

Supplement Article: Late-Life Disability and Care: An Update from the National Health and Aging Trends Study at Its 10-Year Mark

The Changing Tides of Caregiving During the COVID-19 Pandemic: How Decreasing and Increasing Care Provision Relates to Caregiver Well-Being

Amanda Leggett, PhD,^{1,*} Hyun Jung Koo, MS,¹ Bona Park, MPH,² and HwaJung Choi, PhD²

¹Department of Psychiatry, University of Michigan, Ann Arbor, Michigan, USA. ²Department of Internal Medicine, University of Michigan, Ann Arbor, Michigan, USA.

*Address correspondence to: Amanda N. Leggett, PhD, Department of Psychiatry, University of Michigan, Rachel Upjohn Building, 4250 Plymouth Road, Ann Arbor, MI 48109, USA. E-mail: leggetta@med.umich.edu

Received: July 14, 2021; Editorial Decision Date: January 3, 2022

Decision Editor: Vicki A. Freedman, PhD

Abstract

Objectives: Pandemic-specific changes to the caregiving context (e.g., attempts to reduce exposure, physical distancing requirements) may lead to changes in care provision. This study uses the 2020 National Health and Aging Trends Study Family Members and Friends coronavirus disease 2019 (COVID-19) questionnaire to explore changes in the amount of care provision during COVID-19 and associations with stress process outcomes of caregiving.

Methods: The sample includes 1,020 caregivers who provided care for an older adult during COVID-19. Caregivers indicated whether their hours of care decreased, stayed stable, or increased during the pandemic. We describe reasons for change in care and compare changes in care by demographic and care-related characteristics using chi-squares and analyses of variance, and relate changes in care with stress process outcomes (e.g., overload, COVID-related anxiety) using multivariable linear regression.

Results: Caregivers were 60.7 years old on average, 69.3% were female, and 18.6% were non-White. While most caregivers reported no change, 30.5% reported an increase and 11.5% reported a decrease in the amount of pandemic care provided. Relative to maintaining stable care provision, an increase was associated broadly with worse mental health and care-related stress, whereas a decrease was associated with greater emotional difficulty related to care and lower levels of positive affectivity.

Discussion: Those who changed their care provision during the pandemic predominantly did so to protect their care recipient from COVID-19 exposure. Increasing one's care provision was strongly associated with worse mental health and well-being. Supports for caregivers who take on additional care tasks during the pandemic could have great public health benefit.

Keywords: Caregiving, COVID-19, Pandemic, Stress, Well-being

The emergence of a novel coronavirus (hereafter COVID-19) in January 2020 became a global pandemic with particularly high risk for severe complications and mortality

among older adults with preexisting health conditions (Mills et al., 2020; Steptoe & Di Gessa, 2021). While medical systems are acting as the “frontline” during the

COVID-19 pandemic, family and friend caregivers (hereafter caregivers) have become the “home front.” Caregivers help their care recipients stay safe, maintain function, abide by physical distancing principles and other health and preventative recommendations (e.g., mask wearing), access proper medical care, and remain outside of hospitals and clinics, which are disease epicenters (Wang et al., 2020). Yet for older adults and their caregivers, preventative safety precautions, such as shelter-in-place orders and physical distancing practices, and changes to social support structures and health care access may pose challenges with which they must cope (Le Couteur et al., 2020; Losada-Baltar et al., 2021; Mills et al., 2020; Wang et al., 2020). These and other challenges may result in increased or decreased care provision among caregivers. For example, some caregivers may help *more* as other friends and family members have cut back their support due to the pandemic or because of a lack of formal support service availability, while others may help *less* due to the caregiver’s own health concerns or for fear of exposing the care recipient. However, it is unknown the extent of caregiving transitions in care provision made during the pandemic, reasons for these changes, and whether changes in care provision relate to caregiver well-being. The current study utilizes the COVID-19 Family Members and Friends (FF) questionnaire of the nationally representative National Health and Aging Trends Study (NHATS), which examines two caregivers per NHATS participant to explore changes in pandemic care provision and associations with psychosocial well-being outcomes of caregiving.

Theories of Care Transitions and Caregiver Stress and Well-Being

Caregiving is a dynamic process and research outside of the pandemic context suggests that individuals enter, exit, increase, and decrease care over time alongside fluctuating demands and tasks (Bond et al., 2003; Burton et al., 2003; Hirst, 2005; Seltzer & Li, 2000; von Känel et al., 2011). Changes in care provision are key to understand as they may come at great cost to caregivers’ own well-being. Unfortunately, stress associated with caregiving is common and has been linked with psychological distress, depressed mood, anxiety, anger, guilt, a sense of being trapped, feelings of loss, vulnerability to disease, irregular levels of stress hormones/increased allostatic load, and higher morbidity (Aneshensel et al., 1995; Cuijpers, 2005; Fonareva & Oken, 2014; Hinrichsen & Zweig, 1994; Mausbach et al., 2013; Perkins et al., 2013; Pinquart & Sörensen, 2006; Schulz & Beach, 1999; von Känel et al., 2006; Zarit, 2008).

Indeed, theoretically, both life-course perspectives and evidence on caregiving as a “career” suggest that major transitions will occur over the course of caregiving (Aneshensel et al., 1995; Lynch & Danely, 2013; Pearlin,

1992, 2010) and may relate to changes in stress. Stress Process Models posit that caregivers adapt and cope in different ways as they face fluctuating care challenges. Caregiving roles of greater intensity (e.g., greater amount; helping with severe limitations in activities of daily living) tend to be associated with higher reports of stress and depressive symptoms (Abernethy et al., 2009; Aneshensel et al., 1995; Burton et al., 2003; Hirst, 2005; Liu & Lou, 2017). On the other hand, decreases in care intensity have been more overlooked in terms of stress impact (Lyons et al., 2015).

The predominant focus on caregiving transitions has been placed on entry (Abernethy et al., 2009; Burton et al., 2003; Gaugler et al., 2003; Lyons et al., 2015; Seltzer & Li, 2000) or exit (Fredman et al., 2015; Gaugler et al., 2007; Shaffer et al., 2017; von Känel et al., 2011) from caregiving. While such studies typically suggest that entering a care role is associated with increased stress, whereas exiting a role, such as through bereavement, is associated with a reduction in stress, there are contrasting findings (Bond et al., 2003; Burton et al., 2003; Gaugler et al., 2003; Seltzer & Li, 2000). For example, data from both the China Health and Retirement Study and English Longitudinal Study of Aging suggest that entering and continuing in a spousal caregiving role is associated with increased depressive symptoms and reduced quality of life relative to noncaregivers (Liu & Lou, 2017; Rafnsson et al., 2017). Additionally, transitioning into a spousal care role, particularly a high-intensity spousal role, was associated with worsened functional health for the caregiver (Liu & Lou, 2019). On the other hand, exiting a care role was associated with reduced depressive symptoms when caring for a parent in the Chinese sample (Liu & Lou, 2017), whereas exiting from any care role in the English sample was associated with increased depressive symptoms (Rafnsson et al., 2017).

Fewer studies have considered changes in caregiving intensity, but those that do tend to show increasing intensity to be related to worsening psychological well-being (Abernethy et al., 2009; Burton et al., 2003; Hirst, 2005; Lyons et al., 2015). For example, Lyons et al. (2015) found that high-intensity (intensity defined by amount of instrumental care tasks) caregivers had the greatest stress levels among those whose care level remained constant over a study interval (12–18 months). However, low-intensity caregivers who increased their caregiving loads over a study interval had greater stress than those simply continuing in high-intensity roles. Moreover, both high- and low-intensity caregivers who stopped care had similarly low stress levels as noncaregivers. Although this study demonstrates the effect of transitions in caregiving and intensity on caregiver stress, it is limited due to a lack of context as to why caregiver’s intensity levels changed. Understanding reasons for changes in care provision and the impact of such changes can help to identify individualized intervention targets and supports. More work is

needed to examine reductions and increases in caregiving load intensity, and reasons for such changes, particularly in a pandemic context where such changes may be forced and not by choice.

Pandemic Impact on Psychosocial Well-Being and Changes in Care Provision

Perspective pieces (Le Couteur et al., 2020; Losada-Baltar et al., 2021; Mills et al., 2020; Wang et al., 2020) and empirical work (Archer et al., 2021; Budnick et al., 2021; Cohen et al., 2021; Giebel et al., 2021; Lightfoot, Moone, et al., 2021; Lightfoot, Yun, et al., 2021; Park, 2021; Savla et al., 2021) are emerging regarding the psychosocial stress impact of the pandemic and physical distancing measures on highly vulnerable groups such as older adults and their caregivers. On top of typical care responsibilities, caregivers face the additional challenge of protecting high-risk older adults from an “invisible” virus (Archer et al., 2021). Further, studies on social isolation and loneliness in older adults suggest that government-imposed physical distancing restrictions may negatively affect mental and physical health (e.g., increased depression, cognitive decline, coronary heart disease; Cacioppo et al., 2010; Losada-Baltar et al., 2021; Luo et al., 2012; Perissinotto et al., 2012; Rico-Uribe et al., 2018).

Indeed, pandemic studies are showing increased burden, overload, fatigue, somatic symptoms, and psychological distress during, as opposed to, before the pandemic (Archer et al., 2021; Budnick et al., 2021; Cohen et al., 2021; Giebel et al., 2021; Park, 2021; Savla et al., 2021). Qualitative work on a family caregiving sample during the pandemic identified themes of pandemic care challenges such as: social isolation, physical, mental, and cognitive declines among care recipients, a focus on maintaining safety from COVID-19, lack of received support, and changed tasks and responsibilities (Lightfoot, Moone, et al., 2021; Lightfoot, Yun, et al., 2021). Yet, benefits were also cited including relationship building and increased time spent with the care recipient, and new care innovations, such as use of technology for medical visits (Lightfoot, Moone, et al., 2021). Quantitative work also described specific pandemic challenges such as inability to access social services which is associated with decreased mental well-being among caregivers (Giebel et al., 2021).

One study, Cohen et al. (2021), found that just over half of their sample of informal caregivers for someone 50 or older reported increased caregiving intensity during the pandemic and increased burden due to the pandemic. Reduced caregiver burden was associated with decreased intensity of care. However, this study did not use representative data (Amazon MTurk sample with 68.5% male caregivers, average age of 34 years) and reasons for changes in care provision were not examined.

Current Study

The current study builds upon existing literature by utilizing COVID-19 questionnaire data from the nationally representative NHATS, which incorporates interviews with up to two caregivers for each NHATS participant, to explore the dynamics of pandemic-specific changes in informal care provision for NHATS participants with functional or mobility needs. The primary aim of this study is to explore whether pandemic-specific changes in care provision are associated with psychosocial well-being outcomes among caregivers and reasons for such changes. For example, care provision may change during the pandemic due to an effort to reduce risk exposure, lack of availability of services, or changes to support received from other friends or family. It may be that both decreases and increases in care provision are associated with increased care stress, relative to stable care provision, as increases may relate to overload and burden experienced by the caregiver. On the other hand, increases in care may result in more caregiving gains and reduced worry for the care recipient's well-being. *It is thus hypothesized* that both a decrease and increase in level of care provision will be associated with greater stress process outcomes and less positive affect. Understanding fluctuations or consistency in care during the pandemic is critical as caregivers are at the forefront of helping to prevent disease transmission by keeping their care recipients safely in place and out of overburdened health systems. Findings may offer broader implications with which to understand fluctuations in care provision outside a pandemic-context, as well as how caregiver supports during times of reduced or increased care provision may enhance well-being.

Method

Data and Analytic Sample

Data were drawn from 2020 NHATS FF COVID-19 questionnaire, a supplemental mail study to the nationally representative sample of Medicare beneficiaries in the longitudinal NHATS core study. The NHATS questionnaire was mailed in June 2020 and collected through January 2021, whereas the FF questionnaires were collected from July 2020 to March 2021, with most completed in August or September 2020. NHATS participants could identify two adult family member or friend helpers (paid caregivers were ineligible) that provided them the most help during the COVID-19 pandemic and these caregivers were also surveyed about their experiences helping the NHATS participant during the pandemic (the unweighted response rate for the NHATS FF COVID-19 supplement was 65.4%).

As the primary aim is to see the associations between changes in care provision during the pandemic and caregivers' stress and well-being outcomes, we restricted our sample to the caregivers that provided care for at least one household activity (e.g., shopping for groceries), self-care activity (e.g., bathing), or mobility activity (e.g., getting around

inside) before or during the outbreak. Only those who helped the NHATS participant, either before or during the COVID-19 outbreak, because of their health or functioning were asked about hours of care and changes in hours. Of the 2,062 respondents that responded to the NHATS FF COVID-19 questionnaire in 2020, 1,020 participants provided care either before or during the COVID-19 outbreak and hence were included in our baseline sample (Figure 1). There are some missing data in covariates (ranging 0.1% in gender to 29.9% in place of residence of the NHATS participant). A multiple imputation approach was used to impute the covariates using chained equations with 15 replications prior to running multivariable linear regression models.

Measures

Outcomes

Outcomes were chosen to align with Stress Process Models of family caregiving (e.g., emotional difficulty of care, overload, caregiving gains). *Positive Affect and Negative Affect* were each derived by sum scores of three items. The participants were asked how often in a typical month during the COVID-19 outbreak they felt “cheerful,” “calm and peaceful,” and “full of life” for positive affectivity and “bored,” “lonely,” and “upset” for negative affectivity. Each item was assessed on a 5-point scale (*never, rarely, some days, most days, every day*). Higher sum scores indicate higher positive and negative affectivity (ranging 0–12 for positive, $\alpha = 0.86$; 0–12 for negative affectivity, $\alpha = 0.72$). *Depressive symptomatology* was measured via the Patient Health Questionnaire-2 (Kroenke et al., 2003), which asked the participant how often they “had little interest or pleasure in doing things” and “felt down, depressed, or hopeless” in a

typical month during the outbreak on a 4-point scale (*not at all, several days, more than half the days, nearly every day*). The sum score of the two items was calculated where higher scores demonstrate higher depressive symptoms (ranging 0–6; $\alpha = 0.76$). *Generalized Anxiety* was measured via the Generalized Anxiety Disorder-2 (Plummer et al., 2016), which asked the participant how often they “felt nervous, anxious, or on edge” and “been unable to stop or control worrying” in a typical month during the outbreak. Each item was on a 4-point scale (*not at all, several days, more than half the days, nearly every day*) and the sum score of the two items was computed (ranging 0–6). Higher scores show higher anxiety levels ($\alpha = 0.82$). *Emotional difficulty related to caregiving* was derived by combining two items. The respondents were first asked if providing help for the NHATS participant has been emotionally difficult. If yes, then the level of difficulty is rated on a 5-point scale from 1 (*a little difficult*) to 5 (*very difficult*) with the respondents that responded “no” to the initial question given the score of 0 (such that the scale ranges from 0 *not at all difficult* to 5 *very difficult*). *Caregiver overload* was computed by the sum score of four items. Each item asked the caregiver how much they “have been exhausted when have gone to bed at night,” “have had more things to do than one can handle,” “haven’t had time for oneself,” and “have gotten a routine going but the NHATS participant’s needs have changed” on a 3-point scale (*not so much, somewhat, very much*). The sum of the four items were calculated such that higher scores represent higher overload (ranging 0–8, $\alpha = 0.80$). *Caregiving Gains* was measured by combining four items that ask the respondent how much helping the NHATS participant has “made one more confident about one’s abilities,” “taught one to deal with difficult situations,” “brought one closer to the NHATS participant,” and “given one satisfaction that the NHATS participant is well cared for.” Each item was on a 3-point scale (*not so much, somewhat, very much*) and a total sum score was calculated such that higher scores represent higher levels of gain from care provision (ranging 0–8, $\alpha = 0.82$).

Independent variables

Our primary predictor of interest is change in the level of care provision. Following a question on the amount of hours spent helping NHATS respondents on a typical day during the pandemic, the NHATS FF COVID-19 questionnaire asked the participant “during the COVID-19 outbreak, have you helped the NHATS participants more, less, or about the same compared to a typical week before the outbreak started?” This is a categorical measure of: the same (reference), increased, and decreased.

Covariates

Our focus is to assess the potential effect of care change on caregivers’ psychosocial well-being. Accordingly, we included confounding factors that may influence care provision and psychosocial well-being of the caregivers. Caregiver’s age in years, gender, race (White, Black, other), relationship with care recipient (spouse, child, other), education (less than some college, some college or associate’s degree, bachelor’s

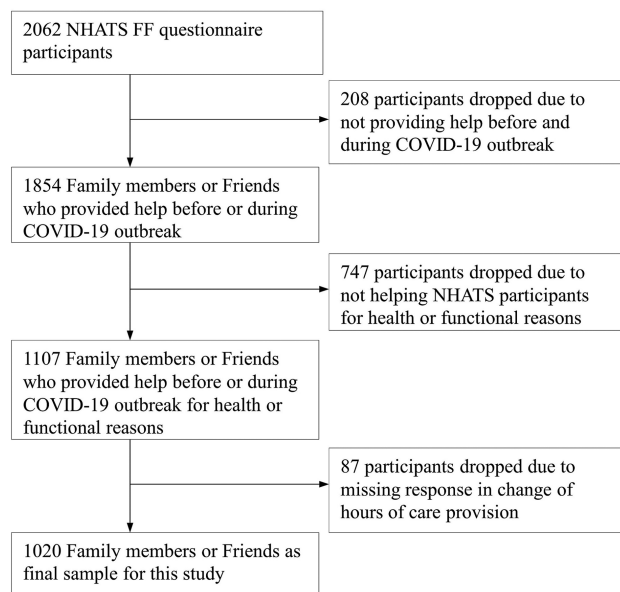


Figure 1. Flowchart of sample selection. COVID-19 = Coronavirus disease 2019; FF = Family Members and Friends questionnaire; NHATS = National Health and Aging Trends Study.

Table 1. Sample Characteristics by Change in Care Provision During the COVID-19 Outbreak

	Overall mean (SD)	%	Changes in caregiving			p Value ^a				
			No change (N: 610, 58.0%)	Increase (N: 278, 30.5%)	Decrease (N: 132, 11.5%)	No change vs increase	No change vs decrease	Increase vs decrease		
<i>Care provider health status</i>										
Total number of observations: 1,020	60.7 (17.0)		63.3 (16.2)	56.6 (13.4)	58.8 (15.5)	<.001	<.001	<.001	.08	.94
<i>Care recipient health status</i>										
Age, mean (SD)										
Gender, %										
Female		69.3	64.4	76.1	75.7		.01	<.001	.06	
Male		30.7	35.6	23.9	24.3					
Race, %										
White		81.4	78.8	84.6	85.8					.84
Black		10.4	12.3	7.6	8.6					
Others		8.2	8.9	7.8	5.5					
Relationship to care recipient, %										
Spouse/partner		23.5	33.8	10.0	7.5					.82
Biological/adopted child		53.2	45.8	63.2	64.2					
Others		23.3	20.4	26.8	28.4					
Marital status, %										
Married		62.2	64.4	63.6	47.7		.85	.01		.02
Not married		37.8	35.6	36.4	52.3					
Proximity to care recipient prior to the COVID-19, %										
Coresident		43.2	56.2	28.8	15.6		<.001	<.001		.03
Nonresident		56.8	43.8	71.2	84.4					
Proximity to care recipient during the COVID-19, %										
Coresident		48.9	58.1	44.2	14.9		.004	<.001		<.001
Nonresident		51.1	41.9	55.8	85.1					
Education										
Less than some college		31.9	37.4	22.2	29.9					.37
Some college or Associate's degree		28.3	28.3	30.2	23.3					
Bachelor's degree or higher		39.8	34.3	47.6	46.8					
Self-rated health, mean (SD)	3.5 (1.4)		3.4 (1.4)	3.7 (1.4)	3.6 (1.4)		<.001	<.001		.46
Hours of help provided on a typical day before COVID-19, mean (SD)	4.1 (7.6)		4.7 (9.3)	3.4 (5.4)	2.8 (2.7)		<.001	<.001		.14
Anxious about COVID-19, mean (SD)	1.3 (0.9)		1.2 (0.9)	1.4 (0.8)	1.4 (1.0)		<.001	<.001		.58
Depressed about COVID-19, mean (SD)	1.1 (1.1)		1.0 (1.4)	1.3 (1.0)	1.2 (0.9)		<.001	<.001		.11
<i>Care recipient health status</i>										
Cognitive impairment		32.8	30.9	29.5	50.7		.74	<.001		.004
Dementia, %										
No dementia, %		67.3	69.1	70.5	49.3					

Table 1. Continued

	Overall mean (SD)	%	Changes in caregiving			p Value ^a		
			No change (N: 610, 58.0%)	Increase (N: 278, 30.5%)	Decrease (N: 132, 11.5%)	No change vs increase	No change vs decrease	
Total number of observations: 1,020								
Provided help with any self-care or mobility activity prior to COVID-19, ^b %		41.8	44.0	36.1	45.7	.13	.82	.17
Provided help with any household activity prior to COVID-19, ^b %		85.1	91.9	70.9	87.7	<.001	.27	<.001
Provided help with any self-care and mobility activity during COVID-19, %		45.8	46.3	53.7	22.7	.16	<.001	<.001
Provided help with any household activity during COVID-19, %		94.5	94.8	97.4	85.7	.13	.004	<.001
Number of self-care and mobility activities helped with prior to COVID-19, mean (SD) ^b	1.2 (3.3)		1.3 (3.3)	0.9 (2.7)	1.3 (2.3)	.01	.86	.11
Number of household task activities helped with prior to COVID-19, mean (SD) ^b	2.6 (2.6)		3.1 (2.0)	2.0 (2.5)	2.2 (2.1)	<.001	<.001	.25
Number of self-care and mobility activities helped with during COVID-19, mean (SD)	1.4 (3.4)		1.3 (3.4)	1.7 (2.8)	0.6 (1.5)	.02	<.001	<.001
Number of household activities helped with during COVID-19, mean (SD)	2.9 (2.2)		3.1 (2.2)	2.9 (1.9)	1.8 (1.7)	.051	<.001	<.001
Place of residence								
Place that offers help with daily activities, %		12.6	9.5	7.2	42.2	.13	<.001	<.001

Notes: ANOVA = analysis of variance; COVID-19 = coronavirus disease 2019; NHATS = National Health and Aging Trends Study; SD = standard deviation.

^aThe p values were computed using chi-square tests (categorical variables) and ANOVA (continuous variables).

^bPrior to COVID-19 values are retrospective items taken from NHATS COVID-19 Family Members and Friends survey. Covariates were imputed but the outcome variables were not and thus missingness remains.

degree or higher), marital status, self-rated health (5-point scale; 1: *poor* to 5: *excellent*), living situation with care recipient before and during COVID-19 (coresident, nonresident), number of hours helped on a typical day before COVID-19 (range 0–24), and presence of care recipient's memory problems were derived from the NHATS FF COVID-19 questionnaire. Caregiver's assistance with self-care, mobility, and household activities were also computed from the questionnaire. Caregivers helped with up to seven self-care and mobility activities including bathing, getting dressed, eating, toileting, getting out of bed, getting around inside, going outside (0: no help, 1: helped with at least one). Caregivers helped with up to five household activities including laundry, meals, shopping, medications, and finances (0: no help, 1: helped with at least one). Place of residence of the NHATS participant (1: place that offers help with daily activities, 0: community-dwelling) was used as a covariate. Finally, feeling anxious or depressed about the COVID-19 outbreak was asked with two separate items, "during the COVID-19 outbreak, in a typical week, how (worried or anxious OR sad or depressed) have you felt about the outbreak?" on a 4-point scale (*not at all, mild, moderate, severe*).

Reasons for change

Caregivers who reported increasing or decreasing their care amount were able to select all reasons for the change that applied from a checklist (e.g., "I do not want the NHATS participant to go out during the outbreak," "other family members and friends are helping more"). Full checklist items can be found in [Table 2](#).

Analyses

We first provided descriptive statistics (mean or percentage) for all covariates by the status of caregiving change (no change, increase, and decrease). Differences in each statistic by the status of caregiving change were tested using chi-square tests and analysis of variance. Second, we calculated frequencies and percentages of caregivers reporting each of given reasons for increasing and decreasing the amount of care provision among those who reported any changes in the amount of care provision. Third, to assess the extent to which caregiver stress and well-being outcomes during the pandemic were associated with change in care provision, we performed multivariable linear regressions controlling for sociodemographic and health confounding factors. We controlled for pandemic-related anxiety and depression in a second model to remove the potential spillover effect.

Analyses take into account the complex survey design and use NHATS FF COVID-19 survey weights which account for the differential probabilities of survey design and sample selection and adjust for possible bias ([Hu et al., 2021](#)). All tests are two-sided and a statistical inference of significance was based on the 5% of significance level.

Results

Sample Characteristics by the Status of Caregiving Change

As summarized in [Table 1](#), there are 1,020 caregivers in the study, the average age of which was 60.7 years. Almost

Table 2. Reasons for Change in the Amount of Care Provision During the COVID-19 Outbreak

Reasons for change	N	%
More hours		
The NHATS participant can no longer get paid care or home care	16	3.9
Other family or friends who usually help had to stop or cut back	65	15.9
I do not want the NHATS participant to go out during the outbreak	203	49.5
The NHATS participant does not want to go out during the outbreak	133	32.4
The NHATS participant's health, functioning, or memory got worse	149	36.3
The NHATS participant and I moved in together	31	7.6
We have been helping out each other during the outbreak	56	13.7
Less hours		
My health keeps me from going out during the outbreak	16	3.9
My other family responsibilities have increased	29	7.1
Other family members and friends are helping more	41	10.0
The NHATS participant's health, functioning, or memory got better	11	2.7
The NHATS participant moved out	5	1.2
The NHATS participant lives in an assisted living or other facility and I am not allowed to visit	76	18.5
I am concerned about exposing the NHATS participant	84	20.5
More or less hours		
Other	26	6.3
The NHATS participant was injured or had surgery	18	4.4

Notes: COVID-19 = coronavirus disease 2019; NHATS = National Health and Aging Trends Study. All the percentages were calculated based on the 410 participants that indicated any change in the amount of care provision during the COVID-19 outbreak. Participants were able to select multiple items across three categories (more, less, more or less hours).

70% of the sample were female and 81.4% were White. Half of the sample were children of the care recipients (53.2%). Over 40% of the caregivers coresided with the care recipient prior to or during the outbreak. Many were providing care for care recipients with dementia (32.8%) and a self-care or mobility need (45.8%).

Most of the sample (58.0%) reported no change in the amount of care provision during COVID-19, whereas 30.5% reported an increase and 11.5% reported a decrease in the amount of care provided. There is significant variation in sociodemographic characteristics of caregivers and health status of care recipients by the status of change in caregiving. Relative to those whose care stayed stable, those who increased or decreased their care provision were more likely to be younger, a child of the care recipient, not coresiding, helped less hours prior to COVID-19, and were more anxious during COVID-19. Caregivers who reported an increase in the amount of

care provision were also more likely to be female, have higher levels of educational attainment, better self-rated health, were more depressed about COVID-19, and provided less household activity support compared to caregivers that reported no change in their amount of care. Caregivers who indicated a decrease in care were also more likely to not be married, providing care for an individual with dementia, their care recipient was more likely to be living in long-term care, and were providing less self-care and mobility support compared to caregivers that reported no change. When comparing caregivers that indicated change, caregivers were more likely to increase rather than decrease care provision if they were married, living with the care recipient, not providing care for an individual with dementia, their care recipient was community-dwelling, and providing support for persons needing greater self-care, mobility, and household activity assistance (full results in Table 1).

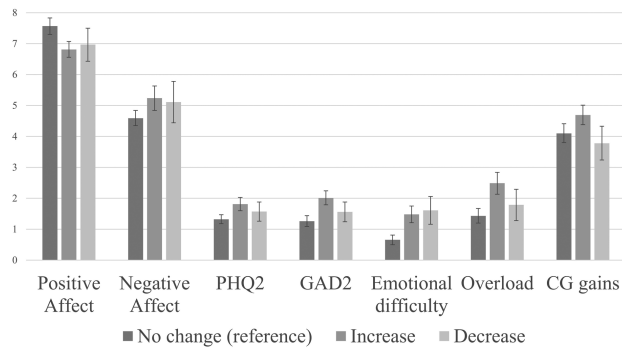


Figure 2. Average values of psychosocial outcomes by changes in caregiving. *Notes:* The error bars correspond to 95% confidence intervals. CG = caregiver; GAD = Generalized Anxiety Disorder; PHQ = Patient Health Questionnaire.

Reasons for the Change in Care Amount During the COVID-19 Outbreak

For those who indicated any change in the amount of care provision, the most common reason for providing *more* hours was that the caregiver did not want the care recipient to go out during the outbreak (49.5%) followed by because the care recipient’s health deteriorated (36.3%). The most common reasons for providing less hours were concern about exposing the care recipient to COVID-19 (20.5%) and visitation restriction while the care recipient stayed in a facility (18.5%). The full list of reasons for care change can be found in Table 2 (Supplementary Table 1 examines mean differences in outcomes by reasons for change).

Table 3. Relationship Between Caregiving Change and Stress Process Outcomes of Caregiving

Outcomes	Adjusted ^a		Adjusted ^b	
	Increase	Decrease	Increase	Decrease
	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)
Positive affect	-0.78*** (-1.16, -0.38)	-0.44* (-1.31, -0.04)	-0.49** (-0.85, -0.14)	-0.52 (-1.10, 0.06)
Negative affect	0.60* (0.05, 1.15)	0.28 (-0.42, 0.97)	0.29 (-0.21, 0.78)	0.10 (-0.49, 0.69)
PHQ-2	0.53*** (0.29, 0.77)	0.25 (-0.11, 0.60)	0.32** (0.10, 0.54)	0.14 (-0.18, 0.45)
GAD-2	0.74*** (0.47, 1.00)	0.21 (-0.16, 0.57)	0.50*** (0.28, 0.72)	0.09 (-0.21, 0.39)
Emotional difficulty	0.69*** (0.44, 0.94)	0.72*** (0.31, 1.13)	0.57*** (0.33, 0.82)	0.66** (0.24, 1.09)
Overload	0.89*** (0.52, 1.27)	0.51 (-0.001, 1.03)	0.75*** (0.36, 1.14)	0.45 (-0.03, 0.92)
CG gains	0.61* (0.09, 1.13)	0.18 (-0.42, 0.77)	0.65* (0.15, 1.16)	0.19 (-0.41, 0.80)

Notes: No change in care provision is the reference. CG = caregiver; CI = confidence interval; COVID-19 = coronavirus disease 2019; GAD = Generalized Anxiety Disorder; PHQ = Patient Health Questionnaire.

^aModels were adjusted for age, gender, race, relationship to CG, education, marital status, self-rated health, living status before and during COVID-19, dementia, self-care, and mobility task limitations (presence), household task limitations (presence).

^bModels were adjusted for all covariates in model^a and pandemic-related anxiety and depression.

p* < .05. *p* < .01. ****p* < .001.

Psychosocial Outcomes Associated With Changes in Care Provision During COVID-19

The unadjusted mean values of psychosocial outcomes with 95% confidence intervals (CIs) are presented by changes in care provision and can be found in Figure 2, and adjusted estimates for differences from no change of care provision are provided in Table 3. Compared to those who had not changed the amount of care provision, caregivers that increased their amount of care provision experienced significantly lower levels of positive affectivity ($B = -0.78$, [95% CI]: [-1.16, -0.38]), higher levels of negative affectivity ($B = 0.60$, [0.05, 1.15]), significantly greater amounts of depressive symptomatology ($B = 0.53$, [0.29, 0.77]), higher levels of generalized anxiety ($B = 0.74$, [0.47, 1.00]), higher levels of emotional difficulty ($B = 0.69$, [0.44, 0.94]), higher levels of caregiver overload ($B = 0.89$, [0.52, 1.27]), and greater amounts of caregiver gains ($B = 0.61$, [0.09, 1.13]). On the other hand, caregivers who reduced the amount of care provision also experienced significantly higher levels of emotional difficulty ($B = 0.72$, [0.31, 1.13]) and significantly lower levels of positive affectivity ($B = -0.44$, [-1.31, -0.04]) compared to those who had not changed the amount of care provision during the outbreak.

When additionally controlling for pandemic-related anxiety and depression in a separate model, results are very similar. However, negative affectivity was no longer associated with increased care and positive affectivity was no longer associated with decreased care. Detailed results can be found in Table 3 (fully adjusted models in Supplementary Table 2; model results for those who provided care both before and during the pandemic can be found in Supplementary Table 3).

Discussion

Examining data on up to two caregivers assisting an older adult with care needs during the COVID-19 pandemic from the nationally representative NHATS, we found that an increase in pandemic care responsibilities was related to a wide range of negative mental health outcomes. These associations were not accounted for by a spillover effect of COVID anxiety and depression. This finding aligns with Stress Process Models and developmental theories, which suggest that care demands change over time, and higher-intensity care loads are associated with worse outcomes (Abernethy et al., 2009; Aneshensel et al., 1995; Burton et al., 2003; Hirst, 2005; Liu & Lou, 2017). Our findings are similar to recent work suggesting that stress process outcomes increased during the pandemic compared to prior to the pandemic among caregivers (Archer et al., 2021; Budnick et al., 2021; Giebel et al., 2021; Park, 2021; Savla et al., 2021). However, our study provides additional nuance that an increase in time spent on caregiving, not just the number of self-care activities, during the pandemic is related to worse mental health. Yet, an increase in care

was also associated with a positive outcome of caregiving gains, which is consistent with prior work suggesting more intense care contexts allow for the experience of gains specific to caregiving (Leggett et al., 2021).

Compared to Cohen et al. (2021), who found that a decrease in care responsibilities was associated with a decrease in caregiver burden, we find, in contrast, a decrease in care to be associated with higher levels of emotional difficulty regarding caregiving. This difference may reflect the emotional component of decreasing one's care, whereas Cohen's findings may suggest a reduction in task-related burden. Further, our sample was significantly older and had a higher proportion of female caregivers than the Cohen sample, which may account for the different finding as females tend to report greater burden (Pinquart & Sörensen, 2006). Moreover, those who decreased care were generally nonspousal and noncoresident caregivers who described a desire not to expose the care recipient as a primary reason for decreasing care. Those who increased care provision, however, were also younger and more likely to be nonspousal care partners than those who stayed consistent in their care provision. This may suggest that care contexts did not change as much for spouses who were already providing care in a home setting. Yet for adult children and other relatives, there appears to be a dichotomy of approach, with some decreasing provision to reduce risk of spread, whereas others increased care to keep the care recipient in the home and to help with increasing care needs during the pandemic. Further, heterogeneity in reasons for decreasing one's care (e.g., positive reasons such as increased support from family or more negative reasons such as concern about exposing the care recipient) may have diminished the overall association of decreasing care on care outcomes.

Indeed, significant differences were seen in care provision changes by demographic and care characteristics. Those who increased and decreased their care showed many of the same demographic and contextual characteristics (e.g., younger age, less coresiding with the care recipient), which contrasted from those who stayed stable in their care. Those who increased their care during COVID-19 were providing the lowest level of self-care and household support on average pre-COVID-19. Yet those who decreased provided less care overall than those who remained stable, suggesting this was not just a regression to the mean phenomenon. Additionally, demographic factors associated with increased risk for severe complications from COVID-19 such as age, race, and health status were generally unrelated to changes in care provision aside from younger caregivers being more likely to increase and decrease care provision.

Generally, a noncoresiding care role had a major impact on changes in care provision during the pandemic. A decrease in care was seen for those assisting an individual living with dementia, which may seem counterintuitive. However, those who decreased were also less likely to be coresiding with the care recipient and a primary reason for decreasing one's care provision was that the care recipient

was living in long-term care. This aligns with dementia care being associated with a decrease in care provision due to the higher proportion of dementia patients residing in long-term care settings, which almost universally held visitation restrictions during the pandemic. This decrease may be stressful as caregivers are key parts of the care infrastructure for residents in facilities (Kemp, 2021).

As described, the primary reasons cited for caregivers increasing their hours of care had to do with the caregiver and/or the care recipient not wanting the care recipient to go out during the outbreak (with one in three caregivers who changed their care provision during the pandemic expressing this as a reason). Concerns about exposing the care recipient was the primary reason cited for decreasing one's care provision. This suggests that health concerns regarding exposure had more of an impact on caregivers increasing and decreasing hours of care than lack of access to services or changes in social supports caregivers received. This is consistent with qualitative work on caregiving concerns and changes during the pandemic, which identified keeping family members safe as a major theme from their qualitative interviews (Lightfoot, Moone, et al., 2021; Lightfoot, Yun, et al., 2021).

Limitations

Our primary predictor was an ordinal scale of increasing, stable, or decreasing care overall. However, caregivers may have increased some types of caregiving but decreased other types of caregiving. Of note, while we could not discern changes in care amount specific to each care type (e.g., self-care vs household activities), in our descriptive results regarding reasons for change in care provision, some caregivers indicated reasons that their care provision both increased and decreased. Future studies may consider ways in which caregivers increased their care provision in some ways and decreased in other capacities. For example, while hands-on care may have decreased for some caregivers, it is possible that virtual or socially distant ways of connecting with the care recipient may have increased (Lightfoot, Moone, et al., 2021; Lightfoot, Yun, et al., 2021). The COVID-19 pandemic may have affected many aspects of caregivers' lives besides caregiving amount (e.g., financial impact, competing demands). Although we controlled for potential confounding factors (demographic, socioeconomic, and health variables) using multivariable linear regression, the observed differences in psychosocial well-being outcomes by changes in the care amount might not suggest a causal relationship.

Despite the limitations, our study extends the COVID-19 caregiving literature in several ways. First, we provide nationally representative estimates for caregivers of Medicare-eligible older adults using the NHATS. As opposed to examining differences in mental health between caregivers and noncaregivers during the pandemic which has been a primary focus of emerging literature, we have the advantage of being able to explore changes in care provision during the COVID-19 outbreak and the potential

impact of such a care transition on a wide variety of both negative and positive stress process outcomes. Findings also provide insights into the reasons of changes in care during the pandemic and caregivers' and care recipient's characteristics associated with the care changes, which will inform intervention programs to identify caregivers who were affected most by the pandemic. For example, clear guidelines and recommendations for caregivers trying to reduce spread (a primary concern among those who increased and decreased care) while maintaining assistance could be very beneficial. As an estimated 17.7 million adults are providing older adult-care roles in the United States (NASEM, 2016), policies, employer-sponsored programs, and community-based programs to support caregivers with intensified care roles during a pandemic may reduce overload and enhance mental well-being, leading to great public health impact.

Supplementary Material

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

Funding

Funding was provided by the National Institute on Aging (P30AG012846 and U01AG032947) and by NIA Career Development Awards to Dr. Leggett (K01AG056557) and Dr. Choi (K01AG057820). This paper was published as part of a supplement sponsored by the University of Michigan and the Johns Hopkins Bloomberg School of Public Health with support from the National Institute on Aging (U01AG032947 and P30AG012846).

Conflict of Interest

None declared.

Acknowledgments

The authors would like to acknowledge Vicki Freedman, Mengyao Hu, and the NHATS and NSOC study team for their support of this work. An earlier version of this paper was presented at the NHATS 10th Anniversary Virtual Conference, May 26–27, 2021. The views expressed are those of the authors alone and do not represent those of their employer or the funding agency.

Author Contributions

A. Leggett conceptualized the study research question and hypothesis, did the literature search, and wrote the paper. H. J. Koo managed the data, ran the analysis, and assisted with the write-up of the paper. H. Choi helped with conceptualization of the study research question, methods, and analysis plan and edited the manuscript. B. Park assisted with the literature search, edited the manuscript, and managed the references.

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