Factors related to sleep in family caregivers of people with dementia: A systematic review

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Abstract

Background: Family caregivers (FCGs) face many problems when taking care of people with dementia.
Purpose: This study wanted to explore the factors related to FCGs' sleep in people with dementia.
Methods: The study used a systematic review approach based on PRISMA. The study focused on FCGs for people with dementia in the home setting. A narrative synthesis was employed.
Results: The result showed that the sleep problem and severity of a patient with dementia have an essential role in their state. Those indirectly impact the FCGs' condition. The majority of the study's sleep problems were related to physical fatigue that influenced the FCGs' distress. Coping mechanisms have an essential role in the caregiver situation. A maladaptive coping mechanism would increase the stress of the caregiver and lead to a sleep problem.
Conclusion: The consequences of those are burden and depression. Therefore, FCGs should be supported by families, friends, and healthcare workers. Community online groups of the FCGs might be helpful to support each other.

Keywords: caregivers, dementia, depression, quality of life, sleep

Introduction

Japan is faced with an extraordinary situation centered on its rapidly increasing elderly population. In Japan, the aging trend hit 28.1% in 2018 and created a super-aged population (Japan Ministry of Health Labour and Welfare, 2015). This is a rather strange case, with no parallels found in the other countries of Asia. Besides, the number of older people with dementia has grown. It is estimated that this figure will exceed some 7,000,000 (20% of the elderly population) in 2025. Moreover, with the introduction of a community-based holistic care scheme, the percentage of elderly with dementia living at home is projected to rise. Moreover, an estimated 50 million older people worldwide suffer from dementia (Alzheimer's Association, 2017) with 10 million new cases per year. People with dementia (PWD) suffer a severe lack of control, mental conditions, and behavioral difficulties. Wandering behavior is a condition frequently displayed by PWDs that entails regular, repeated, time-disordered, and/or spatially-disordered lapping activities, random and/or pacing habits, absconding, as well as losing themselves, unless accompanied (Algase et al., 2007). Prior report showed that 6 out of 10 of community-dwelling PWDs have wandering activity (Alzheimer's Association, 2017) with incidence rates ranging from 17.4% for community-dwelling seniors, 50% for individuals with severe dementia, and 63% for community-dwellers (Cipriani et al., 2014). Dangerous wandering activities, such as absconding and missing outside (Algase et al., 2004), frequently lead to injuries (Pai & Lee, 2016; Rowe & Bennett, 2003). FCGs have the

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most challenging situation to control behavior due to wandering.

Caring for people with dementia puts a tremendous strain on family careers and is limited by the economic outlook, such as productivity loss, which impacts life quality (Shikimoto et al., 2018). It is also said that dementia is one of the disorders of burdening patients and one of the population of geriatric diseases (Matsushita et al., 2016). In comparison, the mental health status of elderly dementia FCGs is poor relative to that of elderly dementia-free caregivers. It is also believed that the stress caused by caring for them could be a factor in the collapse of home care and the neglect of the elderly. For the elderly with dementia, the value of informal human capital such as neighbors, colleagues, district groups and volunteers that will support the families in their neighborhood while strengthening public access is emphasized.

Although the demand for caregivers is growing, there is a reality that only family members typically assume their responsibility for caring for the elderly living in their families. However, the strain of caring for the elderly can have a significant effect on FCGs' quality of life, contributing to social alienation, financial challenges, and psychological and physical fatigue (Knodel & Nguyen, 2015). FCGs face multiple challenges to maintaining their other responsibilities, including child-rearing, employment, and marriages. The impact on FCGs is very nuanced (Chaobankrang et al., 2019). Many FCGs are unpaid and have no bargaining power (Tamdee et al., 2019). According to the study, most over-stressed FCGs did not undergo any instruction before taking care of the elderly (including those with dementia), mostly learning from practice, relationship, and appreciation. It is also stated that the factors associated with stress as FCGs were the health status of FCGs, faith in treatment, the partnership between FCGs and the elderly individual, and the economic burden of care, except for the condition of elderly with dementia (Tamdee et al., 2019).

All of those problems were found to impact directly and indirectly to FCGs' sleep. The previous study found that several aspects of carers' sleep were significantly predicted by factors such as depression, sleep hygiene, burden, and the sleep of care-receivers (Peng et al., 2019). Additionally, stress, depression, and anxiety were found to be major contributors to poor sleep (Almutairi, 2022). Therefore, the goal of this research was to find sleep-related factors in FCGs of elderly with dementia. Specifically, this study explored the factors that impact community FCGs, especially unpaid caregivers.

Methods

Search strategy

A literature search for relevant articles published between 1st January 2010 and 14th February 2020 was performed using several databases including Ovid, MEDLINE, and Web of Science with limitations of publication based on PICO (Table 1). The search terms were "family caregiver," "dementia," and "sleep." After searching for the articles by using each term independently, all of the search words were added together, "family caregiver" AND "dementia" AND "sleep."

Inclusion and exclusion criteria

The search was limited to human studies in English and Japanese with peer reviewing. The references from retrieved articles were reviewed for further relevant studies.

To be included, studies had to meet the following criteria (1) published from 1st January 2010 to 14th February 2020; (2) written in English; (3) with peer reviewing; (4) including at least one word related to caregiver and dementia in the title. Exclusion criteria were as follows: (1) paid caregiver; (2) intervention research / qualitative research / case reports / review or systematic review articles; (3) without full-text; (4) with no information on the factors related to sleep.

Screening

All of the authors did the screening. First, the researcher screened by checking for the same article and out of the topic. Then, the title was screened by using a minimum of one term of "family caregiver," "dementia," and "sleep." The final screening was done using the exclusion criteria. Those articles which were not full-text articles and no information on the factors related to sleep were excluded. Finally, there were 13 articles out of 30 articles obtained which matched with the inclusion criteria and which are shown in Figure 1. Critical appraisal tools from the Joanna Briggs Institute were used to check each relevant article's quality. The answers included yes, no, or not applicable. Critical appraisal was done by each author and discussed to decide

Table 1. PICO Settings

Study Design	publication data
Population	family caregivers caring for people with dementia in the home setting
Interest/Exposure	factors related to sleep in family caregivers of people with dementia
Comparison	-
Outcome	sleep in caregivers of people with dementia

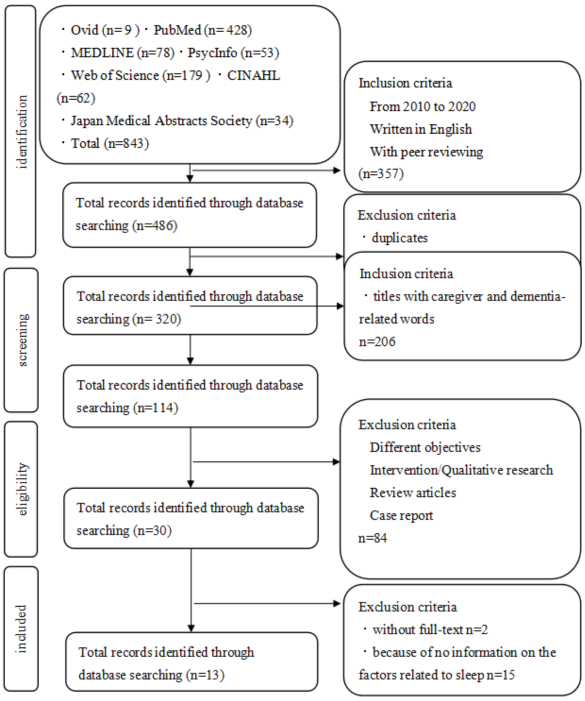


Figure 1. Study Selection Flowchart

low quality, medium, or high.

Results

A total of 843 articles were found from searching, although 357 of them were initially disqualified based on their titles. Of the remainder, 366 were rejected because they lacked full-texts, were off-topic, or duplicated. After applying the exclusion criteria, 101 studies were removed, leaving a total of 13 articles that met the inclusion criteria and which were included in this systematic review. The majority of studies (11) used the cross-sectional method and two studies used cohort.

The total number of FCGs who joined the studies was 2,762 caregivers, of which 273 were spousal, and 2, 257 family care recipients were identified in those studies. One study that involved non-FCGs had a total of 48 non-FCGs. Eight of 14 studies were conducted in the United States, three studies in Taiwan, and two studies in Japan. According to the relationship between patients with dementia and caregiver, mostly family members, most studies were as the primary caregiver and five studies were conducted on secondary caregivers. Three studies showed the family as the primary caregiver and did not use secondary caregiver, and four studies were conducted using a spousal caregiver. The details of the results are presented in Table 2.

Based on Table 3, the study from Japan and Taiwan explained the relationship of FCGs was dominated as child and parent relationship. The study from the United States (US) found the result that the relationship was dominated as spousal, except for one study dominated by child and parent relationship (Leggett et al., 2018). Besides, FCGs in Asia were younger than in the US. The youngest FCGs came from Japan (Mean ± sd = 50.4 ± 12.4) (Okuda et al., 2019) and the oldest came from the US (Mean ± sd = 78.8 ± 7.60) (von Kanel et al., 2014). In contrast, based on the results of the seven studies, the oldest care recipients were from Japan (Mean±sd=83.7±7.63) (Montgomery et al., 2018), and the youngest care recipients were from the US (Mean±sd=77.4±9.02) (Peng et al., 2019) and Taiwan (Mean±sd=77.6±8.62) (Chiu et al., 2014).

FCGs in Japan were quite equal between female and male (Okuda et al., 2019). However, the FCGs were dominated by the females in the Taiwan and US. The seven studies showed that most of the studies were dominated by females for care recipients. One study from Taiwan showed a slightly equal balance between male and female recipients (Chiu et al., 2014), and one study each from Japan and the US was dominated by male care recipients (Montgomery et al., 2018; Peng et al., 2019).

Sleep problems of FCGs

Wang et al. (2016) and Okuda et al. (2019) found FCGs' sleep problems were poor sleep quality by the mean of PSQI score was 8.1. Another study from Japan showed insomnia was one of the most common comorbidities that FCGs experience since becoming caregivers (Montgomery et al., 2018). The study by Chiu et al. (2014) explained the majority of sleep problems in their study were sleep quality problems (99.4%), dozing in the daytime (97.8%), and waking up before the sleep cycle ends (67.8%). Peng et al. (2018) reported that all of the FCGs reported at least one symptom of sleep

Table 2. Overview of the studies.

Author	Country	Primary or secondary	Sleep problems	Factors related to sleep
Okuda et al. (2019)	Japan	Family and secondary caregivers	AD patients diagnosed insomnia. Getting up during the night, sleeping excessively during the day, difficulty falling asleep, awakening too early in the morning, and awakening during the night.	Sleep disturbance in Alzheimer's patients
Chiu et al. (2014)	Taiwan	Family and secondary caregivers (22.2%)	The majority of sleep problems of FCGs were sleep quality problems, dozing in the daytime, and waking up before the sleep cycle ends.	FCGs' depression, fatigue, and the synergistic effects of physical fatigue and depressive symptoms
Polenick et al. (2018)	US	Family/spousal	FCGs had sleep disturbances	The higher number of medical/nursing tasks (especially wound care), and trouble falling back asleep after waking in the night
Wilson et al. (2019)	Ohio/US	Family and secondary caregivers (42.3%)	The mean of PSQI showed poor sleep quality	Short-allele carriers for 5-HTTLPR
Peng et al. (2019)	New York/US	Family and secondary caregivers (22.2%)	FCGs sleep was poor with short sleep duration and low sleep efficiency.	Presence of chronic-conditions, depression, burden, sleep hygiene behaviors, and care recipients' sleep.
Montgomery et al. (2018)	Japan	Family and secondary caregivers (39.7%)	The most common comorbidities that FCGs experienced since becoming caregivers were insomnia	Alzheimer dementia severity
Taylor et al. (2015)	US	Family/spousal	FCGs demonstrated moderate sleep apnea, lower than average sleep efficiencies, and significant sleep complaints.	Avoidant coping
Simpson and Carter (2013)	Texas/US	Family	FCGs had poor sleep efficiency and shorter sleep latency	The frequency of behaviors, and specifically of agitation and apathy,
Peng et al. (2018)	Taiwan	Family	FCGs felt at least one symptom of sleep disturbance with the mean score on the GSDS was poor	Younger FCGs, and eloping behavior
Wang et al. (2016)	Taiwan	Family and secondary caregivers (74.3%)	The average GPSQI was poor	Perceived stress from the frequency of the patient's behavioral and memory problems, and the reactions of caregivers to the patient's behavioral and memory problems
Leggett et al. (2018)	US	Family and secondary caregivers	FCGs sleep interrupted and nighttime awakenings.	Care of recipients with higher fall risk, FCGs with chronic medical conditions, the emotional difficulty of the caring role, and care provision interrupted sleep
von Kanel et al. (2012)	UCSD/US	Family/spousal		Spousal death
von Kanel et al. (2014)	UCSD/US	Family/spousal		Yearly increases in Positive Affect

*AD = Alzheimer's Dementia, PSQI = Pittsburgh Sleep Quality Index, HTTLPR = serotonin transporter-linked polymorphic region, GSDS = General Sleep Disturbance Scale, GPSQI = Global Pittsburgh Sleep Quality Index
*UCDS = University of California, San Diego; US = United States of America

Table 3. The study characteristics of FCGs and care recipients

Authors	Mean age of FCGs (sd)	Mean age of PWD (sd)	FCGs female (%)	Care recipient female (%)	Relationship status (%)		
					Spouse	Child	Other
Okuda et al. (2019)	50.4 (12.4)	82.8 (9.6)	50.2	72.2	4.8	84.5	10.7
Chiu et al. (2014)	56.0 (13.8)	77.61 (8.2)	50.6	65	40.6	55.6	3.3
Polenick et al. (2018)	75.57 (1.15)		59				
Wilson et al. (2019)	65 (12.5)		75		55.4	44.6	
Peng et al. (2019)	65.40 (9.84)	77.40 (9.02)	93	30.2	69.8	27.9	2.3
Montgomery et al. (2018)	53.89 (11.02)	83.70 (7.63)	45	78.7			
Taylor et al. (2015)	73.31 (7.05)		81.7				
Simpson and Carter (2013)	63.3 (12.8)	79.3 (9.1)	88.8	58.8	50.1	41.3	8.8
Peng et al. (2018)	56.0 (13.8)	77.6 (8.2)	65	50.5	40.6	55.6	3.4
Wang et al. (2016)	58.25 (12.88)		78		20.8	79.1	
Leggett et al. (2018)	59.1 (1.5)	80.7 (0.4)	61.1	55.6	35.1	40.6	24.3
von Kanel et al. (2012)	74.1 (8.1)		69.7				
von Kanel et al. (2014)	78.80 (7.60)		69.4				

Note: child includes son, daughter, son in law, and daughter in law; others, include siblings, relatives, and grandchild

disturbance, and the mean score on the General Sleep Disturbance Scale was 55.4 (sd = 36.2).

A study from the US showed 27.8% of FCGs had sleep disturbances on some nights, most nights, or every night in the last month (Polenick et al., 2018). Peng et al. (2019) measured subjective and objective sleep and found they were in agreement which indicated that FCGs sleep was poor with short sleep duration (Mean±sd =5.93±1.2 hours) and low sleep efficiency (79%). Furthermore, Taylor et al. (2015) reported that FCGs have moderate sleep apnea (AHI=10.10±8.39), lower than average sleep efficiencies, and clinically-significant sleep complaints by PSQI scores ≥5 (Mean±sd=6.25±3.2). Simpson and Carter (2015) reported that poor sleepers' sleep efficiency averaged 77%, and sleep latency was shorter (Mean±sd = 27±26.9 minutes). Leggett et al. (2018) found that approximately 20% of FCGs said they were "exhausted" when they went to bed at night as a result of their care duties, and 10% said caregiving caused their sleep to be interrupted most days or every day. FCGs commonly experienced nighttime awakenings as primary outcome: 7% said this happened every night, 10% reporting it happened most nights, and 31% reported it at least some nights.

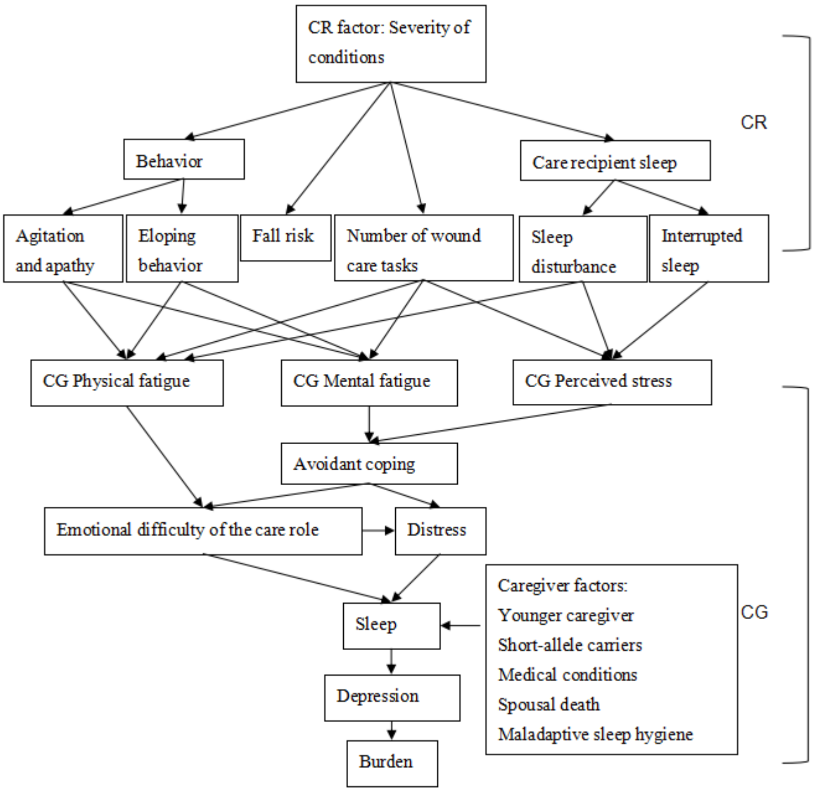
Sleep problems of care recipients

Okuda et al. (2019) found care recipients with sleep problems, with the number of AD patients diagnosed with insomnia by physicians was 50%. The most frequently reported sleep symptoms in the SDI were getting up during the night (84.3%), sleeping excessively during the day (76.8%), difficulty falling asleep (69.0%), awakening too early in the morning (67.5%), and awakening during the night (50.8%). Another study by Peng et al. (2019) explained that care recipients had been diagnosed with dementia for 6.79 years (SD = 3.35 years) with varying levels of sleep disturbances based on an average SDI score of 2.37 (SD = 2.13; range 0–6.98).

Factors related to sleep of FCGs

Factors related to FCGs sleep were divided into two groups. One included factors resulting from care recipients included sleep disturbance in Alzheimer's patients (Okuda et al., 2019), a higher number of medical/nursing tasks, in particular, wound care task (Polenick et al., 2018), care recipients' sleep (Peng et al., 2019), AD dementia severity (Montgomery et al., 2018), the frequency of behaviors that were specifically of agitation and apathy (Simpson & Carter, 2013), absconding behavior (Peng et al., 2018), the frequency of the patient's behavioral and memory problems (Wang et al., 2016), caring for care recipients with higher fall risk, care provision that interrupted sleep (Leggett et al., 2018) and spousal death (von Kanel et al., 2012).

The others were caused by FCGs or themselves. Those were FCGs' depression, fatigue, the



*CR = care recipient or elderly with dementia, CG = family caregiver, caregiver factor = the individual factor,] = scope of the factor, arrow = flow state between factors

Figure 2. The pathway of factors related to sleep in the FCGs

synergistic effects of physical fatigue and depressive symptoms (Chiu et al., 2014), short-allele carriers for 5-HTTLPR (Wilson et al., 2019), depression and sleep hygiene burden (Peng et al., 2019), avoidant coping (Taylor et al., 2015), younger caregivers (Peng et al., 2018), perceived stress (Wang et al., 2016), the reactions of caregivers to the patient's behavioral and memory problems, caregiver characteristics of more chronic medical conditions, the emotional difficulty of the caring role (Leggett et al., 2018) and yearly increases in positive affect (von Kanel et al., 2014).

Discussion

Care recipients' factors

Most of the studies showed sleep problems of care recipients and dementia severity as a significant factor that impacts the FCGs' sleep (Chiu et al., 2014; Leggett et al., 2018; Montgomery et al., 2018; Okuda et al., 2019; Peng et al., 2019; Simpson & Carter, 2013). The condition or severity of dementia increased the FCGs' task, which indirectly reduced the caregiver's time of sleep. Sleep disturbance and severity of dementia impacted the sleep of the FCGs and health, including depression, physical and mental fatigue, and burden. This was in line with the Alzheimer's Association (2018) which reported the impact of Alzheimer's caregiving emotion and well-being, health-related to sleep and finances. The previous studies showed having medical records in which a partner had dementia was associated with an increased risk of death in the following year after accounting for variations in FCGs' age (Alzheimer's Association, 2018; Christakis & Allison, 2006). Another study found that FCGs under pressure are at a greater risk for death than those who are not (Alzheimer's Association, 2018; Perkins et al., 2013), which was in line with the findings of the study that more caregiving-related distress and burden had more sleep problems and higher depression (Chiu et al., 2014; Montgomery et al., 2018; Peng et al., 2019; Wilson et al., 2019). Thus, the sleep and health problems of FCGs' impacted their lifespan as well in the long time.

FCGs' characteristics factors

The characteristics of FCGs have potential factors which influence sleep. One study showed younger caregivers and employed tend to have higher chance of getting sleep problems because the problem might source from the elderly and their children (Montgomery et al., 2018; Peng et al., 2018). Also, that study showed that most FCGs were male, in line with the previous study in the United States that showed older male spouse FCGs was the factor related to sleep efficiency (Mills et al., 2009; von Kanel et al., 2012). Moreover, another study from Japan showed that sleep disturbances negatively affected the burden and health of younger caregivers such as sons and daughters of their care recipients than other classes of aged people such as spouses of care recipients. In contrast, Chiu et al. (2014) showed age and gender did not correlate with sleep disturbance. It might be the potential sleep problem was related to employed young male as the son relationship and older male as a spouse of care recipients. Further study needs to explore FCGs' age, gender, relationship status, employment status, and the interaction to explore the relationship with sleep problems.

Despite the fact that FCGs used secondary caregivers, the stress and burden related to sleep problems could not be permanently reduced. One study showed the presence of a foreign helper would help to reduce mental and physical fatigue. FCGs tried many efforts to help their sleep, which included pharmacology, paying secondary caregivers, asking for help from relatives, and nursing homes. For problems of FCGs which were hard to solve, they might use cultural support such as social support from the relatives, change primary FCGs with siblings periodically, and financial support to help the FCGs' stress. Further studies need to explore factors related to cultural support.

As shown in Figure 2, coping has a significant role in decreased or increased stress. There are two mechanisms of coping, avoidant and approach. Avoidant coping is described as ineffective efforts to suppress excessive or distracting thinking, and approach coping is vice versa (Taylor et al., 2015). Avoidant coping, considered as maladaptive coping, would lead to being distressed and emotional role problems. The accumulation of those problems over a long period would become a sleep problem for the FCGs. Subsequently, FCGs would begin to feel symptoms of depression, which would affect the burden from the caregiver. FCGs with depression would take more time and have difficulty to fall asleep due to physiological processes of depression or worry at bedtime or rumination. That could increase depression and prevent the FCGs from falling asleep (Peng et al., 2019). Otherwise, an adaptive coping mechanism would reduce the stress of the FCGs. Positive affection, such as happiness, cheerfulness, and enjoyment, is the essential part of a good psychological condition, which will make them get healthy sleep.

Limitations

This study's limitations are that the study could not use articles other than English, and Japanese, and so could not explore potential articles which were published in their local language. Another limitation was related to the culture of the country. The primary FCGs might influence the culture, which showed the studies in the US and Taiwan were dominated by females, otherwise in Japan the majority was by males or equal with females. In addition, the US's studies were dominated by spousal caregivers, and in Japan and Taiwan dominated by their child. The culture-related to FCGs' role and health might explain the differences across the countries and continents. Furthermore, a comparison study related to sleep of FCGs and care recipients would give better conditions whether the care recipient stays in the house with the family, adult day care center, community-dwelling, or nursing homes.

Implications for nursing practice

This study has a massive implication for the FCGs and care recipients. Sleep problems are just one of the severe problems that have consequences of depression, burden, and chronic disease leading to death. Prevention action is critical. All countries all over the world face this problem. Preparing policy-related to Alzheimer's dementia is needed, precisely policy related to the adult daycare center, community-dwelling, and nursing homes, which depends on the culture of the country. Technically, preparing primary healthcare to screen the elderly as early as possible, because early detection can help the FCGs to take care of the care recipients. FCGs can prepare their family conditions and finances as well. Nursing care delivery or nursing counseling for nurses in primary healthcare could be developed for FCGs and care recipients. The care delivery model focuses on helping the FCGs to take care of their care recipients and nurses help in maintaining them for the long term. Moreover, technology development could help by big data observation for screening and predicting population growth, which could significantly help prevent FCGs sleep problems in order to prepare them in taking care of the care recipients.

Conclusions

These findings indicate that most of the problems of care recipients affected FCGs physical fatigue, which would lead to emotional problems of the FCGs' role related to stress and distress. Caregiver individual factors such as genetics, poor medical history, and maladaptive sleep hygiene (drinking coffee, napping habits, smoking) have a vital correlation with distress, which might directly affect FCGs' sleep. Furthermore, health problems will also increase. Intervention coping mechanisms and caregiver role might have a significant impact on the FCGs. Any innovation for the FCGs to solve the sleep problem is needed. Besides, caregivers should be supported by families, friends, and healthcare workers. An FCG community online group is beneficial to support each other. Sharing and talking with people in a similar condition will give many benefits to the FCGs. Not only with psychological and sleep problems, but also other problems can be solved.

Declaration of conflict of interest

We declare that there are no conflicts of interest.

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Data Availability

The datasets generated during and analyzed during the current study are available from the corresponding author upon reasonable request.

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