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The Association of Dementia Caregiver Employment with Sleep Quality: Does Being a Spouse Matter?

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Abstract

Background: Family caregivers for a person living with dementia (PLwD) can experience stress and burden which may relate to health consequences such as poor sleep quality. This study aimed to 1) examine the association between caregiver employment status and sleep quality and 2) understand how this association may be moderated by the relationship of the caregiver to the PLwD.

Methods: A sample of primary caregivers for a PLwD (N = 100) were interviewed in person in 2017. A linear regression with the Pittsburgh Sleep Quality Index (PSQI) global score as the outcome and employment status as the key predictor, and an interaction of spousal relationship by employment status was conducted, testing to see whether spousal relationship moderated the employment-sleep quality association.

Results: Participants were 74% female, 55% were 65 years of age or older, and 82% self-identified as white. Caregivers on average were providing 54 hours of care per week. Caregivers providing care for PLwDs with greater dementia severity reported worse sleep quality ($\beta = 0.07$, SE = 0.03, $p < 0.05$). Spousal caregiver status moderated the association between employment and sleep quality such that employed spouses had significantly worse sleep quality ($\beta = 0.97$, SE = 1.99, $p < 0.01$).

Discussion: Findings indicate that employed spousal caregivers may be particularly vulnerable to deleterious effects of care on health. It is important to provide interventions for caregivers to improve sleep quality for their own health and to provide the best care for PLwDs.

The Association of Dementia Caregiver Employment with Sleep Quality: Does Being a Spouse Matter?

Alzheimer's disease and related dementias (ADRD) is a major public health problem worldwide. The Alzheimer's Association (2022) reported that there are an estimated 6.5 million people in the United States of America who are 65 years and older and living with dementia (Alzheimer's Association, 2022). This number is projected to significantly grow by 2060 to nearly 3.8 million people living with dementia as the population of Americans aged 65 and older increases (Alzheimer's Association, 2022). Dementia involves persistent cognitive deterioration which causes a person living with dementia (PLwD) to experience difficulties with memory, language, problem-solving and other cognitive skills, in addition to the behavioral and psychological symptoms and functional impairment (Alzheimer's Association, 2022). A study conducted over a 5-year period estimated that 64% of dementia patients lived at home from a population of 3.3. million people with the disease at the time (Harrison et al., 2019). Community-dwelling PLwD are commonly cared for by informal, unpaid caregivers such as family and friends (Brodaty & Donkin, 2009).

Caregiving Stress and Gains

To sustain a PLwD's quality of life, caregivers are responsible for assisting the care recipient with many different tasks. Caregiving involves providing hands-on-care such as dressing and bathing, helping with medication administration, and managing behavioral psychological symptoms such as wandering, restlessness, depressive and hallucinatory symptoms (Takechi et al., 2012). Informal caregiving demands long care hours that require flexibility and patience (Brodaty & Donkin, 2009). As the disease progresses, the caregiver's role becomes more demanding over time and impacts the well-being of the caretaker. Caregivers have been found to report more physical and mental health problems relative to non-caregivers (Tremont, 2011). Nearly 59% of family caregivers of PLwD reported high levels of emotional stress and burden (*2022 Alzheimer's Disease Facts and Figures*, 2022). Pearlin's stress process model proposes four main areas that contribute to caregiver stress: 1) primary stressors such as objective stressors (e.g., hours of care or physical aspects of providing care) and subjective stressors (e.g., emotional reactions to caregiving), 2) secondary stressors (e.g., role strains), 3) resources available to the caregiver (e.g., social support) and 4) caregiver outcomes such as physical and mental health of caregiver (Perlin et al., 1990). This model demonstrates the association between caregiver stress and well-being outcomes of caregiving. Many caregivers experience caregiver burden due to the primary stressors caused by managing the behavioral and psychological symptoms of dementia (of which one common symptom is sleep disturbances) (Barrera-Caballero et al., 2021). Literature shows that caregiver burden, poor sleep quality and poor physical health are associated with psychological distress such as depressive and anxiety symptoms (Pinquart & Sorensen, 2007). Family caregivers are integral to sustaining the quality of life for PLwD. Therefore, the negative outcomes associated with caregiving are critical to understand as they can impact the quality of care that is provided to the care recipient (Brodaty & Donkin, 2009). This broader area of research is essential to ensuring quality of life in caregivers so that they may maintain and provide person-centered care through the progression of the disease.

Although the stresses of caregiving are well defined, caregiving can also be associated with positive outcomes. Family caregivers are motivated by a variety of reasons to provide care such as the sense of love, duty, and obligation to assist and attend to a loved one with dementia (Brodaty & Donkin, 2009). These motivations can be correlated to both positive and negative outcomes from caregiving. In particular, the REACH study examined several measures of positive outcomes in dementia caregiving. The study concluded that many caregivers reported feeling a degree of satisfaction with providing care, feeling useful and needed, experiencing personal growth, and strengthening relationships with others (Tarlow et al., 2004). Additionally, Shim et al., (2013) described the experience of 11 spousal dementia caregivers in a qualitative study. They found caregivers expressed personal positive meaning in their caregiving experience. Caregivers explained that the process of caregiving has deepened their relationship to the PLwD and has allowed them to grow personally from day to day (Shim et al., 2013). However, research studies demonstrating positive outcomes in caregivers are in the minority when compared to those that display negative outcomes.

Research suggests that the stresses of caregiving are more significantly correlated with negative consequences than positive (Tremont, 2011). One common negative outcome that can result from caregiving is poor sleep quality. One potential causal pathway as to why caregivers report poor sleep quality is related to higher rates of negative affect and worsened perceptions of social support among caregivers (Brummett et al., 2006). Due to high psychological strain such as stress, burden and negative affect and the interfering responsibilities of family caregiving, poor sleep quality is a critical outcome in family caregivers. Furthermore, factors such as employment status may play a role in poor sleep quality in caregivers as well. A study reported that caregivers who were employed slept less and spent less time in bed than non-caregivers (Blinka et al., 2022). Employed caregivers are more vulnerable to sleep loss than employed non-caregivers. Thus, this thesis will explore the significant outcome of sleep quality in caregiving and the role that employment plays in caregiver sleep.

Sleep Quality

An estimated 50-70% of family caregivers of PLwD have sleep complaints due to the quality and quantity of sleep they receive (Peng & Chang, 2013). This is of public health importance as studies show that inadequate amounts of sleep overtime can lead to worsening psychological and physiological health problems (Kryger, Roth, & Dement, 2005). Sleep deprivation in caregivers hinders their ability to respond, react and perform care taking duties (Johansson, Marcusson & Wressel, 2012). Indeed, worsening sleep has shown to impact the quality of care caregivers are able to provide for their care recipient (Reinhard et al., 2008). For example, caregivers responsible for bathing, dressing, and administering medication to their recipient may find that insufficient amounts of sleep inhibit their ability to organize, manage and execute these daily tasks (Johansson, Marcusson & Wressel, 2012; Schulz & Martire, 2004). Furthermore, the declining health of a caregiver can put the care recipients at risk for errors in medication management or neglect (Reinhard et al., 2008). Oken, Fonareva & Wahbeh (2011) conducted a cross-sectional study with 31 dementia caregivers and 25 non-caregivers to examine whether stress produces cognitive dysfunction. They found that dementia caregivers who reported poorer sleep quality and had higher levels of stress than non-caregivers, experienced greater rates of cognitive decline which affected speed, attention and executive function (Oken, Fonareva & Wahbeh, 2011) which is essential to the caregiver's ability to perform care taking tasks.

Factors associated with sleep disturbances in family caregivers include care recipient behavior and psychosocial factors (Peng & Chang, 2013). Sleep disturbances are common in PLwD due to experiencing wakefulness and disruptions through the night which interfere with the caregivers sleep patterns (Peng, Lorenz & Chang, 2018). About 66% of PLwD may experience sundowning (Alzheimer Society of Canada). Sundowning is when someone with dementia is confused, anxious, upset, or restless usually late afternoon or early evening causing disruptions in the sleep/wake cycle due to not being able to distinguish day from night (Alzheimer Society of Canada). A study conducted with 60 caregivers of PLwD reported that 63% of caregivers reported that their sleep was disturbed due to the care recipients' night behavior, such as experiencing restlessness, wandering or needing to use the bathroom (Creese et al., 2008). Moreover, it was found that the severity of dementia directly impacts the caregivers' sleep quality (McCurry et al,. 2008). Lee, Morgan & Lindesay (2007) found that from their sample of 39 caregivers, 77% surpassed the cutoff score for clinically disturbed sleep due to sleep disruptions occurring with the PLwDs wandering, restlessness, wakefulness or using the bathroom. Additionally, a clinical study found that caregivers who exhibit high levels of fatigue due to poor sleep quality reported that they "sleep with an open ear" or "try to sleep lightly" to make sure they can wake up to provide supervision when the PLwD has left the bed during the night (Rowe, Kairalla & McCrae, 2010).

In addition to sleep disturbances in PLwD, other factors such as caregiver depression, stress, and burden can interact with sleep quality as caregivers may experience negative thoughts and feelings through the night (McCurry et al., 2007). Brummett et al,. (2006) determined that caregivers that reported higher levels of depressive symptoms had higher levels of sleep disturbance. Moreover, depression and anxiety in caregivers are well-known risk factors for sleep disorders such as insomnia (Pinquart & Sorensen, 2003). Results from a longitudinal study with 231 dementia caregivers identified that caregiver depression and burden were the most powerful predictors of caregiver sleep disturbances (McCurry et al,. 2004). Poor mood, particularly being worried or depressed, contributes to poor sleep quality as reported by caregivers who found it hard to go back to sleep after being woken up by the PLwD (Gibson, Gander & Jones, 2013). Whereas above average sleep quality and below average sleep disturbances were associated with lower negative affect on a night-to-night basis in older caregivers (McCrae et al., 2014). Furthermore, caregiver sleep is inconsistent from night-to-night, which promotes poor overall sleep quality (Rowe et al., 2008). Dementia caregivers who had more severe symptoms of depression experienced poorer sleep quality and more sleep disturbances (Beaudreau et al., 2008). Specifically, sleep disturbances were associated with caregiver burden and poor self-rated health measures reported by dementia caregivers (Beaudreau et al., 2008).

Dementia caregivers consistently reported poorer sleep quality and greater fatigue than non-caregivers due to stress, anxiety and poor health in combination with PLwD nighttime restlessness. In particular, Liang, Aranda & Lloyd (2020) found a significant association between role overload and sleep disturbances in dementia caregivers. They found that the sleep quality of dementia caregivers may be affected by role overload, as role overload captures multiple stressors experienced by the caregiver (Liang, Aranda & Lloyd, 2020). Corey et al., (2018) found that dementia caregivers who reported using dysfunctional coping strategies and experienced higher levels of guilt had poorer sleep quality than caregivers who engaged in support groups. Additionally, caregivers who reported high levels of guilt experienced high levels of depression and anxiety which are associated with poor sleep quality (Corey et al., 2018). Taken together, this research suggests that high negative affect and caregiving burden are predictors of poorer sleep quality in caregivers of PLwD.

Employment Status of Family Caregiver

The National Alliance for Caregiving (2017) estimated that 60% of caregivers for PLwD are employed in the USA, working an average of 35 hours per week alongside their informal caregiving duties. In Pearlin's stress process model, employment is a secondary stressor which may cause role strains for caregivers (Perlin et al., 1990). For example, caregiving responsibilities may interfere with work which may contribute to caregiver burden (Scott et al., 2018). Struggles in balancing both caregiving duties and work duties can cause conflicts resulting in role strain. A study conducted with employed caregivers of PLwD found that these caregivers experience role strain because of the many adjustments they need to make in their work, such as adjusting work hours, taking time off with and without pay, taking personal phone calls while working, to be able to provide quality care (Dunham & Dietz, 2003). Furthermore, employed caregivers may experience role overload due to being employed while caregiving. In one longitudinal study, caregivers that were consistently employed experienced greater levels of role overload (Liu et al., 2019). Employed caregivers felt that they must split their time and attention between caring for the PLwD and work, contributing to overall stress (Liu et al., 2019). Research demonstrates that dementia caregivers are affected more negatively by their caregiving responsibilities due to complications in employment. Ory et al., (1999) conducted a study examining ways in which dementia care is different from other types of caregiving. They found that a significantly higher percentage of dementia caregivers reported employment-related problems than non-dementia caregivers. In particular, dementia caregivers reported having to take early retirement, turning down promotions, losing job benefits, taking less demanding jobs or having to give up work entirely to focus on caregiving (Ory et al., 1999).

Financial strains are a variable that may indicate whether the employment status of a caregiver is a predictor of negative or positive outcomes. Research suggests that the imbalance between work and caregiving can be stressful for employed caregivers that struggle with adjusting to balance work and life (Sadavoy et al., 2021). Specific job-related experiences result in higher role strain and depressive symptoms among employed family caregivers (Edwards et al., 2002). Employed caregivers who reduced hours of work in order to meet caregiving demands were much more likely to leave their jobs entirely (Lilly et al., 2010). Caregivers reported leaving their job was an undesirable outcome as an important source of income was lost causing financial strains (Lilly et al., 2010). Neubert et al., (2019) did a mixed-studies review on dementia caregiving and employment. They found that employed caregivers were mostly adult-children, or caregivers that lived with the PLwD were at the highest risk for reducing work hours reporting more strain due to caregiving and work conflicts than unemployed caregivers (Neubert et al., 2019). Furthermore, this review found that work conflicts were strongly associated with role overload and strain, depressive symptoms and worry in dementia caregivers (Neubert et al., 2019). Conversely, Neubert et al., (2019) also concluded that positive work experiences were associated with lower depressive symptoms. Moreover, some research studies have shown that employment may not be a disadvantage for all caregivers. Positive outcomes due to employment can be seen in family caregivers of PLwD. Rozario, Morrow-Howell & Hinterlong, (2004) found that family caregivers with multiple roles report significantly better self-rated health measures, role privileges and personal satisfaction.

Relationship Between Caregiver and Care Recipient

Relationship to the PLwD is an important determinant to caregiver well-being as a primary family caregiver. As of 2020, 50% of caregivers were adult-children and 12% were spousal caregivers (Caregiving in the U.S., 2020). Adult-children and spouses differ as spouses are more likely to be older, living with the PLwD, and have a different emotional relationship in comparison to adult-children (Pinquart & Sorensen, 2011). Research shows differences in caregiving outcomes between adult-children and spousal caregivers. Adult-children are more likely to experience higher levels of emotional burden and role strain due to employment and caregiving responsibilities (Pinquart & Sorensen, 2011). Whereas spousal caregivers report higher levels of depressive symptoms, physical burden, financial burden, and relationship strain (Pinquart & Sorensen, 2011). A study conducted with (N =126) Chinese American dementia caregivers analyzed the difference between adult-children and spousal caregivers (Liu, 2021). Liu found that higher depressive symptoms in spousal caregivers were attributed to the higher burden they perceived and that the feeling of burden mediated the association between spousal caregivers and higher depressive symptoms. Moreover, he concluded that adult-children performed less care tasks such as bathing and dressing than spousal caregivers, which may explain why spousal caregivers experience more caregiver burden and stress than adult-children (Liu, 2021). Additionally, a longitudinal study reported that spousal caregivers of PLwD experience greater negative changes in immune function, health, depressive symptoms, and stress (Kiecolt-Glaser et al., 1991). Studies suggest that the functional decline of a PLwD is related to caregiver burden in spouses. Marwit & Meuser (2002) reported that spousal caregivers show a linear increase in experiencing caregiver burden as the disease progresses in severity. Additionally, Conde-Sala et al., (2010) reported that care recipient factors, such as disease severity and symptom onset, are predictors of caregiver burden in spousal caregivers. Moreover, Creese et al., (2008) reported that spousal dementia caregivers reported sleep disturbances due to waking up to manage nighttime behavior of the PLwD, such as wakefulness and confusion.

Research suggests that spousal dementia caregivers face negative health outcomes. As a spouse or partner with dementia, being the primary caregiver can result in high levels of anxiety, depression, poorer sleep quality, and emotional distress as dementia may have a negative impact on the spousal relationship (Mahoney et al., 2005). McLennon, Habermann & Rice (2011) found that 54% of their sample of spousal dementia caregivers (N = 84) reported mild to severe levels of caregiver burden and 30% of the sample indicated suggestive results for clinical depression. Both male and female spouses display declines in health behaviors such as negative sleep patterns, depressive symptoms, and proper nutrition as a result of caregiver stress (Gallant & Connell, 1998). Furthermore, in a 2 year longitudinal study conducted by Joling et al., (2015) found that , spousal caregivers of a PLwD have a higher risk in developing mental disorders. From their sample of 181 spousal caregivers, 60% of spousal caregivers developed a depressive or anxiety disorder within 24 months, 37% developed depression, 55% developed an anxiety disorder, and 32% developed both disorders (Joling et al., 2015). Dura et al., (1990) found that spousal dementia caregivers reported high levels of caregiver distress and depression in comparison to non-dementia caregivers. In particular, spousal dementia caregivers were reported to have higher mortality rates after hospitalization of the PLwD than non-dementia spousal caregivers that had their spouse hospitalized as well (Tremont, 2011). Furthermore, spousal caregivers report to have greater distress due to cognitive and mood symptoms associated with the PLwD (Tremont, 2011).

Research has demonstrated that spousal caregivers of a PLwD experience worse sleep quality. A study conducted by McCurry & Teri (1995) found that 68% of spousal dementia caregivers reported some sort of sleep disturbance and that older spousal caregivers reported greater frequency of awakenings at night. They concluded that sleep disturbances in spousal dementia caregivers were associated with depression, age and the PLwD functional impairment (McCurry & Teri, 1995). Furthermore, McKibben et al., (2005) conducted a study with 73 spousal dementia caregivers and 40 non-caregivers to examine the differences in sleep quality. They found that caregivers of PLwD that had moderate to severe dementia reported poorer sleep quality than non-caregivers. Additionally, they found that older spousal caregivers had less deep sleep and lower sleep efficiency than the younger caregivers and non-caregivers (McKibben et al., 2005). In particular, Willette-Murphy et al., (2006) found wives of a PLwD reported who have less than seven hours of sleep per night have a 30% higher mortality risk than those who sleep between seven to eight hours per night. Taken together, the literature suggests that spousal dementia caregivers are at risk of experiencing poor sleep quality and negative health consequences such as depressive symptoms.

Many studies to date show a variation of results, both positive and negative, involving the well-being of family caregivers of PLwD. In particular, outcomes of sleep quality in caregiving are explored through many research studies demonstrating multiple factors that explain poor sleep quality in family caregivers. Caregiver burden, stress and care recipient factors are just a few of the factors that studies have concluded to explain why family caregivers of PLwD may experience poor sleep quality (McCurry et al,. 2004)(Kiecolt-Glaser et al., 1991)(Pinquart & Sorensen, 2011). Furthermore, research has shown that factors such as the relationship to the PLwD and employment status have positive and negative outcomes. Employment can impact a caregiver both negatively and positively as it can hinder work-life balance or be a break from caregiving. Additionally, the relationship to the PLwD plays an important role in caregiver well-being. Spousal and adult-children both display different outcomes as being the primary caregiver. However, research on how employment status impacts sleep quality in dementia caregivers is lesser known. Thus, this paper will be exploring 1) whether employment status impacts sleep quality in dementia caregivers, and 2) whether the association between employment status and sleep quality in caregivers varies their relationship to their care recipient.

The Current Study

Data analyzed in this thesis was previously collected in 2017 by Principal Investigator Dr. Amanda Leggett at the University of Michigan. This research was coined the STYLE study and measured biopsychosocial outcomes of dementia care management. The sample consisted of 100 adult family or friend caregivers in Michigan who were interviewed in their home or a public setting using mixed-methods interviews and analysis to explore cognitive-behavioral management in dementia care. The purpose of this research is to examine the association between caregiver employment status and sleep quality and to understand how this association is moderated by the relationship of the caregiver to the PLwD. It is expected that employed caregivers will experience reduced sleep quality. Similarly, it is expected that employment is associated with worse sleep for spousal caregivers. Ultimately, the aim of this study is to determine whether employment impacts sleep quality in dementia caregivers and how relationship to the care recipient may be a moderating variable in this association.

Methods

This study was part of a broader mixed-methods study (the STYLE study) on dementia care management and biopsychosocial outcomes of care.

Participants

Participants included 100 adult family or friend caregivers who held the primary responsibility of caring for a person with a diagnosis of Alzheimer’s disease or a related dementia (excluding mild cognitive impairment). Eligibility criteria required caregivers to not be providing care for a person living in a nursing home or assisted living facility or with a life expectancy of less than 6 months as we desired the caregiver to have primary responsibility for care and to not be in the terminal phase of caregiving.

Procedure

Caregivers were recruited through the Michigan Alzheimer's Disease Center's participant database, support groups, other programming, and other University of Michigan recruitment platforms (e.g., UM Health Research Database) as a convenience sample. Participants were interviewed in their homes or a public location of their choosing (e.g., coffee shop) within 60 miles distance of Ann Arbor, MI. All participants gave their signed informed consent in accordance with the University of Michigan IRB policies and received a small stipend for their participation.

Measures

Outcome: Sleep Quality

Participants were asked to answer questions about their sleep quality using the Pittsburg Sleep Quality Index (PSQI). The Pittsburg Sleep Quality Index (PSQI) is a self-rated questionnaire consisting of 24 questions that measures 7 factors of sleep quality: sleep onset length, sleep latency, duration of sleep, sleep efficiency, sleep disturbance, daytime dysfunction, and the global sum of overall sleep quality (Buysse et al., 1989). The questionnaire measures these factors from 0 (best) to 3 (worst) (Buysse et al., 1989). The PSQI global sum score ranges from 0 to 21 where a higher score indicates poorer sleep quality.

Key predictor: Employment Status

Employment status was measured in the demographics questionnaire. Participants were asked to answer yes or no as to if they were employed outside the home. Answers were coded as Yes (1) and No (0).

Moderator: Relationship to the PLwD.

The caregiver's relationship to the care recipient was categorized as spouse (1) or non-spouse (0; e.g., adult child, friend).

Covariates.

The models also account for participant demographics and care characteristics including: caregiver age (dichotomized as 65 years or greater = 1, and under 65 = 0 for ease of interpretation between older adults and middle aged and younger adults), caregiver gender (Female = 1, Male = 0), caregiver race coded dichotomously as White (0) and non-white (1) but surveyed as White, Black, Asian or Other, caregiver educational attainment (dichotomized as college degree or higher = 1 and less than a college degree = 0), coresidence with the care recipient (No = 0, Yes = 1), and total hours providing care per week. The PLwDs disease stage was assessed with the Dementia Severity Rating Scale (DSRS). The DSRS assesses the degree of memory impairment, speech and language impairment, the level of recognition of family members, orientation to time and orientation to place, the ability to make decisions, the level of social and community activity, home activities and responsibilities, the level of cleanliness, the ability to eat, the ability to control urination and bowels and the ability to get from place to place. A higher score on the DSRS indicates greater disease severity from a range of 0, no impairment, to 51, maximally impaired.

Data Analysis

First, descriptive statistics were run to identify full sample characteristics. Chi-square and t-tests were run to examine mean differences in employment status by relationship to the person living with dementia and sleep quality by employment status. A linear regression with the PSQI global score as the outcome and employment status as the key predictor was conducted, controlling for caregiver age, caregiver race, caregiver educational attainment, coresidency with care recipient, total hours providing care per week and dementia severity. Next, an interaction of spousal relationship by employment status was run, testing to see whether spousal relationship moderated the employment-sleep quality association. All models were run in IBM SPSS version 28 (IBM Corp. (2023). IBM SPSS Statistics for Windows (Version 28.0) [Computer software]. IBM Corp.).

Results

Table 1 presents the complete descriptive characteristics of the sample (N = 100). This sample consisted of a majority of female caregivers (74%), 55% who were 65 years of age or older and, 82% self-identified as white. From the sample, 33% of primary caregivers were employed and 75% lived in the same home as the PLwD. Care recipients' on average reported a DSRS score of 24.88 indicating moderate dementia severity. Caregivers reported total weekly time spent caregiving which averaged 54 hours per week (M = 54.24; SD = 37.23).

A Pearson Chi-Square test indicated a significant difference in employment status by relationship to the PLwD (χ = 29.07, df = 1, $p < .001$). In particular, more non-spousal caregivers were employed (63%) than spousal caregivers (11.9%). An independent samples t-test was conducted to determine whether, on average, sleep quality varied by employment status in the sample. The t-test found significant results on how employment status affected sleep quality. On average, unemployed caregivers (N = 67) had better sleep quality (M = 6.51; SD = 3.43) than employed caregivers (N = 33; M= 7.72; SD = 3.65).

In a linear regression controlling for demographic and care characteristics, the DSRS scale was significantly associated with PSQI scores, where greater dementia severity was associated with higher PSQI scores indicating worse sleep quality ($\beta = 0.07$, SE = 0.03, $p < 0.05$). Additionally, we examined whether spousal relationship moderated the association between employment and sleep. A significant interaction was found between spousal caregivers and employment status, suggesting sleep quality was particularly impaired among spousal caregivers who were employed ($\beta = 0.97$, SE = 1.99, $p < 0.01$). Figure 1 demonstrates the interaction between spousal caregivers and employment status. Refer to Table 2 for betas and standardized effects of the linear regression model.

Discussion

The purpose of this study was to determine whether employment status is associated with sleep quality in dementia caregivers and how the relationship to the care recipient may be a moderating variable in the association of employment and sleep. Dementia caregivers are responsible for managing many different tasks that impact their well-being over time. The data analyzed demonstrates that spousal dementia caregivers who were employed experienced significantly poorer sleep quality in comparison to unemployed spousal dementia caregivers. Although there is a gap in the caregiving literature examining the direct correlation between employment and sleep quality within the dementia caregiving population, research has shown that employment plays a role in contributing to overall stress in dementia family caregivers (Liu et al., 2019; Sadavoy et al., 2021). Dunham & Dietz (2003) found that employed caregivers reported higher levels of caregiver stress due to conflicts in role strain. Role strain can result when caregivers make adjustments at work and home to be able to provide quality care for the PLwD. Employed caregivers have reported cutting down hours at work and taking personal calls during work to attend to the PLwD (Ory et al., 1999; Lilly et al., 2010). Furthermore, literature has shown that stress in dementia caregivers correlates with poor sleep quality as they can experience negative feelings or thoughts through the night (McCurry et al., 2007; McCrae et al., 2014). Employed caregivers experiencing burden associated with caregiving duties may report conflicts in role strain and persistent anxious thoughts that lead to worsening sleep quality.

The findings of this thesis indicate a significant interaction between spousal caregivers and employment status. Specifically, where spousal caregivers moderated the effect of employment on PSQI scores. Results from the study demonstrate that employed spousal caregivers report worse sleep quality in comparison to non-spousal caregivers, whereas a distinction was not seen in non-spousal caregivers based on employment status. Literature has demonstrated that spousal caregivers display declines in sleep patterns, such as the time spent sleeping and the quality of sleep, as a result of caregiver stress (Gallant & Connell, 1998; Mahoney et al., 2005). One explanation as to why spousal caregivers are at risk for poor sleep quality is that spousal caregivers are more likely to share a bed with the PLwD. Although living with the PLwD was controlled for in the analysis, there was no data on whether caregivers shared a bed with the PLwD. Therefore, spousal caregivers are more likely to have their sleep impacted by caregiving interferences.

In particular, results of this study showed that employed spousal caregivers experience worsening sleep when compared to unemployed spousal caregivers. These findings suggest that spousal caregivers who are employed are at greater risk for poor sleep quality than unemployed spousal caregivers. Employed spousal caregivers may experience greater risk for poor sleep quality than unemployed spousal caregivers due to role strain. Alongside managing care taking tasks and work, spousal caregivers who work outside the home may be more worried about leaving the PLwD at home. Taken into consideration, these may induce more stress for employed spousal caregivers than unemployed spousal caregivers. Nonetheless, non-spousal caregivers are at equal risk for poor sleep quality regardless of employment status. One explanation as to why non-spousal caregivers such as adult-children, friends or neighbors, are at equal risk for poor sleep quality regardless of employment status is that they may have other responsibilities such as providing care and attention to their own young children or not feel as close to the PLwD as spouse would (Pinquart & Sorensen, 2011). Results from this study are consistent with research on caregiver-care recipient relationship and health outcomes such as sleep quality and caregiver burden. Conde-Sala et al., (2010) studied the differences between adult-children and spousal caregivers. They found that from a sample of 251 family caregivers (spouse N= 112; adult-child N= 139), the relationship to the care recipient played an important factor in determining health outcomes, such as sleep quality and depressive symptoms in caregivers. Their findings concluded that interventions should be targeted differentially at caregivers due to how the relationship with the PLwD is associated more with caregiver health outcomes than age or physical health (Conde-Sala et al., 2010). Thus, the relationship to the PLwD plays an important role in impacting sleep quality in dementia caregivers.

In this study, dementia caregiver age, gender, education, hours providing care per week, and living with the PLwD were not associated significantly with sleep quality, suggesting that sleep quality is unrelated to these demographic factors among this sample. However, Wilcox & King (1999) found that caregiver age, education and employment status was associated with sleep complaints in caregivers who are women. They found that from their sample (N = 90), 33% of caregivers who were employed outside the home faced more challenges to caregiving due to competing roles (e.g., family, employment, caregiving). Furthermore, they found that caregivers who were less educated reported overall more sleep problems and caregivers who were older, such as spousal caregivers, experienced poor sleep quality (Wilcox & King, 1999). Contrary to the findings of this study, Wilcox & King (1999) found no correlation between caregiver relationship to the care recipient and sleep quality.

Although dementia caregiver age, gender, education, hours providing care per week, and living with the PLwD were not associated significantly with sleep quality, this thesis's findings show that dementia severity correlates with sleep quality in caregivers. The Dementia Severity Rating Scale (DSRS) was used to assess the degree of dementia severity in the PLwD. Participant's whose care recipient had higher dementia severity scores also reported worse sleep quality. In line with the literature, dementia severity directly impacts sleep quality in caregivers (Creese et al., 2008; McCurry et al., 2008). Furthermore, Simpson & Carter (2013) examined sleep in dementia caregivers (N = 15) and found that the causes of poor sleep quality can arise from daytime and nighttime behaviors of the PLwD such as agitation, sundowning and wandering. As dementia severity increases in PLwD, caregivers report poor sleep quality due to the increasing symptoms and responsibilities added. Gibson, Gander & Jones (2013) looked at sleep disturbances experienced by PLwD and their family caregivers (N = 24). They found that for caregivers, the PLwD's behaviors such as sundowning contributed to sleep disruptions. Confused awakenings, disorientation and restlessness are symptoms of dementia severity which contribute to caregivers experiencing poor sleep quality as they are woken up mid-night to aid the PLwD (Gibson, Gander & Jones, 2013). Thus, dementia severity may be most prominent in explaining why sleep quality is impacted in caregivers.

Limitations

The sample in this study primarily self-identified as white and reported high socio-economic status. Thus, the sample in the study was not nationally representative and may not generalize to a diverse group of dementia caregivers. Furthermore, the coding for whether the caregiver was employed for pay outside the home in the survey was dependent on subjective interpretation. Participants who work full-time within the home may have not been accounted for depending on the participants interpretation and self-report. Caregivers whose relationship to the care recipient was non-spousal were grouped together. Those that cared for their parents, friend or neighbor were analyzed together despite categorical differences between these groups. A friend or neighbor may be affected differently than an adult-child or spouse. Furthermore, spousal caregivers are also older caregivers, thus age is a variable that may also influence employment status and sleep patterns. However, age was controlled for in our analyses.

Conclusions

Dementia caregivers face significant risk for experiencing worsening sleep quality. In particular, employed spousal caregivers experience worsening sleep when compared to unemployed spousal caregivers. Employment has shown to increase stress in caregivers, which is associated with worsening sleep quality. Additionally, dementia severity was found to impact sleep quality in caregivers regardless of relationship to PLwD. These findings suggest that employment, relationship to the PLwD and dementia severity impact risk for poor sleep quality in dementia caregivers. Caregivers could benefit from intervention practices that increase sleep quality. Sleep interventions such as cognitive-behavioral therapy for insomnia (CBT-I), practicing mindfulness and relaxation have been proven to be effective in improving sleep quality and mood in caregivers (McCurry et al., 2015). Such practices could off-set negative health outcomes associated with worsening sleep harmful to both the caregiver and ultimately the care recipient.

Future Research

This study examined the association between employment status and sleep quality as well as how the relationship to the PLwD moderated this association. Future longitudinal studies observing which parts of employment such income, full-time versus part-time, specifically impact sleep quality and how the relationship to the care recipient moderates the association could determine interventions needed for dementia caregivers. Looking at different forms of intervention may aid dementia caregivers in forming techniques to combat poor sleep quality.

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Table 1. Sample characteristics for caregivers of persons living with dementia; (N = 100)

Variable	Mean or %	SD
Age	63.73	16.15
65 and older	55.00	
Gender		
Female	74.00	
Male	26.00	
Education		
College or greater	72.00	
Less than college	28.00	
Employed	33.00	
Relation to PLWD		
Spouse	59.00	
Non-Spouse	41.00	
Primary Race		
White, Caucasian	80.00	
Black, African-American	12.00	
Asian	2.00	
Other	4.00	
Living with PLWD	75.00	
Hrs/week Providing Care	54.29	37.23
DSRS Total	24.88	11.13
PQSI Global	6.91	3.53
PQSI Cutpoint	59.00	

Note. DSRS = Dementia Severity Rating Scale; PSQI = Pittsburg Sleep Quality Index.

Table 2. Regression Analysis of the Association Between Sleep and Employment

Model	B	β	SE
Constant	14.81	0.00	4.42
Age			
65 and older	1.49	0.21	1.28
Gender			
Female	0.99	1.12	0.80
Education			
College or greater	-1.29	-0.17	0.78
Race			
Non-White	0.03	0.003	0.93
Relationship to PLwD			
Spouse	-7.28*	-1.11	3.11
Hrs/Week Providing Care	0.02	0.21	0.01
Living with PLwD	-1.75	-0.22	1.05
DSRS Total	0.70*	0.22	0.34
Employment Status			
Employed	-6.08*	-0.82	2.72
Employment*Spouse	5.31**	0.97	1.99
Goodness of Fit			
F(df)	3.17(10), *p*<.01		

Notes. Includes all covariates; **p*<.05, ***p*<.01, ****p*<.001; B = beta estimate, β = standardized beta estimate, SE = standard deviation for unstandardized estimates, PLwD = person living with dementia.

Figure 1. Association of Relation to Care Recipient with Sleep Impairment by Employment Status