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SLEEP DISTURBANCE AND OUTCOMES IN PATIENTS WITH HEART FAILURE
AND THEIR FAMILY CAREGIVERS

Dissertation

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Nursing at the University of Kentucky

By

Sami Yousef Al-Rawashdeh

Lexington, KY

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ABSTRACT OF DISSERTATION

SLEEP DISTURBANCE AND OUTCOMES IN PATIENTS WITH HEART FAILURE AND THEIR FAMILY CAREGIVERS

Sleep disturbance is common in patients with heart failure (HF) and the family caregivers. Sleep disturbance is known as a predictor of poor quality of life (QoL) in individual level. The manner in which patients' and caregivers' sleep disturbances influence each other's QoL has not been determined. The purpose of this dissertation was to investigate the associations of sleep disturbance and outcomes in patients with HF and their primary family caregivers. The specific aims were to: 1) examine whether sleep disturbance of patients and their family caregivers predict their own and their partners' QoL; 2) examine the mediator effects of depressive symptoms on the association between sleep disturbance and QoL in patients and family caregivers; and 3) provide evidence of the psychometric priorities of the Zarit Burden Interview (ZBI) as a measure of caregiving burden in caregivers of patients with HF.

The three specific aims were addressed using secondary analyses of cross-sectional data available from 143 patients with HF and their primary family caregivers. To accomplish Specific Aim One, multilevel dyadic analysis, actor-partner interdependence model was used for 78 patient- caregiver dyads. Individuals' sleep disturbance predicted their own poor QoL. Caregivers' sleep disturbance predicted patients' mental aspect of QoL. For Specific Aim Two, a series of multiple regressions was used to examine the mediation effect in patients and caregivers separately. Depressive symptoms significantly mediated the relationship between sleep disturbance and mental aspect of QoL in patients. The mediation effect was similar in caregivers. For Specific Aim Three, the internal consistency and convergent and construct validity of the ZBI in 124 family caregivers of patients with HF were examined. The results showed that the ZBI is a reliable and valid measure of caregiving burden in this population.

This dissertation has fulfilled important gaps in the evidence base for the QoL outcome in patients with HF and caregivers. The findings from this dissertation provided evidence of the importance of monitoring sleep disturbance for better QoL in both

patients and caregivers and the importance of assessing caregivers' sleep disturbance for improving patients' QoL. It also provided evidence of the importance of managing depressive symptoms when targeting sleep disturbance to improve QoL in both patients and caregivers.

KEYWORDS: Heart Failure, Sleep Disturbance, Quality of Life, Family Caregivers, Caregiving Burden.

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SLEEP DISTURBANCE AND POOR OUTCOMES IN PATIENTS WITH HEART
FAILURE AND THEIR FAMILY CAREGIVERS

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CHAPTER ONE

Introduction

Heart failure (HF) is the end stage of cardiovascular related conditions that results in inadequate pumping of blood to meet the metabolic requirements of the body parts and is associated with limited capacity for activity. It is a significant worldwide public health problem especially in developed countries including the United States (US).¹ In US, more 5 million Americans aged 20 years or more have HF and the incidence of the disorder continues to rise.² HF is a chronic disorder associated with high mortality rate,³ frequent hospital admissions,^{4,5} and increased health care expenditures.⁶ It causes high burden on patients and their families⁷ and on health care system and the society as a whole.

Family caregivers play an essential part in the treatment of chronic illnesses and other conditions that affect the individual's ability to perform activities of daily living.⁸ In the US, there are about 65.7 million of adult caregivers providing an average of 20.4 hours of care per week for family member or a friend⁹ with about 42.1 million family caregivers provided care to an adult with some limitations in daily activities.¹⁰ Their work is also valuable to the societies.^{8,11} The cost savings for the health care system of family caregiving was estimated at \$450 billion in 2009.¹⁰ Family caregivers of patients with HF provide significant lifelong support to their family member with HF. They involved in caring of patients with every aspects of patients life including but not limited to helping with tasks of daily living and managing of symptoms, diet, weight, medications, and physician visits. However, this support has been shown to be associated with many negative consequences on caregivers' health^{12,13} that can influence their ability to continue providing support to their family member.¹⁴ The role of being a caregiver is

connected to sleep complaints more prevalent in caregivers than in non-caregivers counterpart.¹⁵

Sleep disturbance is defined as having problems in the qualitative and/or quantitative aspects of sleep.¹⁶ Sleep disturbances are common among patients with HF.^{17,18} About 33% to 74% patients with HF report some forms of disturbed sleep such as trouble in initiation of sleep, early awaking, and difficulty going back asleep.^{19,20} Difficulties in initiation and maintaining sleep are the most common sleep complaints reported by patients with HF.²¹ Patients with HF sleep may influenced by HF symptoms such as dyspnea and dysrhythmias, especially those occurring during sleep^{18,22} or with drugs side effects.²³ Patient's factors such as age and the severity of HF may influence sleep as well.²⁰ Compounding the problem, between 23% - 82% of patients with HF report some forms of sleep-disordered breathing,^{17,18,24-27} in particular obstructive or central sleep apnea.^{24,28} Having sleep-disordered breathing is more common in patients with HF than in gender and age-matched individuals without cardiovascular disease.¹⁷ These forms of apnea are associated with frequent arousals, fragmented sleep, and difficulty in going back asleep.

Family caregivers are also subject to sleep disturbances. In different populations of family caregivers, about 40% to 95% of the caregivers reported complaints related to their sleep.²⁹⁻³⁶ Studies of sleep in family caregivers of patients with HF are scarce, but in a qualitative study, caregivers have reported some changes in their sleep because of their partners' HF.³⁷ Sleep disturbance has been shown to be associated with many poor outcomes. It may influence the individuals cognitive abilities,³⁸ cause depression, and may increase level of fatigue.¹⁸ These may negatively impact individuals' self-care

behavior and the level of adherence to treatment regimen especially the adherence to regular exercise.³⁸⁻⁴⁰ Moreover, disturbance of sleep has been linked to adverse cardiac events and mortality.^{41,42}

Patients with HF^{17,43,44} and their family caregivers reported poor QoL.⁴⁵

Compared with the general population and patients with other chronic diseases, patients with HF reported the poorest level of QoL.⁴⁴ Similarly, family caregivers reported poorer QoL compared to age- and sex-matched non-caregivers.⁴⁶ QoL is an essential part of evaluating treatment of chronic diseases^{47,48} and it has associations with hospital admissions, mortality and morbidity.⁴⁷⁻⁴⁹

There is evidence that sleep disturbance is an important factor associated with poor QoL in patients with HF^{17,21,50-52} and in family caregivers.⁵³⁻⁵⁷ However, it is possible that sleep disturbance in patients or caregivers to be associated with poor QoL in their partners as studies showed that there is interdependence between patients with HF and their family caregivers.^{58,59} No researchers have examined whether sleep disturbance in patients or their caregivers affects the QoL in their partners. Identification of factors that contribute to poor QoL in both patients and caregivers is important in advancing the knowledge of the means of improving their QoL.

The purpose of this dissertation was to investigate the associations of sleep disturbance and outcomes in patients with HF and their family caregivers. Each chapter of this dissertation is part of the inquiry to develop a program of research focused on improving QoL in community dwelling patients with HF and their family caregivers. Secondary data analyses of a cross-sectional data from 143 patients with HF and their primary family caregivers were used in Chapters Two, Three, and Four.

In Chapter Two, the examination of the association between sleep disturbance and QoL in patients with HF and their family caregivers is presented. Although, the negative association between sleep disturbance and QoL has been examined at the individual level (i.e. patients and caregivers separately), this association has not been examined at the patient-caregiver dyad level. This study addressed the need to determine the association of sleep disturbance in a dyad member with the QoL of the partner. The findings may provide insight into the nature of interactions and interdependence between patients and their family caregivers. The multilevel dyadic analysis, called Actor-Partner Interdependence Model was used to evaluate whether sleep disturbance was associated with the aspects of QoL in the individuals themselves and with their partners' aspects QoL. The Actor-Partner Interdependence Model allows for examining two kinds of associations/effects. The first one is the "Actor effect" that represents the effect or association between independent variable (sleep disturbance) and outcome variable (QoL) in the same individual while the "Partner effect", the other associations/effects, represents the effect or association of sleep disturbance in an individual on his/her partner's QoL.⁶⁰ A secondary analysis of data of 78 dyads of patients and their spousal caregivers were used. Sleep disturbance was measured using a composite score of four items related to sleep. QoL was measured using the 12-Item Short Form Health Survey (SF-12).

Chapter Three is a study to determine whether the association between sleep disturbance and QoL is mediated by depressive symptoms in patients with HF and family caregivers. Depression is prevalent in patients with HF and in their family members.⁶¹⁻⁶⁴ It is also more common among family caregivers than in non-caregivers.⁶⁵ Sleep

disturbance has been identified as significant predictor of poor QoL in patients with HF⁵⁰ and in family caregivers.⁶⁶ Sleep disturbance also predicted development of depressive symptoms in cross-sectional and longitudinal epidemiological studies with very large samples.^{67,68} Depressive symptoms also have been strongly linked to poor QoL in both groups.^{62,69} However, no study examined whether depressive symptoms mediate the relationship between the sleep disturbance and QoL in patient with HF and caregiver dyads. This study addressed the need for a better understanding of how depressive symptoms are associated with sleep disturbance and QoL. The results will help in designing more comprehensive interventions for improving QoL in both patients and family caregivers. The mediation effects of the depression on the relationship between sleep disturbance on physical and mental aspects of QoL were examined for patients and caregivers separately. A series of linear regression analyses as outlined by Baron and Kenny⁷⁰ were used to test for the mediation effect. Data from 114 patients and 116 caregivers were used for the purpose of this study. Sleep disturbance and QoL were measured using the same ways described in chapter two. Depressive symptoms were measured using of the depression subscale of the Brief Symptom Inventory.

Chapter Four is a study that was conducted to provide evidence of the reliability and validity of the Zarit burden interview (ZBI) as a measure of caregiving burden in caregivers of patients with HF. Having a reliable and valid measure is important to identify family caregivers with high level of burden in practice and research. The ZBI is a measure developed to assess caregiving burden in caregivers of patients with dementia^{71,72} and its reliability and validity was extensively supported in that population.⁷³⁻⁷⁸ The ZBI have been used to measure caregiving burden of family

members of patients with HF but its reliability and validity have not been provided in this population. This study fulfilled the need to identify a reliability and validity of this measure in this population. The reliability was examined using the internal consistency reliability and item analysis. Validity examined includes convergent and construct validity. Convergent validity was examined using the correlations (Pearson's correlation coefficient) of the ZBI with another measure of caregiving burden (i.e., the Oberst Caregiving Burden Scale). Construct validity was examined using exploratory factor analysis and hypothesis testing. The cross-sectional data were collected from 124 family caregivers of patients with HF.

Chapter Five provides a summary and concluding remarks based on the findings of the three studies. Recommendations for practice and future research are outlined. The findings from each chapter contribute to the knowledge about the poor outcomes in patients with HF and their family caregivers. Results presented in this dissertation could be translated into benefits for improving outcomes and promoting health in patients with HF and their family caregivers for their benefit and the benefit of the community by targeting factors associated with the poor outcomes in both groups.

CHAPTER TWO

Association between Sleep Disturbance and Quality of Life in Patients with Heart Failure and their Family Caregivers

Introduction

Heart failure (HF) is a chronic disorder that requires life-long management. Approximately 5.1 million Americans aged 20 years or more have HF with incidence of 825 thousands cases per year.² Sleep disturbance is defined as having problems in either the qualitative (e.g. restfulness of sleep) or in quantitative aspect of sleep (e.g. time taken to fall asleep and duration of actual sleep).¹⁶ Sleep disturbances are common in patients with HF with 44% reporting having restless sleep, 41% having trouble falling asleep, 39% waking early, and 32% experiencing trouble in returning to sleep.¹⁹ In addition, between 23% - 82% of patients with HF have sleep-disordered breathing.^{17,18,24-27} Family caregivers of patients with HF also report changes in their sleep and sleeping arrangements related to HF in their partners.³⁷

Sleep disturbances have been shown to be associated with poor quality of life (QoL) in general population.⁷⁹ The relationship between sleep disturbance, both subjectively and objectively measured, and QoL is evident in patients with HF.^{17,50-52} Although this relationship is also evident in caregivers,⁵³⁻⁵⁷ this phenomenon has not been examined in HF caregiving context. Research focused on individual level may not give a clear presentation of the actual situation⁸⁰ as individuals with close relationships such as individual- or patient-spouse relationship may be influenced by other member. The interdependence theory suggests that interactions between individuals in a close relationship might have an effect on their partner's outcomes.⁸¹ In addition, it suggests

that individual's emotion, cognition and behavior may influence their own outcomes as well to their partners'. It is possible that sleep disturbance in one partner could affect the QoL of the other partner.

Researchers attempted in two studies to examine the association between sleep disturbances in one member and QoL of the other member within the context of interdependent relationships.^{82,83} However, in these studies either the interdependence between the members' characteristics was ignored⁸² or a statistical technique was used that only accounted for the correlations between individual members' characteristics.⁸³ In such studies, the assumption of interdependence was violated and the results may be biased.⁶⁰ In addition, in the first study by Read, Simonds, Kinali, Muntoni, and Garralda,⁸² the sample size was very small (10 pairs of patients and their caregivers), members had patient-parent relationship, and only correlation analysis was conducted. In the other study, Strawbridge, Shema, and Roberts⁸³ Strawbridge, Shema, and Roberts⁸³ reported in their study of 405 couples that sleep problems in one partner predicted poor physical and mental health in their own as well as their partner's physical and mental health.⁸³

Dyad analysis is the most appropriate analysis for patients-caregivers data as they have a close relationship because both members live the same experience and they may react to the condition and treatment as a unit. This may result in mutual influence on outcomes among dyad members. For example, patients and caregivers might have a reciprocal effect on each other's sleep especially for those who share the bed or the room. The effect may include that caregivers themselves are the source for disturbing patients' sleep.^{84,85} This type of analysis deals with the interdependence between dyad members

and allows researchers to examine how the interdependence among individual members affect the outcomes at the dyad levels.⁵⁸ This approach can also be used to investigate the influences of characteristics of each member of the dyad on his own and his partner outcomes.⁸⁰ No study has examined the association between sleep disturbance and QoL in individuals with interdependent relationships at dyad level. Therefore, the purpose of this study was to examine whether individual's sleep disturbance predicted their own, as well as their partner's QoL in patients' with HF and their family caregivers' dyads. We used the Actor-Partner Interdependence Model (APIM) dyadic analysis approach.

Methods

Design, Sample, and Setting

This is a secondary analysis of cross-sectional data from a longitudinal study designed to determine the impact of family caregivers' emotional distress on patients with HF QoL, re-hospitalization related to HF, and mortality. The parent study included patients who had a confirmed diagnosis of chronic HF and were on stable doses of HF medications and their primary family caregivers. Subjects who were 18 years or more and were able to read, write, and speak English were referred by nurses and physicians from outpatient clinics affiliated with two community hospitals and an academic medical center in Central Kentucky. Inclusion criteria for patients were 1) not receiving active treatment for cancer; 2) did not have history of acute myocardial infarction or hospital admission in the prior 3 months; 3) did not have a terminal illness; and 4) were not referred for heart transplantation. Caregivers were family members or significant others who provided care to eligible patients. Caregivers could not have 1) cognitive

impairment, 2) HF, 3) cancer, 4) dementia or Alzheimer's disease, or 5) terminal illnesses or any other major comorbid condition.

A total of 143 patients with HF and caregivers dyads completed the baseline assessment. In this analysis, we included the 78 patient-spouse dyads with no missing data on the main study variables of sleep disturbance and QoL.

Procedures

Approval from the Institutional Review Board and informed consent was obtained prior to data collection. Researchers approached eligible patients and caregivers either in the outpatient clinics or by phone. Patients identified their own primary family caregivers for the purpose of this study. After screening eligibility of patients and their caregivers, the informed consent was obtained. Participants were asked to complete their own questionnaires without discussing their responses with each other and returned the completed questionnaires via mail or by arranging a pick-up with the research staff. A research nurse obtained clinical information for participants using structured questionnaire, brief interview, and by reviewing patients' medical charts.

Measures

Sleep disturbance. Because there was no standardized measure of sleep disturbance in the primary dataset, the sleep disturbance score was computed based on four common complaints related to sleep in this secondary data analysis. Those items were selected because they reflect common aspects of disturbed sleep in patients and caregivers^{19,21,86,87} and are common aspects assessed in sleep disturbance scales.⁸⁸⁻⁹⁰ The four sleep items were: 1) changes in sleep pattern; 2) difficulty in sleeping; 3) frequency of having trouble falling asleep, staying asleep, or sleeping too much; and 4) problems

with restfulness of sleep. Three of these items were assessed through self-reported survey questionnaires of the Beck Depression Inventory II (BDI-II), Patient Health Questionnaire-9 (PHQ-9), and the Minnesota Living with Heart Failure questionnaire (MLHFQ). The fourth was one of three items that were developed by the primary investigator to assess sleep disturbance specifically focused on assessing uninterrupted sleeping hours and taking a nap during the day.

First item, change in sleep pattern was selected from the Beck Depression Inventory II that is rated 0-6 on a Likert scale. Responses were grouped into categories of 0 – 3; 0, 1 and 2, 3 and 4, and 5 and 6 were recoded into 0, 1, 2, and 3 by following the Beck Depression Inventory II score coding. This 4-point rating was converted to 0-100 score as 0, 33.33, 66.66, and 100 respectively. The second item, difficulty in sleeping because of HF was selected from the Minnesota Living with Heart Failure questionnaire. For caregivers, a modified version of the Minnesota Living with Heart Failure questionnaire was used. This item in caregiver version asked if they have difficulty in sleeping because of their partner's HF. This item is rated on a scale of 0 (no difficulty) – 5 (very much difficulty) and responses were given composite scores of 0, 20, 40, 60, 80, and 100 respectively. Third item, having a trouble falling asleep, staying asleep, or sleeping too much was selected from the PHQ-9 and rated on a 4 point scale from 0 (not at all) to 3 (nearly every day). Responses converted into composite scores same as first item. The fourth item is asking about restfulness of sleep and it is rated on 3-point Likert scale from 1 (very rested) to 3 (not rested at all). The responses for this item were recoded into composite scores of 0, 50, and 100, respectively.

The four item scores were summed and then averaged so that the total scores ranged between 0 and 100. Higher scores indicate higher level of sleep disturbance. The Cronbach's reliability alpha of the sleep disturbance scale was 0.76 for patients and 0.74 for caregivers. Item-item correlations for patients were significant and ranged between .36 and .63. Item-item correlations for caregivers ranged between .21 and .64. All caregivers' item-item correlations were significant except for the correlation between item number 2 (difficulty in sleeping) and item number 4 (restfulness of sleep). The item-item correlations without the correlation between items 2 and 4 ranged between .47 and .64.

Quality of life (QoL). QoL is measured using the Short-Form 12 Health Survey (SF-12). The SF-12 is a short form of a validated generic QoL measure, the Medical Outcome Study health survey short form SF-36,⁹¹ which measures individuals' perceptions of general functional health and well-being. Two standardized scores are generated from the SF-12; the physical well-being and the mental well-being.⁹¹ The physical well-being reflects the physical QoL addressed by physical health, physical functioning, bodily pain, and role limitations impacted by physical health. The mental well-being reflects the mental QoL addressed by mental health, vitality, social functioning, and role limitations impacted by mental health.⁹¹ The possible range for the standardized scores is 0-100 with higher scores indicating better QoL.⁹² In heart and stroke patients, the SF-12 had Cronbach's reliability alpha of 0.84 and 0.81 for the physical and mental well-being subscales respectively, and its construct validity was supported.⁹² Also, it had a good test-retest reliability of 0.89 for physical well-being and 0.76 for the mental well-being among adults population.⁹¹

Data Analysis

All data analyses were performed using the Statistical Package for the Social Sciences version 21 (SPSS Inc., Chicago, IL). The level of 0.05 was chosen a priori as significance level. Descriptive statistics for all variables, including frequency distributions, means, and standard deviations, were calculated as appropriate to the level of measurement of the variables. Paired sample t-test and Chi-square test were used to compare patients and caregivers in regards to their socio-demographic and study variables as appropriate in order to describe sample characteristics. Pearson product-moment correlation was used to examine the correlations among variables of sleep disturbance, physical well-being, and mental well-being within patients and caregivers. To conduct dyadic analysis, individual data were restructured into pairwise data and grand mean scores and Z-scores were created. The Actor-Partner Interdependence Model (APIM) with distinguishable dyads analyses were conducted for outcome, physical and mental well-being with sleep disturbance as predictor. The APIM allows the examination of the effect of the characteristic of each member of the dyad on the outcome in both dyad members.⁶⁰ In the APIM, “the actor effect” means that an individual’s sleep disturbance predicts their own outcome variable while “the partner effect” means that an individual’s sleep disturbance predicts in his/ her partner’s outcome.⁶⁰

Results

Characteristics of patient-spousal caregivers dyads

Of the 143 dyads in the parent study, 78 patient-spousal caregiver dyads were included in this analysis. There were no significant differences between patients who were included and who were not included in the analysis in terms age (62.2 ± 12.4 vs 59.9

± 12.6 years, $p=.26$) or comorbidity scores (3.0 ± 1.7 vs 3.2 ± 2.0 , $p=.72$) but there were more female patients (53.8% vs 25.6%, $p=.001$) and patients with New York Heart Association III and IV (66.1% vs 44.9%, $p=.02$) in the group not included. Among caregivers, there was no significant difference between caregivers included and excluded from the analysis in comorbidity scores (1.3 ± 1.9 vs 0.8 ± 1.2 , $p=.08$) or in percentage of female caregivers (74.4% vs 75.8%, $p=1.0$). However, caregivers included in the analysis were significantly older than the excluded caregivers (59.5 ± 12.3 years vs 52.1 ± 15.9 years, $p=.002$).

The characteristics of and comparisons between patients and caregivers are presented in more detail in Table 2.1. The mean age for the 78 dyads was 62.2 years (± 12.4) for patients and 59.53 years (± 12.3) for caregiver. On average, patients were 2.7 years older than spousal caregivers ($p<.001$). The majority of patients and spousal caregivers were Caucasian and about half of them had no more than a high school education level. There were no significant difference in the percentage of patients and caregivers in terms of education level or ethnicity but patients had higher comorbidity scores and higher percentage of comorbid conditions than caregivers ($p<.05$). Hypertension was the most common comorbid condition in patients and caregivers and it common in patients than in caregivers (77.8% in patients and 44.7% in caregivers, $p<.001$). Half of the patients were New York Heart Association class III or IV.

Both patients and their caregivers had moderate level of sleep disturbance (Table 2.2). Levels of sleep disturbance were similar in patients with HF and their caregivers. The mental well-being scores were similar between patients and caregivers but the physical well-being scores were significantly higher (better) in caregivers (Table 2.2).

Patients had mean physical well-being score of 35 with 92.3% of them having scores less than 50, which is considered poor. About 33% of patients had mental well-being scores less than 50. The percentage of caregivers with scores less than 50 on physical and mental well-being were 62.8% and 33.3%, respectively. Physical well-being in caregivers and mental well-being in both patients and caregivers were considered moderately poor (slightly below the standard mean).

Sleep disturbance scores of patients and caregivers were not significantly correlated (Table 2.3). Sleep disturbance in patients were significantly correlated with their physical well-being but not their mental well-being. Caregivers' sleep disturbance was significantly correlated with their own physical well-being and mental well-being scores. There were no significant correlations between sleep disturbance scores of patients and caregivers in regards to their spouses' physical well-being and mental well-being except that patients sleep disturbance was significantly correlated with caregivers' mental well-being ($p < .01$). Sleep disturbance scores in patients were not correlated with their age ($r = -.203, p = .075$). In spousal caregivers, sleep disturbance scores were correlated with their age ($r = -.220, p = .05$).

Association between sleep disturbance and physical well-being

Sleep disturbance exhibited only actor effects on physical well-being in both patients and caregivers (Table 2.4 and Figure 2.1). That indicates that individuals' higher sleep disturbance predicted their own poor physical well-being in both patients and caregivers. Sleep disturbance had no effect on their partner's physical well-being in either patients or caregivers (p values $> .05$).

Association between sleep disturbance and mental well-being

Patients and caregivers sleep disturbance exhibited an actor effect on mental well-being (Table 2.4 and Figure 2.2) meaning a high level of sleep disturbance predicted each's own poor mental well-being. Patients' sleep disturbance did not exhibit partner effects on caregivers' mental well-being ($p=.451$). For caregivers, we found significant partner effect of sleep disturbance on mental well-being. As an illustration of this partner effect, patients whose caregivers had higher sleep disturbance had poorer mental well-being.

Discussion

Using the APIM dyadic analysis, we found that sleep disturbance in patients and their caregivers had negative association with their own physical and mental well-being QoL. As sleep disturbance increased, an individual's own physical and mental well-being aspects tended to be poorer. This finding is consistent with the results of previous studies of similarly aged married couples⁸³ and in individual patients with HF.^{17,50-52} Strawbridge, Shema, and Roberts⁸³ found that sleep problem put individuals themselves at risk for having poor physical and mental health. Manocchials, Keller, and War⁵² in sample of 229 patients with HF found significant differences in all aspects of QoL using the short form SF-36 between patients with and patients without sleep problems. Subjectively measured sleep was shown to have strong associations with the physical and the mental well-being aspects of QoL.⁵¹ Johansson et al¹⁷ found that the physical well-being was predicted by having difficulties in maintaining sleep and that the mental well-being was predicted by non-restful sleep. The association is also consistent with the findings at individual level in caregivers of patients with breast cancer,⁶⁶ malignant brain

tumors,⁵⁶ and Alzheimer diseases.⁵⁴ In these studies, the poor sleep scores were negatively correlated with the domains of the general QoL^{56,66} and with the physical and mental well-being aspects of QoL.⁵⁴

This relationship was also evident in a study by Redeker and Hilker⁵⁰ who objectively measured sleep duration and continuity using an electronic accelerometer (i.e., Actiwatch atigraph) in 61 patients with stable HF with reduced ejection fraction. They found that total awakening time after sleep onset was a significant predictor of physical function (i.e., SF-36) after controlling for covariates of age, gender, comorbidity, and New York Heart Association class and the duration of awakening bouts after the onset of sleep was significantly associated with the mental well-being.

There is no clear evidence explanation of the mechanism how sleep disturbance may influence QoL at individual level. Sleep disturbance is known to be associated with fatigue⁹³ and inadequate self-care behavior⁹⁴ that may influence the QoL. Riegel and Weaver³⁸ proposed that the effect of sleep problems on QoL is mainly through the effect on individuals' cognitive abilities, that in turn affect self-care and ultimately the QoL.³⁸ In the patient-caregiver dyad, we found that individual's sleep disturbance was not associated with their partner's physical well-being. This finding indicates that patients were shown to be couple-oriented as their mental well-being was influenced by their sleep disturbance as well as their spousal caregivers sleep disturbance and caregivers shown to be actor-oriented (i.e. possessed only actor effect).⁹⁵

An important finding of this study was that caregivers' sleep disturbance negatively associated with patients' mental well-being while sleep disturbance in patients had no association with caregivers' mental well-being. This indicates that the mental

well-being of patients with HF may be influenced negatively by sleep disturbance in their caregivers. In the mental well-being analysis, caregivers shown to be actor-oriented (i.e. possessed only actor effect).⁹⁵ Patients were shown to be couple-oriented as their mental well-being was influenced by their sleep disturbance as well as their spousal caregivers sleep disturbance.⁹⁵

Consistent with our study, Strawbridge, Shema, and Roberts⁸³ in a study of similarly aged married couples, found that spousal sleep problems put the partner at risk for having poor mental health. The odds ratio (OR) for having depressed mood if the spouse had sleep problems was 1.15 (95% CI 1.02-1.30) and 1.23 (95% CI 1.08-1.39) for reporting poor or fair mental health. In physical health, spouses sleep problems were not significantly associated with partner feelings of having less energy than others own age or feelings of being physically disabled. But, inconsistent with our study, they found that spouses sleeping problems were associated with partners reporting that their physical health as fair or poor (OR= 1.16, 95% CI 1.02-1.31). However, physical health was measured by one item asking for self-rating of general health not specifically the physical health. Thus, ratings may reflect all aspects of the health, not only the physical.

This is the first study to examine this relationship at dyad level and so the mechanism by which sleep disturbance in the caregivers may affect the patients' mental well-being aspect of QoL has not been explained. One potential hypothesis is that sleep disturbance decreases the ability of caregivers to support to their patient family member especially to provide psychological support.

Similar effects have been found in other aspects of patients with HF-caregiver dyads. Vellone et al⁹⁶ used dyadic analysis to examine the influence of self-care on

physical and mental aspects of QoL in patients with HF and their spousal caregivers. They found that higher caregivers' self-care confidence was associated with a decrease in physical well-being in patients and that higher patients' self-care maintenance was associated with decrease in mental well-being of caregivers. Chung, Moser, Lennie, and Rayens⁵⁹ found that depression and anxiety in caregivers was associated with patients' poor QoL measured using the Minnesota Living with Heart Failure Questionnaire.

Our study has many strengths including that it was the first study to examine the association between sleep disturbance and QoL at dyad level and used the APIM dyadic approach. The study has also some limitations. First, although we created a score of sleep disturbance using multiple aspects of sleep disturbance and provided some reliability testing, it was not a well-established measure of sleep disturbance. Second, self-reports of sleep disturbance are not consistently correlated with objective measures of sleep.^{97,98} However, the purpose of the study was to determine the relationships of participants' perceptions of their sleep to QoL. Third, several aspects of sample may limit the conclusions that can be drawn. The sample was limited to the patient-spouse caregiver dyads living at the same home and the quality of relationship between dyad members was unknown. It is also unknown whether patients and spouse shared a bedroom. Further, the sample consisted of stable community-dwelling patients with stable HF and their caregivers and the majority of subjects were Caucasians. This sample selection may be biased and may not reflect HF population. Additional research is needed with a broader sample of patient-caregiver dyads.

Fourth, this was a cross-sectional study which prevents the establishment of the causality in these relationships. Finally, other characteristics and clinical variables in

patients and caregivers that have shown associations with QoL were not controlled in this analysis. These characteristics include age, gender, depression, anxiety, marital quality, social support, perceived control level, functional status, comorbid conditions, patients New York Heart Association class, and caregiving burden level.⁹⁹⁻¹⁰⁵ Future studies need to focus on how these characteristics influence these relationships.

Several implications can be derived from the findings of this study. It provided more evidence that patients and their caregivers have interdependent relationships that influence each other's outcomes. Therefore, healthcare professionals should assess for sleep disturbance in both patients and caregivers. The design of interventions targeting improving patients' QoL through sleep improvement may need to be reformed to involve both members of the dyad.

Implications for research include a focus on dyadic approach in regards to QoL in patients with HF and their caregivers. In addition, more studies are in need to focus on the long-term effect of sleep disturbance on dyads' outcomes. Further, studies are needed to examine how other variables such as gender and age are related to the associations between patients and their spousal caregivers and to determine why patients', but not caregivers', mental well-being was sensitive to their partner's sleep disturbance.

Conclusion

This study demonstrated the interdependence between patients with HF and their spousal caregivers and how each individual's sleep disturbance affect their partner's outcomes. In this study, the actor effect of sleep disturbance in members of the dyad on their physical and mental well-being is evident. In addition, sleep disturbance in caregivers exhibited partner effect on mental well-being of patients. These findings

suggest that dyads of patients with HF and their spousal caregivers may benefit from interventions targeting improving sleep disturbance in both of them, as a mean of improving of the physical and the mental well-being. Caregivers should receive same attention as patients and both patients and their caregivers may have to be included in interventions targeting improving QoL and sleep disturbance.

Table 2.1. Characteristics and comparisons between patients and caregivers.

Characteristics	Patients (n=78)	Caregivers (n=78)	p-value
	Mean±SD or n (%)	Mean±SD or n (%)	
Gender, female	20 (25.6)	58 (74.4)	<.001
Age, years	62.2 ±12.4	59.53 ±12.3	<.001
Ethnicity,			
Caucasian	73 (93.6)	75 (96.2)	.719
Others	5 (6.4)	3 (3.8)	
Education,			
≤ high school	34 (43.6)	39 (50)	.661
> high school	44 (56.4)	39 (50)	
New York Heart Association class,			
I- II	43 (55.1)	-	-
III- IV	35 (44.9)	-	
Comorbidity score	3.0 ±1.7	1.3 ±1.8	<.001
Comorbidity score			
None	4 (5.3)	38 (48.7)	<.001

Table 2.1. (Continued)

1 - 3	45 (59.2)	33 (42.3)	
> 3	27 (35.5)	7 (9)	
History of Hypertension	56 (77.8)	38 (44.7)	<.001
History of Diabetes	33 (42.3)	19 (24.4)	.027
History of Stroke/ TIA	14 (18.2)	5 (6.4)	.047
History of chronic lung disease	15 (19.5)	5 (6.4)	.029

SD= Standard deviation

Table 2.2. Comparison between patients and caregivers on variables of sleep disturbance, physical well-being, and mental well-being.

Measure	Patients (n=78)		Caregivers (n=78)		Paired t test	p-value
	Range	Mean±SD	Range	Mean±SD		
Sleep Disturbance	0 - 91.67	38.14±25.4	0- 91.67	36.16±23.8	.558	.579
QoL,						
Physical well-being	11.88 - 57.9	35.3±10.56	20.5 - 64.4	44.17±11.08	-6.303	<.001
Mental well-being	23.2-72.8	51.6±10.5	25.66 - 67.1	49.84±10.5	1.278	.205

SD= Standard deviation

Table 2.3. Correlations among sleep disturbance, physical well-being, and mental well-being in patient-caregiver dyads.

	1	2	3	4	5
1 Patient sleep disturbance	-				
2 Caregiver sleep disturbance	.194	-			
3 Patient physical well-being	-.201	.013	-		
4 Caregiver physical well-being	-.085	-.377**	.341**	-	
5 Patient mental well-being	-.436**	-.326**	.119	.266*	-
6 Caregiver mental well-being	-.147	-.706**	.130	.199	.303**

* p<.05, ** P<.01

Table 2.4. The APIM representing the actor and partner effect of sleep disturbance on physical and mental well-being of quality of life.

	Patients				Caregivers			
	B	β	t	p-value	B	β	t	p-value
Physical well-being								
Actor effect	-.119	-2.89	-2.42	.018	-.203	-4.94	-4.02	<.001
Partner effect	.061	1.52	1.21	.231	-.006	-.158	-.136	.892
Mental well-being								
Actor effect	-.186	-4.54	-4.38	<.001	-.271	-6.62	-7.16	<.001
Partner effect	-.088	-2.19	-2.02	.046	-.027	-.66	-.758	.451

B: the unstandardized coefficients, β : standardized coefficients, t: t test value

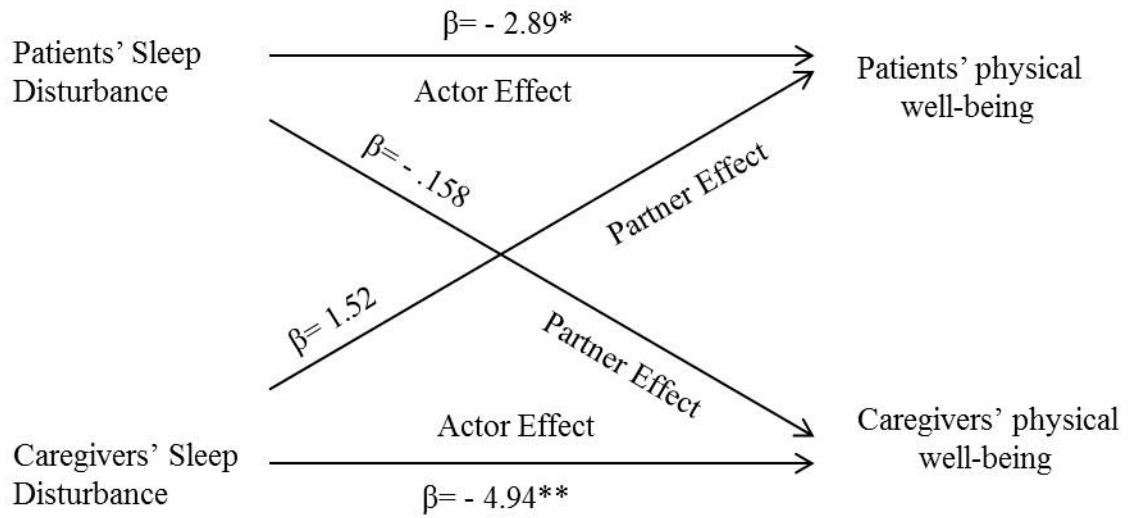


Figure 2.1. Sleep disturbance: The actor and partner effects as predictors of physical well-being using the Actor-Partner Interdependence Model with distinguishable dyads regression model.

* $p < .05$; *** $p < .001$

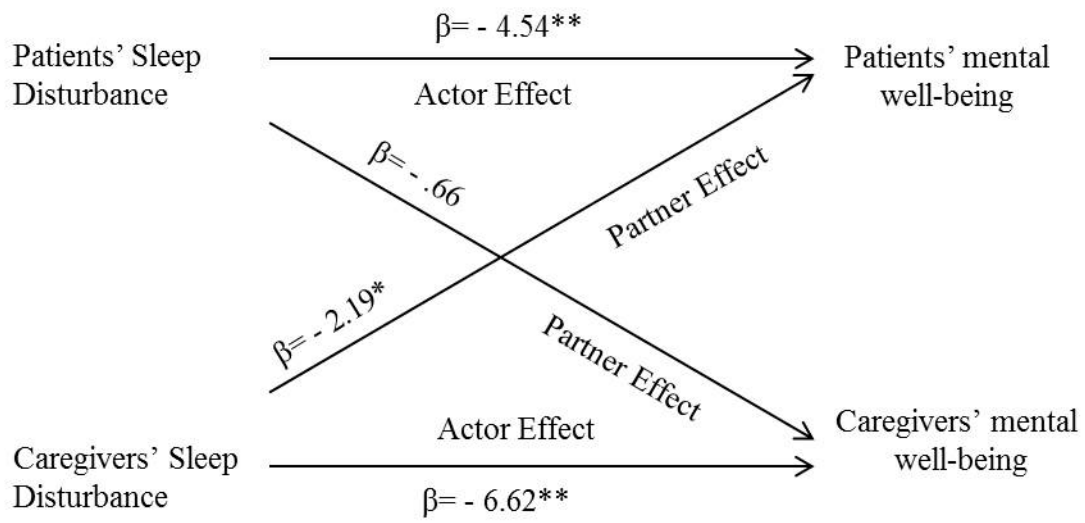


Figure 2.2. Sleep disturbance: The actor and partner effects as predictors of mental well-being using the Actor-Partner Interdependence Model with distinguishable dyads regression model.

* $p < .05$; *** $p < .001$

CHAPTER THREE

Does Depression Mediate the Relationship between Sleep Disturbance and Quality of Life in Patients with Heart Failure and their Family Caregivers?

Introduction

Sleep disturbance defined as having problems in aspects of sleep¹⁶ is prevalent in patients with heart failure (HF)¹⁷ and family caregivers.^{29,65} Problems in sleep initiation, early awaking, and going back to sleep are common and reported by up to about 75% of patients with HF.^{19,20} In family caregivers, high percentage also reported problems related to their sleep.^{33,36} Poor quality of life (QoL) is a common feature of HF,¹⁷ commonly reported by their family caregivers,⁴⁶ and known to be predicted by sleep disturbance in patients with HF¹⁷ and caregivers.⁵⁵

Depression is prevalent in patients with HF⁶² and family caregivers.⁶⁵ It was also identified as predictor of poor QoL in patients with HF¹⁰² and family caregivers.¹⁰⁶ Sleep disturbances and depression have a very close relationship. Sleep disturbance was identified as a predictor for developing depressive symptoms in longitudinal epidemiological study of 1200 adults aged 21-30 years randomly selected from a health maintenance organization.⁶⁷ At the 3.5 years follow-up, after adjusting for gender, the odds ratio (OR) for developing major depression among individuals with history of insomnia (the most common form of sleep disturbance) was 3.95 (95% CI 2.2-7.0).⁶⁷ This relationship was also evident in an epidemiological study of 7954 individuals from the community interviewed at baseline and a year later.⁶⁸ Participants who reported insomnia at both interviews were at higher risk for developing major depression than those who did not report insomnia at either interview (OR= 39.8, 95% CI 19.8-80). For those who

reported insomnia at the second interview only, the odds ratio for developing new major depression a year later was similar (OR =35, 95% CI 21-59).⁶⁸ For participants who had insomnia only at the baseline, the odds ratio for developing new major depression a year later was 1.6 (95% CI .5-5.3).⁶⁸

Additionally, sleep disturbance has been strongly linked to recurrence of depression.¹⁰⁷ Moreover, findings from previous interventional studies aimed improving sleep in different populations of caregivers suggested that sleep disturbance may be the cause of depression. Although, the main component of these interventions was focused on behavioral aspects of sleep including sleep hygiene, stimulus control, and relaxation therapies, findings of these studies indicated that sleep may improve with¹⁰⁸ or without improvements in depressive symptoms¹⁰⁹ and when there was no improvement in sleep, it was usually accompanied by no improvements in depressive symptoms as well.^{110,111}

Thus, there is high possibility that depressive symptoms levels may mediate the relationship between sleep disturbance and different aspects of QoL but this assumption has not been examined in patients with HF or their family caregivers. Accordingly, the specific aim of this study was to examine whether depressive symptoms mediate the relationship between sleep disturbance and QoL in patients and their family caregivers. We hypothesized that the influence of sleep disturbance on QoL would be through the depressive symptoms.

Research Design and Method

Design, Sample, and Setting

This study was a secondary analysis of the baseline data of a longitudinal study that involved stable community dwelling patients with HF on stable on HF medications

and their family caregivers. Patients with HF and their identified primary family caregivers for the parent study were recruited from outpatient clinics in two community hospitals and an academic medical center in Central Kentucky. Patients were excluded if they had a history of acute myocardial infarction or hospitalization in the prior 3 months, had a terminal illness or were receiving active treatment for cancer, or referred for heart transplantation. Caregivers were excluded if they had cognitive impairment, HF, cancer, terminal illnesses or any major comorbid condition, or if their patients were ineligible for the study. The parent study had 143 pairs of patients and their caregivers aged 18 years or more who were able to read, write, and speak English to be included in the study. Participants were included in this secondary analysis if they did not have any missing data on main study variables (patients n=114 and caregivers n=116).

Procedures

After obtaining the approval from the Institutional Review Board and the informed consent from patients and caregivers, subjects were asked to complete self-report questionnaires. In addition, a research nurse used a structured questionnaire, a brief interview, and reviewed medical charts to obtain clinical data.

Measures

Sleep disturbance. Sleep disturbance score was computed using 4 items related to common complaints related to sleep among patients and caregivers^{19,21,86,87} that are the main components of sleep disturbance scales.⁸⁸⁻⁹⁰ Those items included 1) changes in sleep pattern, 2) difficulty sleeping because of HF, 3) trouble falling asleep, staying asleep, or sleeping too much, and 4) restfulness of sleep. Those items were taken from self-reported survey questionnaires of the Beck Depression Inventory II (BDI-II), Patient

Health Questionnaire-9 (PHQ-9), the Minnesota Living with Heart Failure Questionnaire (MLHFQ), and a question added by the researcher and it was asking about restfulness of sleep. The original responses of the change in sleep pattern item (0-6 on a Likert scale) were grouped into categories of 0 – 3; 0, 1 and 2, 3 and 4, and 5 and 6 and then given scores of 0, 33.33, 66.66, and 100 respectively. Difficulty in sleeping that was originally rated on a scale of 0 (no difficulty) to 5 (very much difficulty) were converted into scores of 0, 20, 40, 60, 80, and 100 respectively. Having a trouble falling asleep, staying asleep, or sleeping too much was rated on a scale of 0 (not at all) to 3 (nearly every day) were converted into scores of 0, 33.33, 66.66, and 100 respectively. Having complaints regarding restfulness of sleep was rated on 1 (very rested) to 3 (not rested at all) and the responses were recoded into scores of 0, 50, and 100 respectively. Then the average of the scores of the four items was calculated. The average ranges between 0-100, with higher scores indicating higher level of sleep disturbance.

The scale Cronbach's alpha was 0.78 for patients and 0.77 for caregivers. Item-item correlations ranged between .33 and .57 for patients and between .28 and .59 for caregivers. All item-item correlations were positively correlated (all p values were $<.01$).

Depressive symptoms. The Brief Symptom Inventory (BSI) depressive symptoms subscale was used to measure depressive symptoms. The subscale is composed of six items. Items rated on 5-point rating scale from 0 (not at all) to 4 (extremely). The total scores calculated by averaging of the six responses and high scores indicate high levels of depressive symptoms.¹¹² The BSI depression subscale reliability alpha was .85.¹¹² It is a normative a scale with non-patients individuals had a mean of 0.28 ± 0.41 .¹¹² Its construct and convergent validity have been established.¹¹² In this study, depressive symptoms

subscale had internal consistency reliability alpha of .91 for patients and .89 for their family caregivers.

Quality of life (QoL). QoL was assessed using the physical and the mental well-being of the Short-Form 12 Health Survey (SF-12) is used to measure QoL.⁹¹ The scores of the physical and the mental well-being ranged between 0 and 100, with higher scores indicating better physical or mental well-being aspect of QoL.⁹² The SF-12 was developed from the Medical Outcome Study health survey short form Short-Form-36.⁹¹ It had a good reliability among patients with heart and stroke disease⁹² and in adults.⁹¹ Its construct validity was provided among heart and stroke patients.⁹²

Data Analysis

Data analysis was begun with descriptive statistics of all study variables as appropriate to the level of measurement. The Statistical Package for the Social Sciences version 21 (SPSS v21 Inc., Chicago, IL) was used for the analyses and we set the significance level at 0.05. Four steps of multiple regression analyses outlined by Baron and Kenny⁷⁰ were used to test for mediation (Table 3.1). We calculated the indirect effect and Sobel's test (Z-scores) to determine the significance of the mediation as described in Baron and Kenny⁷⁰ and Joes 2013.¹¹³ Because the sample size was relatively small and the estimated indirect effect is usually not normally distributed,^{113,114} we used the bootstrapping resampling method (5000 samples) using SPSS PROCESS software developed and described by Hayes¹¹⁵ in calculating total, direct, and indirect effect and its 95% confidence level and significance level. The Sobel's test and its significance level were completely congruent using the two methods so we are reporting only the bootstrapping results. Thus, we are reporting in this paper the results of regression

analyses using Baron and Kenny's steps and the results of the total, direct, indirect, and Sobel's test using the PROCESS procedure.

Results

Characteristics of the sample

Slightly more than one-third of patients and two-thirds of caregivers were female. Mean age for patients was 61.5 years and for caregivers was 56.1 years. Most of the patients and caregivers were married /cohabitated and Caucasians. Slightly more than the half of the patients were New York Heart Association class III or IV. Other characteristics of the sample including clinical variables are presented on Table 3.2.

Mediator effect of depressive symptoms on the association between sleep disturbance and physical well-being

Patients

As shown on Table 3.3, patient's sleep disturbance and depressive symptoms significantly predicted physical well-being and sleep disturbance also significantly predicted depressive symptoms. Thus, the first three paths (A, B, C) outlined by Baron and Kenny's model were met. However, in path D, sleep disturbance remained a significant predictor of physical well-being but the proposed mediator of depressive symptoms became non-significant. The total, direct, indirect, and Sobel's test are presented in Table 3.4. The Sobel's test for mediating effect (i.e., the indirect effect) was not significant ($p=.519$)

Caregivers

Caregiver's sleep disturbance significantly predicted the physical well-being (path A, Table 3.3) and depressive symptoms (path B). Caregivers' depressive symptoms

significantly predicted their physical well-being (path C). When both sleep disturbance and depressive symptoms included in the model, both approached but did not reached the significance level (p .054 and .064, respectively). Sobel's test was not significant ($p=.0685$, Table 3.4).

Mediator effect of depressive symptoms on the association between sleep disturbance and mental well-being

Patients

The first three paths of Baron and Kenny's model were met (all p values were $< .05$) in the analyses for examining the mediation for patients' mental well-being (Table 3.3). When both sleep disturbance and depressive symptoms entered in the model, the standardized (β) coefficients for sleep disturbance were decreased in path D compared to its value in path A. The ratio of indirect effect to the total effect was .5043 indicating that about half of the total effect was indirect through depressive symptoms and the Sobel's test demonstrated that this mediation effect is significant (Table 3.4).

Caregivers

For caregivers, we found similar findings as in patients. When both sleep disturbance and depressive symptoms were in the model, both sleep disturbance and depressive symptoms remained significant predictors of the mental well-being (Table 3.3). The standardized (β) coefficient for sleep disturbance was decreased in path D compared to its value in path A. The ratio of indirect effect to the total effect was .3663 indicating that about 36.6% of the total effect was indirect through depressive symptoms and the Sobel's test demonstrated that this mediation effect was significant (Table 3.4).

Discussion

We sought to increase our understanding of the relationship between sleep disturbance and QoL by examining whether depressive symptoms mediated the relationship between sleep disturbance and the physical and mental well-being aspects of QoL in patients with HF and their family caregivers. The major findings of this study were that depressive symptoms were significant mediator of the relationship between sleep disturbance and the mental well-being in both patients and their family caregivers, as hypothesized. We found only one other study in which the mediation effect of depressive symptoms on the relationship between sleep disturbance and quality of life was examined. Cupidi et al.⁵³ investigated the relationship between sleep disturbance and mental well-being among caregivers of patients with Alzheimer's disease and Parkinson's disease. Consistent with our findings, they reported a mediator effect of depressive symptoms on the relationship between sleep disturbance (a subscale of the Pittsburgh Sleep Quality Index) and the psychological aspect of QoL in caregivers (McGill Quality of Life Questionnaire). However, Cupidi et al. did not test the mediation effect of the depressive symptoms in patients, so it was not possible to compare the consistency with our findings related to patients.

In our study, the relationship between sleep disturbance and physical well-being in patients and caregivers was not mediated by depressive symptoms. Previous studies also showed a direct relationship between sleep disturbance and poor physical well-being at individual level in both patients with HF^{21,50} and caregivers.^{55,66} Thus, treating sleep disturbance may be very important in improving the physical well-being in patients with HF and family caregivers.

This study has significant implications for clinical practice and research. There is substantial evidence that sleep disturbance and depressive symptoms influence QoL of patients with HF and family caregivers, but the main findings in this study enhanced our understanding of the association between sleep disturbance and QoL by showing depressive symptoms mediate this relationship. To date, a few interventions have been tested to improve QoL through improving sleep. The interventions targeting sleep in patients with HF focused on improving sleep-disordered breathing mainly through use the continuous positive airway pressure (CPAP)¹¹⁶ or oxygen therapy.¹¹⁷ However, these interventions were not effective to improve QoL. Cognitive and behavioral therapies^{108,110} and exercises¹¹⁸ interventions showed improvement in some sleep outcomes but the effect of these interventions on QoL was equivocal. Our findings suggest depressive symptoms may also need to be targeted when designing interventions aimed improving QoL through improving sleep quality. Consequently, clinicians should assess patients with HF and their family caregivers sleep disturbance and level of depressive symptoms. Researchers should examine the relationships among these variables in conjunction with other covariates to provide a fuller understanding of their interactive effects and to develop comprehensive interventions.

A few limitations might affect the generalizability of the findings from this study. First, the cross-sectional data do not allow for the inferences of the causality among the examined variables. Second, sleep disturbance was not measured by a standardized scale in the dataset, consequently scores were computed based on four sleep- related items from depressive symptoms measurement scales (two items) and one was taken from a QoL measure, the Minnesota Living with Heart Failure Questionnaire (MLHFQ). These

items were chosen because they measure our conceptual definition of sleep disturbance. To avoid potential confounds with measurement of depressive symptoms and QoL, depressive symptoms in this study were measured using the depressive symptom subscale of the Brief Symptom Inventory which has no items related to sleep disturbance and QoL was measured using the SF-12 t which has no items related to sleep disturbance. Finally, we suggest more complex model testing including other factors such as age,^{51,119} gender,¹⁰³ marital status and living arrangement,^{105,120} and caregiving burden¹⁰⁶ known to have associations with the outcome variables. Inclusion of these covariates in future studies will provide additional insight to these relationships.

Conclusion

Sleep disturbance and depressive symptoms had a negative association with both aspects of QoL in patients and their family caregivers. In this sample of patients and caregivers, sleep disturbance relationship to mental well-being aspect of QoL was shown to be a partially mediated by the depressive symptoms. Thus, the influence of sleep disturbance on the mental well-being was partially through depressive symptoms. The influence of sleep disturbance on the physical well-being was mainly direct but not through depressive symptoms. Health care providers should regularly assess patients with HF and family caregivers for sleep disturbance and depressive symptoms. The results suggested that improving QoL especially the mental aspect may be more efficient if the depressive symptoms are assessed and managed.

Table 3.1. Steps for testing for mediation effect.

Model	Step	Path
1	Test whether level of sleep disturbance significantly predicted QoL (either physical or mental well-being)	A
2	Test whether level of sleep disturbance significantly predicted depressive symptoms	B
3	Test whether level depressive symptoms significantly predicted QoL	C
4	Test whether level of sleep disturbance and depressive symptoms significantly predicted QoL	D
5	Calculate the indirect effect and Sobel's test	

Table 3.2. The sample characteristics.

Characteristic*	Patients	Caregivers
Gender, Female	44 (38.6)	83 (71.6)
Age, years	61.54 ±12.78	56.15 ±14.28
Marital Status		
Married/ Cohabitant	93 (81.6)	95 (81.9)
Single/widow/divorced/separated	21 (18.4)	21 (18.1)
Ethnicity,		
Caucasian	104 (91.2)	105 (90.5)
Others	10 (8.8)	11 (9.5)
Education,		
≤ high school	58(50.9)	67 (57.8)
> high school	56 (49.1)	49 (42.2)
Relationship to patient		
Spouse	--	87 (75)
Others	--	29 (25)

Table 3.2. (Continued)

Comorbidity score,		
None	8 (7.0)	60 (51.7)
1 - 3	61 (53.5)	49 (42.2)
>3	45 (39.5)	7 (6.0)
NYHA, I - II class	53 (46.5)	--
NYHA, III - IV class	61 (53.5)	-
History of Hypertension	83 (76.9)	50 (34.1)
History of Diabetes	19 (16.8)	25 (21.6)
History of Stroke/ TIA	22 (19.5)	5 (4.3)
History of chronic lung disease	52 (46)	6 (5.2)
Taking Antidepressant †	15 (17.8)	10 (11.2)
Sleep Disturbance	41.7 ±25.1	34.7 ±23.83
Depressive symptoms	.71 ±.87	.828 ±1.1
Physical well-being	33.5 ±9.95	43.7 ±10.81
Mental well-being	50.23 ±11.03	49.93 ±10.44

*: results presented as mean ±SD or n (%), NYHA: New York Heart Association, †:n= 101 patients and 89 caregivers.

Table 3.3. Regression analyses results for testing depressive symptoms mediating effect in patients and caregivers.

Path	Independent variable	Outcome variable	Model P-value	R ²	B	SE	β	Part correlation	P
Physical well-being									
Patients									
A	Sleep disturbance	Physical well-being	.001	.098	-.124	.036	-.312	-.312	.001
B	Sleep disturbance	Depressive symptoms	< .001	.207	.016	.003	.455	.455	< .001
C	Depressive symptoms	Physical well-being	.038	.038	-2.226	1.058	-.195	-.195	.038
D	Sleep disturbance	Physical well-being	.003	.101	-.112	.04	-.282	-.251	.006
	Depressive symptoms				-.762	1.154	-.067	-.059	.510
Caregivers									
A	Sleep disturbance	Physical well-being	< .001	.133	-.166	.04	-.365	-.365	< .001
B	Sleep disturbance	Depressive symptoms	< .001	.434	.026	.003	.659	.659	< .001
C	Depressive symptoms	Physical well-being	< .001	.131	-4.232	1.00	-.362	-.362	< .001
D	Sleep disturbance	Physical well-being	< .001	.159	-.102	.052	-.224	-.180	.054
	Depressive symptoms				-2.507	1.342	-.214	-.173	.064

Table 3.3. (Continued)

Mental well-being

Patients									
A	Sleep disturbance	Mental well-being	< .001	.262	-.225	.036	-.512	-.512	< .001
B	Sleep disturbance	Depressive symptoms	< .001	.207	.016	.003	.455	.455	< .001
C	Depressive symptoms	Mental well-being	< .001	.467	-8.649	.873	-.684	-.684	< .001
D	Sleep disturbance	Mental well-being	< .001	.518	-.112	.033	-.254	-.226	.001
	Depressive symptoms				-7.188	.936	-.568	-.506	< .001
Caregivers									
A	Sleep disturbance	Mental well-being	< .001	.500	-.310	.029	-.707	-.707	< .001
B	Sleep disturbance	Depressive symptoms	< .001	.434	.026	.003	.659	.659	< .001
C	Depressive symptoms	Mental well-being	< .001	.473	-7.775	.768	-.688	-.688	< .001
D	Sleep disturbance	Mental well-being	< .001	.587	-.196	.035	-.448	-.464	< .001
	Depressive symptoms				-4.44	.908	-.393	-.418	< .001

B: unstandardized coefficient; SE: standard error of the coefficient; β : standardized coefficient.

Table 3.4. Total, direct, and indirect effect size measurements and Sobel's tests with Bootstrapping.

Effect	Physical well-being				Mental well-being			
	Patients		Caregivers		Patients		Caregivers	
	Effect	95% CI*	Effect	95% CI*	Effect	95% CI*	Effect	95% CI*
Total	-.1239	-.194 to -.053	-.1655	-.2439 to -.0872	-.2251	-.2958 to -.1545	-.3096	-.3671 to -.2521
Direct	-.1118	-.191 to -.032	-.1015	-.2046 to .0016	-.1116	-.1760 to -.0472	-.1962	-.2659 to -.1264
Indirect	-.012	-.048 to .0277	-.0640	-.133 to -.0002	-.1135	-.1785 to -.0645	-.1134	-.1703 to -.0674
Ratio indirect to total	.1076	-.185 to .996	.3868	-.0011 to .9869	.5043	-.191 to -.0324	.3663	.2082 to .5573
Sobel test	-.6449		-1.8215		-4.395		-4.313	
<i>P</i> -value	.519		.0685		<.001		<.001	

*: CI: confidence interval

CHAPTER FOUR

Psychometrics of the Zarit Burden Interview in Caregivers of Patients with Heart Failure

Introduction

Self-care in heart failure (HF) is an essential part of the treatment plan. As HF progresses, greater levels of self-care are required from patients and often necessitating more assistance from their family member caregivers. Caregivers of patients with HF have reported burden associated with their caregiving responsibility.¹²¹⁻¹²³ Family members' experiences of physical, psychological or emotional, social, and financial problems due to caring for an ill family member is defined as caregiving burden.¹²⁴ Caregiver's burden has been shown to be associated with caregivers' depression and poor quality of life (QoL) as well as patients' poor outcomes including poor QoL, hospitalization and death.⁶⁹

Quantifying family caregivers' burden using a valid and reliable instrument is vital for identifying caregivers with high burden to prevent the poor outcomes associated with caregiving. Among the scales available to assess caregiving burden, the Zarit Burden Interview (ZBI) is one of the most commonly used in clinical and research settings. The ZBI was originally developed to assess burden among caregivers of community-dwelling persons with dementia.^{71,72} The psychometric properties of the ZBI have been primarily reported in caregivers of patients with dementia. Recently, the ZBI has been used to assess burden of caregivers who take care of patients with cardiovascular diseases, especially caregivers of patients with HF.^{69,125-127} However, the only psychometric property of the ZBI reported in this population is the Cronbach's alpha. The Cronbach's alpha was reported as 0.88 in a very small sample size of 23¹²⁸

and as 0.93 in 102 caregivers of patients with HF.¹²⁶ Therefore, the purpose of this study was to examine the reliability and validity of the ZBI in caregivers of patients with HF.

We examined internal consistency reliability using Cronbach's alpha (reliability α) and item-total and item-item correlations. Convergent validity was tested with a criterion, the Oberst Caregiving Burden Scale (OCBS). Evidence of construct validity was provided through factor analysis and hypothesis testing. Exploratory factor analysis was used to determine the dimensionality of the ZBI. Although the ZBI was developed as a unidimensional scale, recently researchers reported it as a multidimensional scale.^{73-77,129} We tested the hypothesis that caregivers with high burden scores ($ZBI \geq 17$) will have higher depressive symptoms scores than caregivers with lower burden scores. This hypothesis was based on previous findings that caregiving burden and depression were positively correlated in caregivers of patients with HF and other diseases.^{69,75,130}

Methods

Design, Sample and Setting

This study used the baseline data of a longitudinal study involving both patients and caregivers that investigated the effect of family caregivers' emotional distress on outcomes in patients with HF. Patients were referred by nurses and physicians from outpatient clinics from two community hospitals and an academic medical center in Central Kentucky. Eligible patients and their primary family caregivers were invited to participate in the study. Patients were eligible if they had a confirmed diagnosis of chronic HF, were on stable doses of HF medications, were not receiving active treatment for cancer, and did not have terminal illnesses, history of acute myocardial infarction or hospital admission in the prior three months, and were not referred for heart

transplantation. Caregivers were eligible if they had no major comorbid condition such as HF, cancer, or terminal illnesses. Caregivers were excluded if they had difficulty understanding the study or if they had dementia or Alzheimer's disease. All participants had to be more than 18 years old and able to read, write, and speak English.

Procedures

Approval for the parent study was obtained from the Institutional Review Board prior to data collection. Following referral, researchers approached eligible caregivers and patients in the outpatient clinics or contacted them by telephone. After getting informed consent, participants were provided with questionnaires to complete that were returned in a provided stamped and addressed envelope.

Measures

The Zarit Burden Interview (ZBI). The ZBI consists of 22 items rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly always) with the sum of scores ranging between 0-88.⁷² Higher score on the ZBI indicate more severe burden. A score of 17 or more is considered high burden.⁷² The ZBI was reported to have more than two dimensions including personal strain, role strain, impact of caregiving on caregivers' lives, frustration/ embarrassment/ anger, patient's dependency, feeling of guilt, and self-criticism. Although other versions of the ZBI are available, including the abbreviated 4-item and 12-item versions,⁷² the 22-item version of the ZBI is recommended for use in research and clinical settings, in part because it has been shown to have the most reliable responses compared to other versions.⁷¹ The ZBI's psychometric properties were extensively examined in caregivers of patients with dementia⁷³⁻⁷⁸ and has been shown to be reliable and valid as a measure of caregiving burden in that population.⁷² It was also

examined in caregivers of patients with cancer¹³¹ and brain injury.¹³² The reported Cronbach's alpha for the ZBI ranged between .85 and .93.^{74-78,131} The evidence for the ZBI criterion validity has been provided in caregivers of patients with dementia by being highly correlated ($r = 0.73$, $P < 0.0001$) with the Burden Assessment Scale.⁷⁸ Evidence of ZBI construct validity was provided by being highly correlated with General Health Questionnaire-28; as measure of distress.⁷⁸

The Oberst Caregiving Burden Scale (OCBS). The OCBS has two subscales that measure caregivers' perceived amount of the time spent and perceived difficulty associated with caregiving tasks provided to family members. The original OCBS consisted of 15 items to assess burden among caregivers of stroke survivors.¹³³ A modified version with 17 items (only the perceived difficulty of caregiving tasks subscale was modified) has been used with caregivers of patients with HF¹¹ to improve the ability of the scale to better identify the difficulties faced by this caregivers population.¹³⁴ The 17-item version includes the original 14 items and an item regarding difficult behaviors was revised into 3 items. Items added were related to the behaviors of 1) moodiness and irritability, 2) loss of memory, concentration, and attention, and 3) confusion, disorientation, or dementia.¹¹ The Cronbach's alpha for the perceived difficulty of the 17-item version was .92.¹¹ In this study, we used the 17 items version (both subscales) and added an item about managing dietary needs in HF management for both the difficulty and the time subscales. The scale items are rated on five points scales to indicate the amount of time spent (1 = none to 5 = a great amount) and the level of difficulty (1 = not difficult to 5 = extremely difficult) for each task. Each subscale score is calculated by summing the responses of the time spent and the level of difficulty of each task (18

tasks). Higher scores indicate greater time or difficulty of the task.¹³³ Evidence for the 15-item OCBS reliability and validity were provided in a study of caregivers of patients with stroke. Cronbach's alpha for the time subscale was 0.90 and for the difficulty subscale was 0.94.¹³³ The internal consistency reliability of the difficulty subscale of the 17-item OCBS was 0.92 in a sample of 21 caregivers of patients with HF.¹¹ In this study, Cronbach's alpha was 0.92 for the time subscale and .89 for the difficulty subscale.

Patient Health Questionnaire (PHQ-9). We assessed the caregivers' depressive symptoms with the PHQ-9 for hypothesis testing. The PHQ-9 is a self-administered questionnaire in which severity of the depressive symptoms in the previous two week are rated. The nine items were based on criteria for diagnosis of depression in Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV).¹³⁵ Each item is rated on a 4-point scale: 0 "not at all", 1 "several days", 2 "more than half the days", and 3 "nearly every day" The scores range between 0 and 27 with higher scores indicate higher levels of depressive symptoms.^{135,136} Construct and criterion validity were supported in a sample of 6000 patients in eight primary care and seven obstetrics–gynecology clinics.¹³⁵ Internal consistency reliability Cronbach's alpha was .89 in primary care clinics and .86 in obstetrics–gynecology clinics with test-retest reliability of 0.84.¹³⁵ Construct validity also was supported in the general population of 2066 subjects with an age range of 14 to 93 years.¹³⁷ In this study, the Cronbach's Alpha of the PHQ-9 was 0.91.

Data Management and Analysis

All data analyses were performed using the Statistical Package for the Social Sciences version 20 (SPSS Inc., Chicago, IL) and the 0.05 was chosen as significance level prior to analyses. Data were examined, verified, and cleaned prior to analysis.

Reliability. Internal consistency reliability was assessed by Cronbach's alpha coefficient using the 22 items. A coefficient of greater than 0.70 was considered indicative of acceptable internal consistency. Item-total and item-item correlations were used to demonstrate homogeneity of the items as a basis of internal consistency.¹³⁸ Item - total correlation of more than 0.20 were considered acceptable.¹³⁸ Item-item correlations were considered acceptable if ranged between .30 and .70.¹³⁹ Items with correlation greater than .70 were considered redundant and those with correlation less than .30 were considered to not be related to other items in the measure.¹³⁹

Validity. Convergent validity was evaluated by correlating the ZBI scores with OCBS using Pearson correlation. In hypothesis testing for construct validity, independent sample t-test was used to compare depressive symptom levels between caregivers with high burden ($ZBI \geq 17$) and caregivers with low burden. Exploratory factor analysis was conducted to examine dimensionality on 21 items. Item 22 was excluded from the analysis as in previous studies^{74,76} because it measured the global burden rather than any specific dimension of burden. Data appropriateness for factor analysis was examined using the Bartlett's test and the Kaiser-Meyer-Olkin index. Bartlett's test was considered appropriate if it was significant while the Kaiser-Meyer-Olkin index was considered appropriate if it was $>.70$. Factors were extracted on the basis of Eigenvalues and conceptual considerations. Factors with Eigenvalues more than 1 were extracted and rotated using the Varimax rotation with Kaiser Normalization. Based on the results of the Varimax rotation, the ZBI items were categorized into factors.

Results

Sample Characteristics

A total of 124 caregivers participated in this study. The mean age of caregivers was 56.4 years. Most of the caregivers were female, Caucasian, married or cohabitant, and helped patients on a daily basis (Table 4.1). Slightly more than one-third of the caregivers had no comorbidity while hypertension was the common among those with comorbidities (44.6%). Only one third of caregivers were employed full or part-time outside the home. Slightly less than 20% reported not having enough income to make ends meet. Table 4.1 also shows clinical characteristics.

Reliability

Cronbach's alpha for the ZBI was .92, indicating adequate internal consistency. The item-total correlations of the ZBI were acceptable, ranging from 0.395 to 0.764. The Cronbach's alpha did not change significantly when deleting any item, with all remaining close to the scale Cronbach's alpha of .921. Table 4.2 shows items mean, standard deviation, item-total correlations, and alpha if the item is deleted. The item-item correlations were significant and ranged between .30 and .70 except for items 20 and 21, which had correlation less than .30 with almost all other items. Two pairs of items 11(having inadequate privacy) and 12 (suffering in social life) and items 20 (feel could do more for the patient) and 21 (feel could do a better for the patient) had the correlations greater than .70. The correlations of the latter pairs were .80 and .82 respectively. The mean inter-item correlation, a useful index of internal consistency was .365, fell within the acceptable range of .15 - .50¹⁴⁰.

Validity

There were significant and positive correlations between the ZBI scores and the time and difficulty of caregiving tasks scales of the OCBS (Pearson's $r = .466$ and $.583$, $p < .001$, respectively) demonstrating convergent validity. As hypothesized, there was a significant difference in the mean depressive symptoms scores between caregivers with high level of burden ($ZBI \geq 17$) and caregivers with lower burden scores ($t(77.69) = 3.56$, $p < .01$). Caregivers with a high level of burden had depressive symptoms scores (mean = 6.98, $SD = 6.86$) that were twice as high as those of caregivers with lower burden level (mean = 3.11, $SD = 4.35$).

In factor analysis, the significant Bartlett's test (sphericity, $P < .001$), indicated appropriate correlation matrix for the analysis and the Kaiser-Meyer-Olkin index was .864 indicating that the sampling was adequate for analysis. Factor analysis revealed a 4-factor solution with Eigenvalues > 1 that explained 62.84% of the variance (Table 4.3). The percentage of the variance explained and Eigenvalue markedly decreased after the first factor. All items had loading of 0.4 or more on the first factor. Also, all items except six items (8, 16, 18, 19, 20, and 21) loaded strongly (the difference between the largest two loadings of each item was < 0.2) on the first factor. The six items (8, 16, 18, 19, 20, and 21) loaded on more than one factor. Varimax Rotation with Kaiser Normalization was used for rotating the extracted factors. The results are presented in Table 4.3. Any item with a difference between loadings less than .20 is considered cross-loaded. Only loadings of more than 0.3 are shown on the table as loadings less than 0.3 were ignored.¹⁴¹ Nine of the 21 items clearly loaded on only one factor. Loading size and conceptual consideration were taken into account in determining the appropriate

categorization the item loaded on factors. Items loaded on Factor 1 were related to consequences of caregiving on caregiver. Although, items 3, 9 and 10, cross-loaded on both Factor 1 and 2, they conceptually fit with Factor 1. Items loaded on Factor 2 were related to patient's dependence. Items with the strongest loading on Factor 3 conceptually fit into a factor related to caregivers' feelings of exhaustion and uncertainty about caregiving. Lastly, items loaded on Factor 4 were related to caregivers' feelings of guilt (can do better) and fear about the patient's future.

Discussion

The results of this study provide support for the reliability and validity of the ZBI as a measure of caregiving burden in caregivers of patients with HF. There was good evidence of reliability as indicated by acceptable Cronbach's alpha when individual items were deleted. In most previous studies in which the reliability of the ZBI was examined, Cronbach's alphas were similarly reported equal or higher than .90.^{74-78,128} The item-total correlations provided evidence of internal consistency and support that all the items contribute to the measure. The acceptable mean inter-item correlation supported the ZBI internal consistency. Most item-item correlations supported consistency. Items had item-item correlations less than 0.3 maybe not related to other items in the measure. Those items (20 and 21) are related to caregivers feeling that they can do better and fear for patients future. Close examination of items 20 and 21 indicated that those measure how much caregivers feel burdened by the feelings that they can do better for their ill relative. Highly correlated items may indicate redundancy. Items 11 and 12, which had high item-item correlation, are measuring how much caregivers feel that their either their own privacy or social life was constrained by the caregiving responsibility. Items 20 and 21

also are measuring the caregivers feeling regarding the quantity and the quality of the care they are providing to their relatives. Thus, those items are related but not redundant.

The significant positive correlations between ZBI and the OCBS Time and Difficulty subscale scores indicate that the two instruments were measuring the same concept. These correlations support the convergent validity of the ZBI. This is consistent with previous reported strong correlation between the ZBI and the Burden Assessment Scale, a well validated scale that measures objective and subjective caregiver burden, reported in a study of 238 caregivers of dementia patients.⁷⁸

The hypothesis that caregivers with a higher level of burden would have higher level of depressive symptoms was supported providing evidence of construct validity. This finding is consistent with prior studies of findings the relationship between caregiving burden and depressive symptoms in caregivers of patients with HF,^{69,122} HIV-infected individuals,¹⁴² or mild cognitive impairment.¹³⁰ This particular finding suggests that the ZBI is a valid measure in caregivers of patients with HF because it demonstrated a similar validity in caregivers of patients with other chronic conditions.

The factor analysis did not support the previously reported unidimensionality of the ZBI.¹³² We identified four factors. This result is similar to previous studies. In family caregivers of patients with brain injuries, Siegert et al¹³² identified two factors: personal strain and role strain. The same two factors also were reported in caregivers of patients with dementia.¹⁴³ Three factors were identified in caregivers of patients with dementia in two studies including embarrassment/anger, patient's dependency, and self-criticism.^{74,76} Three factors also were identified in study of caregivers of patients with Alzheimer's

disease and related disorders: the effect of caregiving on the social and personal lives of caregivers; psychological burden, and feelings of guilt.⁷³

Although we identified more factors than in other populations, our factors were conceptually similar to factors identified in previous studies (Table 4.4). It is unknown why different studies produced a different number of factors. Providing care for patients with different conditions requiring different levels of caregiving involvement and types of relationships between patients and caregivers may in part explain this phenomenon. Regardless, the variability in factor dimensions across studies supports using only the ZBI total score rather than attempting to use subscale scores based on factor dimensions.

We acknowledge that the sample may not be representative of the whole HF caregiver population. The majority of the participants were female and Caucasian providing care for stable community-dwelling patients with HF which does not represent caregivers who are male, from other ethnic groups, or caregivers of patients with unstable HF.

Conclusions and Implications

This study provides evidence that the ZBI is a reliable and valid measure of caregiving burden in caregivers of patients with HF. We demonstrated good reliability in this population as well as convergent and construct validity. Using the total scores rather than specific dimension is recommended. This study supports using the ZBI as a measure of caregiving burden in this population in future research studies as well as in clinical settings.

Table 4.1. The sample characteristics.

Characteristics	Mean \pm SD or n (%)
Gender, female	95 (76.6)
Age, years	56.4 \pm 14.4
Marital Status,	
Married/ Cohabitant	99 (79.8)
Single/widow/divorced/separated	25 (20.2)
Ethnicity,	
Caucasian	113 (91.1)
African American	11 (8.9)
Education, \leq high school	75 (60.5)
Employment,	
Full or part time outside home	42 (33.9)
Unemployed/retired/homemaker	82 (66.1)
Financial status,	
Comfortable	33 (26.6)
Have enough	69 (55.6)

Table 4.1. (Continued)

Do not have enough	22 (17.7)
Comorbidity burden score	
None	46 (37.1)
1 - 3	67 (54)
4 or more	11 (8.9)
Comorbidity –Hypertension	55 (44.6)
Comorbidity – Diabetes	27 (21.5)
Days helping patient / week,	
7 days	87 (70.2)
Less than 7 days	37 (29.8)
Depressive symptom (PHQ-9)	4.75 ±5.78
Have depressive symptoms (PHQ-9 >9)	21 (16.9)
Burden (ZBI), total scores	15.8 ±12.3
Have burden (ZBI ≥17)	51 (41.1)

Table 4.1. (Continued)

Oberst Caregiving Burden Scale,

Time spent on caregiving tasks	32.35 ±10.66
Difficulty of caregiving tasks	22.35 ±5.97

SD: Standard Deviation

Table 4.2. Mean scores, item–total correlation, and Alpha if item deleted of the ZBI

No.	Item	Mean	SD ‡	Item–total r \$*	α if item deleted
1	Patient asks for more help than he needs	.823	.92	.561	.918
2	Not having enough time for yourself	.839	1.0	.741	.914
3	Stressed of fulfilling different responsibilities	.96	1.0	.693	.915
4	Embarrassed of patient behavior	.363	.74	.549	.918
5	Feel angry around patient	.41	.71	.637	.917
6	Negative effect on other relationships	.476	.77	.633	.917
7	Afraid of patient’s future	1.87	1.1	.491	.920
8	Patient is too dependent	1.74	1.2	.531	.919
9	Feel strained around patient	.573	.82	.680	.916
10	Health affected by caregiving	.508	.88	.685	.916
11	Having inadequate privacy	.597	.97	.552	.918
12	Suffering in social life	.54	.96	.658	.916
13	Uncomfortable having friends	.258	.70	.548	.918
14	Patient expected you to be the only caregiver	.863	1.2	.583	.918
15	Feel financially stressed	.46	.86	.543	.918
16	Feel unable to take care of the patient much longer	.194	.50	.458	.920
17	Sense of losing control over life	.54	.89	.764	.914
18	Wish to leave caring of the patient	.137	.44	.474	.920
19	Feel uncertain of what to do	.427	.81	.482	.919
20	Feel could do more for the patient	1.23	1.1	.395	.922
21	Feel could do a better for the patient	1.27	1.1	.447	.921
22	Feel burdened of caring	.67	.87	.639	.916

\$ r: correlation, ‡SD: Standard Deviation, *All correlations are significant at $p < 0.001$.

Table 4.3. Eigenvalue, percent of variance explained, and items loading into factors with Varimax rotation.

No	Item	Factors			
		Consequences of caregiving	Patient's dependence	Exhaustion and uncertainty	Guilt and fear for patient's future
	Eigenvalue	8.449	1.939	1.558	1.250
	Percent of variance explained	40.234	9.235	7.418	5.954
11	Having inadequate privacy	.858			
12	Suffering in social life	.852			
2	Not having enough time for yourself	.630	.487		
6	Negative effect on other relationships	.551		.389	
17	Sense of losing control over life	.505	.355	.448	.305
5	Feel angry around patient	.489		.358	
15	Feel financially stressed	.447		.357	
3	Stressed about fulfilling different responsibilities	.491	.551		
10	Health affected by caregiving	.460	.549	.304	
9	Feel strained around patient	.526	.530		
8	Patient is too dependent		.767		
1	Patient asks for more help than he needs		.766		
14	Patient expected you to be the only caregiver		.733		
16	Feel unable to take care of the patient for much longer			.791	

Table 4.3. (Continued)

18	Wish to leave caring of the patient			.786	
13	Uncomfortable having friends	.302		.693	
4	Embarrassed of patient behavior		.515	.523	
19	Feel uncertain of what to do		.389	.496	
20	Feel could do more for the patient				.905
21	Feel could do a better for the patient				.875
7	Afraid of patient's future		.337		.583

Table 4.4. The 22- and 21-item ZBI dimensions in this study and the reported in the literature.

1 st author ; year	Sample (N); patients diagnosis	Number of items	Consequences of caregiving	Patient's dependence	Exhaustion and uncertainty	Guilt or Self-criticism	Embarrassment/ anger or frustration	Psychological burden and emotional reactions	Personal strain	Role strain
This study	N=124; HF	21	2, 3, 5, 6,9, 10, 11,12, 15,17	1, 8, 14	4,13,6 ,18,19	7,20,2 1				
Ankri; 2005 ⁷³	N= 152; Dementia	22	1, 6,11, 12, 13, 17			15,16, 20, 21		4,5,9,18, 19,22		
Knight; 2000 ⁷⁶	N= 220 ; Dementia	22		2,8, 14		20, 21	4, 5, 6, 9, 10, 11, 12, 13, 18			
Siegert; 2010 ¹³²	N= 222; Brain injury	21							1, 4, 5, 6, 9,13, 14,16,18,19.	2,3,7,8, 10,11,12, 15,17,22
Springate; 2014 ⁷⁷	N=206; Dementia	22	2, 3,6, 9, 10, 12,11, 17, 18, 22,			5, 9, 20, 21	1, 4, 13, 14			
Whitlatch; 1991 ¹⁴³	N=113; Dementia	22							1,4,5,8, 9,14, 16, 17,18,19, 20,21	2,3,6, 11,12,13

CHAPTER FIVE

Sleep disturbance, a major focus in this dissertation, is common among patients with HF with high percentage of them have insomnia, sleep disorders breathing, and many other complaints related to their sleep.^{17-19,24,26} Similarly, sleep disturbance is a common complaint among family caregivers of patients with different chronic health conditions.²⁹⁻³⁶ Sleep disturbance is negatively associated with poor QoL in patients with HF^{17,50-52} and family caregivers.⁵³⁻⁵⁷ Improving QoL become a major focus of treating chronic conditions including HF. Patients with HF have reported the poor QoL compared to general population and patients with other chronic conditions.⁴⁴ In addition, poor QoL is common in caregivers of patients with HF.⁴⁶ It is import to examine these prevalent poor outcomes in both patients and family caregivers.

This dissertation included three manuscripts that together increase our understanding of the relationships between the common poor outcomes in community-dwelling patients with HF and their family caregivers. The overall purpose of this dissertation was to examine the associations between sleep disturbance and QoL in patients with HF and their family caregivers. Although it is well known that sleep disturbance is associated with poor QoL at individual level, it was unknown whether sleep disturbance in dyads member has an effect on their partners QoL. Therefore, in the first manuscript (Chapter 2), we examined these associations in dyads of patients and caregivers rather than examining these associations at the individual level. This study increased our understanding of the interdepend interactions between patients and their family caregivers, identified whether sleep disturbance in a member of a dyad was

associated with his/her partner's poor QoL, and emphasized the importance in designing interventions targeting improvement of QoL of both members of the dyad.

Disturbance of sleep also has been identified as predictor of the development of depressive symptoms⁶⁷ and both factors were known to have negative influence on QoL^{34,66,102,144} but it was unknown whether depressive symptoms mediate the relationship between sleep disturbance and QoL. In the second study (Chapter 3), we examined the mediation effect of depressive symptoms on the relationship between sleep disturbance and QoL at individual level in both members of dyad.

In the third study (Chapter 4), the reliability and validity of the Zarit Burden Interview as a measure of caregiving burden, another poor outcome associated with the caregiving responsibility, were examined. Caregivers of patients with HF commonly report feeling of being burden by the caregiving responsibility.¹²¹⁻¹²³ Importantly, caregiving burden is linked to sleep disturbances^{145,146} and other poor outcomes.⁶⁹ Caregiving burden also may influence their ability to provide support to their family member. Having a reliable and valid measure of caregiving burden is essential to identify burdened caregivers and prevent the associated poor outcomes in both patients and caregivers.

The purpose of this chapter was to summarize and synthesize the findings of the three studies in this dissertation. This chapter also provides recommendations for practice and future research.

Summary of Findings

First study (Chapter 2) was a dyadic analysis of data from 78 patient-spousal caregiver dyads who were living at the same home conducted to examine whether sleep

disturbance in a member of the dyad has association with the QoL in the other member of the dyad. The multilevel dyadic approach using the Actor-Partner Interdependence Model was used for this purpose. The association of sleep disturbance was examined with two aspects of QoL: the physical and mental well-being. Sleep disturbance in both individual's patients and caregivers was negatively associated with their poor physical and mental well-being. There was a significant association only between sleep disturbance in caregivers and patients' mental well-being.

In the second study (Chapter 3), the association among variables of sleep disturbance, depressive symptoms, and QoL was explored. Our interest was whether depressive symptoms mediated the relationship between sleep disturbance and the physical and mental well-being aspects of QoL at individual level in patients with HF and their family caregivers. Baron and Kenny's steps using linear regression analysis were used for testing mediation effect. The results were supplemented by the bootstrapping results for examining the significance of indirect effect. Depressive symptoms mediated the relationship between sleep disturbance and mental well-being in both patients and caregivers. Indirect effect of sleep disturbance on mental well-being through depressive symptoms in both patients and caregivers was evident. It can be conclude with a certain degree, the relationship between sleep and depressive symptoms is a causal one for the mental well-being in both groups. For the physical well-being, there was no an indirect effect of sleep disturbance on QoL through depressive symptoms. Thus, the main effect of sleep disturbance on QoL was direct.

The third study (Chapter 4) was an evaluation of the reliability and validity of the Zarit Burden Interview (ZBI) in caregivers of patients with HF. Cross-sectional

questionnaire data were collected from 124 caregivers of patients with HF. The ZBI has good internal consistency reliability (Cronbach's alpha) of .921 but with probable redundancy. All item-total correlations were equal or greater than 0.4, demonstrating adequate homogeneity. The convergent validity was supported by having significant correlations with the two subscales of the Oberst Caregiving Burden Scale, another measure of caregiving burden that measures the time spent on and the difficulty of the caregiving tasks. In factor analysis, items loaded on four dimensions of caregiving burden. These four dimensions were consequences of caregiving on caregiver, patient's dependence, exhaustion with caregiving and uncertainty, and guilt and fear for the patient's future. Construct validity by hypothesis testing was supported by caregivers with high burden scores having significantly higher depressive symptoms than caregivers with lower burden scores. This study provided evidence that ZBI can be used for assessing caregiving burden in this population.

Impact of dissertation on the state of the science

In this dissertation, I have advanced the state of the science in HF outcomes related to sleep disturbance, QoL, and caregiving burden in patients with HF and their family caregivers by: 1) demonstrating that sleep disturbance in both patients with HF and caregivers affects their own QoL and sleep disturbance in spousal caregivers affects patients with HF QoL; 2) providing evidence of the mediating effect of depressive symptoms in the relationship between sleep disturbance and QoL of patients and caregivers; and 3) providing evidence of the reliability and validity of the Zarit Burden Interview as a measure of caregiving burden in caregivers of patients with HF. Findings from this dissertation also may have additional significant advancement of the state of

science in promoting the health of both patients with chronic illness and their family caregivers by identifying factors that are necessary to address when designing effective interventions.

Findings in Chapter Two further demonstrated the interdependence between dyads of patients with HF and their spousal caregivers and that a characteristic of a dyad member may influence the outcome in his/her partner. It is known that sleep disturbance is associated with poor QoL in individuals^{17,50-57,79} but it was unknown whether sleep disturbance in one member of the dyad may have an influence on the outcome of the other member of the dyad. I advanced the state of the science in sleep and QoL outcomes research by demonstrating that having disturbed sleep in caregivers especially in spousal caregivers had association with poor mental well-being aspect of QoL outcome in patients with HF. In addition, it was the first study to explore the negative outcomes of sleep disturbance in caregivers of patients with HF.

The study in Chapter Three, identified one of the ways that sleep disturbance has negative influence on QoL in both patients with HF and caregivers. I advanced the state of the science by providing evidence that depressive symptoms play a significant part in the effect of sleep disturbance on QoL in particular the mental well-being aspect of QoL in patients and caregivers and that managing depressive symptoms is important when targeting sleep disturbance and QoL in both groups.

Finally, a valid and reliable measure of caregiving burden is necessary to identify family caregivers with high level of burden, determine the effectiveness of interventions to reduce feelings of being burdened, and to prevent further poor outcomes associated with burden in patients and their caregiver. In Chapter Four, I advanced the state of the

science in caregiving and HF by providing strong evidence of the reliability and validity of the ZBI in caregivers of patients with HF. The evidence supports the use of the ZBI to measure caregiving burden in caregivers of patients with HF.

Limitations

There are some limitations in this dissertation. First, the same data set was used for the purposes of the three manuscripts. Second, because the data analyzed were cross-sectional, causality in the first two studies cannot be confirmed. Third, sleep disturbance scores was not measured using a standardized scale. Fourth, the sample in study one was limited to the dyads of patient-spousal caregiver who were living at the same home. The findings may not be generalizable to patients- caregivers with other kind of relationships. In addition, the majority of subjects in the data set were female and Caucasians and stable community-dwelling patients with HF. Therefore, the results may not represent males, individuals from other ethnicities, or patients with unstable HF. Finally, other factors that affect QoL in both patients and their family caregivers such as age, gender, functional status were not included in the analysis in first two manuscripts.

Recommendations for Practice and Research

For the first study, monitoring sleep disturbances in patients and their family caregivers appears to be important when targeting improving QoL in both of them. In addition, targeting both members of the dyad seems beneficial to them especially for the patients' mental well-being. Future research regarding sleep disturbances among patients and caregivers should focus on both members of the dyad especially for those who are living together. Examining the interdependence between patients and their family caregivers needs to be examined in the future research using the dyadic approach. The

influence of other factors such as age, gender, caregiver- patient relationship, marital status and quality, and employment, on the outcomes of sleep disturbances and QoL in both members needs to be examined. Understanding how long term sleep disturbance may influence the QoL in the same individual and in the partner also needs to be examined. The possible reasons why patients are sensitive to sleep disturbance in their caregivers needs to be investigated. Similarly, future studies focused on the designing and testing of interventions targeting improving QoL through sleep disturbance improvement need to involve both patients and their caregivers to have the best results.

Implications for the second study include that managing depressive symptoms when addressing sleep disturbance management to improve QoL. Future research should focus on understanding of the association among sleep disturbance, depressive symptoms, and QoL in both patients and caregivers. Identifying how covariates affect these relationships should be a focus of the future studies.

For the third study, the ZBI can be used as a measure of caregiving burden in practice and research. Testing the psychometric properties of the ZBI in other ethnic groups including the dimensionality of this instrument are of directions of future research.

Sleep disturbance and QoL are not new concepts but have not been emphasized in the context of HF especially in the family caregivers. Although these concepts have been studied for decades, many areas still need to be investigated. Sleep disturbance and QoL are important and complex complicated because many factors can influence these outcomes. Future studies need to pay more attention to the family caregivers because the caregiver and patients are interdependent and affect each other's outcome.

Effective and feasible interventions should be developed, tested, and adopted by facilities providing care to patients with HF. Health professionals should assess both patients and their family caregivers for common difficulties including sleep disturbances and intervene to prevent further negative consequences in both patients and caregivers. To broaden our understanding, studies are needed to understand of family caregivers from other cultures, ethnicities, different beliefs, and backgrounds to determine how they perceive their roles and identify difficulties they face. This will allow more comprehensive interventions to be developed to promote their health.

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VITA

Education

<u>Institution</u>	<u>Degree</u>	<u>Date Conferred</u>	<u>Field of Study</u>
Jordan University of Science and Technology	B.Sc	June 1998	Nursing
Jordan University of Science and Technology	M.Sc	September 2002	Community Health Nursing

Professional Experience

<u>Dates</u>	<u>Institution and Location</u>	<u>Academic Position</u>
August 2012 - December 2012	University of Kentucky- College of Nursing, Lexington, KY, USA	Research Assistant
October 2005 - August 2011	Hashemite University -College of Nursing, Zarqa, Jordan	Research and Teaching Assistant
January 2004 - June 2005	Hajr Health Sciences Institute (HHSI), Al-Hofuf, Kingdom of Saudi Arabia	Lecturer and Supervisor of Clinical Nursing Diploma Program

<u>Dates</u>	<u>Institution and Location</u>	<u>Clinical Position</u>
April 1999- January 2004	Al-Mafraq Governmental Hospital (Ministry of Health), Al-Mafraq, Jordan	Staff Nurse
July 1998- April 1999	Islamic Hospital, Amman, Jordan	Staff Nurse

Research Presentations

<u>Date</u>	<u>Title and Location</u>
April 11, 2014	Oral presentation of a manuscript titled “The effect of sleep disturbance on quality of life in dyads of patients with heart failure and their family caregivers” at the 10th Annual Student Scholarship Showcase, , University of Kentucky- College of Nursing, Lexington, KY, USA
Nov. 8, 2013	Poster presentation of “Psychometrics of the Zarit Burden Interview in Caregivers of Patients with Heart Failure” at the 23rd Annual Nursing Research Papers Day, University of Kentucky- College of Nursing, Lexington, KY, USA
May, 2002	Oral presentation of a project titled “Helminthes among school age students” at the Seventh International Middle East Nursing Conference (Discovering Reality: A Road for Nursing Success), Jordan University of Science and Technology, Irbid, Jordan

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