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Sleep Quality and Disability for Custodial Grandparents Caregivers in the Southern United States

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Abstract

Sleep quality amongst caregivers with disability may have been compounded by the COVID-19 pandemic. We evaluated differences in sleep quality amongst custodial grandparents from a southern state that were identified through state-based Kinship Care support groups coordinators and online. Participants ($N = 102$) completed the Pittsburgh Sleep Quality Index and self-reported disability statuses. Gamma tests showed a strong negative relationship between disability and sleep duration indicating fewer hours of sleep, higher use of sleep medication and greater sleep disturbances. Disability is not significantly related to sleep latency, sleep efficiency, and daytime dysfunction. *T*-tests showed no strength of relationship between disability and overall sleep quality. During the first year of the COVID-19 pandemic, custodial grandparents with disability had greater issues with their sleep quality than those without disability. Sleep, as it pertains to its overall preponderant role in maintaining good health, should be examined amongst custodial grandparent caregivers and those with disability.

Keywords

sleep quality, disability, custodial grandparents, Southern United States, PSQI

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What This Paper Adds

- Our results give support to the importance of the relationship between sleep and disability of caregivers; particularly custodial grandparents.
- Poor sleep quality could be a social determinant in health outcomes of custodial grandparents in the southern United States.
- Studies generally examine caregiving and sleep quality, but not by custodial grandparent caregivers. This study showed that having a disability as a custodial grandparent was a contributing factor in the use of sleep medication.

Applications of Study Findings

- Sleep quality should be an inclusionary factor by clinicians and support staff when evaluating custodial grandparent caregiver health.
- Caregivers with disability and poor sleep quality has implications for the impact on children receiving care.
- Health professions and support providers of custodial grandparents in the south should monitor caregiver sleep quality and pay additional attention to those with disabilities.

Introduction

It is readily accepted that adequate sleep is an integral component of good health; however, there are many conditions and populations who regularly experience poor sleep and the concomitant complications stemming from this inadequacy. Poor sleep quality is associated with chronic diseases such as risk of developing diabetes (Knutson et al., 2006), obesity (Taheri, 2006), and

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with depression or depressive symptoms (Dinis & Bragança, 2018; O'Leary et al., 2017). Specifically short sleep, which is sleep <5 to 6 hr, is associated with an increased risk of hypertension, diabetes mellitus, hyperlipidemia, obesity, and frequent mental distress (Grandner et al., 2014). Sleep is vital for components of memory (Ellenbogen et al., 2006), immunity (Besedovsky et al., 2012), and inflammatory responses (Mullington et al., 2010). These patterns have been found to be geospatially variant; in the Southeastern United States, which includes Georgia, short sleep (≤7 hr) is most prevalent (Liu, Croft, et al., 2016; Liu, Wheaton et al., 2016). Furthermore, custodial grandparents are one of those populations that are impacted by poorer sleep.

Custodial grandparents, an increasing and vulnerable population, are an aging population whose sleep habits are understudied. Stearns and Nadorff (2020) found that being a custodial grandparent moderated the relationship between poor sleep quality and depressive symptoms. Indeed, the literature on custodial grandparents shows they experience high levels of depressive symptoms and stress (Baker & Silverstein, 2008). Another study reported sleeplessness as a response to stress and fatigue as a health concern for custodial grandparents (Taylor et al., 2017). Custodial grandparent caregivers are likely to be older; thus having health issues that often concur with greater age including problems around sleep and the bodily stressors that can come with caregiving.

Sleep quality declines with age and has an impact on daily activities. Sleep latency, the time from turning off the lights until the onset of sleep, increases with age, particularly after 65 years of age (Ohayon et al., 2004). This decline in sleep quality has an on impact movement and daily functioning. A longitudinal study of independently living adults 60 years and older found that sleep quality contributed bidirectionally to physical activity: better sleep quality improved physical activity while poorer sleep indicated less physical activity (Holfeld & Ruthig, 2014). Regarding daily functioning, instrumental activities of daily living (IADL) are a key component for living unassisted and for quality of life. Everyday functioning included every problem-solving and IADL (Parsey et al., 2015). Sleep quality's impact on daily activities could have a greater impact on specific populations, such as those with disability and caregivers, may have multiple conditions that often occur with increasing age.

One in four Americans in the United States have a disability (Disability Impacts Us All, Center for Disease Control and Prevention [CDC], 2020), which can have a circular effect on disease; poor sleep exacerbates disease and disease exacerbates poor sleep. Individuals with disability are more likely to live in the South, and at a greater number (2 in 5), once reaching 65 years and older (CDC, 2020). In the United States, there are more custodial grandparents in the South, with 25% of the non-Hispanic custodial grandparents being disabled (Siordia & Rauktis, 2016). Custodial grandparents are a group at the crux of disability, chronic disease, and poor sleep quality. Because of the interrelationship of custodial grandparent stressors, chronic disease, and sleep, this study examined sleep amongst custodial grandparents with disability in Georgia early Fall 2020 to Spring 2021.

Methods

Data were collected via a self-administered online cross-sectional survey study of custodial grandparents in Georgia during the first fall and spring of the COVID-19 pandemic in 2020 and 2021. Participants were recruited from Division of Aging Services (DAS) Kinship Navigator (Statewide Kinship Navigators) support groups and online. Grandparents that were recruited online were verified for Georgia residency using IP addresses verified by latitude and longitude and verification of home address. Participants were required to provide written consent before beginning the survey. The Georgia State University Institutional Review Board approved this study, IRB number H21077.

All Georgia custodial grandparents completed an online survey in Qualtrics (Qualtrics, Provo, UT) (2005) that included background questions and multiple survey instruments related to social determinants of health. Reported here are responses on sleep quality and disability. The Pittsburgh Sleep Quality Index (PSQI) was used to assess the quality of sleep. It includes 24 items, grouped into seven dimensions: subject sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbance, use of sleep medication, daytime dysfunction, and the overall global sleep quality. Each dimension received a score of 0 (no difficulty) to 3 (severe difficulty), where the total score of Global Sleep Quality ranges from 0 to 21, with higher scores indicating worse sleep quality. The PSQI is a valid and reliable instrument to assess subjective sleep quality (Buysse et al., 1989), including older adults (Smyth, 2008). The questions related to usual sleep habits during the past month and indicated the most accurate reply for most days and nights in the past month. Disability was reported as yes or no with option to specify type of disability.

Participants were included in the study using a tier system based on the number of completed responses about sleep; participants with greater number of completed items were included. To preserve statistical power and due to the small sample size, this study employed pairwise deletion (Newman, 2009). Thus, the sample size per analytical test varies based on item nonresponse for study measures. Inclusion criteria included the following: being a custodial grandparent with custody of a least one grandchild in the home, having

Table 1. Descriptive Statistics of Custodial Grandparents in Georgia During COVID-19 Pandemic.

	Overall ($n=102$)		Disabled ($n=22$)		Not disabled ($N=80$)	
	M (*SD*)	Range	*M* (*SD*)	Range	*M* (*SD*)	Range
Age						
Age (years)	56.97 (9.28)	31–78	58.64 (8.39)	38–78	56.51 (9.51)	31–75
Household						
Number of adults	2.90 (1.40)	1–7	2.23 (0.97)	1–4	3.09 (1.45)	1–7
Number of children	1.44 (0.67)	1–4	1.40 (0.68)	1–3	1.45 (0.68)	1–4
	%		%		%	
Race						
Black	35.29		50.00		31.25	
White	53.90		27.27		49.02	
Other	10.81		22.73		19.73	
Ethnicity						
Hispanic	2.94		0.00		3.75	
Marital status						
Single	22.55		31.82		20.00	
Married	48.04		31.82		52.50	
Divorced	7.84		9.09		7.50	
Widowed	10.78		13.64		10.00	
Other	10.79		13.63		10.00	
Employment status						
Employed full-time	28.43		4.55		35.00	
Employed part-time	24.51		27.27		23.75	
Retired	16.67		9.09		18.75	
Disabled	10.78		36.36		0.00	
Other	19.61		22.73		22.50	
Education						
Less than high school	19.61		22.73		18.75	
High school and GED	17.64		27.27		15.00	
Some college	38.24		22.73		42.50	
College graduate	24.51		27.27		23.75	

provided an email or physical address for incentive, having completed the survey in 900 s or greater, no more than two participants living at the same address, and verified as Georgia residents based on their IP address with no more than two participants living at the same address. Exclusion criteria included not being a custodial grandparent, no grandchildren living in the home, no email or physical address provided, completion of the survey in less than 900 s, not a resident of Georgia and more than two participants living at the same address.

Gamma tests were conducted to compare the sleep dimensions (i.e., subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbance, use of sleep medication, and daytime dysfunction) of older adults without disabilities and older adults with disabilities. Independent sample *t*-tests were conducted to examine the relationship of overall sleep quality amongst those with and without disability. Both were tested at a significance level of $p < .05$, with values at below .05 considered significant. All statistical analysis was performed using STATA 16 software (Statacorp 2019, College Station, TX: StataCorp LLC).

Results

Data collection took place between September 2020 and April 2021. Of the participants recruited, 102 were included that completed the demographic data and study questionnaires that included sleep quality and disability status (mean age = 56.97, range = 31–78 years of age). Seventy-eight percent of older adults were not disabled, 53.90% were white, were married (48.04%), were employed full-time (28.53%) and had some college education (38.24%). Older adults with disabilities and older adults without disabilities had similar number of children in the (mean of 1.40 and 1.45, respectively), with a range of 1 to 3 if they were disabled, and 1 to 4 of they were not disabled. General characteristics are shown in Table 1.

Sleep and disability status are associated, particularly sleep duration. There was a strong negative relationship between disability status and sleep duration for grandparents ($\Gamma = -.409$, $p = .034$). Thus, grandparents with disabilities have a higher sleep efficiency score, meaning fewer hours of sleep ($M = 1.30$, $SD = 0.657$) than grandparents without disabilities ($M = 0.95$, $SD = .732$). Sleep

Table 2. Sleep Quality Components by Disability Status of Grandparent.

		Descriptive statistics			Analysis		
Sleep component	Disability status	*M*	*SD*	*N*	Γ/*t*-test[a]	*p* Value	Sig
Subjective sleep quality	With disability	1.68	0.839	22	−.588	.002	**
	Without disability	1.08	0.689	80			
Sleep latency	With disability	2.00	0.970	18	−.239	.246	
	Without disability	1.69	0.950	77			
Sleep duration	With disability	1.30	0.657	20	−.409	.034	*
	Without disability	0.95	0.732	79			
Sleep efficiency	With disability	0.82	1.296	22	−.049	.840	
	Without disability	0.66	1.043	80			
Sleep disturbance	With disability	1.74	0.562	19	−.567	.012	*
	Without disability	1.34	0.579	76			
Use of sleeping medication	With disability	1.68	1.287	22	−.533	.006	**
	Without disability	0.73	0.843	79			
Daytime dysfunction	With disability	1.20	0.696	20	−.023	.913	
	Without disability	1.14	0.679	78			
Overall sleep quality	With disability	9.75	3.975	16	1.940[a]	.700	
	Without disability	7.77	3.614	69			

[a]Analysis conducted via independent sample *t*-test.

duration, though significant, was the least significant with *p*-value of .034. Followed by the use of sleep medication (Γ = −.533, $p = .006$), sleep disturbance (Γ = −.567, $p = .012$) and subjective sleep quality (Γ = −.588, $p = .002$) (Table 2).

This meant that grandparents with disabilities have a higher use of sleep medication ($M = 1.68$, $SD = 1.287$) than grandparents without disabilities ($M = 0.73$, $SD = 0.843$). Sleep medication use between custodial grandparents with and without disability had the largest difference (i.e., 1.68 and 0.73, disability and without disability, respectively). Those with disability had more sleep disturbances ($M = 1.74$, $SD = 0.562$) than grandparents without disabilities ($M = 1.34$, $SD = 0.579$) and fewer hours of sleep ($M = 1.30$, $SD = 0.657$ and $M = 0.95$, $SD = 0.732$). Finally, subjective sleep quality was the most significant with the lowest *p*-value of 0.002. Grandparents with disability had a higher subjective sleep quality score ($M = 1.68$, $SD = 0.839$) than grandparents without disabilities ($M = 1.08$, $SD = 0.689$).

The components of the PSQI that were not associated with disability were sleep latency, sleep efficiency and daytime dysfunction (Γ = −.239, −.049, and −.023: $p = .246$, .840, and .913, respectively). Overall sleep quality, analyzed using independent sample *T*-test, indicated no strength of relationship between disability and overall sleep quality (*T*-test = 1.941. $p = .700$). See Table 2 for the complete results.

Discussion

Main Findings

As hypothesized, we observed that sleep was associated with disability status of custodial grandparents in Georgia during the early months of the COVID-19 pandemic, demonstrating the need for further examinations of custodial grandparents with disabilities. The instrumentation and delivery format of this study were ideal for answering the research question(s) posed by this study, examining sleep quality amongst custodial grandparents with disability. An online survey was particularly advantageous for groups that may not have been able to meet in person during the pandemic, such as older disabled adults and the immunocompromised, and those with children (Reid et al., 2021). It also offered a greater breadth and reach of custodial grandparents throughout Georgia. Exclusion criteria delimited participants who were not in Georgia and may have in fact been bots: each physical address was verified on a map, IP (internet protocol) addresses were checked for latitude and longitude location, removed presumed nonsensical ages of custodial grandparents and time to complete survey. Exclusion criteria are particularly important as surveys moved online during the pandemic and to prevent the use of untrustworthy data in studies of underrepresented minorities (Bybee et al., 2022).

The PSQI has been shown to be an easily understood survey for participants with disability (Altman et al., 2018; Chien et al., 2015; Tabrizi & Radfar, 2015; Zarrabian et al., 2014) and custodial grandparents (Stearns, 2019). Mostly, the PSQI is administered for other types of caregivers and not custodial grandparent caregivers. This further emphasizes the need of examining the sleep quality pattern differences for older adults.

Sleep Duration. Though using different time-based tools, other studies found positive associations between disability and sleep duration. A nationally representative study of American adults found that having a disability

was positively associated with short sleep duration than those without disabilities (Okoro et al., 2020; Shandra et al., 2014). Okoro et al. (2020) used BRFSS (Behavioral Risk Factor Surveillance System) data that reported "average hours of sleep in a 24-hr period," and found that adults with any disability had a higher prevalence of short sleep duration, <7 hr over a 24 hr period, than those without disability (43.8% vs. 31.6%, $p<.001$). We found similar results for adults with a disability, though only moderately strong ($\gamma=-.408$, $p=.034$). Short sleep duration, compared to normal sleep duration, significantly increases diabetes, hypertension, cardiovascular disease, coronary heart disease and obesity (Itani et al., 2017). Of all the components of sleep quality, it is integrally essential to disease states, thus overall health. It is particularly impactful for custodial grandparents raising grandchildren, who are at higher risk for negative changes to their physical and mental health (Hadfield, 2014).

Sleep Medication. As it applies to disability and sleep, the type of disability may impact the use of sleep medication for patients as compared to those without a disability. Compared to healthy individuals, patients with multiple sclerosis and spinal pathology use of sleep medication were significantly correlated to their disability (Lobentanz et al., 2004; Zarrabian et al., 2014) however, not ALS (amyotrophic later sclerosis; Coco et al., 2011). It may be that the use of sleep medication changes based on the type and the etiology of the disability.

In a related study, Stearns and Nadorff (2020) examined if poorer sleep quality was associated with greater depressive symptoms and if it was moderated by grandparent caregiving status. They found that custodial grandparents reported significantly more use of sleep medication than non-custodial grandparents. Our study found that disability status of custodial grandparents was a contributing factor of the use of sleep medication. It could be that living with a disability has side effects impacting sleep that are further exacerbated by the duties incurred when caregiving for a grandchild(ren).

Subjective Sleep Quality. Globally, sleep quality in older adults is important to understand its potential impact on population health. In a related study, Zhang et al. (2020) compared demographic variables amongst adults 65 years of age and older in China using the PSQI. As it related to this study and measures of disability, family history of psychiatric disorders and major medical conditions are the nearest variable that is similar to disability, as in our study. Major medical conditions and family history of psychiatric disorders were each significantly associated with poor quality sleep (Zhang et al., 2020). Alternatively, in our study if you had a disability you had poorer sleep quality, however, it was not significant. The major medical conditions from Zhang et al. (2020) included hypertension, diabetes, cerebrovascular disease, gastrointestinal disease, and cancer. These are all conditions that can lead to disability, particularly diabetes, cerebrovascular disease, and cancer. In sum, custodial grandparents are one of those populations that are impacted by poorer sleep. We found that for custodial grandparents, disability was associated with sleep duration, higher use of sleep medication, sleep disturbances and sleep disturbances and fewer hours of sleep.

Given the significant and substantive differences between custodial grandparents with and without disabilities, an additional analysis should be conducted to understand how subcomponents of subjective sleep quality are associated with each other for custodial grandparents. Moreover, analysis of subcomponents will allow a deeper understanding of associations between these subcomponents for custodial grandparents, regardless of disability status.

Sleep quality is tied to nearly all health outcomes that yield good healthy. Generally, healthcare practitioners should be cognizant of sleep quality and health outcomes and provide patients with information on establishing healthy sleep across all subcomponents of sleep quality and not just medication use: sleep medication should be the last resort. Furthermore, food security was a common theme when examining disability literature. The intersection of disability, food security, and sleep should be further examined and could support the involvement of nutrition-based healthcare professionals such as dietitians and nutritionists.

Study Limitations

Sampling for this study was an online convenience sample within Georgia during the first fall and spring of the COVID-19 pandemic. Our study was limited to grandparents in Georgia, and may be criticized as biased toward those able to use technology to complete the Qualtrics survey. While the Qualtrics survey increased the ability to access a greater number of custodial grandparents, it was biased to grandparents with internet access or adjacent technology like smart phones. We may have missed those living in areas on the digital divide: rural and exurban communities.

Our cross-sectional study did not collect data on their sleep hygiene practices, except those within the PSQI tool or the specific disability. Custodial grandparents are not all seniors over the age of 65. The youngest included in this sample was 31 years old. Because custodial grandparents exist along the age spectrum, our research may not have captured those differences.

We did not explicitly ask if the custodial grandparents were diagnosed with COVID-19, if anyone in their home had COVID-19 or were dealing with the effects of long-covid, as this was not the focus of the study. Data on a COVID-19 diagnosis and their experiences of long COVID may have provided an additional facet of their disability and their caregiving responsibility. Also, results

are not generalizable to adults who are caregivers or have a disease that they do not consider to be a disability.

Conclusion

The custodial grandparent caregivers in this Southern state in the US during the COVID-19 pandemic displayed differences in components of sleep quality between grandparents with and without a disability. The largest significant differences between those with and without a disability were in subjective sleep quality and the use of sleep medicine. Perhaps doctors and practitioners can counsel custodial grandparent caregivers on multiple modes of stress reduction that directly relate to better sleeping and less use of sleep medication.

It is clear that sleep quality and components of sleep quality should be further investigated in more custodial grandparent caregivers; particularly caregivers with any type of disability. Caregivers, particularly those that care for children, with a disability may benefit from further examination, attention and treatment addressing quality of sleep. As a high risk and vulnerable population, they experience compounding effects of age related caregiving and disability.

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Declaration of Conflicting Interests

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Ethical Approval

The Human Research Protection Program (HRPP) is a unit of the University Research Services & Administration (URSA). The Georgia State University IRB is part of the HRPP. IRB number H21077.

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