health status (P) Caregiving time (P) Behavioral and psychological symptoms of dementia (P) Living arrangement (P)
Pawl, Lee, Clark, & Sherwood, 2013 Descriptive cross-sectional	Sleep disturbance Cancer	N=133 FCGs Mean age = 53.3yrs Female = 36% Poor sleep = 31.6%	Subjective: PSQI sleep quality subscale. Objective: Bodemedia Sensewear Armband accelerometer (TST, WASO, sleep latency, naps, and sleep-wake cycle)	Caregiver anxiety (P)	Gender (P) Physical functioning (P) Employment status (P)

Pawl et al., 2013 Cross-sectional Correlational	Sleep loss Cancer	N=130 Mean age = 51.6yrs Female = 69.2% College Education = 94.5% Poor sleep=32%	Subjective: PSQI sleep quality subscale. Objective: Bodemedia Sensewear Armband accelerometer (TST, WASO)	Poor quality of life (O)	Physical health (O) IL-1ra (O) IL-6 (O) Depression (O)
Miaskowski et al., 2010 Randomized trial	Sleep disturbance Cancer	N= 85 FCGs Mean age= 62.5 yrs Female= 71.8%	Subjective: General Sleep Disturbance Scale (GSDS)	Older age (P) Genotype – IL-6 polymorphism (P) Baseline sleep disturbance (P)	
Von Kanel et al., 2010 Cross-sectional	Impaired Sleep Alzheimer	N=253 (85 caregivers, 168 patients) Mean caregiver age = 72.4yrs Female = 71%	Subjective: PSQI (no cut off point indicated); Sleep diaries Objective: Actigraphy (72 hours)	Higher IL-6 (O) Higher CRP (O) Higher Von Willebrand Factor (O)	
Gibbins et al., 2009 Prospective Descriptive	Sleep-wake disturbance Cancer	N=60 FCGs Median age = 66yrs Female = 45% Poor sleep= 42%	Subjective: sleep history survey (baseline - author designed) Sleep diary (7 days), ESS. (day 7) Objective: Actigraphy (7 days)	Higher levels anxiety (O) Greater bodily Pain (O) Higher psychological distress (O)	

Aslan, Sanisoglu, Akyol, & Yetkin, 2009a Descriptive cross-sectional	Sleep disturbance Cancer	N=90 FCGs Median age = 42yrs Female = 53.3% Median caregiving duration = 5 months College education = 15% Poor sleep = 72.2%	Subjective: PSQI (cut off >5 = 72.2%)	Cancer-related problems including emotional distress, anxiety finance, support (P) Noncancer-related problems including caregiver illness and fatigue (P)	Age (P) Gender (P) Education (P) Caregiving duration (P)
Mills et al., 2009 Cross-sectional	Sleep Quality Alzheimer	N = (81 FCGs, 41 non caregivers) Female = 71.6%	Objective: Polysomnography (1 full night)	Older age, (P) Male gender (P) Alzheimer disease severity (P) D-dimer (O)	IL-6 (O)
McCurry, Pike, Vitiello, Logsdon, & Teri, 2008 Randomized Trial	Sleep disturbance Alzheimer	N=(44 FCGs, 44 care recipient) Mean age = 64.6yrs Female = 66%	Objective: wrist actigraphy (7 days)	Male gender (P) Poor sleep the previous night (P) Higher use of encouragement as a behavioral management strategy (P)	Age (P) Sharing a room (P) Depression (P) Health Status (P)

Creese, Bedard, Brazil, & Chambers, 2008 Cross-sectional	Sleep disturbance Alzheimer	N=60 FCGs Mean age = 73.7yrs Female= 68% Caregiving duration=5.1yrs Caregiving time= 13.3 hours/week Poor sleep=58%	Subjective = sleep survey (author designed)	Mental health (O) Depressive symptoms (O) Caregiver burden (O) Nocturnal behavior of care recipient - bathroom use & wandering (P)	Sharing the same room/bed (P) FCG self-rated physical health (P)
Beaudreau et al., 2008 Cross-sectional	Sleep disturbance Alzheimer	N=60 FCGs Mean age = 64.8yrs Mean education years = 15.2 Mean caregiving duration= 4.3yrs Mean caregiving time: 13.3 hours/week	Subjective: sleep diaries Objective: wrist actigraphy (72hrs)	Older age (P) Mental health (P) Higher levels of depressive symptoms (P) Poor health rating (P)	Caregiving duration (P) Care recipient nocturnal behaviors (P)
Chang, Tsai, Chang, & Tsao, 2007 Cross-sectional	Sleep Quality Cancer	N=61 FCGs Mean age = 45.1yrs Female=18% Caregiving length= 5.3months Poor sleep=88.5%	Subjective: PSQI (≥5)	Poor quality of life (O) Psychological health (O) Social function (O) Physical environment (O)	

Cater & Chang, 2000 Descriptive, correlational, cross-sectional	Sleep problems Cancer	N=51 FCGs Mean age = 53.6yrs Female = 80.4% Mean Caregiving length = 2years Mean caregiving time= 16hrs/day Poor sleep=95%	Subjective: PSQI (≥5)	Depressive symptoms (O)

P = Predictor variable O = Outcome variable IL-1ra = Interleukin-1 receptor antagonist IL-6=Interleukin 6 PSQI=Pittsburgh Sleep Quality Index BMI=Body Mass index

Table 2.2

Health Outcomes Associated with Family Caregivers Sleep

Study	Health Outcomes
	Physical Wellbeing^{+} *
Al-Rawashdeh, Lennie, & Chung, 2017	Menta health^{+} *
McCrae et al., 2016	Caregiver Mood^{+} *
Morris et al., 2015	Emotional Distress^{-} *
Von Kanel et al., 2014b	Positive affect^{+} *
Pawl et al., 2013	QOL^{+} *
	Depressive symptom
	Physical health
	IL-1ra
	IL-6
Von Kanel et al., 2010	Il-6^{-} *
	CRP^{-} *
	VWF^{-} *
Gibbins et al., 2009	Anxiety^{-} *
	Depressive symptoms^{-} *
	Bodily Pain^{-} *
Mills et al., 2009	D-dimer^{-} *
	Il-6

Crease et al., 2008	Depressive symptoms $^{-}$ *
Chang, Tsai, Chang, & Tsao, 2007	QOL^{+} * Psychological health $^{+}$ *
Carter & Chang, 2000	Depressive symptoms $^{-}$ *

$^{+}$Positive association $^{-}$Negative association *Significant association

QOL=Quality of Life IL-1ra = Interleukin 1 receptor antagonist

IL-6 = interleukin 6 CRP= C-reactive Protein VWF= Con Willebrand Factor

Table 2.3

Recommendations for Future Research

1) Longitudinal studies are needed to explore the complex interactions amongst FCGs sleep quality, caregiving situation, disease characteristics, and health outcomes. More explorations are needed on physiologic responses to stress and poor sleep quality in FCGs, considering the length and duration of caregiving.
2) The trajectory and treatments of heart failure differ from Alzheimer's disease and cancer Managing HF can be complex and FCGs experience high burden. Additional studies with larger heterogenous samples related to HF disease characteristics, caregiving stress, and caregiving trajectory, are needed to understand how caregiver's sleep is affected in this population of caregivers.
3) The relationship of FCGs' depression and poor sleep quality remains unclear. More research is needed to ascertain the bidirectionality of FCGs' depressive symptoms and sleep quality, and to explore how changes in these vary over the caregiving trajectory.

CHAPTER III

Factors Associated with Sleep Quality in Family Caregivers of Persons with Heart Failure

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Keywords: Family Caregivers, Heart Failure, Sleep Quality, caregiver stress

Abstract

Title: Factors Associated with Sleep Quality in Family Caregivers of Heart Failure Persons

Background: Family caregiving for persons with heart failure (HF) is demanding and stressful and may affect sleep quality of family caregivers (FCGs). Although FGCs report sleep disturbances, little is known about factors associated with sleep quality of FCGs of persons with HF. The purpose of this study was to examine the sleep quality of FCGs of persons with HF and associated sociodemographic, clinical and FCG stress factors to ultimately determine factors amenable to intervention to improve sleep quality.

Methods: Baseline data from a FCG intervention study were used. Participants were FCGs of persons with HF (N=127, mean age 55.3 ± 1.5 years, 92% women, 58% African American). Variables measured were self-reported overall sleep quality (Pittsburgh Sleep Quality Index; PSQI), sociodemographic characteristics (age, gender, race), comorbidities (Charlson Comorbidity Index), perceived health, life changes resulting from caregiving (Bakas Caregiving Outcome Scale; BCOS), caregiving difficulty (Oberst Caregiving Burden Scale - Difficulty; OCBS-D), and care recipient HF severity (New York Heart Association Classification; NYHA Class). Analysis included descriptive statistics, correlations, and multiple regression.

Results: A large percentage of FCGs (82%) reported a PSQI score ≥ 5, the cut-off point for poor overall sleep quality. Overall, the majority of FCGs rated their perceived health as good (68%). Correlates of the PSQI score, in a bivariate analysis, were scores from the BCOS ($r = -0.46$, $p<0.01$) and the OCBS-D ($r = 0.23$, $p<0.05$). Age, gender, and FCG comorbidities were not significantly associated with sleep quality. Multivariate regression analysis using variable selection method and controlling for covariates of smoking history ($p<0.01$) and use of sleep medications ($p<0.05$), revealed greater BCOS ($p<0.01$) and OCBS-D scores ($p=0.04$) were associated with higher PSQI scores and explained 25% of the variation in caregiver sleep quality (adj. $R^2 = 0.255$).

Conclusion: Poor sleep quality is prevalent in FCGs of persons with HF. Sleep quality was associated with perceived family caregiving stress factors including life changes from caregiving and caregiving difficulty but not with sociodemographic factors or comorbidities. Targeted interventions to reduce family caregiving stress may be important to consider for improving FCGs’ sleep quality and overall caregiving experience.

Keywords

Sleep quality; family caregivers; caregiving stress; heart failure

Introduction

HF is a chronic and debilitating condition that affects over 6.5 million adults in the United States.[1] Among persons age 65 years and older, HF prevalence is expected to increase by 46% by the year 2030. [1] Family members play a significant role in the management of HF patients after initial hospitalization. [2] Usually, the spouse or adult child takes up the role of caring at home for the person with HF. This often requires a long-term commitment that places an enormous demand on FCGs. In caring for persons with HF, the focus of the healthcare system has mainly been on the patient, although FCGs' role and wellbeing are now gaining increasing attention. This is an important trend in that the health and wellbeing of FCGs may have an impact on patient's outcome, [3] yet little evidence is available to guide focused support of FCGs of persons with HF.

Caregivers provide support to persons with HF in areas such as physical exercise and activities of daily living, complex medication monitoring and adherence, communicating with the healthcare team, diet management, as well as monitoring for variability, and signs and symptoms of HF decompensation. [4, 5] FCGs also need to be alert for changes in the person with HF's symptoms and understand what to do during an emergency. [6] As HF condition deteriorates through its trajectory, persons with HF experience greater physical limitations that tend to increase their dependency on their FCGs. [7] Although positive aspects of caregiving have been reported, [8] these demands of caregiving have been associated with increased caregiving burden and stress among FCGs of persons with HF. [2, 9] FCGs often respond to these demands by neglecting their own selfcare. Selfcare needs of FCGs of persons with HF have been identified and include managing their own physical and psychological well-being, and sleep. [5, 10]

One area of FCGs' health that may be affected by caregiving stress is the FCGs' sleep health. Sleep is an important process that is essential for health and well-being. [11] Consequently, poor sleep quality can negatively affect FCGs' health. Because poor sleep quality, experienced over a long period of time, can lead to negative mood, and poor physical and cognitive performance, [12, 13] FCGs who experience poor sleep may not be in the best health condition – physically and emotionally - to successfully care for the person with HF and this may lead to poor outcomes for the person with HF, [2] as well the caregivers themselves. [14]. Factors contributing to poor sleep in FCGs are multifactorial and may include the disruption and sleep variability of the person with HF.[15]

In the general population, sociodemographics such as age, gender, and race are known to be associated with poor sleep quality. [16-20] However, these relationships have not been investigated in FCGs of persons with HF. In addition, studies on the sleep behavior of FCGs of HF persons are sparse and have mostly focused on the qualitative aspect. No quantitative study using a standardized sleep instrument has been found that addressed factors associated with poor sleep quality in FCGs of persons with HF. Comorbidity factors which might account for poor sleep quality have not been examined in FCGs of persons with HF. The purpose of this quantitative study was to describe the overall sleep quality of FCGs of persons with HF and associated factors which include FCGs' sociodemographic characteristics, comorbidities, and caregiving demand and stress factors. The hypotheses were: 1) older age, African American race and caregiver comorbidities will be associated with worse sleep quality in FCGs and 2) higher family caregiving demands, and stress factors will be related to worse sleep quality.

Methods

Design

A secondary analysis (correlational, cross-sectional design) was used to examine baseline data of FCGs participating in a prospective randomized control trial.

Sample and Setting

The parent study enrolled 127 FCGs of persons with HF. Participants were recruited through major metropolitan hospitals with HF clinics in the southeastern United States. FCGs inclusion criteria were 1) required to be a relative who lives with the person with HF or is in contact with the person with HF in a caregiving relationship at least four times a week for at least one hour, 2) 21 years of ages and older, and 3) fluent in the English language. FCGs who had medical, physical or psychiatric conditions were excluded

Measurements

Family Caregivers Sleep Quality

FCGs sleep quality was measured using the Pittsburgh Sleep Quality Index (PSQI).[21] The PSQI is a self-report questionnaire that consists of five open-ended and 14 Likert type items that provide a comprehensive assessment of sleep quality and disturbance over a 1-month time interval. The nineteen individual items produce a global sleep quality score as well as seven component scores on sleep latency, sleep duration, habitual sleep efficiency, sleep disturbance, use of sleeping medications, and daytime sleepiness. The sum of scores for these seven components yields one global score with higher scores (range = 0 – 21) indicating poorer sleep quality. A global PSQI score $\geq$ 5 yielded a diagnostic sensitivity of 89.6% and specificity of 84.4% (kappa = 0.75, p =.001) in discriminating poor versus good sleep. [22] The PSQI is the most common subjective instrument used to measure sleep quality and has been used with multiple FCG populations. [23, 24] Test-retest reliability and validity have been established [21, 22, 25]

Theoretical variables

Predisposing Factors: These are factors known to increase the risk of poor sleep quality in the general population and include sociodemographic (age, race) and comorbidities were self-reported. Comorbidity was measured with the Charlson Comorbidity Index (CMI) developed to measure the risk of death from co-morbid diseases, [26] and documents conditions which may account for sleep issues within FCGs

Caregiving Stress Factors: Three instruments were used representing life changes with caregiving, caregiving difficulty with performing caregiving tasks and severity of the care recipients' HF.

Life changes resulting from caregiving was measured with the Bakas Caregiving Outcomes Scale (BCOS), a 15-item questionnaire with a 7-point response scale on which FCGs rate how their lives have changed since initiating care. [27] Transformed and summed scores are interpreted with higher scores indicating perceptions for a better change and lower scores indicating negative perceptions of caregiving. Internal consistency, test-retest reliability, and criterion-related validity have been established in FCGs of stroke patients. [28]

The Oberst Caregiving Burden Scale measures the time and perceived difficulty spent on caregiving tasks. [29] Items are rated on a 5-point response scale, with higher scores indicating greater time or difficulty (Cronbach alpha of .82).[30] The Oberst Caregiving Burden Scale was used to describe the HF FCGs perceptions and compare with historical or published norms. Evidence of internal consistency reliability and construct validity have been documented. [31]

HF severity of care recipients was collected using questions and ratings of symptoms by the FCG. HF severity categories are Class I to IV. Additional factors that reflected potential caregiving burden such as whether the caregiver provided care for others, and lived with the care recipient were obtained.

Procedures

After Institutional Board Approval at all institutions and written informed consent was obtained, FCGs completed questionnaires on sociodemographic and comorbidity variables, and the caregiving stress questionnaires. In addition, they reported on HF symptoms observed with the activity of the HF care recipient which was mapped onto the NYHA classification criteria.

Data Analyses

Data analysis was performed using SPSS version 25. Descriptive statistics were used to describe the sample characteristics and key study variables All variables were examined for normality by examining plots and using Shapiro-Wilk test for normality. Bivariate analysis was conducted to examine correlations between sleep quality and the independent variables, as well as the strength and direction of the relationship between variables. Pearson and Spearman's rank correlations were used for parametric and non-parametric analysis respectively. Other factors were examined as possible covariates and confounders including education, caregiver living with the person with HF caring for others, use of alcohol history of depression and use of sleep medications. Only the use of sleep medications and smoking history were significantly correlated with overall sleep quality and were controlled for in the regression analysis.

Multiple regression analysis was used to test hypotheses. Model diagnostics were performed to ascertain whether or not the assumptions for linear regression model were satisfied. Multicollinearity was assessed using tolerance values and the variance inflation factor (VIF). In this study, the tolerance values ranged from 0.84 to 1.06, and VIF values ranged from 0.85 to 1.18. There was independence of residuals, as assessed by a Durbin-Watson statistic for sleep quality (1.808). Stepwise variable selection method was used in building the final model. Participants with missing data were excluded from the analysis through the listwise deletion method. A two-tailed probability value of less than 0.05 was considered statistically significant.

Results

Characteristics of Family Caregivers

A total of 127 FCGs participated in the study. Of the 127 participants, a total of 113 were analyzed as a result of excluding 13 due to missing data in the OCBS-D. Participants with missing OCBS-Difficulty data were not different in demographics, comorbidities, and overall sleep quality from the other participants. The vast majority of FCGs were predominantly female with slightly more than half were African American, spouses and lived with the care recipient. On average FCGs were middle-aged with ages ranging from 28 to 80 years. Most of the FCGs rated their health as good/excellent (86.3%). Half of the FCGs took care of persons with HF categorized as NYHA class III and IV and about one-third were caring for additional family members. Around 32% of FCGs had at least one comorbidity. About half of FCGs reported the use of alcohol, and more than one third had a smoking history, and a few reported the use of sleep medications. The details of FCGs' characteristics and theoretical variables are shown in Table 3.1.

Family Caregivers Sleep Quality

About 82% of FCGs reported a total global sleep quality score greater than the established cutoff point (≥ 5) on the PSQI indicating poor sleep. FCGs who reported a history of sleep apnea (8%) also scored higher on the PSQI than those who did not (M = 9.2 ± 4.9 Vs M = 8.3 ± 4.3). Sleep disturbance (M = 1.58 ± 0.64) and sleep latency (M = 1.40 ± 1.10) contributed to higher scores on FCGs total sleep quality.

Relationships Among Overall Sleep Quality, Family Caregiver Sociodemographic, Co-morbidity, and Family Caregiving Stress Factors

Bivariate relationship between global sleep quality and independent variables are provided in Table 3.2. No significant associations were found between overall sleep quality and caregivers' age and race. In addition, the number of comorbidities that a FCG has was also not associated with caregiver overall sleep quality. However, age and race were found to be significantly correlated with some parameters of the PSQI. Age was negatively correlated with sleep disturbance. Similarly, race was significantly related to sleep duration with African Americans reporting shorter sleep duration than Caucasians. Comorbidity was not significantly related with any of the sleep parameters. Significant correlations were observed between overall sleep quality and the OBCS-D subscale and BCOS. Use of sleep medications ($r = .31$, $p < .001$) and smoking history ($r = .25$, $p = .005$) were both associated with increased PSQI scores and used as covariates in subsequent analysis. No significant relationship was found between HF severity of care recipients and overall sleep quality, although it was weakly correlated with day dysfunction due to sleepiness. Although FCGs with the history of sleep apnea, had poorer sleep quality than those without sleep apnea, no correlation was found between sleep apnea and the PSQI.

Multiple Regression Analysis

Factors that were significantly associated with overall FCG sleep quality, after controlling for use of sleep medications and smoking history, included the BCOS ($\beta = -.294$, $p = .001$) and the OCBS-D ($\beta = .188$, $p = .044$) which explained 25.5% of the variance in FCG overall sleep quality (see Table 3.3). NYHA Classification, or severity of the HF of the care recipient, was not significant and was not retained in the final model. The overall model was significant at F(1, 108)=10.57, adjusted R squared = .255. p < .001. Age, race, and comorbidities were not significant in the final model.

Discussion

This study revealed a high proportion (81.9%) of FCGs of persons with HF had poor sleep quality. This is consistent with other findings from caregiver sleep studies. [32] About half of the FCG cared for a family member with a HF classification of III and above. None of these FCG characteristics were significantly associated with caregiver overall sleep quality. FCG age and race were also not associated with overall sleep quality in the multivariate model. This is inconsistent with findings from other studies that found older age, African American race to be associated with worse sleep quality, [16-20] and comorbidity. [33] Although weak correlations were found between age, race, and indices of sleep quality, these variables were not significant in the regression analysis. This lack of association could be attributed to older FCGs perceiving poor sleep as a part of the aging process and may be less likely to report their sleep quality as poor. About 32% of the study participants had at least one comorbidity. Contrary to findings from other studies, [33] no relationship was found between FCGs' comorbidity and sleep quality. It could be that FCGs had few comorbidities and a majority rated their health as good.

Similar to past studies of other caregiving populations, [34, 35] caregiving demands, and stress contributed to poor sleep quality. Life changes resulting from caregiving was the most significant caregiving stress factor associated with poor sleep quality in FCGs of persons with HF. FCGs who rated their lives as having changed for the worse since initiating caregiving, and who perceived caregiving task as difficult, were more likely to experience worse sleep quality. This study found no association between care recipient HF severity and overall sleep quality. Although it is expected that worsening HF would require greater monitoring that might decrease caregiving sleep quality no association was found. FCGs who have been in the role of caregiving through the trajectory of HF condition may have developed some confidence and efficacy in handling and monitoring of HF severity. Future studies should examine the contribution of persons with HF 's sleep disturbance which may include factors associated with worsening HF such as nocturia and HF person sleep apnea to FCGs' sleep quality. Also, future studies may benefit from including sleep diaries asking family members how many times they were awakened and why they were awakened. If family members have to get up in the night to help the person with HF one might need a different intervention than if they awaken because of worrying about the future of caring for their loved one.

Risky health behaviors that have been shown to contribute to poor sleep quality include the use of alcohol [36] and smoking. [37]These variables were examined and controlled for in the analysis. Although more than half of the participants reported the use of alcohol, a majority of participants that used alcohol were light to moderate drinkers (less than 8 drinks per week), and no associations were found with sleep quality. However, smoking history and the use of sleep medications were significantly correlated with overall worse sleep quality and were used as covariates in the regression model. The dataset was limited in determining the length of time since FCGs had quit smoking in order to further examine the true relationships between smoking and overall sleep quality. In addition, it could not be ascertained if FCGs who used sleep medications had prior sleep problems that were exacerbated by caregiving.

Information derived from the findings of this study indicate that FCGs of persons with HF experience high levels of poor sleep quality that is associated with chronic caregiving stress and individual health risk behavior. These findings are important in that they were strong modifiable predictors amenable to nursing interventions versus factors such as sociodemographic variables which are difficult to change. The healthcare team should assess for poor sleep quality in FCGs during healthcare visits. Interventions geared toward reducing caregiving stress and promoting sleep hygiene may enhance FCGs sleep quality.

Limitations

This study has some limitations. First, the cross-sectional design does not allow for examining casual relationships. Second, measures of sleep quality used in this study were subjective and based on self-report, although it has strong evidence of reliability and validity. Third, the database is limited in some variables that would have been useful for the analysis. The relationship between gender and sleep quality could not be examined given the low proportion of male FCGs in the sample, and lack of the history of care recipient’s sleep apnea which may have interfered with the FCGs sleep.

Conclusion

FCGs of persons with HF report poor sleep. The negative changes of caregiving on the lives of FCGs of persons with HF may hinder FCGs from getting adequate sleep needed for optimal functioning. Similar, FCGs with poor sleep are at risk of developing adverse physical and psychological outcomes. Further investigation is required to better understand these associations and to develop interventions to promote caregiver sleep quality.

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Table 3.1

Descriptive Statistics of Family Characteristics and Theoretical Variables

		N, Mean	%, [SD]
Age (Range: 25-80 years)		55.3	[11.5]
Race	African American	74	58.3
	Caucasian	51	40.2
	Asian	2	1.6
Gender	Female	117	92.1
	Male	10	7.9
Education (=>College)		89	70.1
Comorbidity (>0)		41	32.3
Family NYHA Class III/IV[a]		62	50
Live with Family Member		107	84.3
Care for others		42	33.1
Health Rating	Fair	9	15
	Good	87	68.5
	Excellent	21	16.5
		N, Mean	%, [SD]
History of depression		24	18.9
Alcohol use		70	55.2
Smoking history		50	39.4

Use of sleep medications	17	13.4
Caregiver stress (BCOS)	54.5	[16.9]
Caregiving difficulty (OCBS-Difficulty)[b]	36.6	[14.7]
Overall sleep quality (PSQI)		
Overall sleep quality (range: 0 – 21)	8.4	[4.4]
Overall Sleep quality ≥ 5	104	81.89
Sleep apnea	10	7.9
PSQI sleep parameters (range: 0-3)		
Sleep disturbance	1.58	[0.64]
Sleep latency	1.40	[1.10]
Sleep quality	1.28	[0.87]
Sleep duration	1.27	[0.91]
Sleep efficiency	1.09	[1.22]
Daytime dysfunction	1.04	[0.83]
Use of sleep medications	0.75	[1.16]

[a] Variable has 2 missing data points [b] Variable has 13 missing data points

NYHA=Newyork heart failure Association BCOS= Bakas Caregiving Outcome Scale

OCBS=Oberst Caregiving Burden Scale PSQI=Pittsburgh Sleep Quality Index

Table 3.2

Relationships among Sleep Quality, Specific Sleep Characteristics, and Caregiving Stress Factors

	Age	Race	Comorbidity	BCOS	OCBS-Difficulty	Heart Failure Severity
Overall sleep Quality	-.04	.03[c]	.02	-.46[b]	.30[b]	.07[c]
PSQI Sleep parameters						
Sleep disturbance	.18[a]	.03[c]	.060	-.32[b]	.27[b]	-.04[c]
Sleep latency	-.10	.02[c]	.01	-.23[a]	.12	-.13[c]
Sleep quality	-.18	.03[c]	-.01	-.44[b]	.24[a]	.16[c]
Sleep duration	-.17	.24[bc]	-.04	-.21[a]	.14	.10[c]
Sleep efficiency	-.01	.05[c]	.03	-.20[a]	.18	-.01[c]
Daytime function	-.13	-.07[c]	.04	-.41[b]	.36[a]	.19[ac]
Sleep medication	.14	-.18[ac]	.03	-.28[a]	.06	.06[c]

[a] $p < 0.05$ [b] $p < 0.01$ [c] Spearman Correlation

PSQI, Pittsburgh Sleep Quality Index BCOS= Bakas Caregiving Outcome Scale

OCBS=Oberst Caregiving Burden Scale

Table 3.3

Final Regression Model Predicting Sleep Quality (PSQI) Scores

	B	SE B	β	t	P
Covariates					
Use of sleep medicine	2.59	1.03	0.21	2.53	0.01
Smoking history	0.94	0.35	0.22	2.71	0.01
Family caregiving factors					
BCOS	-0.077	0.023	0.294	-3.378	0.00
OCBS-D	1.884	0.926	0.176	2.034	0.04
Adjusted R^2					**0.26**
Overall Model	F(4,113)=	11.72	P<.001		

PSQI=Pittsburgh Sleep Quality Index BCOS= Bakas Caregiving outcome Scale

OCBS-D= Oberst Caregiving Burden Scale-Difficulty

Chapter IV

Heart Failure Family Caregiver Sleep Quality, and Physical, Psychological and Physiologic Health Outcomes

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Abstract

Background: Sleep is an important restorative process that is essential for health and well-being. Although poor sleep quality is prevalent among family caregivers (FCGs) of persons with heart failure (HF), little is known about the influence of poor sleep quality on their health outcomes. The purpose of this study was to examine the associations among sleep quality, physical, psychological and physiologic function in FCGs of persons with HF.

Methods: Baseline data of participants (N=127) from a caregiver intervention study were analyzed. Variables measured were self-reported overall sleep quality (Pittsburgh Sleep Quality Index; PSQI), physical function (SF-36 Physical Function Subscale), anxiety (State Trait Anxiety Index; STAI), depressive symptoms (Center for Epidemiology Studies Depression; CES-D), salivary cortisol and interleukin 6 (IL-6). Covariates included sociodemographic (age, race), health (self-reported health rating, BMI), caregiving stress variables (Bakas Caregiving Outcome Scale; BCOS), and physical activity (Community Healthy Activities Program for Seniors; CHAMPS). Analysis included descriptive statistics, correlations, and multiple linear regression.

Results: About 82% of the FCGs experienced poor sleep ($PSQI \geq 5$, Mean=8.4, SD=4.4). After controlling for covariates, worse sleep quality was significantly associated with lower physical function ($p=.023$), higher anxiety ($p=.034$), and higher depressive symptoms ($p < .001$). Sleep quality was not significantly associated with salivary cortisol and IL-6.

Conclusion: FCGs who experience poor sleep had worse health outcomes including worse physical and psychological function than those with better sleep quality. Future

studies are needed to develop and test interventions that improve caregiver sleep quality and health outcomes.

Introduction

Family caregivers (FCGs) of persons with (HF) commit to caring for their loved one over the trajectory of the HF disease course. HF is a chronic disease characterized by frequent exacerbation and hospitalization, fatigue, dyspnea, anxiety, mood swings and physical limitations resulting in increasing dependence on FCGs as the HF condition progresses. [1] FCGs provide support to persons with HF with activities of daily living and exercise, complex medication monitoring and adherence, communicating with the healthcare team, diet preparation, as well as monitoring for variability, signs, and symptoms of HF decompensation. [2, 3] Supporting persons with HF places physical and emotional burden on FCGs, [4] which may require FCGs to make life alterations [5-7] and exposes them to impaired personal health behavioral patterns including poor sleep which may continue throughout the caregiving trajectory. [3, 8, 9] An estimated 90% of FCGs of persons with HF report poor sleep quality. [3, 8, 9] Good sleep quality is not only essential for FCGs' optimal health but is also important in providing good care to their loved ones.

Chronic poor sleep quality has long-term health consequences. First, providing care for persons with HF exposes caregivers to chronic stress. [5-7] Further, chronic stress has been shown to inhibit sleep regulation and is a common cause of sleep problems. [10] Some researchers consider poor sleep as a physiologic stressor, [11, 12] yet, others have suggested that sleep and stress vary in how they affect the immune system. [13, 14] Both chronic stress and poor sleep quality are linked to poor health outcomes, as well as physiologic changes including increases in the levels of cortisol and, pro-inflammatory cytokines through hyperarousal of the hypothalamic-pituitary-adrenocortical (HPA) axis. [15] However, studies suggest that sleep problems may have a higher impact on health outcomes than those caused by stress alone. [13] Evidence suggests that good sleep quality improves daytime physical function. [16] In the care of persons with HF, it is important that FCGs maintain good physical function to successfully assist the care recipient in self-care and other care-related activities mentioned earlier.

Second, poor sleep quality is frequently linked with both anxiety and depression. [17] These psychological conditions are common among FCGs. [18, 19] The relationship between sleep quality and psychological outcomes may be bidirectional; [20] thus, poor sleep quality may act as a precursor, [21] as well as a consequence of negative psychological health outcomes. [22] Although studies have been conducted to confirm the effect of depression on sleep using standard objective measures such as polysomnography, it remains uncertain if poor sleep quality predisposes one to develop depression. [15]

Third, evidence suggests that poor sleep quality is associated with greater altered endocrine and immune function and increased risk for cardiovascular diseases than stress alone. [12, 13] In addition, increased levels of pro-inflammatory cytokines, during sleep restrictions did not return to baseline after nights of sleep recovery but remained elevated. [23] This has great implication for FCGs of persons with chronic diseases such as HF, as poor sleep quality may be experienced over a protracted period until the caregiving ends. In addition, studies have shown that caregivers may not return to their pre-caregiving sleep habits after caregiving stops. [24]

Factors associated with poor health outcomes in FCGs are multifactorial. Therefore, it is difficult to implicate one factor as being responsible for adverse health outcomes. However, poor sleep quality and its implications in health variations has not been examined in FCGs of persons with HF. Good quality sleep is a protective and restorative process that helps the body to return to its homeostatic state. This study uses the theory of Allostasis and Allostatic Load [25] as a guide to understanding the health responses of FCGs to chronic exposure to poor sleep. Poor sleep quality may increase the allostatic load of FCGs to a level that might be detrimental to health. We posit that poor sleep quality, after controlling for covariates and confounders, will be associated with, 1) reduced physical function, 2) increased anxiety, 3) higher depressive symptoms, 4) higher levels of cortisol and 5) higher levels of proinflammatory cytokine (IL-6).

Methods

Design and Sample

This was a cross-sectional correlational study using baseline data from FCGs of persons with HF (N=127) who were participating in a prospective randomized control trial.[26] Participants were recruited through major metropolitan hospitals in the southern United States. FCGs were eligible for enrollment if they were at least 21 years of age, lived with, or was in contact with the person with HF in a caregiving relationship at least four times a week for at least one hour, and were fluent in the English language. FCGs who were not sedentary (i.e. exercised greater than 90 minutes a week) or had medical, physical or psychiatric conditions, or who were on corticosteroids or other anti-inflammatory drugs were excluded due to the conditions of the parent study. Surveys, questionnaires, saliva samples and blood (venipuncture) were collected at baseline. Study procedures were approved by the Emory University Institutional Review Board and participating institutions. Participants were provided with written informed consent and written instructions on how to prepare for the first evaluation which included salivary cortisol collection and fasting blood work.

Measurements

Health Outcome Measures

Caregiver health outcomes were categorized into three categories and included physical function, psychological function (anxiety and depressive symptoms), and physiologic function (salivary cortisol and pro-inflammatory cytokine – IL-6).

Physical Function

Caregiver physical function was measured using the SF-36v2 Physical Function Subscale, one of the dimensions representing quality of life, that assesses the ability to carry out activities that require physical capability, ranging from self-care (activities of daily living) to more rigorous activities that require increasing degree of mobility, strength, or endurance [27]. Participants were asked to rate on a 3-point scale the extent to which their health limited their ability to engage in the various activities over the past 4 weeks (1=limited a lot, 2=limited a little, and 3=not limited at all). Standard scoring algorithms transform raw scores to a 0 to 100 scale, with higher scores reflecting better physical function. Reliability (Cronbach's alpha .8-.91) and construct validity have been documented. [28, 29]

Psychological Function

Psychological function included anxiety and depressive symptoms. Anxiety was measured using the state component of the State-Trait Anxiety Inventory (STAI) [30] which consists of 20 items to which participants rate how they feel at the moment about each item on a 4 point scale with higher scores indicating higher levels of anxiety. The cut point for the STAI scores is equal to or greater than 40, which indicate the presence of severe and clinically significant anxiety. This instrument is valid and reliable (internal consistency reliability is .94) and has been widely used by researchers. [31, 32]

Depressive symptom was measured using the Center for Epidemiological Studies Depression Scale (CES-D), [33] a 20- item scale designed to assess depressive symptoms in the general population. Participants rate items according to how they have been feeling the past week. A cut off score of equal to or greater than 16 on the CES-D is an indicator of possible clinical depression, [33] with higher scores indicating the presence of more depressive symptoms. The CES-D has been used extensively with caregivers [34, 35]. Internal consistency reliability and criterion validity for the CES-D have been established with reported Cronbach alpha of .83 - .92. [33, 36]

Physiologic Function

Salivary Cortisol

Salivary cortisol represents the free fraction of circulating cortisol and is a reflection of the biologically active fraction of cortisol. Cortisol secretion surges immediately after awakening with a decline during the day. Elevated cortisol levels in response to awakening within 30 mins have been shown to be a better indicator of chronic stress with higher intraindividual stability than basal cortisol levels in the morning or later in the day. [37] Participants were provided detailed instructions on how to collect the saliva sample upon awakening and 30 minutes after awakening using Salivettes® and to freeze and store the samples until the next clinic visit. Samples were analyzed using radioimmunoassay and assessed in triplicate for salivary cortisol levels. Difference in the awakening and 30 minutes after awakening cortisol levels collected over three days at baseline was used for analysis.

Interleukin 6

Il-6 was measured using standard laboratory procedures. To control for circadian variations in immune biomarkers, blood was drawn preferably in the morning of the baseline data collection session. Samples were obtained in chilled EDTA-coated tubes and within 30 minutes were centrifuged (spun at 1000g) for 15 minutes at 4°Celcius. Plasma was collected and stored at −80°C for later batched analysis of the inflammatory cytokine IL-6. Concentrations of IL-6 were assessed in duplicate using high sensitivity multiplex bead-based assays (R& D Systems) and analyzed on a MAGPIX CCD imager (Luminex). [38, 39] Mean inter- and intra-assay coefficients of variation (CV) reflecting the repeatability and precision of the assays were acceptable at <10%).

Sleep Quality

FCGs sleep quality was measured using the Pittsburgh Sleep Quality Index (PSQI). The PSQI is a self-report questionnaire that consists of five open-ended and 14 Likert-type items that provide a comprehensive assessment of sleep quality and disturbance [40] over a 1-month time interval. Nineteen individual items produce a global sleep quality score as well as seven component scores on sleep latency, sleep duration, habitual sleep efficiency, sleep disturbance, use of sleeping medications, and daytime sleepiness. The sum of scores for these seven components yields one global score (range = 0-21) with higher scores indicating poorer sleep quality. A global PSQI score ≥ 5 yielded a diagnostic sensitivity of 89.6% and specificity of 84.4% (kappa = 0.75, p =.001) in discriminating poor versus good sleep. [41] The PSQI is the most common subjective instrument used to measure sleep quality. Test-retest reliability and validity have been established [40-42].

Covariates

Possible covariates identified from previous studies and theoretical relationships included demographics (age, race), body mass index (BMI) which was calculated by dividing weight in kilograms by height in meter square, self-reported health rating, caregiving stress (Bakas Caregiving Outcome Scale) factors, and health (physical activity measured with the Community Health Activities Model Program for Seniors (CHAMPS). [43-45] The CHAMPS is a 41-item questionnaire used to measure physical activities ranging from light to vigorous over the last 4 weeks. This instrument has been validated in older adults, and culturally diverse populations including FGGs and African Americans.[46-48]

Only covariates that were significantly associated at p<.05 in a bivariate analysis were included in the multivariate models.

Data Analyses

Data were analyzed using IBM SPSS Statistics for Windows, Version 25, released 2017. Data were assessed for normality by examining plots and Shapiro-Wilk test for normality. Descriptive statistics were used for describing sample characteristics. Bivariate analysis was conducted to examine the relationship between overall sleep quality and health outcomes being investigated using Pearson and Spearman correlations. To test hypotheses, multiple linear regression analyses were performed. Cortisol and IL-6 data were right skewed and were log transformed to obtain a normal distribution. Race was re-coded as a dichotomous variable with Caucasian as the reference group compared with African American (AA). The sample contained two Asian participants that were included in the Caucasian group. Participants with missing data were excluded from the analysis through the listwise deletion method. All other measures were used as computed with no mathematical transformation, and other than race, no other measures were dichotomized. A two-tailed probability value of less than 0.05 was considered statistically significant.

To examine the relationship between overall sleep quality and physical function, multiple regression analysis using stepwise variable selection method was done. Age, self-reported health rating, BMI, and physical activities were included in the model. Following this, the relationship between sleep quality and psychological function, and sleep quality and physiologic function were examined using hierarchical regression analysis. Covariates in these models included age, race, health rating, and caregiving stress. The first model included age, race and health rating, and BCOS and PSQI were sequentially added in the second and third models respectively. There was linearity as assessed by a partial regression plot and plots of residuals against predicted values. There was independence of residual as assessed by the Durbin – Watson statistics. No evidence of multicollinearity was present as indicated by the Variance Inflation factor (VIF).

Results

Characteristics of the sample are shown in Table 4.1. FCGs were middle-aged on average, predominately female, and slightly more than half identified as African American. A majority of FCGs lived with the HF care recipient and more than half had at least a college education. Most of the FCGs self-rated their health as good/excellent (86.3%), self-reported that they engaged in moderate exercise (71.7%) and the average caregiver BMI was in the obese category. Over three-quarters of the sample reported poor overall sleep quality, and about a third had at least one comorbidity.

Sleep Quality and Physical Function

Bivariate relationships between physical function and other variables are shown in Table 4.2. Correlates include age, self-reported health rating, BMI, CHAMPS and the BCOS. Caregiver age and BMI were negatively correlated with physical function. Self-reported health rating, the CHAMPS and BCOS were positively correlated with physical function indicating better health, more physical activities and less caregiving stress are associated with better physical function.

A stepwise multiple regression analysis was conducted to determine if age, health rating, BMI, BCOS, CHAMPS, and overall sleep quality, was associated with FCG physical function. Age, health rating, BMI and overall sleep quality were significantly related to caregiver physical function. Total R^2 was .264, indicating that age, self-reported health rating, BMI and overall sleep quality accounted for about 26.4% of the variance in physical function. Caregiving stress (BCOS) and physical activity (CHAMPS) did not enter the model. The addition of overall sleep quality to the prediction of physical function led to a statistically significant increase in R^2 of .031, F(4,120) = 12.14, $p<0.001$ (See Table 4.3).

Sleep Quality and Psychologic Function

About 43% and 41% of FCGs scored above the clinical cut off point for anxiety (≥40) and depressive symptoms (≥16) respectively. Age, health status, and the BCOS were negatively correlated with anxiety and depressive symptoms, race only was related to anxiety in that African Americans had higher levels of anxiety (See Table 4.2). Variables that had the strongest relationship with anxiety and depressive symptoms include the BCOS and the PSQI.

A hierarchical multiple regression analysis was performed to determine if the addition of FCG overall sleep quality improved the prediction of psychological function over and above covariates and caregiving stress (See Table 4.4 for details of each regression model). The full model that included age, race, health rating, BCOS and the PSQI to predict psychological functions of anxiety (R^2 = .462, F(5,120) = 16.752, $p < .001$; adjusted R^2 = .387) and depressive symptoms (R^2 = .462, F(5, 121)= 20.758, $p<.001$; adjusted R^2 = .439) accounted for moderate to large significant amount of the variance respectively. The addition of the PSQI to the prediction of anxiety and depressive symptoms (Block 3) led to a statistically significant increase in R^2 of .023 F(1,120) =4.620, $p=.034$ for anxiety and a statistically significant increase in R^2 of .087

F(1,121) =19.645, p<.001 for depressive symptoms, although caregiver stress contributed a larger part of the variance of the dependent variables.

Sleep Health and Physiologic Function

Significant bivariate relationships for salivary cortisol and IL-6 are shown in Table 4.2. In a hierarchical multiple regression analysis that contained age, race, health rating, and BCOS as covariates, none of the demographic and health variables were significantly associated with either salivary cortisol or IL-6 (see Table 4.5). The BCOS was independently associated with salivary cortisol but not with IL-6. The addition of PSQI did not account for any significant variation in measures of physiologic function, after controlling for covariates. The final model (Block 3) was not significant for cortisol (F(5, 120)= 1.010, p=.415, adjusted R^2=.000) as well as for IL-6 (F(5, 117)= 1.808, p=.117, adjusted R^2=.013).

Discussion

This study examined the relationship between sleep quality and health outcomes of FCGs of persons with HF, and to our knowledge, is the first of such studies.

Most of the FCGs in this study were female, and more than half reported their overall health as good or excellent. A large percentage of FCGs reported experiencing poor sleep which indicates the high prevalence of poor sleep quality among FCGs of persons with HF. Overall subjective sleep quality of FCGs was additionally associated with caregiver physical function after controlling for other covariates and potential confounders including age, self-reported health rating, and BMI. Although all covariates considered were significantly related to physical function, health rating contributed most to the variability in physical function. It may be that FCGs who had positive perception about their health were better motivated to be engaged in physical and other mobility activities. The significant association of caregiver’s sleep quality with physical function indicates that FCGs’ sleep quality, a modifiable behavioral factor, may benefit from targeted interventions that attenuate its contribution to poor physical function. Understanding this relationship is crucial for family members of persons with HF given that their role as caregivers may include carrying out activities of daily living and other physically exerting routines for the care recipients. FCGs need to be in good physical health to carry out these routines and support care recipients with physical limitations that result from HF progression. In addition, a good physical function is necessary for caregiver's own independent living. Although this finding agrees with other research findings that observed poor physical functioning among community-based older adults [16, 49-51], no prior study has examined this relationship in FCGs. Lorenz and colleagues (2014) found that poor sleep was associated with early stage of physical function decline that places them at high risk of clinical disability. Evidence suggests that mental fatigue resulting from poor sleep quality may mediate the relationship between sleep quality and poor physical function. [52] Further studies are needed to understand the mechanism by which poor sleep quality affects physical function in FCGs of persons with HF.

Of concern, is that 41% of FCGs reported moderate to severe anxiety, and they also scored above the cut-off point on the CES-D indicating a possible risk for significant depressive symptoms. . Poor sleep quality in FCGs was associated with poor psychological outcomes. The association between sleep quality and anxiety was influenced by age, race and caregiving stress. Being African American, younger in age and worse caregiving stress were associated with higher levels of anxiety. Similarly, age and caregiving stress were also associated with higher levels of depressive symptoms.

This study confirms previous studies that have linked these demographics and caregiving stress factors to poor psychological outcomes among FCGs. [53, 54] In addition, this study also observed an additional association between poor sleep quality and psychological outcomes. Although poor psychological function has been identified as precursor to poor sleep quality, [55] our study uses model building and while not causal, demonstrates that poor sleep may contribute to FCGs anxiety and depressive symptoms.

We hypothesized that poor sleep quality would be associated with increased level of salivary cortisol awakening response, and IL-6. Sleep quality was not significantly associated with cortisol and IL-6 in this study. Similarly, no significant association was observed between caregiving stress and cortisol. This is a surprising finding given that cortisol response to stress has been well documented [56, 57]. This could be due to variations in methods of cortisol collections. and The association between sleep quality and physiologic function is unclear. Family caregiving studies have primarily examined physiologic responses resulting from caregiving stress and have not examined the influence of sleep quality on physiologic health outcomes. These studies, however, have reported conflicting results. We found no associations between sleep quality and salivary cortisol.

Similarly, in agreement with other studies, we observed no significant associations between FCGs sleep quality and Il-6. [58, 59] However, other studies have indicated that sleep quality contributes to alterations in cortisol and IL-6 levels. [60, 61] For example, one study found that caregivers with short sleep duration had a significant increase in their cortisol awakening response [62] These contrary findings may be attributed to differences in the conceptualization and measurement of sleep and physiologic variables. More FCG studies are needed to clarify these findings

.

Limitations and Strengths

Several limitations should be acknowledged. First, this is a cross-sectional study of baseline data and causal relationships could not be determined. Second, the use of subjective self-reported measures such as the PSQI may introduce some bias, although the PSQI has been widely used and validated. Future studies should incorporate the use of a more objective measure of sleep. Third, the majority of FCGs were female and we were not able to test the effect of gender on the relationship between sleep quality and health outcomes which may have important implications. Fourth, the measure of cortisol was completed by participants in the home, and the degree of compliance with the protocol in terms of time of day of the obtained samples is unknown. However, this study has several strengths. Our study had a larger sample than previous sleep studies in this population, and in the analysis controlled for demographic, health and family caregiving stress, covariates previously observed to be associated with sleep quality and the outcome variables

Conclusion

A majority of FCGs of persons with HF experience poor sleep. Overall perceived sleep quality was additionally associated with poor physical function, anxiety and depressive symptoms but not with physiological function. Overall, our findings indicated that perceived sleep quality additionally influenced FCGs health outcomes, although caregiving stress contributed largely to FCGs' poor health outcomes. In addition, FCGs' sociodemographic and health characteristics were significantly associated with both physical and psychological outcomes. Sleep quality of FCGs of persons with HF deserves further investigation. Future studies should integrate objective sleep measurements, use more rigorous collection methods for physiological stress measure of cortisol, and test interventions that may improve FCGs' sleep and ultimately improve FCGs' health outcomes.

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Table 4.1

Description of Family Caregivers Demographic and Health Characteristics

Characteristics		Min-Max	N, Mean	%, [SD]
Age (yrs)		25 - 80	55.3	[11.5]
Race	African American		74	58.3
	Caucasian		51	40.2
	Asian		2	1.6
Gender	Female		117	92.1
	Male		10	7.9
Education (=>College)			89	70.1
BCOS		20 - 105	54.5	[16.9]
Engage in physical activity			91	71.1
Comorbidity (>0)			41	32.3
Live with Family Member			107	84.3
Care for others			42	33.1
Health Rating	Fair		9	15
	Good		87	68.5
	Excellent		21	16.5
BMI[a]		19.6 – 65.6	31.1	[7.2]
STAI ≥ 40			55	43.3
Average STAI		20 – 78	41.0	[14.9]
CES-D ≥ 16			43	41.7
Average CES-D		0 – 46	15.2	10.4

Physical Function	19-57	49.3	[7.9]
Salivary Cortisol (CAR) (mcg/dl)	-.96 - .86	-.13	[.27]
Interleukin 6 (IL-6) (pg/ml)	.3 – 18.3	2.4	[2.6]
Engage in physical activity (CHAMPS)		91	71.7
Overall Sleep quality (PSQI ≥ 5)		104	81.9
Average PSQI score	0 - 21	8.4	[4.4]

[a] Variable has 2 missing data

BCOS = Bakas Caregiving Outcome Scale; BMI = body mass index; CES-D = Center for Epidemiological Studies Depression Scale; STAI = State Trait Anxiety Inventory; PSQI = Pittsburgh Sleep Quality Index   CAR = Cortisol Awakening Response   CHAMPS = Community Healthy Activities Model Program for Seniors

Table 4.2

Relationship among Independent and Outcome Variables (N=127)

Variables	Physical Function	Anxiety	Depressive symptoms	Cortisol	IL-6^{e}
Age	-.24^{b}	-.18^{a}	-.16	.11	.09
Race (AA=1)	.10	-.19^{a}	-.06	-.09	.08
Health Rating	.37^{b}	-.18^{a}	-.20^{a}	-.12	-.23^{a}
BMI^{d}	-.32^{b}	.03	-.01	.14	.31^{b}
CHAMPS	.25^{b}	-.20^{a}	-.12	.06	-.12
BCOS	.24^{b}	-.53^{b}	-.56^{b}	-.11$^{.}$	.14
PSQI	-.21^{a}	.40^{b}	.55^{b}	-.04	-.08

^{a}p<.05 ^{b}p<.01

^{c}Variable has 1 missing data ^{d}Variable has 2 missing data ^{e}Variable has 4 missing data

AA = African American BCOS = Bakas Caregiving Outcome Scale BMI = body mass index CHAMPS = Community Health Activities Model Program for Seniors PSQI = Pittsburgh Sleep Quality Index; Pearson's Correlation Coefficients IL-6 = Interleukin 6

Table 4.3

Multiple Regression Analysis of Factors that Contribute to Family Caregivers Physical Function Score

	Physical Function (n=125)				
Predictors	**B**	**SE B**	**β**	**R^2**	**ΔR^2**
Health Rating	3.72	1.15	.27[b]	.14	.14
Age	-.19	.05	-.28[b]	.19	.05
BMI	-.30	.09	-.27[b]	.26	.06
PSQI	-.33	.14	-.18[a]	.29	.03[a]
Total Adjusted R2				.26	
Overall Model	F(4,120)=	12.14	P<.001		

[a]p<.05 [b]p<.01

BMI = body mass index; PSQI = Pittsburgh Sleep Quality Index

Table 4.4

Relationship between Overall Sleep Quality and Psychological Function

	Anxiety (n=126)				Depressive Symptoms (n=127)			
Predictor Variables	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2
Block 1:								
Age	-.37	.10	$-.28^b$		-.18	.06	$-.20^a$	
Race	-6.23	2.29	$-.21^a$		-.71	1.51	-.03	
Health rating	-3.33	1.97	-.13	$.16^b$	-1.00	1.31	-.05	$.08^a$
Block 2:								
BCOS	-.38	.07	$-.43^b$	$.23^b$	-.26	.05	$-.42^b$	$.30^b$
Block 3:								
PSQI	.59	.27	$.17^a$	$.02^a$	.80	.18	$.34^b$	$.09^b$
Total R^2			.41					.46
Adjusted R^2			.39					.44
Overall Model	F(5,120)=	16.75,	P <.001		F(5, 121)	=20.76,	P <.001	

$^a p < .05$ $^b p < .01$

BCOS = Bakas Caregiving Outcome Scale; PSQI = Pittsburgh Sleep Quality Index

Table 4.5

Relationship between Overall Sleep Quality and Psychological Function

	CAR (n=126)				Interleukin 6 (n=123)			
Predictor Variables	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2
Block 1:								
Age	.00	.00	.10		.01	.01	.13	
Race	-.00	.06	-.00		.08	.14	.06	
Health rating	-.07	.05	-.15	.03	-.23	.12	-.19	.04
Block 2:								
BCOS	.00	.00	-.13	.02	.01	.00	.18	.03
Block 3:								
PSQI	-.01	.01	-.01	.02	-.00	.02	.02	.00
Total R^2				.00				.08
Total Adjusted R^2				.10				.01
Overall Model	F(5, 120)	=1.01,	p =.412		F(5, 117)=	1.81,	P=.117	

$^a p < .05$ $^b p < .01$

BCOS = Bakas Caregiving Outcome Scale; PSQI = Pittsburgh Sleep Quality Index CAR = Cortisol Awakening Response

CHAPTER V

Summary and Conclusions

The goal of this study was to examine sleep quality and its correlates in family caregivers (FCGs) of persons with heart failure (HF). Specifically, the study aims were to first describe FCGs sleep quality and associated sociodemographic, clinical and family caregiving stress factors, second, to examine associations among FCGs sleep quality and physical and psychological function, and third, to examine the relationship between FCGs' sleep quality and physiologic outcomes (inflammatory biomarkers). This study was based upon the theoretical underpinning of Allostasis and Allostatic load. Overall study findings, conclusion, implication and recommendation for nursing practice and research are summarized in this chapter.

FCGs are important contributors to the home care and self-management of HF. Family caregiving for patients with HF can be stressful, and FCGs often report changes in their health outcomes including poor physical and psychological health after assuming a caregiving role. [1] Health promoting behaviors such as maintaining good quality sleep may receive less attention with long-term caregiving as FCGs prioritize their family member's needs above their own selfcare. [2] In general, poor sleep quality has been associated with poor health outcomes and morbidity. [3-5] Although studies have investigated caregivers' sleep quality in other populations, there is a paucity of literature on sleep studies in FCGs of persons with HF. There is little evidence regarding the potential factors that are associated with the high prevalence of poor sleep in this population of FCGs. Given the projected increase in the demand of FCGs of persons with HF in the coming years, [6] it is important to examine correlates of FCGs sleep quality in order to identify areas of caregiving that may benefit from targeted interventions to improve caregivers' health. This study contributes to the limited knowledge of FCGs sleep experience and health outcomes in this vulnerable understudied population and examined potential predictors and covariates of sleep quality and health outcomes.

This dissertation included three manuscripts. The first manuscript summarizes existing evidence of poor sleep quality in FCGs in three populations of FCGs including cancer, Alzheimer's Disease (AD) and HF (chapter 2); the second manuscript describes the prevalence of poor sleep quality and identified potential predictors of poor sleep quality in FCGs of persons with HF (chapter 3), and the third manuscript examined the associations among FCGs sleep quality and adverse health outcomes including poor physical function, anxiety, depressive symptoms and physiologic biomarkers of cortisol and interleukin 6 (Il-6) (chapter 4). Overall, the study addressed three specific aims.

The first aim was addressed in chapters two and three and described the presence and prevalence of poor sleep quality in FGCs of persons with HF and sociodemographic, clinical and caregiving stress factors associated with FCGs sleep quality. FCGs of persons with HF experience poor sleep as do other caregiving populations like cancer and AD. The proportion of FCGs experiencing poor sleep quality in this study was 82% which is higher than that found in FCGs of cancer and AD populations. Lee, Yiin, Lin, & Lu (2015) investigated predictors of sleep disturbance is cancer FCGs, and they reported that 72.2% of FCGs experienced poor sleep. Similarly, Liu et al (2017) found a similar prevalence (78%) of poor sleep in FCGs of persons with AD. Although researchers used different scoring cut off point for the Pittsburg Sleep

Quality Index (PSQI) which poses some challenges in comparing the studies, our study suggests that the prevalence of poor sleep quality in FCGs of persons with HF tend to be slightly higher than those of other chronic diseases like cancer and AD.

Demographic and clinical factors that were examined included age, race and caregiver comorbidity were not significantly associated with poor sleep quality. Although this finding did not support our hypothesis that older age, African American race, and caregiver comorbidity will be associated with worse sleep quality, they are consistent with several other studies, [7-10] but contrary to that observed by Aslan, Samisoghu, Akyol, & Yetkin (2009). Similarly, Mills et al (2009) observed that FCG older age and male gender were related to poor sleep [11]. This study did not examine the association between caregiver gender and sleep quality because of the sample gender composition (92% female) which does not provide adequate variability for analysis. However, descriptively men reported slightly higher PSQI mean score than female.

Caregiving stress factors examined in our study were caregiving difficulty, life changes since assuming caregiving role and disease severity (HF severity). Factors associated with poor sleep quality included caregiving difficulty and life changes since assuming caregiving. Specifically, FCGs who reported caregiving as difficult and who perceived their lives to have changed negatively since assuming the caregiving role were more likely to report poor perceived sleep quality. This finding partially supports our hypotheses that higher family demands and caregiving stress factors will be related to worse sleep quality in FCGs, and it is similar to results from other studies linking caregiver burden to poor sleep in FCGs. [7, 10, 12] Mills et al (2009) found that males caring for patients with advance AD had worse sleep than females caring for persons with advance or moderate AD. Poor sleep has also been observed at the beginning of the caregiving trajectory in some cancer FCgs who recently learned about the cancer diagnosis [7]. It could be that a recent cancer diagnosis elicited worry and anxiety that led to poor sleep in caregivers. In this study, HF severity was not associated with poor sleep quality, although other HF-specific characteristics such as care recipient depression, sleep apnea, and nocturia were not examined. It is unknown if caring for persons with HF places a higher caregiving stress on FCGs than other populations given the complexities in HF management. However, evidence suggests that different populations may experience caregiving stress and sleep problems differently.

The second aim examined the associations among FCGs sleep quality and physical and psychological health outcomes. Psychological outcomes include FCGs anxiety and the presence of depressive symptoms. This aim was addressed in chapter four. Findings from this study support our hypothesis. Poor sleep quality contributes to FCGs poor health outcomes. Sleep quality was found to be positively correlated and significantly associated with physical function, suggesting that FCGs with poorer sleep quality are more likely to experience poorer physical function. In non-caregiving populations, objective measures of sleep disturbance including total sleep time, total numbers of awakening and total wake time were found to be significantly associated with poor physical function [13]. Similar findings have been observed among community-dwelling adults as well. [14, 15] For FCGs of HF persons, a good physical function is important in the everyday caregiving routine and assisting care recipients in activities of daily (ADL), particularly with functional decline as HF progresses.

FCGs' anxiety and depressive symptoms were significantly associated with both caregiving stress and caregiver sleep quality. However, FCG sleep quality was an independent contributor to higher anxiety and depressive symptoms observed in FCGs of persons with HF. FCGs who perceived their sleep quality as poor had higher anxiety and worse depressive symptoms. This is an important finding, given the multifaceted nature of factors associated with FCG outcomes, to identify target areas and to test interventions that attenuate poor psychological outcomes in FCGs of persons with HF, as well as to reduce poor outcomes in care recipient who depend on FCGs for optimal management of HF disease. Evidence suggests that family caregiving is strongly associated with poor psychological outcomes. There is strong evidence on the relationship between sleep and psychological outcomes in the caregiving and non-caregiving population. [9, 16] In general, the risk of developing depression is twice as high in people who experience poor sleep than in people who have no sleep problems. [17, 18] Being a caregiver further contributes to this risk.

The third aim was also addressed in chapter four and examines the relationship between FCGs sleep quality and physiologic biomarkers, specifically inflammatory biomarkers of salivary cortisol and IL-6. Findings from this study did not support our hypothesis. No associations were found between FCGs sleep quality and physiologic biomarkers. Poor sleep quality has been linked with stress hormones such as cortisol and proinflammatory cytokines [19, 20]. In the general population, studies have shown that people with poorer sleep quality also show greater production of pro-inflammatory cytokines including Il-6, independent of age. [19, 21] However, this association has received mixed conclusions in family caregiving populations. Several caregiving studies have also found no associations between cortisol, as well as interleukin-6, and sleep variables. [11, 22] These discrepancies may be due to differences in design and methodical issues including the cross-sectional design of the studies and lack of participants' adherence to the protocol for collecting of salivary cortisol. In addition, caregiving duration indicating chronic stress may contribute to the levels of physiologic responses to chronic poor sleep.

Overall, findings from this study indicate that FCGs of persons with HF have high allostatic load relating to caregiving stress that potentially influences FCGs sleep quality and health outcomes. Thus, our hypotheses were partially confirmed. This study found that caregiving stress was associated with poor sleep quality, and that poor sleep quality was related to poor physical and psychological health outcomes. However, the relationships between FCGs sleep quality, sociodemographic and comorbidity were not confirmed, neither was any association found between sleep quality and physiologic outcomes. Further research is needed to elucidate these findings and verify this component of the model.

Strengths and Limitations of the Study

This was the first study to examine sleep quality of FCGs of persons with HF using quantitative methods and a large sample size (n=127). In addition, this study controlled for potential covariates and confounders that may affect the accurate interpretation of study results.

This study also has several limitations such as the cross-sectional design which does not o establish a causal association between independent and outcome variables.

Longitudinal studies are needed to illuminate these associations. Moreover, data on HF characteristics were not collected in the parent study to examine their effect on FCGs' sleep quality and outcomes specific to HF population. Future studies should examine factors relating to caring specifically for HF persons to determine if FCGs in this population experience burden and sleep differently from other populations. In addition, there is a need for better agreement on the cut-off score of the PSQI, which is the most commonly used subjective measure for sleep quality.

The study was also limited in the data collected. Data such as the length of time since initiating caregiving may have provided greater insight into the associations observed in this study. This a consistent limitation with secondary data analysis. Further, sleep quality was measured using subjective measures. For studies examining sleep quality as a primary outcome, it may be necessary to include an objective measure such as the wrist actigraphy to validate the perception of FCGs sleep quality and to determine discrepancies in areas of sleep parameters. However, we used a well-established self-report measure that has been validated using objective measures. In addition, most of FCGs in this study were female. Although women tend to report worse sleep quality, the low number of men prohibited an in-depth exploration of gender differences. Our study did not measure other life stressors that may contribute to poor sleep quality in FCGs. Therefore, future studies should examine theses possible contributors. To better understand sleep problems, it may be helpful to get FCGs perspectives on factors that contribute to their poor sleep quality through qualitative studies.

Although evidence suggests a bidirectional relationship among depression, anxiety and poor sleep in the general population, [23] this study did not examine this bi-directionality. It is not certain if FCGs prior depression contributed to poor sleep quality, although 85% of FCGs in this sample self-rated their health as either good or excellent, and only 19% reported a history of depression. Future longitudinal studies are needed to examine caregivers' psychological health prior to assuming the caregiving role, caregiving trajectory and whether caregiver depression and anxiety predicted poor sleep quality.

Implications for Practice and Research

Patients with HF require continued home-based self-management after initial hospitalization. With the projected increase in chronic conditions, particularly HF, and the expected increase in the demands of FCGs to care for these patients, attention on FCGs and their caregiving situation should be viewed as a healthcare priority. The cost of HF management is high and projected to be 30 billion by 2030, and family caregiving contributes an additional 35% increase in indirect cost to HF management. [24, 25] In addition, caregiving increases the tendency for FCGs to minimize their selfcare, and increases the risk of developing poor health outcomes including cardiovascular disease, poor mental health, and poor overall health. [26] These adverse health outcomes may further drive the prevalence of these chronic diseases, increase morbidity and mortality, and place increasing burden on the healthcare system.

Caring for persons with HF is complex. FCGs need to be in good health to be able to assume and cope with the challenges and issues involved in the home-based management of HF. Only recently has the healthcare professional began to focus on the family member supporting the HF patient. However, healthcare professionals have not addressed FCGs sleep quality which has high potential to influence FCGs stress levels and health outcomes. Sleep is a modifiable behavior that can be assessed during clinic and hospital visits. FCGs can benefit from health education on sleep hygiene and can be directed to other resources that may beneficial in improving their sleep quality.

Given the multiple factors that have been associated with FCG burden and poor health outcomes, this study provides evidence of the potential harm that poor sleep quality over a long period of time may have on FCGs physical and psychological health and the need to develop and test targeted interventions geared toward improving FCGs sleep and overall health outcomes. This was a preliminary study to understand associations and correlates of poor sleep quality in FCGs of persons with HF using baseline data of a previous intervention study. Future studies are needed to elucidate factors that contribute to poor sleep among FCGs of persons with HF while addressing design and methodological issues identified in this study. HF disease-specific factors such as care recipient depression, sleep apnea, and nocturia, FCGs gender and other covariates not included in this study should be considered in future studies.

Summary

This study sought to describe the prevalence of poor sleep in FCGs of persons with HF and to identify correlates of poor sleep quality. The study provides evidence of the high prevalence of poor sleep quality among FCGs of persons with HF, in comparison to other caregiving populations. In addition, caregiving difficulty and stress were associated with poor sleep quality, suggesting that FCGs may experience worse sleep quality in highly demanding and stressful caregiving situations. Further, FCGs poor sleep quality was positively associated with physical and psychological functions. This study did not find any associations among FCGs sociodemographic, clinical and sleep quality. Similarly, no associations were found between FCGs sleep quality and physiologic functions including cortisol and interleukin-6. Overall, this study demonstrates the need for targeted intervention in the caregiving situation of FCGs of persons with HF, specifically, improving caregivers' sleep quality and associated health outcomes. The study also identified gaps that warrant more investigation and the need to address design and methodological issue to better understand and address family caregiver sleep.

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