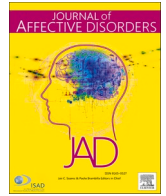




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Research paper

# Mental health, substance use, and suicidal ideation among unpaid caregivers of adults in the United States during the COVID-19 pandemic: Relationships to age, race/ethnicity, employment, and caregiver intensity

Mark É Czeisler<sup>a,b,c,\*</sup>, Alexandra Drane<sup>d</sup>, Sarah S Winnay<sup>d</sup>, Emily R Capodilupo<sup>d,e</sup>, Charles A Czeisler<sup>a,f,g</sup>, Shantha MW Rajaratnam<sup>a,b,f,g</sup>, Mark E Howard<sup>a,b,h</sup>

<sup>a</sup> Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Victoria, Australia

<sup>b</sup> Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia

<sup>c</sup> Department of Psychiatry, Brigham and Women's Hospital, Boston, Massachusetts, United States

<sup>d</sup> ARCHANGELS, Boston, Massachusetts, United States

<sup>e</sup> Whoop Inc., Boston, Massachusetts, United States

<sup>f</sup> Division of Sleep and Circadian Disorders Departments of Medicine and Neurology Brigham & Women's Hospital, Boston, Massachusetts, United States

<sup>g</sup> Division of Sleep Medicine, Harvard Medical School, Boston, Massachusetts, United States

<sup>h</sup> Division of Medicine, Dentistry and Health Sciences, University of Melbourne, Melbourne, Victoria, Australia

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## ABSTRACT

**Background:** Unpaid caregivers of adults play critical roles in health care systems by providing care to older adults and those with chronic conditions. The COVID-19 pandemic has heightened caregiving needs, forcing some into caregiving roles and disrupting others. We sought to estimate the prevalence of and identify factors associated with adverse mental health symptoms, substance use, and suicidal ideation amongst unpaid caregivers of adults versus non-caregivers.

**Methods:** During June 24–30, 2020, surveys were administered to U.S. adults. Quota sampling and survey weighting were implemented to improve sample representativeness of age, gender, and race/ethnicity.

**Results:** Of 9,896 eligible invited adults, 5,412 (54.7%) completed surveys and 5,011 (92.6%) met screening criteria and were analyzed, including 1,362 (27.2%) caregivers. Caregivers had higher adverse mental health symptom prevalences than non-caregivers, including suicidal ideation (33.4% vs 3.7%,  $p < 0.0001$ ). Symptoms were more common among caregivers who were young vs older adults (e.g., aged 18–24 vs  $\geq 65$  years, aPR 2.75, 95% CI 1.95–3.88,  $p < 0.0001$ ) and with moderate and high vs low Caregiver Intensity Index scores (2.31, 1.65–3.23; 2.81, 2.00–3.94; both  $p < 0.0001$ ).

**Limitations:** Self-report data may be subject to recall, response, and social desirability biases; unpaid caregivers were self-identified; child caregiving roles were not assessed; and internet-based survey samples might not fully represent the U.S. population.

**Conclusions:** Caregivers experienced disproportionately high levels of adverse mental health symptoms. Younger caregivers and those with higher caregiving intensity were disproportionately affected. Increased visibility of and access to mental health care resources are urgently needed to address mental health challenges of caregiving.

## 1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has been associated with mental health challenges related to direct effects of SARS-CoV-2 infection (Boldrini et al., 2021; Taquet et al., 2021) and to

indirect effects of social and economic impacts of COVID-19 prevention measures, fears about COVID-19 (Ornell et al., 2020), and bereavement from morbidity and mortality caused by the disease (Simon et al., 2020). Early studies have documented elevated levels of adverse mental health symptoms in the United States (Czeisler et al., 2020a, 2021a; Ettman et al., 2020; Holman et al., 2020) and around the globe (Czeisler et al.,

\* Corresponding author.

E-mail address: [mark.czeisler@fulbrightmail.org](mailto:mark.czeisler@fulbrightmail.org) (M.É. Czeisler).

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2021e; Pierce et al., 2020, 2021; Shi et al., 2020; Varma et al., 2021) compared with previous years. Young adults and unpaid caregivers of adults (caregivers) were among highly affected populations.

A pre-pandemic meta-analysis found that caregivers, who perform activities such as assisting others with activities of daily living and medical tasks, experienced higher levels of depression and perceived stress and lower levels of general well-being than did non-caregivers (Pinquart and Sørensen, 2003). Subsequent studies have characterized an association between subjective caregiver burden and depressive symptoms (Del-Pino-Casado et al., 2019), which in some cases limited provision of care (Fekete et al., 2017).

During June 2020, caregivers reported a significantly higher prevalence of adverse mental and behavioral health symptoms than did non-caregivers, including symptoms of an anxiety disorder, depressive disorder, or COVID-19-related trauma- and stressor-related disorders (TSRDs), having started or increased substance use to cope with the pandemic, and suicidal ideation (Czeisler et al., 2020a). A study of 1,459 pediatric and adult brain tumor patients and 530 caregivers in 33 countries found that caregivers were significantly more anxious than patients, and that 42.8% of caregivers felt that their caregiver burden has significantly increased during the pandemic (Voisin et al., 2020).

Caregivers represent a significant demographic in the US. In 2020, the pre-pandemic prevalence estimate of caregivers was 19.2% of adults aged  $\geq 18$  years, or approximately 47.9 million Americans (The National Alliance for Caregiving and Public Policy Institute, 2020). This estimate represented an increase in the caregiving population of more than eight million compared with 2015 (The National Alliance for Caregiving and Public Policy Institute, 2015). People may have taken up unplanned caregiving roles during the pandemic due to mobility restrictions related to community mitigation activities designed to reduce potential exposure to SARS-CoV-2 for older adults. Moreover, some caregivers who had been providing care before the pandemic may have faced barriers and disruptions to their routines and livelihood. Both scenarios would require caregivers to care for others during a time when their own lives may have been disrupted.

Addressing the needs of the disproportionately affected population of caregivers is critically important for the health and well-being of caregivers, and, in turn, that of the persons for whom they provide care. To effectively address these needs during the COVID-19 pandemic and afterwards, studies are needed to determine the prevalence and characteristics of caregivers, and to identify stressors that may be targets for support systems and prevention and intervention efforts. This study had three specific aims: (1) to estimate the prevalence of U.S. caregivers during the COVID-19 pandemic and compare the demographic characteristics of this population with non-caregivers, (2) to evaluate demographic characteristics associated with adverse mental and behavioral health symptoms separately among caregivers and non-caregivers, and (3) to analyze caregiving characteristics associated with adverse mental and behavioral health symptoms among caregivers.

## 2. Methods

### 2.1. Study design and participants

To assess mental and behavioral health among adults aged  $\geq 18$  years with residence in the U.S. who had provided unpaid care for adults during the COVID-19 pandemic, we conducted a cross-sectional analysis of an Internet-based survey study conducted during June 24–30, 2020 for The COVID-19 Outbreak Public Evaluation (COPE) Initiative ([www.thecopeinitiative.org](http://www.thecopeinitiative.org)). Surveys were administered by Qualtrics, LLC (Provo, Utah, and Seattle, Washington, U.S.), a commercial survey company with a network of participant pools consisting of hundreds of suppliers. Further details on Qualtrics recruitment and methodology are provided in the Supplement (p 1).

Participants included both first-time respondents and respondents who had completed related surveys during April 2–8, May 5–12, 2020,

or both intervals. Demographic quota sampling was used to recruit respondents based on national adult population estimates for age, gender, race, and ethnicity based on the 2010 U.S. Census. Potential respondents likely to qualify based on demographic characteristics listed in their Qualtrics panelist profile were targeted during recruitment; demographic questions were then included in the survey to determine their eligibility. Potential respondents received invitations and could opt to participate by activating a survey link directing them to the participant information and consent page preceding the survey. Ineligible respondents who did not meet inclusion criteria (e.g., age  $< 18$  years, not a U.S. resident) or exceeded set quotas (i.e., maximum demographic characteristic quota already met) were not empaneled in the survey.

### 2.2. Survey instrument

The survey instruments included individual questions, validated questionnaires, and COVID-19-specific questionnaires used to assess respondent attitudes, behaviors, and beliefs related to COVID-19 and its mitigation, along with mental and behavioral health consequences of the COVID-19 pandemic.

Demographic variables included gender, categorized age, combined race/ethnicity, disability status, marital status, household occupancy, 2019 household income, U.S. Census region, urban/rural classification using self-reported ZIP codes, employment status, and, among employed respondents, self-identified essential worker status and weekly paid work hours. Caregiving variables included the method by which caregivers provided care (in-person in-home only; in-person out-of-home only; virtually only; and both in-person and virtually), the person for whom they were providing care, weekly unpaid caregiving hours, caregiver experience in months, and caregiving intensity assessed using the 12- or 14-item ARCHANGELS Caregiver Intensity Index (CII; see Supplement (p 1) for additional details), which is composed of three subscales: Caregiver Load based on four items (situation stability, impact on expenses, family strife, and preparedness), Caregiver Impacts based on four items (emotional state, work, personal time, and stress), and Caregiver Buffers based on six items (support, insurance knowledge, self-efficacy, financial knowledge, sense of purpose, and employer support). Caregivers who were also employed completed all 14 items, while those who were not employed completed all items except for the work and employer support items. The sum of items in each subscale is normalized from 0–100, and the normalized sum of the three subscales is used to categorize total CII scores as Low (0–25), Moderate (26–55), or High ( $\geq 56$ ).

Symptoms of anxiety or depression were assessed via the four-item Patient Health Questionnaire (PHQ-4), a clinically validated screening instrument (Löwe et al., 2010, 2004). Symptoms of COVID-19 TSRDs were assessed via the six-item Impact of Event Scale (IES-6) to screen for overlapping symptoms of posttraumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders (ADs) (Hosey et al., 2019). Respondents also reported whether they had started or increased substance use, (e.g., alcohol, drugs) to cope with stress or emotions related to COVID-19, or if they had seriously considered trying to kill themselves (suicidal ideation) in the prior 30 days. See Supplement (pp 1-2) for additional details.

### 2.3. Quality screening

All surveys underwent Qualtrics, LLC standard data quality screening procedures, and a secondary cleaning conducted by the investigators; see Supplement (p 2). Respondents who failed an attention or speed check, along with any responses that failed data quality screening procedures, were excluded from the analysis.

### 2.4. Statistical analysis

All statistical analyses were conducted using Python (version 3.7.8;

Python Software Foundation) and using R software (version 4.0.2; The R Foundation) with the R survey package (version 3.29). Iterative proportional fitting and weight trimming ( $0.3 \leq \text{weight} \leq 3.0$ ) were employed to improve the cross-sectional sample representativeness of the 2010 U.S. population by age, gender, and combined race/ethnicity (Supplement p 2). Rounded, weighted values are reported unless otherwise specified.

#### 2.4.1. Specific Aim 1: to estimate the prevalence of U.S. caregivers during the COVID-19 pandemic and compare the demographic characteristics of this population with non-caregivers

Summary statistics (counts and percentages) were used to describe the distribution of demographic characteristics among caregivers and non-caregivers. For each demographic category (e.g., gender, age group, race/ethnicity), univariable Rao-Scott adjusted Pearson chi-squared tests were used to test for differences in observed and expected frequencies among groups by characteristic with a Bonferroni adjustment and evaluated at a significance level of  $\alpha = 0.05$ .

#### 2.4.2. Specific Aim 2: to evaluate demographic characteristics associated with adverse mental and behavioral health symptoms separately among caregivers and non-caregivers

Summary statistics (counts and percentages) were used to estimate the prevalence of adverse mental and behavioral health symptoms among caregivers and non-caregivers, overall and by demographic characteristics. Univariable Rao-Scott adjusted Pearson chi-squared tests were used to test for differences in observed and expected frequencies among groups by characteristic with a Bonferroni adjustment and evaluated at a significance level of  $\alpha = 0.05$ . Additionally, to identify whether specific demographic characteristics were independently associated with adverse mental and behavioral health symptoms within these populations, multivariable Poisson regressions with robust standard errors were used to estimate adjusted prevalence ratios (aPRs) and 95% confidence intervals (95% CIs) for adverse mental and behavioral health symptoms among caregivers, evaluated at a significance level of  $\alpha = 0.05$ .

#### 2.4.3. Specific Aim 3: to analyze caregiving-specific characteristics associated with adverse mental and behavioral health symptoms among caregivers

Summary statistics (counts and percentages) were used to estimate the prevalence of adverse mental and behavioral health symptoms among caregivers, overall and by caregiving characteristics. Univariable Rao-Scott adjusted Pearson chi-squared tests were used to test for differences in observed and expected frequencies among caregivers by characteristic with a Bonferroni adjustment and evaluated at a significance level of  $\alpha = 0.05$ . To identify whether specific caregiving characteristics were independently associated with adverse mental and behavioral health symptoms, multivariable Poisson regressions with robust standard errors were used to estimate aPRs and 95% CIs for adverse mental and behavioral health symptoms, evaluated at a significance level of  $\alpha = 0.05$ .

As an exploratory analysis of individual CII items to determine the relative strength of correlations between caregiver perceptions and adverse mental and behavioral health symptoms, non-parametric Spearman correlations were calculated between each CII item and mental and behavioral health measures.

#### 2.5. Study approval and informed consent

The Monash University Human Research Ethics Committee reviewed and approved the study protocol (ID #24036). All participants provided informed electronic consent prior to study commencement. Investigators received anonymized responses.

### 3. Results

#### 3.1. Prevalence estimates of U.S. caregivers and demographic characteristics of caregivers and non-caregivers

Of 9,896 eligible invited adults, 5,412 (54.7%) completed Internet-based surveys during June 24–30, 2020, including 3,638 (68.1%) first-time respondents and 1,729 (31.9%) respondents who first completed a survey for The COPE Initiative during April 2–8, 2020. Among the 5,412 respondents, 5,011 (92.6%) met secondary screening criteria and were included in this analysis (Figure S1). These 5,011 respondents included 1,362 (27.2%) caregivers and 3,649 (72.8%) non-caregivers (Table 1). There was not a significant difference in caregiver status by gender or 2019 household income, though compared with non-caregivers, caregivers were significantly more commonly of young age (e.g., 18–24 years = 26.6% vs 8.0%, respectively, group  $p < 0.0001$ ) and either Black or Hispanic race/ethnicity (Black = 18.8% vs 9.7%; Hispanic = 29.0% vs 11.6%, group  $p < 0.0001$ ). White respondents accounted for 44.5% of caregivers and 70.8% of non-caregivers. Caregivers also more commonly reported living with a disability than not (37.9% vs 17.0%,  $p < 0.0001$ ), and, among employed caregivers, essential than nonessential worker status (73.7% vs 47.8%,  $p < 0.0001$ ) (Table 1).

#### 3.2. Adverse mental and behavioral health symptoms by demographic characteristics of caregivers and non-caregivers

Adverse mental and behavioral health symptoms were more prevalent among caregivers than among non-caregivers (symptoms of anxiety or depressive disorder = 57.6% vs 21.5%, respectively; symptoms of a COVID-19-related TSRD = 49.0% vs 17.9%; having started or increased substance use to cope with the pandemic = 35.0% vs 6.3%; suicidal ideation = 33.4% vs 3.7%; one or more of these symptoms = 69.6% vs 31.0%; all  $p < 0.0001$ ) (Tables 2,3).

Among caregivers, adverse mental and behavioral health symptoms were most prevalent among adults aged 18–24 years (e.g., one or more symptom, vs those aged  $\geq 65$  years; 88.5% vs 18.8%, group  $p < 0.0001$ ), and were more prevalent among Black and Hispanic caregivers than White caregivers (80.2% and 89.4%, respectively, vs 53.4%, group  $p < 0.0001$ ) and among those with than those without disabilities (85.8% vs 59.8%,  $p < 0.0001$ ) (Table 2). There were also differences by employment status, as caregivers who were employed (76.1%) or students (79.0%) had higher prevalences of adverse mental and behavioral health symptoms than those who were retired (29.9%) or unemployed (59.3%) (group  $p < 0.0001$ ). Among employed caregivers, adverse mental and behavioral health symptoms were more common among essential than among nonessential workers (81.6% vs 60.6%,  $p < 0.0001$ ), and were most prevalent among those who worked  $>60$  hours in the previous week and decreased with weekly work hours (e.g., vs those who worked  $\leq 20$  h; 96.9% vs 59.3%, group  $p < 0.0001$ ). Overall, demographic characteristics associated with adverse mental and behavioral health symptoms among caregivers were also observed among non-caregivers (Table 3).

Adjusted prevalence ratios for select demographic variables associated with significantly different prevalences of symptoms of anxiety or depressive disorder, suicidal ideation, and one or more adverse mental or behavioral health symptom, are shown in Figure S2. Specifically, adjusted prevalence ratios for adverse mental health symptoms were higher among young caregivers aged 18–24 years vs caregivers aged 45–64 years (e.g., anxiety or depressive disorder symptoms, aPR 1.47, 95% CI 1.21–1.79,  $p = 0.0001$ ; suicidal ideation, 1.88, 1.26–2.82,  $p = 0.0023$ ; one or more of these symptoms, 1.48, 1.28–1.71,  $p < 0.0001$ ) and those with vs without disabilities (1.22, 1.10–1.35,  $p = 0.0002$ ; 2.01, 1.65–2.46,  $p < 0.0001$ ; 1.18, 1.10–1.26,  $p < 0.0001$ , respectively). Suicidal ideation was more prevalent among Black vs White caregivers (1.48, 1.15–1.90,  $p = 0.0022$ ), as was one or more of these symptoms

**Table 1**  
Respondent Characteristics by Caregiver Status.

	All respondents		All respondents		Unpaid caregivers of adults		Not unpaid caregivers of adults		Unpaid caregivers versus non-Caregivers
	unweighted n	(%)	weighted n (%)	(%)	weighted n (%)	(%)	weighted n (%)	(%)	$\chi^2$ p-value*
Total Respondents	5011	(100)	5011	(100)	1362	(27.2)	3649	(72.8)	-
Gender									
Female	2613	(52.1)	2546	(50.8)	683	(50.1)	1863	(51.1)	>0.99
Male	2398	(47.9)	2465	(49.2)	679	(49.9)	1786	(48.9)	
Age group, years									
18-24	399	(8.0)	655	(13.1)	362	(26.6)	293	(8.0)	<0.0001
25-44	1185	(23.6)	1753	(35.0)	566	(41.6)	1187	(32.5)	
45-64	1783	(35.6)	1739	(34.7)	335	(24.6)	1404	(38.5)	
≥65	1644	(32.8)	864	(17.2)	99	(7.2)	766	(21.0)	
Race/ethnicity <sup>†</sup>									
White, non-Hispanic	3365	(67.2)	3191	(63.7)	606	(44.5)	2584	(70.8)	<0.0001
Black, non-Hispanic	500	(10.0)	611	(12.2)	256	(18.8)	355	(9.7)	
Asian, non-Hispanic	538	(10.7)	240	(4.8)	55	(4.1)	184	(5.1)	
Other race or multiple races, non-Hispanic	163	(3.3)	151	(3.0)	50	(3.7)	101	(2.8)	
Hispanic, any race or races	445	(8.9)	819	(16.3)	395	(29.0)	424	(11.6)	
Disability status <sup>‡</sup>									
Yes	1051	(21.0)	1134	(22.6)	516	(37.9)	619	(17.0)	<0.0001
No	3960	(79.0)	3877	(77.4)	846	(62.1)	3030	(83.0)	
Marital status									
Married or living with partner	3084	(61.5)	2971	(59.3)	809	(59.4)	2162	(59.2)	0.0005
Divorced or separated	547	(10.9)	468	(9.3)	99	(7.3)	369	(10.1)	
Never married	1132	(22.6)	1399	(27.9)	428	(31.5)	971	(26.6)	
Widowed/widower	248	(4.9)	173	(3.5)	25	(1.8)	148	(4.1)	
2019 household income (USD)									
<25,000	615	(12.3)	669	(13.3)	155	(11.3)	514	(14.1)	0.8336
25,000-49,999	1018	(20.3)	1039	(20.7)	306	(22.5)	733	(20.1)	
50,000-99,999	1742	(34.8)	1722	(34.4)	487	(35.7)	1235	(33.9)	
≥100,000	1636	(32.6)	1581	(31.5)	414	(30.4)	1167	(32.0)	
Employment status									
Employed	2590	(51.7)	3069	(61.3)	1018	(74.8)	2051	(56.2)	<0.0001
Retired	1740	(34.7)	1138	(22.7)	147	(10.8)	991	(27.1)	
Unemployed	563	(11.2)	633	(12.6)	130	(9.6)	503	(13.8)	
Student	118	(2.4)	170	(3.4)	66	(4.8)	104	(2.9)	
Essential worker									
Yes	1343	(51.9)	1732	(56.4)	751	(73.7)	981	(47.8)	<0.0001
No	1247	(48.1)	1337	(43.6)	268	(26.3)	1070	(52.2)	
Hours of paid work in previous week									
≤20	455	(17.6)	468	(15.2)	124	(12.2)	344	(16.8)	<0.0001
21-40	1425	(55.0)	1673	(54.5)	472	(46.3)	1201	(58.5)	
41-60	585	(22.6)	741	(24.1)	290	(28.5)	450	(22.0)	
>60	125	(4.8)	188	(6.1)	132	(13.0)	56	(2.7)	

\* Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test was used to test for differences in observed and expected frequencies among groups. Significance was assessed at  $p < 0.05$ .

<sup>†</sup> “Other” race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

<sup>‡</sup> Persons who had a disability were defined as such based on a qualifying response to either one of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

among Hispanic vs White caregivers (1.14, 1.04–1.25,  $p = 0.0044$ ). Conversely, adjusted prevalence ratios for adverse mental health symptoms were significantly lower among older adults aged ≥65 years vs caregivers aged 45–64 years (e.g., one or more adverse mental health symptom, 0.54, 0.39–0.74,  $p = 0.0002$ ).

### 3.3. Adverse mental and behavioral health symptoms by caregiving characteristics of caregivers

Among caregivers, mental and behavioral health also differed by caregiving characteristics (Table 2); 93.0% of 126 caregivers providing care to multiple types of relationships reported adverse mental or behavioral health symptoms, compared with 55.6% of 261 caregivers providing care for a parent or parent-in-law (group  $p < 0.0001$ ). Similarly, 89.0% of 370 who had been providing care for 4–6 months, compared with 44.7% of 199 caregivers who had been providing care for more than 12 months (group  $p < 0.0001$ ) (Table 4). There were also difference by CII score; 91.1% of 335 caregivers with high CII scores reported one or more adverse mental or behavioral health symptom,

compared with 20.7% of 31 caregivers with low CII scores (group  $p < 0.0001$ ).

The multivariable analysis revealed that adjusted prevalence ratios for adverse mental health symptoms were higher among caregivers with ≤12 vs those with >12 months of experience (anxiety or depressive disorder symptoms, 1.24, 1.06–1.44,  $p = 0.0059$ ; suicidal ideation, 1.75, 1.27–2.41,  $p = 0.0006$ ; one or more of these symptoms, 1.25, 1.12–1.40,  $p = 0.0001$ ), those with >6- vs ≤6-hour weekly caregiving commitment (1.34, 1.16–1.56,  $p = 0.0001$ ; 1.58, 1.19–2.11,  $p = 0.0018$ ; 1.19, 1.07–1.31,  $p = 0.0009$ , respectively), and, compared with those in the low-intensity CII group, caregivers in the moderate-intensity (2.52, 1.61–3.94,  $p < 0.0001$ ; 1.92, 0.95–3.88,  $p = 0.070$ ; 2.30, 1.64–3.23,  $p < 0.0001$ , respectively) and high-intensity (3.34, 2.12–5.26,  $p < 0.0001$ ; 2.91, 1.43–5.93,  $p = 0.0034$ ; 2.80, 1.99–3.93,  $p < 0.0001$ , respectively) groups.

In the exploratory analysis of the correlation of individual CII items with adverse mental and behavioral health symptoms, the strongest average positive correlations among all adverse symptoms were observed for employment absenteeism ( $\rho$ s between 0.36 and 0.46, all  $p$



**Table 2**  
Adverse Mental and Behavioral Health Symptoms Among Unpaid Caregivers of Adults During June 24–30, 2020, by Select Respondent Demographics\*.

Caregiver Demographics	All respondents		Symptoms of an anxiety or depressive disorder		Symptoms of a COVID-19 TSRD		Started or increased substance use		Seriously considered suicide in previous 30 days		≥1 adverse mental or behavioral health symptom	
	unweighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)		
Total Caregivers	1100 (22.0)	1362 (27.2)	785 (57.6) <sup>†</sup>	667 (49.0) <sup>†</sup>	477 (35.0) <sup>†</sup>	454 (33.4) <sup>†</sup>	948 (69.6) <sup>†</sup>					
Gender												
Female	586 (53.3)	683 (50.1)	396 (58.0)	320 (46.8)	209 (30.7)	209 (30.6)	478 (70.0)					
Male	514 (46.7)	679 (49.9)	389 (57.2)	348 (51.2)	267 (39.3)	245 (36.1)	470 (69.2)					
Age group, years												
18–24	210 (19.1)	362 (26.6)	255 (70.5)	211 (58.2)	152 (41.9)	164 (45.3)	320 (88.5)					
25–44	357 (32.5)	566 (41.6)	402 (71.0)	354 (62.5)	274 (48.3)	258 (45.6)	467 (82.5)					
45–64	343 (31.2)	335 (24.6)	113 (33.7)	90 (27.0)	46 (13.8)	29 (8.7)	143 (42.5)					
≥65	190 (17.3)	99 (7.2)	14 (14.4)	13 (13.0)	5 (5.4)	3 (3.2)	19 (18.8)					
Race/ethnicity <sup>‡</sup>												
White, non-Hispanic	552 (50.2)	606 (44.5)	277 (45.6)	236 (38.9)	142 (23.4)	118 (19.5)	324 (53.4)					
Black, non-Hispanic	189 (17.2)	256 (18.8)	164 (64.2)	142 (55.4)	117 (45.8)	119 (46.4)	205 (80.2)					
Asian, non-Hispanic	118 (10.7)	55 (4.1)	23 (41.6)	24 (42.6)	10 (18.2)	11 (19.1)	33 (59.6)					
Other race or multiple races, non-Hispanic	47 (4.3)	50 (3.7)	28 (56.1)	23 (46.6)	14 (27.8)	15 (30.3)	33 (67.1)					
Hispanic, any race(s)	194 (17.6)	395 (29.0)	293 (74.2)	243 (61.6)	194 (49.1)	191 (48.5)	353 (89.4)					
Disability**												
Yes	364 (33.1)	516 (37.9)	374 (72.5)	317 (61.4)	276 (53.5)	299 (57.9)	442 (85.8)					
No	736 (66.9)	846 (62.1)	411 (48.5)	351 (41.4)	201 (23.7)	156 (18.4)	506 (59.8)					
Marital status												
Married or living with partner	680 (61.8)	809 (59.4)	458 (56.6)	409 (50.5)	295 (36.4)	281 (34.7)	555 (68.6)					
Divorced or separated	85 (7.7)	99 (7.3)	58 (58.3)	45 (45.4)	42 (41.8)	40 (40.1)	72 (72.5)					
Never married	307 (27.9)	428 (31.5)	253 (59.0)	207 (48.2)	134 (31.2)	124 (29.0)	303 (70.8)					
Widowed/widower	28 (2.5)	25 (1.8)	16 (64.3)	7 (26.7)	7 (26.2)	9 (35.8)	18 (70.5)					
2019 household income (USD)												
<25,000	115 (10.5)	155 (11.3)	85 (55.2)	64 (41.5)	49 (31.7)	41 (26.5)	107 (69.3)					
25,000–49,999	242 (22.0)	306 (22.5)	171 (55.9)	155 (50.7)	96 (31.3)	82 (26.9)	216 (70.3)					
50,000–99,999	396 (36.0)	487 (35.7)	299 (61.5)	241 (49.5)	167 (34.3)	161 (33.1)	345 (70.8)					
≥100,000	347 (31.5)	414 (30.4)	229 (55.3)	207 (50.0)	165 (39.8)	170 (41.1)	281 (67.8)					
Employment status												
Employed	739 (67.2)	1018 (74.8)	638 (62.7)	551 (54.2)	423 (41.6)	410 (40.3)	775 (76.1)					
Retired	207 (18.8)	147 (10.8)	33 (22.6)	28 (19.1)	8 (5.7)	4 (2.7)	44 (29.9)					
Unemployed	114 (10.4)	130 (9.6)	66 (50.4)	48 (37.1)	23 (17.4)	14 (11.1)	77 (59.3)					
Student	40 (3.6)	66 (4.8)	47 (72.0)	40 (59.9)	22 (33.8)	26 (39.4)	52 (79.0)					
Essential worker												
Yes	501 (67.8)	751 (73.7)	512 (68.2)	449 (59.9)	366 (48.8)	355 (47.3)	613 (81.6)					
No	238 (32.2)	268 (26.3)	127 (47.3)	102 (38.2)	57 (21.2)	55 (20.6)	162 (60.6)					
Hours of paid work in previous week												
≤20	105 (14.2)	124 (12.2)	61 (49.0)	51 (41.4)	33 (26.5)	29 (23.7)	73 (59.3)					
21–40	359 (48.6)	472 (46.3)	280 (59.4)	255 (54.1)	182 (38.5)	147 (31.1)	343 (72.6)					
41–60	196 (26.5)	290 (28.5)	188 (64.9)	147 (50.7)	136 (46.8)	139 (48.0)	231 (79.5)					
>60	79 (10.7)	132 (13.0)	109 (82.4)	97 (73.7)	73 (55.2)	95 (71.7)	128 (96.6)					

\* See Table 3 for the adverse mental and behavioral health symptoms among those who were not unpaid caregivers of adults, by select respondent demographics.  
<sup>†</sup>  $p < 0.05$  for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between caregivers and non-caregivers.  
<sup>‡</sup>  $p < 0.05$  for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between demographics among caregivers.

<sup>§</sup> “Other” race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.  
<sup>\*\*</sup> Persons who had a disability were defined as such based on a qualifying response to either one of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

< 0.0001), preparedness ( $\rho$ s between 0.25 and 0.45, all  $p < 0.0001$ ), resentment ( $\rho$ s between 0.30 and 0.40, all  $p < 0.0001$ ), impact on expenses ( $\rho$ s between 0.26 and 0.45, all  $p < 0.0001$ ), and family strife ( $\rho$ s between 0.24 and 0.42, all  $p < 0.0001$ ) (Table S1). The strongest average negative correlation was observed for sense of purpose ( $\rho$ s between -0.11 and -0.22, all  $p \leq 0.0002$ ). All correlations were in the expected direction based on their subscale categorization, except for employer support, which had a positive correlation with all adverse mental or behavioral health symptoms ( $\rho$ s between 0.16 and 0.26, all  $p < 0.0001$ ) despite being in the Buffer subscale.

#### 4. Discussion

More than one-quarter (1,362 [27.2%]) of 5,011 U.S. adult respondents identified as having had roles as unpaid caregivers of adults in

the three months preceding the survey in June 2020. This estimated prevalence of caregivers in the U.S. during the COVID-19 pandemic represents an increase over the 19.2% estimate based on data collected in 2019 (The National Alliance for Caregiving and Public Policy Institute, 2020). While differences in survey sampling methodologies limit direct comparisons between these figures, this increase might partially reflect an increased need for caregivers during the pandemic. Overall, 7 in 10 (948 of 1,362 [69.6%]) caregivers reported having experienced one or more adverse mental or behavioral health symptom. More than one-half of caregivers screened positive for symptoms of an anxiety or depressive disorder (785 [57.2%]), and more than one-third reported having started or increased substance use to cope with the stress or emotions related to COVID-19 (477 [35.0%]) or seriously considered suicide in the prior month (454 [33.4%]). Caregivers reported having experienced elevated levels of adverse mental and behavioral health

**Table 3**

Adverse Mental and Behavioral Health Symptoms Among People Who Were Not Unpaid Caregivers of Adults During June 24-30, 2020, by Select Respondent Demographics\*.

Non-Caregiver Demographics	Allrespondents		All respondents		Symptoms of an anxiety or depressive disorder		Symptoms of a COVID-19 TSRD		Started or increased substance use		Seriously considered suicide in previous 30 days		≥1 adverse mental or behavioral health symptom	
	unweighted n (%)	(78.0)	weighted n (%)	(72.8)	weighted n (%)	(21.5) <sup>†</sup>	weighted n (%)	(17.9) <sup>†</sup>	weighted n (%)	(6.3) <sup>†</sup>	weighted n (%)	(3.7) <sup>†</sup>	weighted n (%)	(31.0) <sup>†</sup>
<b>Total Non-Caregivers</b>	3911	(78.0)	3649	(72.8)	785	(21.5) <sup>†</sup>	653	(17.9) <sup>†</sup>	231	(6.3) <sup>†</sup>	135	(3.7) <sup>†</sup>	1130	(31.0) <sup>†</sup>
<b>Gender</b>														
Female	2027	(51.8)	1863	(51.1)	475	(25.5)	355	(19.1)	134	(7.2)	76	(4.1)	655	(35.2)
Male	1884	(48.2)	1786	(48.9)	310	(17.4)	298	(16.7)	97	(5.4)	60	(3.3)	475	(26.6)
<b>Age group, years</b>														
18-24	189	(4.8)	293	(8.0)	161	(54.9)	116	(39.7)	35	(11.8)	41	(13.9)	198	(67.6)
25-44	828	(21.2)	1187	(32.5)	334	(28.1)	303	(25.5)	105	(8.9)	56	(4.7)	474	(39.9)
45-64	1440	(36.8)	1404	(38.5)	225	(16.0)	178	(12.7)	72	(5.2)	27	(1.9)	347	(24.7)
65+	1454	(37.2)	766	(21.0)	66	(8.6)	56	(7.3)	19	(2.5)	12	(1.6)	112	(14.6)
<b>Race/ethnicity<sup>‡</sup></b>														
White, non-Hispanic	2813	(71.9)	2584	(70.8)	479	(18.5)	369	(14.3)	131	(5.1)	63	(2.4)	684	(26.5)
Black, non-Hispanic	311	(8.0)	355	(9.7)	98	(27.6)	100	(28.1)	38	(10.7)	24	(6.7)	151	(42.4)
Asian, non-Hispanic	420	(10.7)	184	(5.1)	30	(16.5)	31	(16.8)	10	(5.5)	7	(3.8)	52	(28.2)
Other race or multiple races, non-Hispanic	116	(3.0)	101	(2.8)	31	(31.1)	27	(26.4)	4	(3.9)	5	(4.9)	44	(43.6)
Hispanic, any race(s)	251	(6.4)	424	(11.6)	146	(34.4)	127	(29.9)	48	(11.2)	36	(8.6)	200	(47.1)
<b>Disability status**</b>														
Yes	687	(17.6)	619	(17.0)	241	(38.9)	173	(27.9)	62	(10.1)	49	(8.0)	293	(47.3)
No	3224	(82.4)	3030	(83.0)	544	(18.0)	481	(15.9)	169	(5.6)	86	(2.8)	837	(27.6)
<b>Marital status</b>														
Married or living with partner	2404	(61.5)	2162	(59.2)	366	(16.9)	330	(15.3)	106	(4.9)	52	(2.4)	563	(26.0)
Divorced or separated	462	(11.8)	369	(10.1)	73	(19.8)	51	(13.9)	25	(6.7)	15	(4.2)	105	(28.5)
Never married	825	(21.1)	971	(26.6)	314	(32.4)	248	(25.5)	90	(9.3)	61	(6.3)	422	(43.4)
Widowed/widower	220	(5.6)	148	(4.1)	31	(20.9)	25	(16.6)	10	(6.8)	7	(4.7)	41	(27.6)
<b>2019 household income (USD)</b>														
<25,000	500	(12.8)	514	(14.1)	176	(34.1)	136	(26.5)	47	(9.1)	30	(5.9)	225	(43.8)
25,000-49,999	776	(19.8)	733	(20.1)	188	(25.7)	146	(19.9)	44	(6.0)	40	(5.4)	262	(35.8)
50,000-99,999	1346	(34.4)	1235	(33.9)	250	(20.2)	208	(16.8)	72	(5.8)	44	(3.6)	352	(28.5)
≥100,000	1289	(33.0)	1167	(32.0)	171	(14.7)	163	(14.0)	69	(5.9)	21	(1.8)	291	(25.0)
<b>Employment status</b>														
Employed	1851	(47.3)	2051	(56.2)	455	(22.2)	436	(21.2)	154	(7.5)	86	(4.2)	686	(33.5)
Retired	1533	(39.2)	991	(27.1)	109	(11.0)	91	(9.2)	33	(3.4)	20	(2.0)	175	(17.7)
Unemployed	449	(11.5)	503	(13.8)	177	(35.1)	96	(19.1)	30	(6.0)	20	(3.9)	214	(42.6)
Student	78	(2.0)	104	(2.9)	44	(42.0)	30	(29.2)	14	(13.4)	10	(9.7)	54	(51.6)
<b>Essential worker</b>														
Yes	842	(45.5)	981	(47.8)	225	(22.9)	223	(22.8)	86	(8.7)	50	(5.1)	345	(35.2)
No	1009	(54.5)	1070	(52.2)	230	(21.5)	212	(19.9)	68	(6.3)	35	(3.3)	341	(31.9)
<b>Hours of paid work in previous week</b>														
≤20	350	(18.9)	344	(16.8)	69	(20.1)	63	(18.4)	22	(6.4)	13	(3.8)	109	(31.7)
21-40	1066	(57.6)	1201	(58.5)	269	(22.4)	261	(21.8)	92	(7.7)	53	(4.4)	411	(34.2)
41-60	389	(21.0)	450	(22.0)	99	(22.0)	91	(20.2)	31	(6.9)	17	(3.8)	142	(31.4)
>60	46	(2.5)	56	(2.7)	18	(32.3)	20	(36.3)	8	(14.5)	2	(2.9)	25	(44.6)

\* See Table 2 for the adverse mental and behavioral health symptoms among those who were unpaid caregivers of adults, by select respondent demographics.

<sup>†</sup>  $p < 0.05$  for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between caregivers and non-caregivers.

<sup>‡</sup>  $p < 0.05$  for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between demographics among caregivers.

<sup>§</sup> “Other” race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

\*\* Persons who had a disability were defined as such based on a qualifying response to either one of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

symptoms compared with non-caregivers in this study, including three times the prevalence of symptoms of anxiety or depressive disorder or a COVID-19-related TSRD, six times the prevalence of having started or increased substance use to cope with the pandemic, and nine times the prevalence of having seriously considered suicide.

Both caregivers and non-caregivers who were young, Black, Hispanic, living with disabilities, essential workers, and working long hours had disproportionately high levels of adverse mental health, consistent with findings during the pandemic (Czeisler et al., 2020a, 2021c; Gold, 2020; Son et al., 2020; Varma et al., 2021; Wang et al., 2020). However, caregivers more commonly identified as members of these disproportionately affected populations than non-caregivers. Of caregivers, more than two-thirds (928 [68.1%]) were aged below 45 years, more than one-half (756 [55.5%]) non-White, more than one-third living with disabilities (516 [37.9%]), and nearly three-quarters employed as

essential workers (751 of 1,018 [73.7%]). These demographic characteristics could be associated with additional stressors. Long work hours, which were also common among employed caregivers, were associated with increased odds of adverse health outcomes, including depression, anxiety, and impaired sleep (Wong et al., 2019), an effect that may be exacerbated by caregiving roles outside of work. Committing long hours to paid work and unpaid care limits opportunities for core elements of health, including sleep, exercise, nutrition, social interaction, and medical care. Among caregivers, those who had provided care for more hours and those who had been caregiving for fewer than 12 months had higher prevalences of adverse mental health symptoms, which may reflect stressors from being forced into a caregiving role, starting as a caregiver during the pandemic, or survival bias (Czeisler et al., 2021d), whereby those who were still providing care after 12 months were more resilient to stressors associated with the role.

**Table 4**  
Adverse Mental and Behavioral Health Symptoms Among Unpaid Caregivers of Adults During June 24–30, 2020, by Caregiving Roles and Intensity.

	All respondents		All respondents		Symptoms of an anxiety or depressive disorder		Symptoms of a COVID-19 TSRD		Started or increased substance use		Serious suicidal ideation in previous 30 days		≥1 adverse mental or behavioral health symptom	
	unweighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)
Total Caregivers	1100 (22.0)	1362 (27.2)	785 (57.6)	667 (49.0)	477 (35.0)	454 (33.4)	948 (69.6)							
Caregiving method														
In-person in-home only	462 (42.0)	553 (40.6)	318 (57.4)	293 (53.0)	193 (35.0)	187 (33.8)	385 (69.6)							
In-person out of home only	455 (41.4)	570 (41.8)	346 (60.7)	268 (47.0)	223 (39.2)	211 (37.1)	404 (70.9)							
Virtually only	81 (7.4)	110 (8.0)	59 (54.0)	49 (44.5)	39 (35.7)	40 (36.7)	77 (70.4)							
Both in-person and virtually	102 (9.3)	130 (9.5)	62 (48.1)	58 (44.6)	21 (16.0)	16 (12.2)	82 (63.2)							
Person receiving care														
Parent or parent-in-law	425 (38.6)	470 (34.5)	209 (44.4)	160 (34.1)	99 (21.0)	88 (18.7)	261 (55.6)							
Spouse or partner	204 (18.5)	236 (17.3)	135 (57.0)	133 (56.2)	102 (43.1)	105 (44.6)	165 (70.0)							
Older related adult	140 (12.7)	206 (15.1)	142 (68.8)	124 (60.1)	86 (41.9)	76 (36.7)	169 (82.0)							
Older unrelated adult	124 (11.3)	148 (10.9)	80 (54.0)	75 (50.6)	34 (23.0)	33 (22.7)	101 (68.2)							
Sibling	75 (6.8)	108 (7.9)	65 (60.4)	59 (55.0)	51 (47.0)	46 (42.3)	85 (78.6)							
Young unrelated adult	53 (4.8)	59 (4.3)	39 (67.2)	25 (42.8)	19 (32.4)	19 (32.2)	41 (69.7)							
More than one of these relationships	79 (7.2)	136 (10.0)	115 (85.0)	92 (67.4)	86 (63.3)	88 (64.6)	126 (93.0)							
Hours of unpaid caregiving per week														
<6	324 (29.5)	361 (26.5)	137 (37.8)	138 (38.1)	71 (19.5)	55 (15.2)	187 (51.9)							
6–10	331 (30.1)	442 (32.5)	295 (66.8)	241 (54.6)	178 (40.2)	178 (40.1)	353 (79.9)							
11–20	229 (20.8)	310 (22.8)	217 (69.8)	176 (56.7)	146 (47.2)	140 (45.3)	246 (79.4)							
>20	216 (19.6)	248 (18.2)	136 (54.9)	113 (45.3)	82 (32.9)	82 (32.8)	161 (65.0)							
Duration of role as caregiver, months														
≤3	229 (20.8)	314 (23.1)	189 (60.3)	171 (54.4)	105 (33.5)	113 (36.0)	236 (75.2)							
4–6	268 (24.4)	416 (30.5)	303 (73.0)	275 (66.3)	227 (54.7)	222 (53.5)	370 (89.0)							
7–12	140 (12.7)	188 (13.8)	129 (68.9)	91 (48.4)	80 (42.8)	73 (38.9)	143 (76.3)							
>12	463 (42.1)	445 (32.6)	162 (36.5)	130 (29.3)	64 (14.4)	46 (10.3)	199 (44.7)							
CII Total Score														
Low (0–25)	166 (15.1)	151 (11.1)	22 (14.5)	17 (11.2)	7 (4.4)	9 (5.7)	31 (20.7)							
Moderate (26–55)	679 (61.7)	843 (61.9)	464 (55.0)	374 (44.4)	283 (33.6)	247 (29.2)	582 (69.0)							
High (56 or above)	255 (23.2)	368 (27.0)	299 (81.2)	276 (75.1)	187 (50.8)	199 (54.1)	335 (91.1)							
CII Burden Subscale														
Low (0–25)	263 (23.9)	261 (19.2)	72 (27.5)	49 (18.7)	54 (20.6)	52 (19.9)	92 (35.1)							
Moderate (26–55)	417 (37.9)	519 (38.1)	265 (51.0)	220 (42.5)	154 (29.8)	145 (27.9)	350 (67.5)							
High (56 or above)	420 (38.2)	582 (42.7)	448 (77.1)	398 (68.4)	268 (46.1)	257 (44.3)	506 (87.0)							
CII Consequences Subscale														
Low (0–25)	279 (25.4)	284 (20.8)	93 (32.7)	69 (24.3)	62 (21.9)	47 (16.5)	118 (41.6)							
Moderate (26–55)	409 (37.2)	500 (36.7)	254 (50.9)	213 (42.6)	125 (25.0)	112 (22.3)	327 (65.4)							
High (56 or above)	412 (37.5)	579 (42.5)	438 (75.6)	386 (66.7)	289 (50.0)	296 (51.2)	504 (87.0)							
CII Buffer Subscale														
Low (0–25)	33 (3.0)	44 (3.2)	37 (83.4)	24 (53.6)	26 (57.7)	19 (42.8)	39 (87.1)							
Moderate (26–55)	309 (28.1)	404 (29.7)	241 (59.5)	194 (48.0)	130 (32.2)	124 (30.7)	312 (77.2)							
High (56 or above)	758 (68.9)	913 (67.1)	507 (55.5)	449 (49.2)	321 (35.2)	311 (34.1)	597 (65.4)							

\*  $p < 0.05$  for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between groups among caregivers.

The findings in this report reveal that unpaid caregiving for adults is common, has likely increased during the COVID-19 pandemic, and is represented broadly across demographics. Further, the report underscores the significant impact associated with caregiving on mental and behavioral health and highlights the compounding impact of intersectionality with those who identify in multiple groups having elevated experiences of adverse mental and behavioral health. Addressing mental health among caregivers represents an urgent unmet medical and public health need, and group-specific interventions and communication strategies are needed to increase awareness of, comfort with, and access to resources for the diagnosis and treatment of adverse mental and behavioral health conditions, especially given the time constraints faced by caregivers, many of whom are also employed.

Effective communication strategies may include promoting recognition of caregivers so that they feel seen (O'Connor, 2007), addressing stigma associated with mental healthcare (Horsfield et al., 2020; Picco et al., 2018; Schomerus et al., 2019), and continuing to expand telehealth (Koonin et al., 2020), which has delivered promising results in treatment for depression, substance use disorder, and suicidal ideation (Hailey et al., 2008). However, telehealth may not address all needs, with barriers to access (e.g., English-language proficiency, lack of Internet access) and limitations to provision of some care (Gajarawala and Pelkowski, 2021; Pierce and Stevermer, 2020; Rodriguez et al.,

2021). Campaigns to increase help-seeking behavior may also be beneficial, as caregivers more commonly avoided medical care due to concerns about COVID-19 (Czeisler et al., 2020b, 2021b), which may be related to a combination of their own perceived risk of SARS-CoV-2 infection and to their perceived risk and grief about potentially infecting the person for whom they are caring.

#### 4.1. Strengths and limitations

Strengths of this study include recruitment of a large sample of unpaid caregivers from a demographically diverse sample of U.S. adults and utilization of validated screening instruments for mental health. Limitations of this study follow. First, unpaid caregivers of adults were self-identified, and whether they were caregivers of children or adolescents was not assessed; future research could continue to assess mental health among multigenerational caregivers. Second, a diagnostic evaluation for anxiety disorder or depressive disorder was not conducted; however, clinically validated screening instruments were used to assess symptoms. Third, substance use was self-reported; therefore, responses might be subject to recall, response, and social desirability biases. Fourth, the novel nature of the ARCHANGELS Caregiver Intensity Index and the specific use within this research precludes exact comparisons with normative data on caregiving intensity before the



pandemic. Finally, Internet-based survey samples might not be fully representative of the 2020 U.S. population and may therefore have limited generalizability. However, standardized and supplementary data quality screening procedures were applied, and the prevalence of symptoms of anxiety disorder and depressive disorder were largely consistent with findings from the Household Pulse Survey during June 2020 (Centers for Disease Control and Prevention, 2020).

The COVID-19 pandemic both introduced new challenges (e.g., barriers to in-person care provision, COVID-19 concerns) and exacerbated longstanding challenges (e.g., financial and time strains) associated with caregiving. Therefore, prevention efforts and cultural changes may be required both during and beyond the pandemic to properly address the factors associated with caregiving that contribute to elevated experiences of adverse mental health. This is of increasing importance to the economy, as even before the pandemic, a 2015 study estimated the value of unpaid caregiver labor to be USD\$470 billion (Beltrán-Sánchez et al., 2015).

Given the high prevalence of employed caregivers and its compounding mental health impact, reducing the stigma that can be associated with caregiver status and establishing visible and easily accessible workplace programs should be prioritized. Employee Assistance Programs, Workplace Health Promotion Programs, personalized flexible work arrangements, and expanded options for leave that may reduce caregiving intensity if expanded (Robbins et al., 2021) and effectively utilized (Lilly, 2011). Assistive technologies may also decrease workloads required from caregivers, though may inadvertently increase the load if mismanaged or improperly designed (Marasinghe et al., 2015). Beyond these institutional changes, given the protective benefit of a caregiver's sense of purpose and evidence that self-esteem and positive aspects of caregiving are associated with improved mental health (Fauziana et al., 2018), creating a culture that more openly celebrates caregivers and their efforts may lead to communities of caregivers that reduce the mental health risks associated with social disconnectedness and isolation (Bhatti and Haq, 2017; Newman and Zainal, 2020). Caregivers might also benefit from preparation for specific caregiving roles. For example, a largescale survey of adults in the U.S. found that caregivers who were providing care to adults with mental health or substance use conditions, or with active COVID-19 illness, had the highest odds of adverse mental health symptoms (Czeisler et al., 2021c). Similarly, a study of 350 caregivers of people with COVID-19 in Iran reported prevalence estimates of anxiety, depression, and stress between 75% and 80%, with higher levels among those who were younger, not exercising, or employed as in a health-related occupation (Jafari-Oori et al., 2021). Finally, given that approximately 20% of bereaved caregivers experience psychiatric symptoms following the passing of their loved ones, including of depression and complicated grief (Schulz et al., 2008), caregivers might benefit from preparation for and support during this experience.

## 5. Conclusion

Further characterization of caregivers and assessment of mental health, substance use, and suicidal ideation will be required to determine the extent to which increased prevalence of caregiving and elevated adverse mental and behavioral health symptoms progress over the course of the pandemic and beyond. Investment in support systems that reflect the diverse caregiving population and improves their ability to provide care will improve societal health and well-being during this critical health crisis and beyond.

## Author statement

All authors contributed to the study concept and design. MÉC, CAC, SMWR, and MEH collected the data, and MÉC conducted all analyses and wrote the first manuscript draft. All authors provided critical intellectual input and revision. SMWR and MEH provided supervision.

MÉC, SMWR, and MEH had access to the underlying data.

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## Declaration of Competing Interest

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## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.jad.2021.08.130](https://doi.org/10.1016/j.jad.2021.08.130).

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