




Sleep Quality Among Informal Caregivers During the COVID-19 Pandemic: A Cross-Sectional Study

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Abstract

Sleep is an integral component of health. The impact of the COVID-19 pandemic on sleep quality among informal caregivers, individuals who provide unpaid care or assistance to family members or friends, assisting older adults is not well understood. Therefore, informal caregivers in the United States providing care for individuals aged 50+ were recruited via Amazon's Mechanical Turk, an online platform for enrolling study participants into social and behavioral science research, to complete an online survey. The sample of informal caregivers ($n = 835$) was 69% male and 55% non-Hispanic. Multivariable linear regression models were constructed to assess the associations between sleep disturbance scores (SDS) and sleep-related impairment scores (SIS) and caregiving-related measures (hours caregiving/week, length of time spent caregiving, and caregiver burden), demographics, and region of the United States. The analysis determined that Black ($\beta = 2.6$, 95% CI $[-4.3, -0.9]$) and Asian informal caregivers ($\beta = -1.8$, 95% CI $[-3.4, -0.3]$) had lower mean SIS than White caregivers, the referent group. In addition, increasing caregiver burden was associated with increased SDS ($\beta = 0.8$, 95% CI $[0.6, 1.0]$) and SIS ($\beta = 1.3$, 95% CI $[0.7, 1.6]$). In conclusion, higher caregiver burden was associated with higher SIS and SDS, suggesting that informal caregivers' sleep should be assessed, and when needed interventions should be offered.

Keywords

aging, caregiving and management, quality of life, community

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Introduction

Sleep is an integral component of health and health-related quality of life, and inadequate sleep can negatively impact physical (Chaput et al., 2007; Watanabe et al., 2010) and psychological well-being (Medic et al., 2017). The COVID-19 pandemic is a traumatic event affecting the psychological well-being of people across the globe (Serafini et al., 2020; Tsamakidis et al., 2021). Results of research examining the pandemic's effect on sleep are mixed. Some research indicates it is associated with increased sleep problems (Jahrami et al., 2021) and reduced sleep quality (Casagrande et al., 2020), whereas other research suggests sleep duration has increased during the pandemic (Robbins et al., 2021; Zheng et al., 2020).

An estimated 41.8 million informal caregivers in the United States provide unpaid care or assistance to adults 50 years of age

or older (American Association of Retired Persons [AARP], 2020). Informal caregivers provide unpaid care or assistance to family and friends (e.g., the care recipient) with long-term illnesses, chronic conditions, or disabilities. A recent analysis of nationally representative data from caregivers aged 18

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and older who cared for an adult aged 50+ in 12 months before completing the survey determined that the majority of care recipients live in their own home (46%) or the caregiver's home (37%). In addition, 4% live in someone else's home, 5% in independent living/retirement community, and 8% live in nursing home/long-term care facility or assisted living (AARP, 2020). The number of informal caregivers will likely grow due to the increasing prevalence of chronic diseases and population aging (Reinhard et al., 2019). Research conducted in the United States has found that informal caregivers are more likely to report fair or poor health status and more days of poor physical and mental health than non-caregivers (Cohen, et al., 2021). Research also suggests that caregiver burden may negatively impact caregivers' ability to engage in healthy behaviors (Mochari-Greenberger & Mosca, 2012) and increase caregiver risk of poor health and chronic diseases (Miyawaki et al., 2020). Protecting the health and well-being of informal caregivers is essential due to the care they provide. Informal caregivers are a vital component of the United States healthcare system. The services informal caregivers provide save essential resources that would be spent on formal caregiving, including paid in-home help or long-term care facilities (Chari et al., 2015).

Informal caregivers have likely been impacted by policies implemented to curtail the spread of the coronavirus, including social distancing and the cessation of supports. Recent research indicates that for many informal caregivers, the pandemic has had negative effects. For example, a study of informal caregivers in Germany found that 31.1% of the main caregivers reported that their caregiving situation was somewhat worse/much worse due to the COVID-19 pandemic, with a greater percentage of caregivers for persons with dementia (39.7%) and caregivers who usually had professional help (34.8%) (Budnick, et al., 2021). Another study, conducted in the United States, found that 66.6% of unpaid caregivers for an adult ≥ 18 years of age reported at least one adverse mental or behavioral health condition versus 31.8% of non-caregivers (Czeisler et al., 2020). Furthermore, a longitudinal analysis of data from study participants who completed three monthly surveys (April, May, and June 2020) determined that unpaid caregivers for adults were more likely to report symptoms of anxiety or depressive disorders to report staring or increase substance use to cope with stress or emotions associated with COVID-19 and were more likely to have considered suicide in the previous 30 days than non-caregivers (Czeisler et al., 2020).

Understanding aspects of informal caregivers' health-related quality of life, including achieving adequate sleep during the pandemic, is critical to protecting caregiver health. Advocacy groups such as AARP, Alzheimer's Association, Family Caregiver Alliance, American Cancer Society, National Alliance for Caregiving have called for attention to be given to caregivers during the pandemic (Beach et al., 2021). Yet, limited pandemic-related research has focused on informal caregivers. A study conducted in Spain found that among caregivers of persons with dementia, 21% reported experiencing sleep disturbances during

mandatory confinement (Carcavilla et al., 2021), while a study, conducted in the United States during the pandemic, found that short and long-term caregivers were more likely to report fatigue than non-caregivers (Park, 2021). Another study surveyed members of the University of Pittsburgh's University Center for Social & Urban Research registry and found that caregivers were more likely to report less ability to participate in social activities and to have anxiety, depression, fatigue, and sleep disturbance than non-caregivers during the pandemic (Beach et al., 2021). Nonetheless, limited research has examined changes in sleep during the COVID-19 pandemic among informal caregivers. Therefore, the objective of this exploratory study was to investigate how caregiver burden and intensity of caregiving are associated with sleep disturbances and sleep-related impairment during waking hours among a sample of informal caregivers in the United States during the COVID-19 pandemic.

Methods

Data collection

In June 2020, we recruited participants using Amazon's Mechanical Turk (MTurk), which is used globally for enrolling study participants into social and behavioral science research (Mason & Suri, 2012; McCredie & Morey, 2019; Paolacci & Chandler, 2014). Registered MTurk users, referred to as workers, complete surveys and/or tasks referred to as Human Intelligence Tasks (HITs), posted on the MTurk site for a small incentive. Registered MTurk workers who saw the study's HIT, which included information about the incentive (\$1.50), and were interested in participating in the study accessed a link to Qualtrics, an online survey, provided informed consent, and completed questions assessing eligibility. Eligibility criteria included being an unpaid informal caregiver for an individual 50 years of age or older with a major health condition, disability, or cognitive decline, living in the United States, and having the ability to read English. After completing the survey ($\geq 80\%$), respondents received \$1.50 as compensation for their time and effort via the MTurk platform.

Outcome measures

The main outcome measures were sleep disturbance scores (SDS) and sleep-related impairment scores (SIS), which were measured using the Short-Form Patient-Reported Outcomes Information System (PROMIS) (Yu et al., 2012), which has been used in previous studies (Carlozzi et al., 2019; Hanish & Han, 2018). The SDS is comprised of four items that assess self-reported sleep quality, difficulties falling asleep, sleep problems, and whether sleep was refreshing within the past 7 days. The SIS also includes four items and assesses the ability to get things done, problems during the day, ability to concentrate, and sleepiness during waking hours in the previous 7 days. Each SDS and SIS item includes a 5-point Likert-type scale response option (Hanish & Han, 2018). The SDS

and SIS are calculated by summing the four items, with higher scores indicating greater levels of sleep disturbances (range: 4–20) or sleep impairment (range: 4–20). These scores were converted to T-scores based on the PROMIS scoring guide, and all analyses were conducted using the T-scores

Caregiving-related predictor variables

The main predictor variables were hours spent caregiving per week (<10, 10–19, 20–39, and 40+), length of time spent caregiving (<6 months, 6 months – <2 years, 2 – <5 years, 5+ years), and the Caregiver Burden Inventory (CBI) score. The CBI is a 24-item instrument that assesses the impact that informal caregivers' caregiving for older adults has on their health, well-being, activities, social interactions, and other elements of caregiver burden (Novak & Guest, 1989). The CBI measures the time-dependence burden, developmental burden, physical burden, social burden, and emotional burden associated with being an informal caregiver (Novak & Guest, 1989). With the exception of four items, all items are scored from 0 (not at all disruptive) to 5 (very disruptive). The four items have four response options scored from 0 to 4, and these responses are multiplied by 1.25 to be equivalent to the other items. All items are then summed to create a total CBI summary score (range 0–100), with higher scores indicating greater caregiver burden. The CBI summary score was used in all analyses. It was hypothesized that greater caregiver burden and greater caregiving intensity would be associated with more sleep disturbances and sleep-related impairments.

Informal caregivers' demographic characteristics

Examined covariates included the informal caregivers' gender (male, female), age (<30, 30–39, 40+), education (bachelor's degree or higher, [yes,no]), Hispanic ethnicity (yes, no), and Race (Asian, Black, White, Other). Due to the sample size in each group, individuals who identified as Native Hawaiian or Other Pacific Islander, American Indian or Alaskan Native, or multi-racial were classified as "Other." Respondents also reported if they had been diagnosed with COVID-19 (yes, no), and whether someone living with the respondent had been diagnosed with COVID-19 (yes, no). Additional covariates included whether the caregiver lives with the care recipient (yes, no), and caregivers' region of residence in the United States (Northeast, South, West, Midwest), which was based on respondents' reported state of residence.

Data analysis

Descriptive statistics were obtained for all variables: means and SDs for the continuous variables and frequencies for categorical variables. All analyses were conducted using the SIS and SDS T-scores. Differences in the mean SIS and SDS and each of the caregiving-related variables (hours spent caregiving per week, length of time spent caregiving, and CBI

summary score) were assessed using t-tests and one-way analysis of variance (ANOVA). It was hypothesized that the mean SIS and SDS would increase with increasing hours of caregiving per week, time spent caregiving, and CBI. Similarly, it was hypothesized that Spearman correlations for dichotomous, other categorical, and ordinal or rank predictor variables would show positive relationships between SIS and SDS and hours of caregiving per week, time spent caregiving, and CBI. Bivariable and multivariable linear regression models evaluated the associations between each of the caregiving-related variables and the SIS and SDS. Three sets of models were produced: (1) bivariable models for each exposure variable (demographics and caregiving-related measures), (2) a full model, and (3) a best-fitting model as ascertained through a stepwise, backward-elimination procedure using individual variables and blocks of indicator variables. All model assumptions for linear regression were checked, including the normality of the residuals. SPSS version 26.0 (Armonk, NY) and SAS version 9.4 (Cary, NC) were used for all analyses, and statistical significance was established at $p < 0.05$. The study was approved by the University of Rhode Island's Institutional Review Board (1606088-2)

Results

Respondents

In total, 2574 MTurk workers accessed the study link: 464 did not meet eligibility requirements. Of the 2110 people who met eligibility, respondents who completed 80% or less of the survey ($n = 1171$) and/or duplicate IP addresses ($n = 104$) were excluded, resulting in an analytic sample of $n = 835$. As shown in Table 1, the majority of respondents were male (68.5%), non-Hispanic (55.3%), White (54.8%), and had at least a bachelor's degree (85.7%). The average age of respondents was 34.0 years. Nearly half of the respondents (48.4%) reported providing between 10 and 19 hours of informal caregiving per week, and 96.2% reported providing care or assistance to a relative. At the time of survey completion, approximately 49% of respondents had been providing care for less than 6 months. The sample had a mean CBI summary score of 38.1 (range 0–83). Notably, 53.9% of the sample reported that they had been diagnosed with COVID-19.

Respondents' mean SIS was 56.7 (SD = 8.4) and the mean SDS was 53.6 (SD = 4.4). Figure 1 and Figure 2 display the means and 95% confidence intervals for the SIS and SDS T-scores. Table 1 also displays the descriptive statistics for the T-scores by each predictor variable (caregiving-related variables and informal caregivers' demographic characteristics) and p values for associations between each predictor variable and both scores, while Table 2 displays the 95% confidence for the SIS and SDS T-scores in the bivariable, full model, and the final, best-fitting models.

The association between the demographic variables and SDS and SIS T-scores

As observed in Table 1, respondents in the Midwest region had higher average SIS than those in the Northeast ($p = .03$). Male

Table 1. Sleep-related Impairment Scores (SIS) and Sleep Disturbance Scores (SDS) T-Scores by Demographics and Caregiving Characteristics of the Informal Caregiver.

Variable	N or mean	% or (SD)	SIS T-scores	p value	SDS T-scores	p value
Gender						
Female	263	31.5	55.8 (8.8)	0.03	53.7 (4.5)	0.80
Male	571	68.5	57.2 (8.3)		53.6 (4.4)	
Hispanic						
Yes	373	44.7	57.4 (8.3)	0.03	53.9 (4.1)	0.14
No	461	55.3	56.2 (8.6)		53.4 (4.7)	
Race						
Black	115	13.8	54.6 (8.4)	<0.001*	53.6 (4.9)	0.02**
Asian	182	21.9	55.6 (7.3)		53.0 (4.2)	
Other	79	9.5	60.6 (10.0)		54.8 (4.5)	
White	456	54.8	57.1 (8.3)		53.7 (4.4)	
Age – mean (SD)	34	(9.7)				
Age group						
<30	353	42.4	58.0 (8.5)	0.001***	53.9 (4.2)	0.32
30–39	278	33.4	56.0 (8.0)		53.6 (4.9)	
≥40	201	24.2	55.6 (8.6)		53.3 (4.2)	
Bachelor's degree or higher						
Yes	716	85.7	57.0 (8.1)	0.09	53.7 (4.3)	0.28
No	113	14.3	55.3 (10.4)		53.2 (4.9)	
Had COVID-19						
Yes	442	52.9	57.8 (7.6)	<0.001	54.3 (3.7)	<0.001
No	393	47.1	55.6 (9.2)		52.9 (5.0)	
Lives with someone who had COVID-19						
Yes	325	38.9	58.3 (7.9)	<0.001	54.5 (3.8)	<0.001
No	510	61.1	55.7 (8.6)		53.1 (4.7)	
Care recipient is relative						
Yes	804	96.2	56.8 (8.4)	0.065	53.7 (4.4)	0.40
No	31	3.8	54.0 (9.7)		53.0 (4.2)	
Lives with care recipient						
Yes	330	39.5	57.1 (9.1)	0.261	53.8 (4.8)	0.45
No	505	60.5	56.4 (8.0)		53.5 (4.2)	
US region						
Northeast	102	12.2	55.1 (9.0)	0.025	53.6 (4.6)	0.47
South	210	25.1	56.4 (8.1)		53.5 (4.2)	
West	275	32.9	56.5 (7.3)		53.5 (3.9)	
Midwest	174	20.8	58.1 (9.9)		54.1 (5.1)	
Missing	74	8.9	56.7 (8.4)		53.7 (4.4)	
Hours per week caregiving						
<10	231	28.2	55.4 (9.4)	0.006 (s)	52.9 (4.6)	0.008 (s)
10–19	397	48.4	57.0 (7.9)		53.8 (4.2)	
20–39	146	17.8	58.1 (7.4)		54.2 (4.4)	
40+	48	5.6	56.3 (10.7)		54.0 (5.8)	
Time caregiving						
<6 months	399	48.5	57.2 (8.2)	0.260 (s)	54.0 (4.2)	0.13 (s)
6 mo–2 years	253	30.7	56.5 (8.3)		53.1 (4.5)	
2–<5 years	97	11.8	55.6 (9.0)		53.4 (4.8)	
5+ years	74	9	56.1 (9.9)		54.0 (4.9)	
CBI ^a – mean	38.1	(14.2)				
CBI tertiles						
Tertile 1	298	35.7	54.6 (9.6)	<0.001 (s)	52.5 (4.7)	<0.001 (s)
Tertile 2	262	31.4	57.2 (6.2)		53.8 (4.0)	
Tertile 3	275	32.9	58.5 (8.6)		54.8 (4.2)	

Notes: Due to missing data, totals for all variables may not = 835.

*Sig diffs: White versus Black, White versus Other, Black versus Other, Asian versus Other.

**Sig diff: Asian versus Other.

***Sig diffs: <30 versus 30–39 and <30 versus >40; Sig diff: Northeast versus Midwest; (s) Spearman correlation.

^aCaregiving Burden Index summary score.

($p = .03$) and Hispanic respondents ($p = .03$) had significantly higher SIS than females and non-Hispanics respondents. There also were significant differences in SIS by race and age. Furthermore, respondents who had been diagnosed COVID-19 or were living with someone who has had COVID-19 had significantly higher SIS and SDS than those who did not have COVID-19 or were not living with someone who had COVID-19 ($p < .001$ for all).

The association between the caregiving-related variables and SDS and SIS T-scores

Regarding the caregiving-related variables, as seen in Table 1, higher CBI was associated with higher SDS and SIS ($p < .001$ for both). In addition, there was a significant correlation between hours per week of caregiving SDS ($p = .008$) and SIS ($p = .006$), with increasing time spent caregiving was associated with increasing SIS and SDS.

The final, best-fitting models

In the final, best-fitting model (see Table 2), compared to White caregivers, the referent group, Black caregivers ($\beta = -2.6$, 95% CI [-4.3, -0.9]), and Asian caregivers ($\beta = -1.8$, 95% CI [3.4, -0.3]) had significantly lower SIS, while caregivers classified as Other had significantly higher SIS ($\beta = 2.1$, 95% CI [0.1, 4.1]). Increasing age also was associated with decreasing SIS ($\beta = -0.09$, 95% CI [-0.15, -0.03]), while higher educational attainment was associated with greater SIS ($\beta = 1.8$, 95% CI [0.1, 3.5]). Additionally, increasing CBI ($\beta = 1.3$, 95% CI [0.9, 1.7]) and living with someone who was diagnosed with COVID-19 ($\beta = 2.3$, 95% CI [1.0, 3.5]) were associated with a higher mean SIS. Furthermore, increasing CBI ($\beta = 0.8$, 95% CI [0.6, 1.0]) and living with someone who was diagnosed with COVID-19 ($\beta = 1.0$, 95% CI [0.3, 1.6]) were associated with increased SDS. Informal caregivers who had provided care for 6 months to less than 2 years had lower average SDS than those who provided care for 6 months ($\beta = -0.8$, 95% CI [-1.5, -0.1]).

Discussion

In this convenience sample of informal caregivers providing assistance/care to older adults, the mean SDS was 53.6 and the mean SIS was 56.7, which is slightly higher than the mean for the general population score of 50 (US Department of Health and Human Services, 2021). Scores ranging from 55 to <60 are considered indicative of mild impairment. Thus, the mean SIS score represents mild sleep-related impairments (US Department of Health and Human Services, 2021) and suggests that informal caregivers may be in need of interventions to increase sleep quality, irrespective of the pandemic. Although not assessed in the current study, it is possible that the SDS and SIS were associated with changes in caregiving responsibilities and tasks. Indeed, in another study conducted

with the same sample, we found that survey respondents reported an increase in caregiver burden and caregiving intensity (Cohen, Kunicki et al., 2021). Similarly, a study on informal caregivers (45.3% male) for adults aged 60+ in Germany found that 31.1% reported that the COVID-19 pandemic negatively impacted their caregiving situation, with a greater percentage among caregivers of persons with dementia (39.7%) and those who had professional support (34.8%) (Budnick et al., 2021). Others have also determined that informal caregivers have reported increased caregiver burden due to the pandemic (Altieri & Santangelo, 2021). In the present study, higher caregiver burden was associated with higher SIS and SDS. It is possible that caregiver burden associated with COVID-19 could explain this finding; however, the cross-sectional study design does not allow for this to be determined. Nonetheless, these studies suggest the need for increased support for informal caregivers in times of crisis such as weather-related emergencies and future pandemics.

A study by Beach et al. (2021) conducted during the pandemic found that informal caregivers (not limited to caregivers for older adults) had a greater mean SDS than non-caregivers. In the current study, differences in SDS by length of informal caregiving were identified. Respondents who had provided care for 6 months to less than 2 years had a lower average SDS than those who provided care for 6 months or less. The reason for this difference is not clear, but it is possible that recently becoming an informal caregiver and caregiving-related responsibilities were associated with stress and/or caregiving responsibilities that disrupted sleep. Other research, conducted early in the pandemic, examining the effect of the pandemic found that informal caregivers who had been providing care for the short-term (up to 1 year) and long-term (>1 year) reported worse mental health and greater fatigue than non-caregivers (Park, 2021). This same study found that long-term caregivers were more likely to report somatic physical symptoms (headaches, body aches, and abdominal discomfort) than short-term caregivers and/or non-caregivers (Park, 2021).

In addition, the study identified other caregiving characteristics associated with SDS, including hours per week caregiving and CBI. Caregiving characteristics associated with SIS included hours per week caregiving and CBI. These findings align with a cross-sectional analysis of data from 57 low-, middle-, and high-income countries that found that informal caregivers who completed a greater number of caregiving activities were at increased likelihood of having sleep problems (Koyanagi et al., 2018). Similarly, a Dutch study examining caregiver burden on informal caregivers aged 19–64 showed that caregiver burden was associated with providing informal care, providing informal care to their own child(ren), perceived poor health, and loneliness (Koopman et al., 2020).

In the final models, demographic characteristics of the informal caregiver that were associated with SIS included increasing age, education, and race. Increasing age was associated with decreasing SIS, which could be due to older

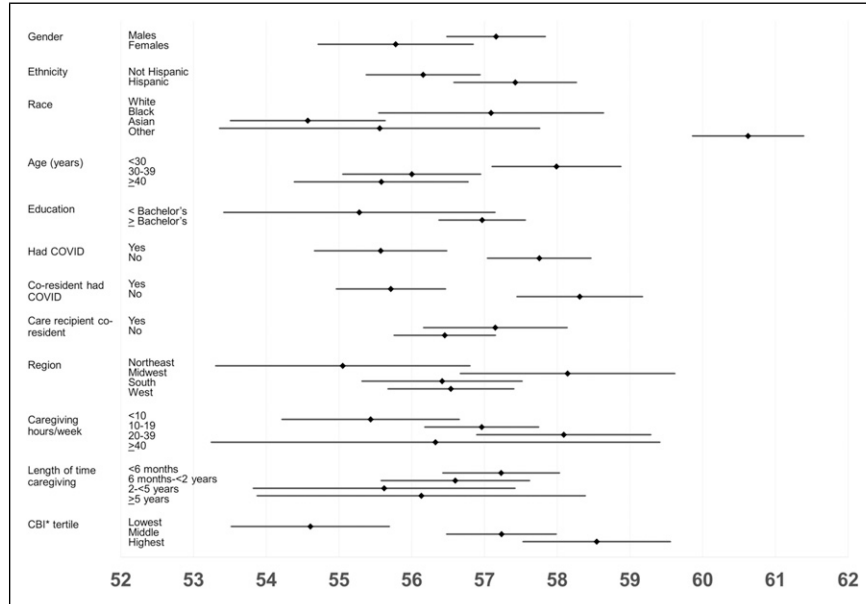


Figure 1. Sleep-related Impairment Scores (SIS) T-scores by Demographic Characteristics

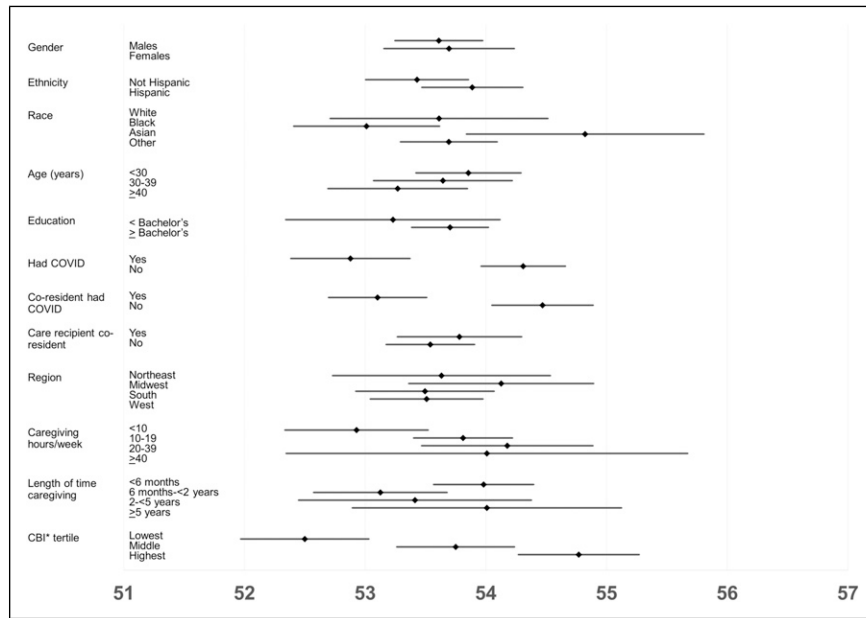


Figure 2. Sleep Disturbance Scores (SDS) T-scores by Demographic Characteristics

respondents having increased caregiving experience. Informal caregivers who identified as Black and Asian caregivers had significantly lower SIS than caregivers identifying as White, while caregivers classified as Other had significantly higher SIS. Reasons for these differences are not clear and warrant further exploration. The final model results also revealed that living with someone who had COVID-19 was associated with SDS and SIS. Other studies have been conducted to examine pandemic-related changes in sleep. It is difficult, however, to compare results across studies due to the use of different

samples and measures assessing sleep and/or sleep quality. For example, a study with college students found that 32.0% rated their sleep quality and 44.6% perceived their sleep duration as being worse during the pandemic, although a number of respondents reported better sleep quality (15.5%) and duration (17.1%) (Du et al., 2021). More specifically, studies focused on caregivers have identified perceived changes in sleep quality. One study of caregivers (family caregiver, in-home paid caregivers, and nursing home staff) of older adults conducted in China in March 2020 found that 10.8% of respondents

Table 2. Estimated Model Parameters for the Outcome of Sleep-related Impairment Scores (SIS) and Sleep Disturbance Scores (SDS) T-Scores with 95% Confidence Intervals (CI).

	SIS T-scores			SDS T-scores		
	Bivariate	Full model	Final best-fit model	Bivariate	Full model	Final best-fit model
	β (95% CI)	β (95% CI)	β (95% CI)	β (95% CI)	β (95% CI)	β (95% CI)
Gender						
Female	-1.4 (-2.6, -0.1)	-0.7 (-1.9, 0.6)		0.1 (-0.6, 0.7)	0.4 (-0.3, 1.0)	
Male	Ref	Ref		Ref	Ref	
Hispanic						
Yes	1.3 (0.1, 2.4)	0.5 (-0.8, 1.7)		0.5 (-0.2, 1.1)	-0.1 (-0.7, 0.6)	
No	Ref	Ref		Ref	Ref	
Race						
Black	-2.5 (-4.2, -0.8)	-3.0 (-4.7, -1.3)	-2.6 (-4.3, -0.9)	-0.1 (-1.0, 0.8)	-0.1 (-1.0, 0.8)	
Asian	-1.5 (-3.0, -0.1)	-2.3 (-4.0, -0.7)	-1.8 (-3.4, -0.3)	-0.7 (-1.4, 0.1)	-0.6 (-1.5, 0.2)	
Other	3.5 (1.6, 5.5)	1.4 (-0.7, 3.5)	2.1 (0.1, 4.1)	1.1 (0.1, 2.2)	0.3 (-0.8, 1.4)	
White	Ref	Ref	Ref	Ref	Ref	
Age (years)	-0.09 (-0.15, -0.04)	-0.08 (-0.14, -0.02)	-0.09 (-0.15, -0.03)	-0.04 (-0.07, -0.01)	-0.03 (-0.06, 0.00)	
Bachelor's degree or higher						
Yes	1.7 (0.1, 3.3)	1.8 (0.1, 3.5)	1.8 (0.1, 3.5)	0.5 (-0.4, 1.3)	0.4 (-0.5, 1.3)	
No	Ref	Ref	Ref	Ref	Ref	
Had COVID-19						
Yes	2.2 (1.0, 3.3)	0.5 (-0.8, 1.9)		1.4 (0.8, 2.0)	0.8 (0.0, 1.5)	
No	Ref	Ref		Ref	Ref	
Lives with someone who had COVID-19						
Yes	2.6 (1.4, 3.8)	1.7 (0.3, 3.0)	2.3 (1.0, 3.5)	1.4 (0.8, 2.0)	0.7 (-0.1, 1.4)	1.0 (0.3, 1.6)
No	Ref	Ref	Ref	Ref	Ref	Ref
Lives with care recipient						
Yes	0.7 (-0.5, 1.9)	0.8 (-0.5, 2.0)		0.2 (-0.4, 0.9)	0.2 (-0.5, 0.8)	
No	Ref	Ref		Ref	Ref	
US region						
Northeast	-3.1 (-5.1, -1.0)	-1.5 (-3.5, 0.5)		-0.5 (-1.6, 0.6)	0.3 (-0.8, 1.3)	
South	-1.7 (-3.4, -0.1)	-0.9 (-2.6, 0.7)		-0.6 (-1.5, 0.3)	-0.3 (-1.2, 0.6)	
West	-1.6 (-3.2, 0.0)	-1.2 (-2.7, 0.4)		-0.6 (-1.5, 0.2)	-0.4 (-1.2, 0.5)	
Midwest	Ref	Ref		Ref	Ref	
Missing						
Hours per week caregiving						
<10	Ref	Ref		Ref	Ref	
10-19	1.5 (0.2, 2.9)	1.4 (0.1, 2.8)		0.9 (0.2, 1.6)	0.6 (-0.1, 1.4)	
20-39	2.7 (0.9, 4.4)	1.7 (-0.1, 3.6)		1.2 (0.3, 2.2)	0.9 (-0.1, 1.9)	
40+	0.9 (-1.8, 3.6)	0.3 (-2.7, 3.3)		1.1 (-0.3, 2.5)	1.0 (-0.6, 2.6)	
Time caregiving						
<6 months	Ref	Ref		Ref	Ref	Ref
6 month-2 years	-0.6 (-1.8, 0.7)	-0.5 (-1.9, 0.9)		-0.9 (-1.6, -0.2)	-0.8 (-1.6, -0.1)	-0.8 (-1.5, -0.1)
2-<5 years	-1.6 (-3.5, 0.3)	-1.3 (-3.3, 0.7)		-0.6 (-1.6, 0.4)	-0.5 (-1.5, 0.6)	-0.2 (-1.2, 0.7)
5+ years	-1.1 (-3.2, 1.0)	-0.7 (-3.0, 1.6)		0.0 (-1.1, 1.1)	0.3 (-0.9, 1.5)	0.4 (-0.7, 1.4)
Caregiver burden index (CBI, per 10 points)						
Mean CBI	1.5 (1.1, 1.9)	1.2 (0.7, 1.6)	1.3 (0.9, 1.7)	0.9 (0.7, 1.1)	0.7 (0.5, 0.9)	0.8 (0.6, 1.0)

Boldface indicates statistical significance ($p < 0.05$).

reported sleep problems (Li et al., 2021b). Another study also conducted in China with family caregivers of persons living with neurocognitive disorders, such as dementia or mild cognitive impairment, found that 9.4% of respondents reported sleep problems (defined as sleep duration of less than 4 or more than 8 hours/night, reduced sleep quality) (Li et al., 2021a). A study conducted in the United States with caregivers of childhood cancer survivors (55% in active surveillance/follow-up care) found that about half of caregivers were not sleeping as well during the pandemic (Wimberly et al., 2021). Additionally, a study in Spain of informal caregivers of persons with dementia found that 34% believed that the pandemic had contributed to sleep disorders (Carcavilla et al., 2021). Although the current study did not assess changes in sleep quality, taken together, these studies suggest that the pandemic may negatively impact the sleep quality of informal caregivers for older adults and suggest the need for intervention.

Prior research has demonstrated the efficacy of interventions on improved sleep quality of informal caregivers providing care for individuals with dementia (Gao et al., 2019). It is estimated that replacing informal caregivers in the United States with paid, formal caregiving services and/or institutionalization of older adults would cost between \$221 and \$642 billion annually (Spillman, 2014). Furthermore, labor shortages would make it difficult to provide all needed services (Fleming et al., 2003). Therefore, it is imperative that the health of informal caregivers needs to be protected and that they be provided the opportunities for health promoting behaviors such as physical activity and achieving adequate sleep as they are crucial to allowing older adults the opportunity to age in place and/or delay entering assisted living or nursing homes.

Study limitations include using a convenience sample, with a notable percentage of people accessing the survey being excluded as they did not finish 80% or more of the survey (55%, 1171/2110), use of self-reported measures, and data collected in the early stages of the pandemic (June 2020). In addition, the cross-sectional study design does not allow for changes in SIS and SDS from before the pandemic to during the pandemic to be assessed or for causality to be determined. It is important to note that the sample differed from other samples of informal caregivers, which have been primarily women, older, and less educated (Cohen et al., 2019), limiting the generalizability of findings. We did not assess whether the survey respondent was the primary informal caregiver or a more distal role. It also should be noted that the sample had a much higher cumulative incidence (53%) of having had COVID-19 than the public, which limits the generalizability of study findings. We also did not assess the severity of symptoms among those who reported being diagnosed with COVID-19. Some research does suggest that MTurk respondents are younger, have less income, are less likely to be Black (Berinsky et al., 2012; Krupnikov & Levine, 2014), and are more likely to be male (McCredie

& Morey, 2019). Other research suggests MTurk workers are more likely to be female (55%) versus male (45%) (Ross et al., 2010); however, recent research has determined that post quarantine workers completing social science HITs are more likely to be male than female (Arechar & Rand, 2021). Nonetheless, research indicates that online convenience samples tend to provide valid results for research (Berinsky et al., 2012; Weinberg et al., 2014). The study has several strengths. The sample is relatively diverse, with 45.2% of respondents identifying as non-White, and the study also is novel. It is one of the first studies to explore SDS and SIS among informal caregivers during the COVID-19 pandemic, who serve a vital role in the U.S. healthcare system.

In summary, the current study found that being diagnosed with COVID-19 or living with someone who was diagnosed was associated with higher SIS and SDS. In addition, study results indicate that a higher caregiver burden, assessed by the CBI, was associated with higher SIS and SDS. This finding suggests that informal caregivers' sleep quality and caregiving burden can be assessed and that these assessments repeatedly occur to identify changes and offer possible interventions if warranted. Assessment could take place at the informal caregiver's or the care recipient's medical appointments or be conducted via telehealth. Interventions to promote sleep quality should be offered if warranted and could include providing caregiver supports to reduce caregiver burden, increasing social support, and offering health education materials that present strategies to identify and seek social support and offer information about promoting good sleep hygiene. It will likely be important to offer interventions in several modalities such as print and via mHealth or other remote interventions to reduce some access issues. However, computer literacy and internet access could be issues of concern.

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