

Research Report

Caregivers' Mental Health and Somatic Symptoms During COVID-19

Sung S. Park, PhD*,¹

Center for Population and Development Studies, Harvard University, Cambridge, Massachusetts.

*Address correspondence to: Sung S. Park, PhD, Center for Population and Development Studies, Harvard University, 9 Bow St., Cambridge, MA 02138. E-mail: sspark@hsph.harvard.edu

Received: June 15, 2020; Editorial Decision Date: July 28, 2020

Decision Editor: Deborah S. Carr, PhD, FGSA

Abstract

Objectives: This study examines differences in the mental and physical health of the U.S. population during the early stages of the COVID-19 pandemic among 3 groups: noncaregivers, short-term caregivers (1 year or less), and long-term caregivers (greater than 1 year).

Methods: Data from the Understanding America Study are used to describe group differences in reports of psychological distress and somatic symptoms. Logistic and negative binomial regression models are used to examine whether these differences persist after adjusting for demographic, socioeconomic, and prepandemic health conditions. To understand within-group differences in caregiving demands, the intensity of care provided by short-term and long-term caregivers, as well as selected patients' health conditions are summarized.

Results: Adults' mental and physical health varied substantially by caregiver status. Caregivers continued to fare worse than noncaregivers in terms of mental health and fatigue, and long-term caregivers were more likely to report headache, body aches, and abdominal discomfort than both short-term caregivers and noncaregivers, net of controls. The nature of caregiving differed between short-term and long-term caregivers, with the latter more likely to provide greater hours of care, and to be looking after patients with permanent medical conditions.

Discussion: Efforts to understand and mitigate the impact of the pandemic on population health should include caregivers, whose mental and physical health were already vulnerable before COVID-19.

Keywords: Caregiving, Health disparities, Mental health

The COVID-19 pandemic has significantly affected Americans' health, particularly for vulnerable populations, and is expected to exacerbate existing health disparities (van Dorn et al., 2020; Sritharan & Sritharan, 2020). One such group, informal caregivers, who often already suffer from psychological and physical maladies (Billings et al., 2000; Pinquart & Sorenson, 2003), face additional challenges during the pandemic. A highly contagious virus, COVID-19 is most harmful to older adults and individuals with preexisting conditions, placing care recipients at higher risk of severe illness. With the added stress brought about by this knowledge, caregivers must navigate new,

pandemic-induced social and economic circumstances, in continuing to provide care. With more than 47 million caregivers in the United States looking after an ill or disabled adult family member or friend (National Alliance for Caregiving, 2020), understanding their well-being during this public health crisis is a matter of national importance.

Caregiving is associated with greater mental distress, especially depression and anxiety (Adelman et al., 2014). Often used as an example of a "chronic stress experience" (Schulz & Sherwood, 2008), mental health is poorer among those who provide intensive care in duration and/or scope (i.e., medical/nursing tasks and bathing), usually to patients with

more advanced physical or cognitive impairments. Behavioral disturbances common with certain conditions such as neurodegenerative diseases and intellectual disabilities may also negatively affect a caregiver's psychological well-being (Collins & Swartz, 2011; Maes et al., 2003; Swinkels et al., 2019).

Caregivers also often report physical ailments such as fatigue and bodily pain typical of "caregiver burden" (Grover et al., 2006; Spillman et al., 2014). More broadly, psychologically distressed individuals have comorbid somatic symptoms because of shared neurological pathways (Kruetzer et al., 2009; Trivedi, 2004). While physical pain also increases with age (Zimmer & Zajacova, 2020), population-based studies have established a relationship between mental health and somatic symptoms, independent of age (Haug et al., 2004). Furthermore, mind-body interaction research finds that the greater the number of somatic symptoms, the higher the chance of a mood disorder, and a positive relationship between having at least one physical symptom and the duration of depression (Ohayon & Schatzberg, 2003). Individuals with sustained care responsibilities, such as dementia caregivers, report more exhaustion and physical difficulties (Dassel & Carr, 2016).

Recognizing the gravity of caregivers' circumstances before COVID-19, this brief report describes the mental and physical health of caregivers compared to noncaregivers in the United States during the early part of the pandemic, differentiating between short-term and long-term caregivers. Second, this study examines whether differences among these groups are explained by controlling for demographic, socioeconomic, and prepandemic health. Third, to understand potential differences in caregiving demands between short-term and long-term caregivers, care recipients' health conditions and the intensity of assistance are summarized.

Method

This study uses data from the Understanding America Study, a nationally representative internet panel of more than 8,500 adults. Members were selected through address-based sampling, with oversamples of underrepresented groups. Internet-connected tablets were provided when needed. This study uses data from respondents who completed a caregiving survey fielded in January 2020 and a COVID-19 study fielded from April to May 2020 that captured information on their circumstances during the pandemic. Among the 5,558 individuals who completed both surveys, 339 were dropped based on missing values for the dependent variables, and an additional 435 were dropped due to missing values on the existing covariates, resulting in 4,784 respondents in the final analytic sample. Logistic and negative binomial regressions are used to examine whether the association between caregivers' status and the specific health outcomes described below persist after controlling for demographic, socioeconomic, and preexisting health conditions.

Measures

This study examines one mental health and five physical health outcomes. Whether the respondent reported any psychological distress (0/1) in the past 14 days is constructed from the Patient Health Questionnaire-4. There are four indicator variables of the most prevalent somatic symptoms experienced in the past 7 days: headache, fatigue, body aches, and abdominal discomfort. The number of somatic conditions is a measure ranging from 0 to 4, based on summing the presence of the aforementioned somatic symptoms. See [Supplementary Table 1](#) for the items used in creating these measures.

Caregiver status is categorized as noncaregiver, short-term caregiver, and long-term caregiver. A caregiver is identified from a response to the following question focused on adult caregiving: "In the past 30 days, did you spend any time assisting a family member or close friend (e.g. parent, grandparent, wife, husband, adult child, other family member, neighbor or close friend) with their basic personal activities? By that we mean daily activities such as dressing, eating, bathing, paying bills, managing medication, food preparation, grocery shopping, doctor visits, emotional support, driving, and other types of personal assistance." Using a question on the duration of care with response categories of 1 month, 2–3 months, 4–6 months, 7–12 months, and longer than 1 year, individuals who reported assuming their caregiving role for a year or less are considered short-term caregivers, and those helping for greater than 1 year are treated as long-term caregivers. This demarcation also aligns with findings of worse health among caregivers of at least a year ([National Alliance on Caregiving, 2020](#)).

Controls

The multivariate analyses control for the following demographic characteristics: sex (0/1), age (18–29, 30–39, 40–49, 50–64, 65–74, and 75 and older), and race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, and non-Hispanic Other). Non-Hispanic Other includes groups with sample sizes too small to distinguish separately: Asians, Native Americans, and multiracial individuals. There are three socioeconomic controls: holds a college degree (0/1), currently employed (0/1), and household income in U.S. dollars (<25,000, 25,000–49,999, 50,000–69,999, 75,000–99,999, and 100,000+). Because pandemic-related changes vary by locality, there is a control for geographic region (Northeast, Midwest, South, and West). As caregivers likely had poorer prepandemic health relative to noncaregivers, there are two controls for preexisting conditions: the number of chronic conditions (0, 1, and 2+) and any anxiety or depression (0/1). Family and household characteristics that likely affect well-being include couple status (0/1) where coupled is defined as married or cohabiting, living with a child younger than 18 years (0/1), and household size.

Table 1. Descriptive Statistics of Sample by Caregiver Status

	Noncaregiver (N = 3,433)	Short-term caregiver (up to 1 year; N = 689)	Long-term caregiver (greater than 1 year; N = 662)
	% or Mean (SE)		
Any psychological distress ^a	35.2	42.3	46.5
Somatic symptoms ^b			
Headache	21.5	22.8	31.5
Fatigue	19.9	24.5	28.8
Body aches	13.5	17.9	20.1
Abdominal discomfort	7.5	7.7	12.0
Number of somatic symptoms (0–4)	0.62 (0.018)	0.73 (0.041)	0.92 (0.044)
<i>Independent variables</i>			
Male	51.4	40.4	43.9
Age (years)			
18–29	11.5	13.7	9.7
30–39	24.9	20.7	16.8
40–49	15.1	16.1	17.7
50–64	27.0	30.3	35.1
65–74	14.6	13.9	16.4
75+	6.9	5.2	4.3
Race/ethnicity			
Non-Hispanic White	67.8	65.2	64.7
Non-Hispanic Black	10.3	13.5	11.8
Hispanic	12.6	14.2	9.5
Non-Hispanic Other ^c	9.3	7.0	14.1
Coupled	56.2	55.4	57.1
Minor child in the household	32.7	34.7	33.6
Household size	2.72 (1.437)	2.82 (1.501)	3.01 (1.613)
Has college degree	36.6	30.7	29.4
Currently employed	59.7	55.5	55.7
Household income (in U.S. dollars)			
< 25,000	19.2	21.9	20.4
25,000–49,999	20.3	23.9	23.8
50,000–69,999	18.6	17.8	22.3
75,000–99,999	13.9	12.2	13.2
100,000+	28.0	24.3	20.2
Region			
Northeast	21.9	19.1	19.5
Midwest	17.4	20.0	20.1
South	37.8	39.0	38.3
West	22.9	21.9	22.2
Number of preexisting chronic conditions ^d			
None	48.8	42.8	40.8
One	26.6	24.0	25.6
Two+	24.6	33.2	33.7
Anxiety or depression prior to pandemic ^e	21.5	26.5	31.6

Note: Weighted using sample weights.

^aMeasure of any psychological distress is constructed from reports of experiences in the past 14 days.

^bMeasures of somatic symptoms are constructed from reports of experiences in the past 7 days.

^cThis category includes groups with small sample sizes: mixed race, Asian, and American Indian.

^dChronic conditions include diabetes, cancer, heart disease, high blood pressure, asthma, chronic lung disease such as chronic obstructive pulmonary disease or emphysema, kidney disease, autoimmune disorders, and obesity.

^eThe period prior to the pandemic is before March 10, 2020.

Results

Table 1 presents higher proportions of poorer health during the pandemic across all outcomes among caregivers compared to noncaregivers, with long-term caregivers reporting the highest rates, followed by short-term caregivers. Among the study outcomes, psychological distress was the most common, reported by 35.2%, 42.3%, and 46.5% of noncaregivers, short-term caregivers, and long-term caregivers, respectively. There are modest differences between short-term caregivers and noncaregivers for headaches and abdominal discomfort. However, disparities in somatic symptoms between long-term caregivers and noncaregivers are consistently much larger (44%–60% higher).

Further inspection across these groups suggests that these disparities are likely partially explained by compositional differences, as populations with fewer resources experience worse health (Braveman et al., 2010). Caregivers are more racially diverse and less likely to hold a college degree or be employed. They also live in larger households but have lower household incomes. As expected, 33.7% of caregivers live with multimorbidity compared to 24.6% of noncaregivers. Long-term caregivers are more prone than short-term caregivers to have had a mental health condition prior to the pandemic (31.6% vs. 26.5%), and both are more likely than noncaregivers (21.5%).

To understand whether these attributes explain the observed differences in health during the pandemic by caregiver status, six separate regression models were run, controlling for the independent variables in Table 1 (see Supplementary Table 2 for full results). The predicted probabilities by caregiver status shown in Figure 1 are derived from these models, setting the other covariates at their means. Controlling for demographic, socioeconomic, and preexisting health traits reduces differences between long-term caregivers and noncaregivers most appreciably, although statistically significant differences for these two groups remain across all outcomes. Short-term caregivers also remain more likely to report psychological distress than noncaregivers. They are not, however, statistically more likely to report somatic symptoms than noncaregivers. In terms of within-caregiver differences, short-term and long-term caregivers are equally likely to report fatigue, but long-term caregivers are statistically more likely to report headaches, body aches, abdominal discomfort, and more somatic symptoms.

Table 2 offers additional evidence that care demands vary considerably among caregivers. Long-term caregivers provide greater hours of care (117.6 hr/month) than their short-term counterparts (80.9 hr/month), with almost twice the proportion providing near round-the-clock care (greater than 480 hr/month, or 16+ hr/day). Long-term caregivers are also more likely to report looking after someone with permanent medical conditions, such as neurodegenerative diseases or intellectual or developmental disabilities. Other conditions that require high levels of caregiver vigilance,

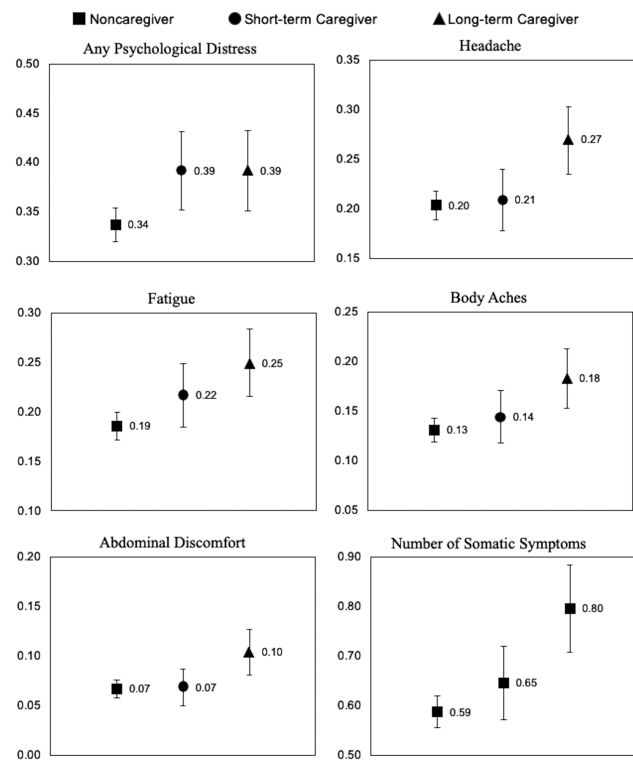


Figure 1. Predicted probabilities of mental health and somatic symptoms by caregiver status. A measure of any psychological distress is constructed from reports of experiences in the past 14 days. Measures of somatic symptoms are constructed from reports of experiences in the past 7 days. Models control for covariates held at their means: sex, age, race/ethnicity, couple status, whether a minor is in the household, household size, education, employment status, household income, geographic region, number of preexisting chronic conditions, whether the respondent reported any anxiety or depression prior to the pandemic, and survey week.

such as a mental illness or impaired vision, are also more common among long-term caregivers' patients.

Discussion

During the early part of the COVID-19 pandemic, adults' mental and physical health varied substantially by caregiver status. Caregivers continued to fare worse than noncaregivers in terms of mental health and fatigue, and long-term caregivers were more likely to report headache, body aches, and abdominal discomfort than both short-term caregivers and noncaregivers, even after adjusting for demographic, socioeconomic, and preexisting health traits. Consistent with other studies (National Alliance on Caregiving, 2020; Wolff et al., 2016), the intensity of care increases with longer durations of care. Thus, the caregiver status measure is potentially capturing intensive versus less intensive caregiving as well. Long-term caregivers' patients were more likely to have permanent medical conditions. These differences in caregiving responsibilities suggest other potential mechanisms through which caregiver health

Table 2. Selected Caregiving Characteristics by Caregiver Status (*N* = 1,351)

	Short-term (<i>N</i> = 689)	Long-term (<i>N</i> = 662)
	% or Mean (<i>SE</i>)	
Hours of caregiving in the last 30 days		
Mean	80.9 (10.79)	117.6 (13.52)
Distribution		
1–5	26.8	20.6
6–20	39.6	38.6
21–40	10.4	10.7
41–80	6.6	8.5
81–240	5.7	7.0
241–480	4.5	2.5
>480	6.5	12.2
Care recipient condition ^a		
Neurodegenerative disease ^b	17.0	17.8
Mental illness or psychiatric disability	11.2	17.1
Intellectual or developmental disability	4.5	8.1
Debilitating arthritis	6.3	10.1
Impaired vision or blindness	8.1	9.7

Note: Weighted using sample weights.

^aCare recipient conditions are not mutually exclusive.

^bThis category includes Alzheimer’s disease or other dementia, Multiple Sclerosis, and Parkinson’s disease.

is affected. For example, the physical burden of tasks may directly affect physical health, while caregiving intensity can limit the time available for caregivers to manage their own health (Spillman et al., 2014).

It is important to note that while this study controls for preexisting physical and mental health conditions at the time of the caregiving survey but prior to the pandemic, it remains unclear whether individuals with poorer health are self-selected into caregiving roles, or if their health is a negative consequence of caregiving. Furthermore, some respondents, particularly short-term caregivers, may have stopped caregiving by the start of the pandemic, potentially modestly underestimating the health of noncaregivers. Also, practices intended to protect the infirm such as physical distancing may have had unintended consequences on caregiver responsibilities. Caregiving could intensify for long-term caregivers who tend to look after individuals with greater health challenges, helping with activities of daily living that cannot be postponed. Moreover, additional assistance may be required to help care recipients manage health complications related to interruptions in medical treatment or COVID-19 exposure. In contrast, caregivers who mostly provide support for instrumental activities of daily living such as transportation and shopping may be able to pause or outsource some tasks during the pandemic.

Given the protracted nature of the pandemic, new challenges that are consequential for caregiver health are bound to emerge. Preliminary mortality data suggest some caregivers, such as racial minorities and those who care for individuals in noncommunity-dwelling settings, are more likely to have a family or friend die of COVID-19 (Van Houtven et al., 2020). Furthermore, the economic fallout from the pandemic is still unfolding, potentially compounding caregivers’ existing financial responsibilities (Institute of Medicine, 2016). COVID-19 has clearly revealed the “frailties and inequalities” (United Nations, 2020) of American society, underscoring the need to include caregivers in current efforts to understand and mitigate the impact of the pandemic on population health.

Supplementary Material

Supplementary data are available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

Funding

This work was supported by the Sloan Foundation.

Conflict of Interest

None declared.

Acknowledgments

The project described in this paper relies on data from survey(s) administered by the Understanding America Study, which is maintained by the Center for Economic and Social Research (CESR) at the University of Southern California. The content of this paper is solely the responsibility of the authors and does not necessarily represent the official views of USC or UAS. The collection of the UAS COVID-19 tracking data is supported in part by the Bill & Melinda Gates Foundation and by grant U01AG054580 from the National Institute on Aging.

References

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *Journal of the American Medical Association*, 311(10), 1052–1060. doi:10.1001/jama.2014.304

Billings, D. W., Folkman, S., Acree, M., & Moskowitz, J. T. (2000). Coping and physical health during caregiving: The roles of positive and negative affect. *Journal of Personality and Social Psychology*, 79(1), 131–142. doi:10.1037//0022-3514.79.1.131

Braveman, P. A., Cubbin, C., Egerter, S., Williams, D. R., & Pamuk, E. (2010). Socioeconomic disparities in health in the United States:

- What the patterns tell us. *American Journal of Public Health*, 100(Suppl. 1), S186–S196. doi:10.2105/AJPH.2009.166082
- Collins, L. G., & Swartz, K. (2011). Caregiver care. *American Family Physician*, 83(11), 1309–1317.
- Dassel, K. B., & Carr, D. C. (2016). Does dementia caregiving accelerate frailty? Findings from the health and retirement study. *The Gerontologist*, 56(3), 444–450. doi:10.1093/geront/gnu078
- van Dorn, A., Cooney, R. E., & Sabin, M. L. (2020). COVID-19 exacerbating inequalities in the US. *Lancet (London, England)*, 395(10232), 1243–1244. doi:10.1016/S0140-6736(20)30893-X
- Grov, E. K., Fosså, S. D., Sørebo, O., & Dahl, A. A. (2006). Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden. *Social Science & Medicine* (1982), 63(9), 2429–2439. doi:10.1016/j.socscimed.2006.06.008
- Haug, T. T., Mykletun, A., & Dahl, A. A. (2004). The association between anxiety, depression, and somatic symptoms in a large population: The HUNT-II study. *Psychosomatic Medicine*, 66(6), 845–851. doi:10.1097/01.psy.0000145823.85658.0c
- Institute of Medicine. (2016). *Families caring for an aging America*. National Academies Press.
- Kreutzer, J. S., Rapport, L. J., Marwitz, J. H., Harrison-Felix, C., Hart, T., Glenn, M., & Hammond, F. (2009). Caregivers' well-being after traumatic brain injury: A multicenter prospective investigation. *Archives of Physical Medicine and Rehabilitation*, 90(6), 939–946. doi:10.1016/j.apmr.2009.01.010
- Maes, B., Broekman, T. G., Dosen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*, 47(Pt 6), 447–455. doi:10.1046/j.1365-2788.2003.00513.x
- National Alliance on Caregiving. (2020). *Caregiving in the U.S. (May 2020 Report)*. National Alliance on Caregiving. <https://www.caregiving.org/caregiving-in-the-us-2020/>
- Ohayon, M. M., & Schatzberg, A. F. (2003). Using chronic pain to predict depressive morbidity in the general population. *Archives of General Psychiatry*, 60(1), 39–47. doi:10.1001/archpsyc.60.1.39
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250–267. doi:10.1037/0882-7974.18.2.250
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, 44, 105–113. doi:10.5175/JSWE.2008.773247702
- Spillman, B., Wolff, J., Freedman, V. A., & Kasper, J. D. (2014). *Informal caregiving for older Americans: An analysis of the 2011 National Study of Caregiving*. U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy.
- Sritharan, J., & Sritharan, A. (2020). Emerging mental health issues from the novel coronavirus (COVID-19) pandemic. *Journal of Health and Medical Sciences*, 3, 157–162. doi:10.31014/aior.1994.03.02.109
- Swinkels, J., Tilburg, T. V., Verbakel, E., & Broese van Groenou, M. (2019). Explaining the gender gap in the caregiving burden of partner caregivers. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 74(2), 309–317. doi:10.1093/geronb/gbx036
- Trivedi, M. H. (2004). The link between depression and physical symptoms. *Primary Care Companion to the Journal of Clinical Psychiatry*, 6(Suppl. 1), 12–16.
- Understanding America Study (2020). *The Understanding America Study*. Social Security Administration and the National Institute on Aging. Retrieved June 1, 2020 from <https://uasdata.usc.edu/index.php>
- United Nations. (2020). *COVID-19 pandemic exposes global "frailties and inequalities": UN deputy chief*. Retrieved from <https://news.un.org/en/story/2020/05/1063022>
- Van Houtven, C. H., Boucher, N. A., & Dawson, W. D. (2020). The impact of COVID-19 outbreak on long term care in the United States. Country report in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 24th April.
- Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*, 176(3), 372–379. doi:10.1001/jamainternmed.2015.7664
- Zimmer, Z., & Zajacova, A. (2020). Persistent, consistent, and extensive: The trend of increasing pain prevalence in older Americans. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 75(2), 436–447. doi:10.1093/geronb/gbx162