Original Article

Sleep Disturbance in Informal Caregivers of Persons with Dementia: **Systematic Review**

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Abstract

Background: Dementia is one of the most pervasive neurogenerative illnesses. It has been a huge burden on the health care system and families to care for and support persons with dementia (Cao et al., 2020).

Aim: The aim of this systematic review was to synthesize and examine the literature on sleep disturbance in informal caregivers of patients with dementia.

Methods: PRISMA guidelines were followed to identify articles. An extensive search of scholarly databases was conducted to conduct the review. The search was conducted utilizing the four databases: PubMed, CDSR, PsycINFO, and CINAHL. The timeframe for the literature search ranged from January 1, 2010, to January 1, 2022. The following key terms were used to search the literature: Alzheimer's, dementia, Lewy, vascular dementia, AND caregivers, family caregivers, caregiving, informal caregivers, AND sleep, sleep quality, sleep disorder, sleep disturbance. The inclusion criteria in this review were limited to English language articles, involved adult participants, published in a peer-reviewed journal, measured sleep in caregivers, discussed sleep quality or disturbance in caregivers, and reported a factor affecting sleep or sleep as an outcome.

Results: By conducting a systematic search, a total of 921 articles were identified. Only 14 articles met the inclusion criteria. The 14 articles were grouped into two categories: Measurement of sleep and finding and factors associated with sleep disturbance.

Conclusions: The results indicated that poor sleep quality and sleep disturbance are high among caregivers of person with dementia. Sleep disturbances among caregivers were associated with anxiety, depression, and physical fatigue. Study findings suggested that caregivers of dementia patients often experience emotional strain, so improving sleep quality may have a positive impact on their psychosocial well-being. Conversely, anxiety, depression, and stress emerged as significant predictors of poor sleep, Thus, managing negative factors associated with caregiving may positively impact sleep quality.

Keywords: Dementia, Alzheimer, Caregivers, Family Caregivers, Sleep, sleep disturbance, Sleep quality.

Introduction

Dementia is one of the most pervasive neurogenerative illnesses. It induces impaired thinking, memory loss, and declining ability to perform activities of daily living. According to many statistics, the global number of people living with dementia was estimated at 50 million in 2020, and the number will almost triple by 2050 Dementia (Alzheimer's Association, 2020).

accounts for the most considerable contribution to disability in developing countries as the number of older people rapidly increases (Cao et al., 2020). In addition, it has been a huge burden on the health care system and families to care for and support persons with dementia (PWD) (Cao et al., 2020). Globally, the cost of dementia has been approaching US \$1 trillion every year (Cao et al., 2020). Dementia is considered one of the most challenging age-related diseases for caregivers due to the patients' loss of independent functioning, such as grooming, bathing, memory loss, and eating problems (Gao et al., 2019). This challenge increases the responsibilities of the caregivers as the health of the people with dementia deteriorates and it becomes similar to adding a part-time job. Caregivers are persons who routinely provide direct care to others who are limited by chronic conditions (Amankwaa, 2017). There are two types of caregivers - - formal and informal. Formal caregivers are those who are either paid or volunteer employees while informal caregivers are typically family members, relatives, or friends who are the primary sources for providing care for another person (Amankwaa, 2017). Most of the care for PWD is provided by family members who are informal caregivers. In the United States, eightythree percent of the care provided to persons with disabilities is provided by informal caregivers (Alzheimer's Association, 2020). In 2020, friends or family members provided nearly \$257 billion in unpaid care while caring for PWD (Alzheimer's Association, 2020). According to some statistics, 16 million adults in the United States spend more than 20 hours per week serving as caregivers for PWD (Pignatiello et al., 2021). Caregiving typically involves tasks that may be uncomfortable or physically exhausting, unpleasant, and psychologically stressful. Much research has shown that informal caregivers experience a high levels of stress and low levels of physical and mental wellbeing (Amankwaa, 2017). Informal caregivers play a crucial role in supporting PWD throughout their illness and are considered one of the greatest health system resources. Primary caregivers also provide emotional support and coordinate with the other family members to organize the care and ensure safety for the PWD. Sleep is one of the important domains that is more likely to be affected when caring for a PWD. Getting good sleep is considered a high priority for most people and poor sleep is more common among caregivers of PWD (Pignatiello et al., 2021). Poor sleep can negatively affect the caregiver's physical and psychological health (Smyth et al., 2020). There is cumulative evidence that PWD have a variety of sleep problems or disturbances because of the neurological disease of dementia that may affect the sleep-wake variations (McKibbin et al., 2005). Research also has shown that 70% of PWD in the early stage have sleep disturbances (Fonareva et al., 2011). Poor sleep and altered circadian rhythms in PWD are predictive of poorer outcomes, including severe neuropsychiatric symptoms, aggression, agitation, and poorer daily function (Fonareva et al., 2011). Caregivers for PWD face particular challenges during the moderate to severe stages of dementia while their care recipients experience losses in orientation, judgment, and effective communication, such as physical and verbal aggression (Alzheimer's Association, 2020). PWD also require increasing levels of supervision as the symptoms worsen. Providing long-term care for PWD seriously impacts the caregiver's quality of life and exposure to high levels of stress over time adversely affects the caregiver's overall health and particularly their quality of sleep. Further, caregivers' sleep can be affected by the tasks performed while providing care to PWD (Peng et al., 2019). Over time, disturbance of sleep can lead to such negative health consequences as fatigue, depression, and stress (Peng et al., 2019). Caregivers' poor sleep is associated with increased sleep medication usage and daytime dysfunction (Peng et al., 2019). In addition, various physical or mental health conditions can affect caregivers' sleep. According to a research study, approximately 67% of caregivers reported the use of sleep medications (Peng et al., 2019). Moreover, research has shown that the Pittsburgh Sleep Quality Index (PSQI) indicated that most family caregivers reported poor sleep quality (Peng et al., 2019). Caregivers experience short durations of total sleep time and greater frequency of awakening (Peng et al., 2019). Declines in caregiver health can diminish their ability to provide optimal care, which may place the care recipient at risk for neglect or medication/treatment errors (Peng et al., 2019). Caregivers' sleep issues are growing because of the increased demand for informal caregivers, and sleep disturbance in this population is underaddressed.

The objective of this systematic review was to synthesize and examine the literature on sleep disturbance in informal caregivers of persons with dementia (PWD).

Methods

This systematic review was conducted in compliance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses PRISMA statement (Page et al.,2021). The PRISMA statements consist of a four-phase flow diagram and a 27-item checklist. PRISMA focuses on ensuring the complete and transparent reporting of a systematic review. Using the PRISMA helps to optimize the review process and the quality of the reporting (Page et al.,2021).

In general, the selection of keywords has a significant impact on the results of the systematic review. It is important to filter the number of published articles and narrow down the results to reflect those that are relevant. For this review on sleep disturbance in caregivers of PWD, the following key terms were used to search the literature: Alzheimer OR dementia OR Lewy OR vascular dementia AND caregivers OR family caregivers OR caregiving OR informal caregivers AND sleep OR sleep quality OR sleep disorder OR sleep disturbance. The timeframe for the literature search ranged from January 1, 2010, to January 1, 2022. The range for this timeframe was determined to reflect the most recent information and articles published related to sleep disturbance and caregiving for persons with PWD. The search was conducted using the following four databases: National Library of Medicine (PubMed), Cochrane Database of Systematic Reviews (CDSR), PsycINFO, The Cumulative Index to Nursing and Allied Health Literature (CINAHL). PubMed provided access to the literature from biomedical and health from MEDLINE and other resources. The CDSR is considered the leading journal and database of systemic review in health care; It attempts to appraise and synthesize empirical evidence and reflect the finding in new evidence. The PsycINFO database provided access to literature in mental health and behavioral science produced by American Psychology Association. The CINAHL covers the literature in nursing, therapy, nutrition, physical dietetics. and occupational therapy; It includes books, book chapters, and dissertations. Together, these databases were selected in order to identify peerreviewed articles across many disciplines, including psychology, nursing, social care, and medicine.

The types of studies included in this review were quantitative, qualitative, observational, and crosssectional. This broad representation of study designs facilitated the investigation of sleep disturbance among family caregivers of PWD and the identification of the effects of sleep disturbance

across different caregiver populations. In addition, it helped to determine which outcomes were most important for the caregivers, their care recipients with dementia, health care professionals, and other stakeholders. The studies included in this review were limited to the English language and were restricted to adult participants. The following criteria were used to determine whether a study was included in the review: 1) Publication in a peerreviewed journal; 2) Included informal caregivers of persons with PWD; 3) Discussed sleep quality or disturbance in caregivers; and 4) Measured sleep in caregivers; or 5) Identified sleep as an outcome; or 6) Reported a factor affecting sleep. Research that included paid or formal caregivers and intervention studies were excluded from this systematic review. The study also involved financial and pharmaceutical ethical issues, and nonpharmacological treatments ,books, theses and dissertation were excluded.

Results

This systematic review was conducted in compliance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses PRISMA statement (Page et al., 2021). The results are summarized in the PRISMA flow diagram (Figure 1). Accordingly, in the initial stage of this systematic review, a total of 921 articles were identified through database searching. These articles were downloaded into Zotero reference manager software, version 6.0 (Corporation for Digital Scholarship, 2021). The PRISMA Flow Diagram indicates the processes used for the extraction, search, and identification of articles that met the inclusion criteria. Of the total of 921 articles found, 196 articles were from PubMed using Mesh term and advanced search technique, 267 articles were from PsycINFO, 267 articles were from CINAHL, and 191 articles were from CDSR. Using Zotero, 344 duplicates were identified. Following the removal of these duplicates, 577 articles remained to be screened.

During the screening, 21 articles were removed because they were written in a language other than English. After screening the titles and abstracts of the remaining articles according to the PRISMA guidelines, 452 more articles were excluded for not meeting the inclusion criteria. The primary reasons for exclusion were: 1) No examination of sleep quality or sleep disturbance as an outcome (183 articles); 2) Intervention studies (129 articles); 3) care recipients had disorders other than dementia (56 articles); 4) Involved financial or ethical issues (8) articles). and 5) Pharmacological or nonpharmacological treatment (76 articles). The full text of the remaining 104 articles was examined for eligibility and 87 articles were excluded based on the following criteria: 1) Not related to sleep in caregivers (42 articles); 2) Did not involve informal dementia caregivers (35 articles); 3) Dissertation (6 articles); and 4) sleep disturbance was not the outcome (7 articles). As a result, a final total of 14 articles met all pre-stated eligibility criteria and were included in this systematic review. For the purpose of further analysis and discussion, the 14 articles were grouped into two categories: 1) Measurement of sleep and associated findings (5 articles); and 2) Factors associated with sleep disturbance (9 articles).

Study characteristics: The 14 studies comprising this systematic review were published between 2010 to 2022 (Table 1). These 14 studies are summarized in terms of their authors, dates of publication, study participants, research designs, objectives, form of sleep measurement and findings in caregivers, and factors associated with sleep disturbance in caregiving.

Measurement of sleep and finding: From the 14 studies, 5 fell under the measurement of sleep and associated findings category, which can be found within the six columns in the summary table. The Pittsburgh Sleep Quality Index (PSQI) was used most frequently as a subjective measure to assess self-reported sleep quality in the past months. Two studies used wrist Actigraphy as an objective instrument to assess sleep over seven days. One study used the Epworth Sleepiness Scale (ESS) to measure daytime sleepiness. The findings from these studies indicated that the family caregivers of PWD were found to experience poor sleep quality regardless of the living arrangement (Song and Kim, 2021). Four studies reported the use of a sleep medication among family caregivers of PWD.

Factors associated with sleep disturbance: From the 14 studies included in this systematic review, 9 studies fell under the category of factors associated with sleep disturbance, as indicated in the 7 columns in the summary table. The findings indicated that depressive symptoms contributed most significantly to diminished sleep quality in family caregivers of PWD. One study reported that the subjective sleep quality subscale was associated with agitation, apathy, and depression. Further, PSQI scores were significantly associated with anxiety and depression. One study found that significant factors that affect sleep quality in caregivers of PWD were their depression and education level.

Discussion

The aim of this systematic review was to synthesize and examine the literature on sleep disturbance in caregivers of PWD. Through this review, the opportunity emerged to examine the methods used to measure sleep quality in informal caregivers of persons with PWD as well as factors associated with their sleep disturbance. Based on the findings, various instruments were identified to evaluate sleep, including the assessment of sleep by subjective and objective methods. In this review, the objective instrument used to assess sleep was Actigraphy. The most frequently used subjective measure to assess sleep quality was the Pittsburgh Sleep Quality Index (PSQI).

An assessment of subjective sleep quality for the past month can be obtained by completing the PSQI, a self-report questionnaire (Buysse et al., 1989). The PSQI assesses sleep experience on seven subscales: sleep latency, subjective sleep quality, depression, sleep medication use, sleep duration, sleep disturbances, efficiency. (Buysse et al., 1989). The PSQI continues to be the gold standard of self-report measures, with high reliability and validity (Buysse et al., 1989). A PSOI global score of five or below means good sleep quality, while a score of more than five means poor sleep (Buysse et al., 1989). Poor sleep quality and sleep disturbance were the most frequently reported problems and were described in the 14 studies. The majority of the studies revealed that the global score of the PSQI was high in the family caregiver of PWD. Further, family caregivers of PWD not only suffer from poor sleep or insufficient sleep but also increased daytime dysfunction and increased sleep disturbances (Peng, 2013; Song and Kim, 2021). The findings from the review indicated that both non-cohabitating and cohabitating caregivers of PWD experienced poor sleep quality compared to non-caregivers (Song and Kim, 2021). According to the studies in the review, having a PWD in the family, regardless of living arrangement, may result in poor sleep quality (Song and Kim, 2021). The findings from the review also showed that family caregivers of PWD were found to have a high risk of cognitive impairments, poor physical health conditions, and poor psychological health, including stress, anxiety, and depression (Peng, 2013; Song and Kim, 2021). Further, the higher use of sleep medications among family caregivers shows the difficulty that caregivers have in trying to obtain good sleep.



Figure(1): PRISMA Flow Diagram of the Selection Process of the Studies

Authors	Date	Participants	Research Design	Objectives	Measuring of sleep in caregivers and finding	Factors associated with sleep disturbance in caregiving
Song & Kim	2021	201,679	Retrospective, cross-sectional	-Examine associations between dementia caregivers and poor sleep quality in cohabitating, non- cohabitating caregivers compared to non-caregivers.	- PSQI>5 - Global PSQI scores was higher in both cohabitating and non- cohabitating caregivers than non- caregivers	- the finding indicated that family caregivers of PWD experienced poor sleep quality regardless of living arrangements.
Simpson& Carter	2013	80	Nonexperimenta l cross-sectional design	- To examine the caregivers' quality of sleep, especially relative to the nighttime, daytime behaviors, and psychological symptoms exhibited by a person with dementia.	- PSQI>5 -7.51 was the mean score for global sleep quality for the caregivers, which indicated poor sleep	 -PSQI score was related to depression and gender. - the most significant contribution variable in sleep quality were depression symptoms in comparison with all other variables. - Sleep quality subscale was associated to apathy, agitation, and depression.
Smyth et al.	2020	104	Cross-sectional, descriptive, correlation design	 -To explore the Sleep Characteristics and disturbance among Australian caregivers of a PWD. -Evaluating the association between psychosocial wellbeing and sleep in caregivers. - Understand the factors that influence sleep quality in caregivers 	 -PSQI used to assess the quality of sleep. -94% reported poor sleepers. -85% difficulty initiating sleep. -72% difficulty maintaining sleep. -34% reported using sleep medication 	 76% of caregivers were female. -44% had two or more co-morbidities. PSQI scores indicated a significantly positive association with anxiety and depression. The finding identified stress as a significant predictor of sleep quality.

Caregivers: A Longitudinal Study with a Focus on the Effects of Major Patient Transitions on Sleep. *Sleep*, 35(2), 247–255.

Peng et al.	2018	43	Cross-sectional	-Identify factors associated with family caregivers' sleep	 Subjective sleep quality was assessed using the PSQI. 92% of caregivers had a PSQI >5 , indicating poor sleep quality. The objective sleep assessment Actigraphy was used to assess sleep over 7 days. Objectively, caregivers had frequent awakenings, , a short total sleep time, and poor sleep efficiency. 	 Poor sleep was associated with sleep medication usage, and more daytime dysfunction. Caregivers with higher depressive symptoms, care recipients' sleep, poor sleep hygiene, and burden were related to more sleep problems, including more sleep medications use.
Park et al. (Park et al., 2021)	2021	156	Descriptive study	- Identify the factors that impact the sleep quality in family caregivers of PWD in South Korea.	 Daytime sleepiness was measured with the Epworth Sleepiness Scale (ESS). the Pittsburgh Sleep Quality Index (PSQIK)Korean version measured sleep quality. The mean sleep quality score indicates poor quality of sleep. 	 The finding reported that depression and education level were the significant factors affecting sleep quality in caregivers of PWD. The finding proposed that it is necessary to check the depressive status of the family caregivers and the cause of depression and mitigate them.
Chiu et al. (Chiu et al., 2014)	2013	180	Cross-sectional	- In this study, the stress process model of multilevel stressors was used to examine the sleep disturbances of caregivers of persons with dementia.	 Chinese General Sleep Disturbance Scale (GSDS) was used to measure sleep disturbance. 179 Family caregivers reported worse sleep quality. Dozing in the daytime was an experience by the majority of family caregivers. 55 used substances to help with sleep. 	-The finding indicated that family caregivers' sleep disturbance was not significantly related to a person with dementia demographic characteristics. - The finding proposed that physical fatigue and depressive symptoms were the most significant factors associated with family caregivers' sleep disturbance and the synergistic effect of both.
Merrilees et al.	2014	22 Caregivers (9 semantic dementia (SD) and 13 behavioral	-Quantitative	-to study sleep characteristics in patients with frontotemporal dementia(FTD) and their family caregivers.	 -Actigraphy was used to measure sleep and activity data for two weeks. -PSQI was used to assess the sleep quality of the caregivers during the last month. -PSQI score for bvFTD caregivers was 7.8 	 -patients with bvFTD reported more often nighttime disruption than semantic dementia(SD). - there was a strong positive correlation between the caregiver distress related to sleep disruption and nighttime behaviors in person with bvFTD.

		variant FTD (bvFTD)).			 -PSQI score was 4.9 for SD caregivers. -the result of the Messile et al. study indicated poor sleep quality for bvFTD and adequate quality for SD caregivers. -One of the studies reported that around 54 percent of bvFTD caregivers take sleep medications three times a week or more. In addition, the review from one study shows that the worry, anxiety about the patients, and other issues such as health care-related decisions prevent the caregivers from having a good sleep at night. 	 -Female caregivers reported poor sleep quality compared to male caregivers. - In a study of bvFTD caregivers, 54 percent reported taking sleep medications. -Daytime dysfunction was reported in 92% caregivers of bvFTD. -37% of SD caregivers reported daytime dysfunction. -the presence of depression, being overcommitted at work, and a lower level of social support were factors associated with poor sleep quality.
Cupidi et al.	2012	80 caregivers and 150 controls	observational study	- Studying subjective sleep quality and its impact on Quality of life (QoL) in caregivers of Alzheimer's disease (AD) and Parkinson's disease (PD).	-PSQI used to evaluate sleep quality -PSQI score >5 in caregivers of patients with AD and PD. -Sleep disturbance is considered to be a major nighttime problem.	 Poor sleep quality is significantly associated with poorer perceived quality of life in caregivers of patients with AD and PD. Poor sleep is significantly associated with depression symptoms
Lee et al.	2014	-132 caregivers of patients with amnestic mild cognitive impairment (aMCI) and dementia. -56 non- caregivers control group.	- Prospective study	-The purpose of this study is to identify sleep patterns and sleep disturbances among caregivers of patients with amnestic mild cognitive impairment (aMCI) and dementia.	 PSQI was used to measure sleep quality. Cronbach's alpha in the study was 0.732 Both caregivers (aMCI and dementia caregivers) had significantly higher PSQIs than non-caregivers. The GDS contributes to the variance of the experience of quality of sleep in dementia caregivers. 	 -the Geriatric Depression Scale (GDS) was higher for dementia caregivers than for the control group. -there is a significant relationship between the age of the caregiver, education years of the caregivers, Insomnia Severity Index (ISI)score, and PSQI global score. -There were significant interactions between depression, appetite change, and PSQI global score in dementia caregivers. -ISI - Sleep disturbances were more common among spouse caregivers than offspring caregivers.

Gibson &Gander	2021	526	-cross-sectional study	- to explore the predictor factors associated with poor sleep in family caregivers of patients with dementia or cognitive impairment.	 Insomnia Severity Index (ISI) used to measure sleep -23.5% of carers scored moderate- sever range in ISI score. -Among caregivers, 43% scored in the mild range for ISI. -Approximately 30% of respondents rated their sleep as satisfactory. 	 Findings showed that women caregivers were more likely to suffer from sleep disturbance. -female caregivers were more likely to use sleep medications. There is an association between ISI score and the number of waking symptoms of the care recipient. -less sleep triggered by stress, hormonal disruptions, unbalanced roles, and social life. The caregivers' sleep was predicted by the sleep of the care recipient. - anxiety and depression are exacerbating insomnia-related sleep disturbances.
Simpson &Carter The Impact of Living Arrangemen ts on Dementia Caregiver's Sleep Quality	2015	80 caregivers -59 community- dwelling caregivers were living with the patient with dementia (PWD. - 21 living apart from the PWD.	Secondary analysis of the non- experimental cross-sectional study.	Evaluate the sleep quality and health of caregivers who live with the PWD and caregivers that live apart.	 -PSQI used to measure sleep quality -Both groups reported poor sleep quality. -Caregivers living with PWD reported more sleep disturbance by PWD. -Caregivers living apart from PWD reported receiving a phone call from PWD (who was confused or disoriented) or a sibling at night to help calm PWD. 	 Regarding the living arrangement, both caregivers reported poor sleep quality. The study points out the necessity of assessing the sleep quality of caregivers who live apart from the PWD. there are no statistical differences in the health outcome between the two groups of caregivers. both caregivers experienced the same level of stress and depression.
Chen et al.	2019	-98 patients with AD and their spousal caregivers. -75 non- caregivers	-Quantitative study	Explore the sleep quality of caregivers of patients with Alzheimer's disease (AD). -examine the relationship between the neuropsychiatric symptoms of the patient with AD and	-PSQI used to measure sleep quality -Caregivers had increased sleep disturbance compared to non- caregivers.	 Anxiety and depression were significantly higher among caregivers than non-caregivers. the findings indicate a positive correlation between the psychiatric symptoms in patients with AD and the sleep quality of caregivers.

		control group.		the sleep quality of caregivers.		-Higher PSQI scores are associated with the caregiver's depression scores. - sleep disturbance is associated with the patient's physical and mental health.
Simpson &Carter	2013	15	Qualitative	Explore the lived experience of sleep in family caregivers of patients with Dementia	-PSQI is used to measure the Quality of sleep - the caregivers reported poor sleep quality.	 -Caregivers reported that their sleep fluctuated based on the PWD status. -the nighttime behavior of the PWD caused sleep disturbance in caregivers. -Caregivers' worry causes poor sleep. -5 caregivers reported using sleep aid to help with sleep. -Caregivers reported some activities to help with good sleep, such as exercise or journaling.
Kanel et al.	2012	109 spousal caregivers of people with AD. -48 non caregivers	Longitudinal study	-examine the caregivers' sleep and effects of dementia caregiving and major transitions in caregiving.	 -PSQI and actigraphy used to measure sleep. -PSQI higher in caregivers compared to non-caregivers. -PSQI increased by 1 point with the AD spousal death. -AD Spousal death associated with increased PSQI in older caregivers. 	 -caregivers whose spouses died experienced a decrease in nighttime sleep. There was a significant interaction between the depression symptoms and caregivers' status. -Caregivers had more depressive symptoms compared to non-caregivers. - Depressive symptoms are associated with a high PSQI score.

Discussion cont.

The findings from this review indicated that depressive symptoms and stress made the most significant contribution to their caregivers' sleep quality (Fonareva et al., 2011; Smyth et al., 2020). This finding contributes to the Previous work, which identified the association between poor sleep and depression in caregivers (Fonareva et al., 2011; Smyth et al., 2020) .In addition, the review found that poor sleep quality was associated with subjective feelings of stress, anxiety, and depression (Fonareva et al., 2011; Smyth et al., 2020)-this finding is consistent with the previous literature on psychosocial distress and caregiving. Family caregivers of PWD are often older, with significant levels of psychological distress and co-existing morbidities. In addition, there is a risk that the caregiver's physical and mental health may decline as their care recipient's dementia worsens and the need for continued, prolonged caregiving emerges (Fonareva et al., 2011; Simpson and Carter, 2013; Smyth et al., 2020). The most commonly reported factors associated with caregivers' sleep disturbance were stress and depression. Across all the studies, there was a significant association between sleep disturbance and depression. The overwhelming nature of the caregiving task may increase the risk of caregivers for developing depression. There are many factors that may interfere with sleep quality in caregivers, such as developing negative thoughts and feelings. A crosssectional design was used in most of the studies, which does not imply a causal relationship between sleep disturbance and depression as might be found in a longitudinal study. In this review, only one study evaluated the caregivers' gender, education level, and age in relation to sleep. None of the studies in the review reported any information about caregivers' current or previous diagnosis of sleep apnea or depression. The findings from this review indicated that the caregivers' sleep was associated with stress, presence of depression, care recipient's sleep, and chronic conditions. The findings from this systematic review were limited in that the majority of the studies were predominantly crosssectional designs with small sample sizes. Additionally, objective sleep measures were used far less frequently than subjective sleep measure instruments such as PSQI. However, objective measures of sleep may be challenging for caregivers

to wear as they go about their daily activities as they need to wear a device to measure their sleep. This systematic review contains studies that may be subject to reporting and selection bias because of its restrictions in terms of years of publication, use of the English language, and the four chosen databases. As a result, books, non-English reviews, dissertations, or theses were not included.

It is crucial to assess the severity and nature of sleep disturbances and increase consciousness of the serious health outcomes of poor sleep quality. Further studies are needed to measure the covariates such as preexisting sleep disorder to improve the evidence and knowledge about sleep disturbances in family caregivers of PWD. More research is needed to understand the variability in sleep disturbance in family caregivers from night to night. Further research is needed to clarify the associated factors among a more diverse population of caregivers using longitudinal designs to better understand the risk factors. Clinicians must provide support and education about sleep disturbance for informal caregivers of PWD. Additionally, providers need to consider practical interventions such as addressing stress management in caregivers. Finally, clinicians should screen caregivers' sleep quality and provide recommendations in order to improve their sleep quality. Indeed, improving sleep quality among caregivers of PWD is essential for enabling them to continue to provide safe and effective care for their care recipients. In conclusion, sleep disturbance and poor sleep quality are highly prevalent among caregivers of PWD. Anxiety, depressive symptoms, and physical fatigue were associated with caregivers' sleep disturbance. Understanding the relationship between risk factors and sleep disturbance may help to identify caregivers at high risk for developing sleep disturbance. Poor sleep quality in caregivers may have a negative consequence and may be connected with decreased ability to provide care. For example, they are unable to make reasonable judgments or forget to administer medications. Further, the findings from studies in this systematic review highlighted the correlation between emotional distress and sleep quality in dementia caregivers, suggesting that improving the sleep quality in family caregivers of PWD may benefit their psychosocial well-being. On the other hand, anxiety, depression, and stress are significant predictors of poor sleep, so managing negative factors associated with caregiving may positively impact sleep.

References

- Alzheimer's Association. (2021). Alzheimer's & dementia : the journal of the Alzheimer's Association, 17(3), 327–406.
- Amankwaa, B. (2017). Informal Caregiver Stress. ABNF Journal, 28(4), 92–95.
- Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh sleep quality index: A new instrument for psychiatric practice and research. *Psychiatry Research*, 28(2), 193–213.
- Cao, Q., Tan, C.-C., Xu, W., Hu, H., Cao, X.-P., Dong, Q., Tan, L., & Yu, J.-T. (2020). The Prevalence of Dementia: A Systematic Review and Meta-Analysis. *Journal of Alzheimer's Disease*, 73(3), 1157–1166.
- Chen, Y., Wang, J.-Y., Liu, X.-Y., Meng, F.-X., Li, A.-P., & Peng, G.-P. (2019). Sleep quality of spousal caregivers is associated with neuropsychiatric symptoms and living ability of patients with Alzheimer disease. *Chinese Medical Journal*, 132(12), 1490–1493.
- Chiu, Y.-C., Lee, Y.-N., Wang, P.-C., Chang, T.-H., Li, C.-L., Hsu, W.-C., & Lee, S.-H. (2014). Family caregivers' sleep disturbance and its associations with multilevel stressors when caring for patients with dementia. *Aging & Mental Health*, 18(1), 92–101.
- Corporation for Digital Scholarship. Released 2021. Zotero Reference Manager for Windows, Version 6.0, Fairfax, VA: George Mason University.
- Cupidi, C., Realmuto, S., Lo Coco, G., Cinturino, A., Talamanca, S., Arnao, V., Perini, V., Piccoli, T., D'Amelio, M., Savettieri, G., & Lo Coco, D. (2012).
 Sleep quality in caregivers of patients with Alzheimer's disease and Parkinson's disease and its relationship to quality of life. *International Psychogeriatrics*, 24(11), 1827–1835.
- Fonareva, I., Amen, A. M., Zajdel, D. P., Ellingson, R. M., & Oken, B. S. (2011). Assessing sleep architecture in dementia caregivers at home using an ambulatory polysomnographic system. *Journal of Geriatric Psychiatry and Neurology*, 24(1), 50–59.
- Gao, C., Chapagain, N. Y., & Scullin, M. K. (2019). Sleep Duration and Sleep Quality in Caregivers of Patients With Dementia: A Systematic Review and Meta-analysis. *JAMA Network Open*, 2(8), e199891.
- Gibson, R., & Gander, P. (2021). Factors associated with the sleep of carers: A survey of New Zealanders supporting a family member with cognitive impairment or dementia. *Dementia*, 20(3), 919–935.
- Lee, D., Heo, S. H., Yoon, S.-S., Chang, D.-I., Lee, S., Rhee, H.-Y., Ku, B. D., & Park, K.-C. (2014). Sleep Disturbances and Predictive Factors in Caregivers of Patients with Mild Cognitive Impairment and

Dementia. *Journal of Clinical Neurology*, *10*(4), 304–313.

- Merrilees, J., Hubbard, E., Mastick, J., Miller, B. L., & Dowling, G. A. (2014). Sleep in persons with frontotemporal dementia and their family caregivers. *Nursing Research*, 63(2), 129–136.
- Page M J, McKenzie J E, Bossuyt P M, Boutron I, Hoffmann T C, Mulrow C D et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews BMJ 2021; 372 :n71
- Park, H., Kim, E. K., Jeoung, S. Y., Moon, K. J., & Lee, E. S. (2021). The Comprehensive Factors Affecting the Sleep Quality in Family Caregivers of Patients with Dementia in the Community of South Korea. *Journal of Korean Gerontological Nursing*, 23(1), 85–95.
- Patterson, T. L., & Grant, I. (2005). Sleep in Spousal Caregivers of People With Alzheimer's Disease. *Sleep*, 28(10), 1245–1250.
- Peng, H.-L. (2013). Sleep in family caregivers of individuals with dementia. (UMI Order AAI3554488) [State University of New York at Buffalo].
- Peng, H.-L., Lorenz, R. A., & Chang, Y.-P. (2019). Factors associated with sleep in family caregivers of individuals with dementia. *Perspectives in Psychiatric Care*, 55(1), 95–102.
- Pignatiello, G. A., Martin, R., Kraus, N., Gutierrez, A., Cusick, R., & Hickman, R. L. (2021). Sleep Interventions for Informal Caregivers of Persons with Dementia: A Systematic Review. *Western Journal of Nursing Research*, 01939459211019033.
- Simpson, C., & Carter, P. (2013). Dementia Caregivers' Lived Experience of Sleep. *Clinical Nurse Specialist*, 27(6), 298–306.
- Simpson, C., & Carter, P. (2013). Dementia Caregivers' Lived Experience of Sleep. *Clinical Nurse Specialist*, 27(6), 298–306.
- Simpson, C., & Carter, P. (2015). The Impact of Living Arrangements on Dementia Caregiver's Sleep Quality. *American Journal of Alzheimer's Disease & Other Dementias*®, *30*(4), 352–359.
- Smyth, A., Whitehead, L., Quigley, E., Vafeas, C., & Emery, L. (2020). Disrupted sleep and associated factors in Australian dementia caregivers: A crosssectional study. *BMC Geriatrics*, 20(1), 312.
- Song, M. J., & Kim, J. H. (2021). Family Caregivers of People with Dementia Have Poor Sleep Quality: A Nationwide Population-Based Study. *International Journal of Environmental Research and Public Health*, 18(24).
- von Kanel, R., Mausbach, B. T., Ancoli-Israel, S., Dimsdale, J. E., Mills, P. J., Patterson, T. L., Ziegler, M. G., Roepke, S. K., Chattillion, E. A., Allison, M., & Grant, I. (2012). Sleep in Spousal Alzheimer

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