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Caregiving in a Pandemic: COVID-19 and the Well-being of Family Caregivers 55+ in the U.S.

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1156 15th St NW Suite 700 Washington DC 20005 202-545-6002 Title: Caregiving in a Pandemic: COVID-19 and the Well-being of Family Caregivers 55+ in the U.S. Keywords: COVID-19, Family Caregiving, Mental Health, Aging, Long-term care

Abstract: Little is known about the effects of COVID-19 on family caregivers in the US. Using data from a national sample of 2,485 US adults aged ≥55, we aimed to describe the magnitude of disruptions to family care arrangements during the initial wave of the COVID-19 pandemic, and the associations between these disruptions and the mental health outcomes (depression, anxiety, loneliness, and self-rated health) and employment outcomes (job loss or furlough, hours or wages reduced, transition to work-from-home) of family caregivers. We found that COVID-19 disrupted over half of family caregiving arrangements, and that care disruptions were associated with increased depression, anxiety, and loneliness among caregivers, compared to both non-caregivers and caregivers who did not experience disruptions. Family caregivers who experienced pandemic-related employment disruptions were providing more care than caregivers who did not experience disruptions. These findings highlight the impact of the pandemic on an essential and vulnerable health care workforce.

INTRODUCTION

Most Americans take on multiple, unpaid caregiving responsibilities over the courses of their lives. Beyond childcare, more than one in 10 adults in the US provides care to a spouse, elderly parent, or other relative, and more than one in three grandparents regularly care for their grandchildren (David et al., 2019; Freedman & Wolff, 2020; National Alliance for Caregiving & AARP, 2020). Further, most older adults with disabilities rely on care provided by family or friends, a trend that has accelerated in recent decades (Van Houtven et al., 2020). Beginning in March 2020, the Coronavirus disease 2019 (COVID-19) pandemic complicated caregiving arrangements for families with care needs (Friedman et al., 2021; Van Houtven et al., 2020). Nursing homes across the country became epicenters of COVID-19 transmission and mortality, while schools and child care services shut down (Barnett & Grabowski, 2020; Chen et al., 2020; Conlen et al., 2020). Non-coresident family and formal care arrangements of all types became not only logistically more difficult due to pandemic control measures, but posed a direct health threat as older adults, who are both recipients and providers of family care, are at high risk of severe COVID-19 morbidity and mortality (AP-NORC Center for Public Affairs Research, 2020; CDC, 2020).

Family caregivers take on a range of tasks and responsibilities in a variety of settings, including in their own home, in the care recipient's home, or an institutional setting such as a nursing home. Many care arrangements involve multiple caregivers, which may include family and friends, formal caregivers, or services such as daycare (David et al., 2019; Freedman & Wolff, 2020; National Alliance for Caregiving & AARP, 2020; Van Houtven et al., 2020). Tasks can range from running errands and providing companionship to administering complicated medical care (Freedman & Wolff, 2020; Wolff et al., 2016). Prior to COVID-19, the substantial physical, mental, and economic costs of family caregiving had been well-documented (Bom et al., 2019; Coe & Van Houtven, 2009; Hirst, 2005;

Schmitz & Westphal, 2017; Van Houtven et al., 2013). Recognizing these costs, as well as the potential health benefits and implicit dollar value of the services provided by family caregivers (Chari et al., 2015), federal efforts such as the National Family Caregiver Support Program and the Veterans Affairs caregiver support program were designed provide information, service referrals, counseling and support groups, training, and, in some cases, financial compensation to family caregivers (Van Houtven et al., 2019; Wolff et al., 2016). However, many family caregivers have limited or no access to services and supports, as the provision of respite services such as meal delivery and adult day care, financial compensation, and paid family caregiving leave, have remained largely at the discretion of state legislatures (Dawson et al., 2020; Feinberg, 2018).

The piecemeal structure of the US long-term care system is likely to have left families with caregiving needs vulnerable to sudden and widespread disruptions induced by the COVID-19 pandemic. However, little is known about how the pandemic has impacted the provision of family care and the consequences for family caregivers as they contend with such disruptions. In this paper, we use national data to provide the first comprehensive assessment of the magnitude of disruptions to family caregiving arrangements during the initial wave of COVID-19 among family caregivers aged 55 and over, and we document the associations between these disruptions and the mental health, self-rated health, and employment outcomes of family caregivers.

COVID-19 may have had substantial acute impacts on the well-being of middle aged and older family caregivers. Adults aged 55 and over provide important non-parental forms of family caregiving, while facing age-based elevated risks for COVID-19 morbidity and mortality (CDC, 2020). The physical isolation necessitated by COVID-19 coupled with potentially significant changes in caregiving roles may compound the risks of adverse mental health outcomes such as anxiety, depression and loneliness in this population (Czeisler et al., 2020; Kobayashi et al., 2021; Lyons et al., 2015; National

Alliance for Caregiving & AARP, 2020; Park, 2020). Further, prior to the pandemic, over half of family caregivers in the US were balancing paid work and family care responsibilities (Freedman & Wolff, 2020). Those family caregivers who are approaching or working beyond retirement age may face difficult tradeoffs during the COVID-19 pandemic, as they may experience increased or different caregiving roles and expectations about future care needs (Van Houtven et al., 2013). As the population ages, family caregiving will continue to play an increasingly central role the national health care system. In this study, we provide evidence that formal supports for non-parental family caregiving, including for the sizable number of aging family caregivers who are simultaneously engaged in paid work, will be critical amidst recovery from COVID-19 (Friedman et al., 2021; joebiden.com, 2020).

DATA AND STUDY METHODS

Data Sources

Data were from the baseline of the COVID-19 Coping Study, a national cohort of US adults aged \geq 55 years (Kobayashi et al., 2021). Data collection began on April 17^{th,} 2020, approximately two weeks after much of the country adopted intensive social distancing and shelter-in-place orders to mitigate the spread of the SARS-CoV-2 virus and ended on May 15th, 2020. The sampling frame was drawn from an existing online research panel maintained by the professional survey company, Dynata. Sampling quotas were used for age, gender, race, ethnicity, and education that matched the general US population aged \geq 55 based on CDC Wide-ranging ONline Data for Epidemiologic Research (WONDER) (Kobayashi et al., 2021). Data were collected through an online questionnaire designed to take approximately 17 minutes on computer, tablet, and smartphone interfaces. The questionnaire included questions about regular caregiving responsibilities prior to the pandemic, caregiving disruptions experienced as a result of the pandemic, employment prior to the pandemic, employment disruptions experienced as a result of

the pandemic, and a series of validated research scales to evaluate depressive symptoms, anxiety symptoms, loneliness, and self-rated health (Fisher et al., 2005; Lewinsohn et al., 1997; Radloff, 1977; Russell, 1996). The full questionnaire is available at: <u>https://sph.umich.edu/covid19copingstudy/</u>. We merged these data with county-level information on COVID-19 case rates and deaths compiled by the New York Times and distributed by the Inter-university Consortium for Political and Social Research (ICPSR), and 2019 county-level population data from the Census Bureau (New York Times, 2020; US Census Bureau, 2019). The University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board approved the COVID-19 Coping Study protocol (HUM00179632) (Kobayashi et al., 2021).

Study Sample

Our eligible sample included all COVID-19 Coping Study respondents recruited through Dynata (N=2,485). Some analyses were restricted to respondents who were caregivers prior to the start of COVID-19 (N=535), and those who were employed prior to the start of COVID-19 (N=808).

Outcomes and Measures

We identified a caregiver as anybody who reported having regular caregiving responsibilities in their "usual life, before the COVID-19 (coronavirus) pandemic." This definition included care provided to spouses, parents, children, grandchildren, other relatives, or non-relatives with long-term illness or disability. We used reports of relationships with household members to identify which caregivers were caring for co-residents. Among respondents with pre-pandemic caregiving obligations, we identified two (mutually exclusive) categories of disrupted caregivers: those who reported providing more care or had new caregiving obligations as a result of the pandemic, and those who reported providing less care or being unable to provide care as a result of the pandemic. To evaluate the associations between caregiving, caregiving disruptions, and mental and selfrated health, we constructed the following four binary outcomes: high depressive symptoms (defined as scoring \geq 3 on the 8-item Center for Epidemiological Studies Depression Scale; CES-D), high anxiety symptoms (defined as scoring \geq 10 on the 5-item Beck Anxiety Inventory), high loneliness (defined as scoring \geq 6 on the 3-item UCLA loneliness scale), and fair or poor self-rated health (based on a 5-point Likert-type scale) (Fisher et al., 2005; Lewinsohn et al., 1997; Radloff, 1977; Russell, 1996). To evaluate the associations between caregiving, caregiving disruptions, and self-reported effects of COVID-19 on employment, we included binary indicators for experiencing each of: any employment change, a job loss or furlough, reduced hours or income, or, working from home.

Statistical Analysis

First, we calculated descriptive statistics comparing caregivers and non-caregivers on a range of demographic characteristics and county-level COVID-19 cases and death rates. We then explored demographic factors associated with experiencing any caregiving disruption (defined as providing more or new care, or providing less or no care), as well as with caregiving disruptions by type. We tested for bivariate differences across groups using two-sample t-tests.

Next, we estimated covariate-adjusted regressions to determine the relationships between each of 1) caregiver status and 2) caregiving disruptions by type with the mental and self-rated health outcomes using the following linear probability model:¹

$$y_{ics} = \beta_1 C G_{ics} + \beta_2 C G Disruption_{ics} + \beta_3 X_{ics} + \beta_4 C_{cs} + \delta_s + \varepsilon_{ics}$$
(1)

¹ Although all of our outcomes were binary, we used linear probability models (OLS) instead of logistic models because linear probability models produce marginal effects that are directly interpretable and comparable across models with different covariates (Norton & Dowd, 2018).

Here, y_{ics} is the mental health outcome for individual *i* living in county *c* in state *t*, CG_{ics} is a binary indicator for pre-pandemic caregiver status (yes, no) and $CGDisruption_{ics}$ is a binary indicator for if caregiving was disrupted by the pandemic. The coefficient β_1 captures the covariate-adjusted mean difference in the probability of each outcome, expressed as percentage points, between non-caregivers and caregivers who did not experience disruptions, and the coefficient β_2 captures the difference for caregivers experiencing disruptions relative to non-caregivers. In some models, we replaced *CGDisruption_{ics}* with two mutually exclusive indicators for disruption type (providing more or new care and providing less or no care).

All models included a vector of individual controls, X_{tcs} , which were age, age², marital status, race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, other), education (less than high school, high school, some college, college degree or higher), housing tenure (home owned outright, home owned with mortgage, renter in a market rental, renter in subsidized housing, living rent-free, other), being employed pre-pandemic (yes, no), health history (previous physician diagnosis of each of: high blood pressure, diabetes, heart disease, asthma, chronic obstructive pulmonary disease, cancer, depression, anxiety, other physical or mental health condition), use of a mobility aid (yes, no), and a 5-point pre-pandemic social isolation index that incorporated frequency of contact with each of children, other family, friends, participation in social clubs or organizations, and living alone (Steptoe et al., 2013). We included state fixed effects δ_s to control for any unmeasured differences between US states that may have influenced the relationship between caregiving and the outcomes of interest, such as long-term care policies and COVID-19 responses, as well as C_{cs} , the average confirmed COVID-19 cases and deaths per 1000 population members in the respondent's county of residence over the 4-week survey period. Standard errors were clustered at the state level. All models were weighted to the US general

population aged ≥ 55 based on 2018 American Community Survey data on age, sex, race, ethnicity, education, and marital status (Kobayashi et al., 2021). Finally, we tested that $\beta_1 = \beta_2$ using a postestimation linear test and report the associated p-values.

For analysis of employment outcomes, we restricted the sample to respondents who reported working prior to the pandemic (N= 808) and dropped the control variable for pre-pandemic employment status. We used the same covariate-adjusted linear probability models to estimate the relationships between caregiving status and self-reported effects of the COVID-19 pandemic on employment (each of job loss or furlough, reduction in wages or hours worked, and transition to working from home, versus no effect on employment, as well as an indicator for any versus no employment disruption). Finally, we repeated this analysis further restricting our sample to exclude respondents working in health, health-related, or personal care professions (N=106) to minimize any possible overlap with paid caregivers. We do not exclude these respondents from the main analysis because here is evidence that nearly two-thirds of formal caregivers also provide unpaid care to family members (C. Van Houtven, DePasquale, et al., 2020).

RESULTS

Descriptive statistics

In this national sample of Americans aged 55 and over, 23% (535/2,485) reported having caregiving responsibilities prior to the COVID-19 pandemic (Table 1). Among caregivers, 47% (95% CI: 43%, 51%) provided care to a spouse, 27% (95% CI: 23%, 31%) provided care to parents or parents-in-law, 22% (95% CI: 18%, 25%) provided care to children, and 19% (95% CI: 16%, 23%) provided care to grandchildren. Over 60% (95% CI: 57%, 66%) of respondents reported caring for co-resident recipients, and 20% (95% CI: 16%, 23%) reported more than one caregiving role.

Caregivers were, on average, two years younger than non-caregivers (66.2 vs 68.2 years) and were also more likely to be female (58% vs 53%), less likely to be white (68% vs 74%), and more likely to be Hispanic (14% vs 9%) than non-caregivers (Table 1). Caregivers and non-caregivers reported similar levels of education, but caregivers were more likely to be married (67% vs 56%) and to be diagnosed with a health condition than non-caregivers (Table 1). Caregivers were more likely to be participating in the labor market prior to the pandemic than non-caregivers (Table 1). Caregivers were almost five percentage points more likely to be employed (35% vs 29%), and less likely to identify as retired (45% vs 56%) than non-caregivers (Table 1). We observed no differences in county-level COVID-19 cases or deaths between caregivers and non-caregivers.

Table 2 compares characteristics of caregivers, according to their experiences of caregiving disruptions during COVID-19. The pandemic disrupted caregiving routines for more than half of the caregivers in this sample (Table 2). Over 30% of caregivers reported more or new care responsibilities as a result of the pandemic, and 20% provided less care or were unable to provide care (Table 2). Caregivers who experienced disruptions were less likely to be caring for spouses, and more likely to be caring for parents or grandchildren than those who did not experience disruptions (Table 2). Caregivers who had coresident care arrangements prior to the pandemic were less likely to be disrupted than those in non-coresident care arrangements (Table 2). Among caregivers with disruptions, those providing more care were likely to be caring for non-coresident recipients, including spouse and children, while those providing less care were more likely to be caring for non-coresident recipients, including parents and grandchildren. These patterns are consistent with the COVID-19 pandemic making non-coresident caregiving more challenging because of logistical or virus transmission risk concerns.

There were also significant sociodemographic differences between caregivers who did and did not experience disruptions. Caregivers who experienced disruptions were younger, more likely to be

female, and less likely to be white than those who did not experience disruptions (Table 2). Caregivers who provided more care were nearly twice as likely to be Black and two-thirds more likely to be Hispanic than caregivers who did not experience disruptions (though these differences are not statistically significant at conventional levels). Caregivers who experienced disruptions were more likely to have ever been diagnosed with a health condition, including depression or anxiety, than caregivers who did not experience disruptions (Table 2). Caregivers who experienced disruptions were more likely to be employed and less likely to be retired than those who did not experience disruptions (Table 2). Finally, caregivers who experienced disruptions lived in counties with higher COVID-19 case and death rates than those who did not experience disruptions (Table 2).

Caregiving status, disruptions, and mental and self-rated health

We next compared mental and self-rated health outcomes across non caregivers and caregivers by disruption type using covariate-adjusted, population-weighted linear probability models. The results from estimating Equation (1) on mental and self-rated health are presented in Table 3. Each column presents results from a separate regression model. There were no differences in the mental and self-rated health outcomes between caregivers who did not experience disruptions and non-caregivers (Table 3). However, caregivers who experienced disruptions were more likely to screen positive for each of depression, anxiety and loneliness than both of non-caregivers and caregivers who reported no disruptions (Table 3). Caregivers reporting disruptions were 18.1 percentage points more likely than non-caregivers to screen positive for depression (a 69.3% increase relative to a prevalence of 26.1% among non-caregivers), 19.5 percentage points more likely than non-caregivers to screen positive for anxiety (83%, relative to a prevalence of 23.4% among non-caregivers), and 16.1 percentage points more likely to screen positive for loneliness (61.6%, relative to a prevalence of 26.1% among noncaregivers), 19.5 percentage points more likely than non-caregivers), and 16.1 percentage points caregivers). There was no difference in the reporting of fair or poor self-rated health according to caregiving status or disruptions (Table 3).

Figure 1 graphically presents the results of Equation (1) with separate indicators for disruption by type (provided more care; provided less or no care). The associations between caregiving disruptions and the mental health and self-rated health outcomes were similar according to type of disruption. Caregivers who provided more (less) care were 16.2 (15.6), 16.5 (15.8), and 13.4 (17.6) percentage points more likely to screen positive for each of depression, anxiety, and loneliness, respectively, compared to non-caregivers. There was no difference in the reporting of fair or poor self-rated health according to caregiving status or caregiving disruptions (Figure 4).

Caregiving status, disruptions, and employment outcomes

Over one-third (206/535) of caregivers and 623 non-caregivers in this sample worked prior to the pandemic. Among those employed prior to COVID-19, caregivers who experienced care disruptions were 13.9 percentage points more likely to experience any type of employment disruption than non-caregivers in covariate-adjusted, population-weighted linear probability models, while caregivers who did not experience care disruptions were also less likely to experience any employment disruption (Table 4). As reported at the bottom of Table 4, these effects are statistically significantly different from each other (p-value of 0.043). Models for different types of employment disruptions (job loss or furlough, reduced hours or wages, working from home), indicated that the associations observed for overall employment disruptions were driven by job losses and furloughs (Table 4).

Among caregivers who experienced care disruptions, the types of employment disruptions differed by type of caregiving disruptions. As visualized in Figure 2, caregivers who provided more care as a result of the pandemic were also 18.9 percentage points more likely than non-caregivers to have their employment affected, primarily in the forms of job loss or furlough or a work-from-home

transition. Caregivers who provided less or no care as a result of the pandemic were 16.2 percentage points more likely to experience a job loss or furlough than non-caregivers (Figure 2). When we re-ran these models excluding caregivers who were employed in a health, health-adjacent, or personal care profession prior to the pandemic, the relationship between providing less or no care and job loss became smaller in magnitude (8.6 percentage points vs. 16.2 percentage points) and was imprecisely estimated. The remainder of the estimates were negligibly impacted, indicating that employment in formal care is not responsible for the observed positive relationship between providing more care and employment disruptions (Figure 3).

DISCUSSION

As COVID-19 fundamentally changes an already fragile caregiving landscape in the US, understanding the pressure that the pandemic puts on family care is key to addressing future population care needs as the population ages. In this national sample of Americans aged ≥55 during the first wave of the COVID-19 pandemic, we identified that half of respondents with caregiving responsibilities prior to the pandemic experienced disruptions to their caregiving. Non-co-resident care arrangements were more likely to be disrupted, and caregivers who experienced disruptions were disproportionately younger, female, and Black or Hispanic. Caregivers who experienced disruptions had elevated symptoms of depression, anxiety, and loneliness compared to non-caregivers, as well as caregivers who did not experience disruptions. Caregivers in the labor force who experienced disrupted care arrangements, especially those providing more care, were also likely to experience disrupted employment, particularly in the forms of job loss or furlough or a work-from-home transition.

Our findings are consistent with pre-pandemic evidence demonstrating that caregiving, particularly transitions in and out of caregiving roles, can negatively impact the mental and emotional

health of family caregivers (Bom et al., 2019; Coe & Van Houtven, 2009; L. Feinberg et al., 2011; Lyons et al., 2015; Riffin et al., 2017). Our results are also consistent with findings showing that family caregivers in the US experienced worse mental and physical health than non-caregivers (Czeisler et al., 2020; Park, 2020). We add evidence that COVID-19-related disruptions to caregiving provided by middle-aged and older adults are associated with a mental health symptom burden and are often experienced alongside employment disruptions. Our findings are also consistent with recent studies showing the disproportionate impacts of COVID-19 on racial/ethnic minorities and women, who are overrepresented among both professional and family caregivers as well as frontline and essential workers (Dawson et al., 2020; Grooms et al., 2020; Van Houtven et al., 2020).

The associations we observed between the provision of more care during the pandemic and job disruptions are consistent with research indicating that pandemic-related school and day care closures have placed significant pressure on the productivity and labor supply of parents, particularly mothers (Ewing-Nelson, 2020; Handwerker et al., 2020). A lack of childcare has been a key driver in the disproportionate impact of the COVID-19-related recession on women, and these changes are likely to be permanent (Dingel et al., 2020). We expand upon these studies, finding that middle-aged and older family caregivers (who were primarily non-parental caregivers) who experienced employment disruptions in the first months of the pandemic were also providing more care than they did before the pandemic. American workers who are approaching or working beyond retirement age are already at risk for employment discrimination and for leaving the labor market during recessions (Coile et al., 2014; Neumark et al., 2018). It is possible that family care needs during the COVID-19 crisis may permanently affect the labor supply of some middle-aged and older workers.

Our study cannot identify the directions or mechanisms of the relationships between caregiving disruptions, mental health, and employment. Caregivers who provided more care may have found

themselves overwhelmed, while those providing less care may have felt distress at not being able to support their loved ones (Herships, 2021; Savla et al., 2020). Although we adjusted for self-reported previous physician-diagnosed anxiety and depression, our findings could also be explained if preexisting mental health symptoms led some caregivers to proactively change their caregiving arrangements due to fear of COVID-19 transmission. This interpretation highlights how the pandemic may have placed additional burden on the most vulnerable caregivers. Future research is necessary to understand the mechanisms behind these associations.

While our sample has coverage across all 50 US states and the District of Columbia, and aligns with national estimates for major sociodemographic groups, it is not a probability-based sample and does not represent non-Internet users. In the context of our research question and methodology, our observed estimates would be affected by selection bias if participation in the study is driven by factors that are uncorrelated with the sociodemographic factors incorporated in our sampling weights but correlated with the caregiving disruptions as well as outcomes under study (Rothman et al., 2013). While we believe this scenario is unlikely, we recommend caution when interpreting results beyond Internet users. Additionally, our data do not provide fine-grained descriptions of the specific types of care provided, whether the caregiver was paid or otherwise compensated, or the intensity or frequency of care, except to specify "regular" care. We performed robustness checks excluding individuals employed in health care or health care-adjacent professions, which showed similar results to the main analysis.

Strengths of this study include its large national sample of middle-aged and older Americans, and its timeliness in collecting rich data on caregiving, employment, mental health, and other social, economic, and health-related factors during the first wave of the COVID-19 pandemic. While existing and ongoing surveys of family caregiving and COVID-19 compare caregivers to non-caregivers

(Czeisler et al., 2020; Park, 2020) or follow caregivers longitudinally, our study identified COVID-19related caregiving disruptions and compared disrupted caregivers to those who did not experience disruptions as well as to non-caregivers. Findings from our research may inform hypotheses for future research on longer-term disruptions to family care provision, as well as the potential persistence or trajectories of mental health and economic situations of middle-aged and older family caregivers as the COVID-19 pandemic continues. Indeed, an AP/NORC survey of adult caregivers from August 2020, three months after this survey was conducted, found roughly similar percentages of caregivers with care disruptions, suggesting that the early impacts of COVID-19 on families with caregiving needs were both immediate and persistent (AP-NORC Center for Public Affairs Research, 2020).

The COVID-19 pandemic has simultaneously highlighted both the national reliance on family care and caregivers' deep vulnerability to disruptions under the current system. While some US states took advantage of emergency waivers to expand access to supports including telehealth, meal delivery, and financial compensation, these programs are temporary and only available to Medicaid-eligible care recipients with significant functional limitations (Fox-Grage et al., 2020). Many working caregivers found themselves without access to paid family leave or sick leave. The Families First Coronavirus Response Act (FFCRA) provided emergency paid leave only to parents caring for children or those caring for somebody with a COVID-19 diagnosis, ignoring the obligations of those caring for non-child family members such as spouses (Feinberg, 2018; Waldfogel & Liebman, 2019). Some previously employed caregivers who lost work while managing changes to their care arrangements may have relied on the CARES Act pandemic unemployment compensation benefits, which expired in December 2020. No systematic approach was taken to provide testing, training, or personal protective equipment to family caregivers, and few states prioritized caregivers in early vaccine priority groups (Friedman et al., 2021; Halley & Mangurian, 2021; Van Houtven et al., 2020). Our study points to the urgent need to

explicitly consider family caregivers as essential workers as well as integral members of primary care medical teams, and to provide them with respite to support their care provision, mental health, and engagement in the labor force where appropriate. More research is needed to understand the impact of the pandemic on their immediate and long-term well-being.

CONCLUSION

We newly identified that over half of middle-aged and older US family caregivers experienced disruptions to their ongoing care provision in the first wave of the COVID-19 pandemic. These disruptions were associated with elevated symptoms of depression, anxiety, and loneliness for caregivers, and were often experienced alongside employment disruptions. Caregivers who were most vulnerable to experiencing care disruptions were disproportionately younger, female, Black, and Hispanic, highlighting the potential for inequalities to emerge in the mental health and economic impacts of the pandemic on middle-aged and older family caregivers in the US. These findings inform how the COVID-19 pandemic has impacted key family support systems, while identifying middle-aged and older family caregivers as an important demographic that is vulnerable to mental health and economic consequences during the pandemic.

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 Table 1: Characteristics of a national sample of Americans age 55+ by caregiving status, April 17th to May 15th,

	Caregivers		Non-Caregivers		
	(Unweighted N=535)		(Unwei	ghted N=1,950)	
	Percent	95% CI	Percent	95% CI	
Caregiving Characteristics					
Any caregiving	22.7	[21.1, 24.4]			
Caring for:					
Spouse	47.4	[43.2, 51.7]			
Parent	26.9	[23.1, 30.7]			
Child	21.6	[18.1, 25.1]			
Grandchild	19.2	[15.9, 22.6]			
Other	10.3	[7.70, 12.9]			
Coresident	61.4	[57.3, 65.6]			
Multiple recipients	19.6	[16.2, 22.9]			
Descriptive Characteristics					
Age (mean)	66.2	[65.4, 66.9]	68.2	[67.8, 68.6]	
Female	58.0	[53.8, 62.2]	52.7	[50.5, 54.9]	
Non-Hispanic White	68.0	[64.1, 72.0]	73.8	[71.9, 75.8]	
Non-Hispanic Black	10.0	[7.50, 12.6]	10.2	[8.90, 11.6]	
Hispanic	14.3	[11.4, 17.3]	9.30	[8.00, 10.6]	
Married	67.4	[63.4, 7.13]	56.2	[54.0, 58.4]	
College degree	28.8	[24.9, 32.6]	28.5	[26.5, 30.5]	
Number of chronic health conditions (mean)	0.96	[0.86, 1.05]	0.75	[0.70, 0.79]	
Previously diagnosed with depression	14.9	[11.9, 17.9]	10.7	[9.3, 12.1]	
Previously diagnosed with anxiety	18.8	[15.5, 22.1]	10.7	[9.3, 12.1]	

Employment Characteristics				
Employed (any)	34.8	[30.8, 38.9]	29.9	[27.9, 32.0]
Retired	44.5	[40.3, 48.7]	55.8	[53.6, 58.0]
County-level COVID 19 Burden				
Cases per 1,000 (mean)	2.80	[2.43, 3.17]	2.81	[2.63, 2.99]
Deaths per 1,000 (mean)	0.14	[0.12, 0.16]	0.14	[0.13, 0.15]

Source: Authors' calculations using data from the COVID-19 Coping Study and the New York Times COVID-19

database

Notes: All estimates are population-weighted using survey weights. All variables are binary except age, number of health conditions (which ranges from 0-8), and COVID-19 cases per 1,000 and deaths per 1,000

	No	Any	Caregiving D	isruption Type
	Caregiving Disruptions	Caregiving Disruption ^a	More Care	Less or No Care ^b
	Percent	Percent	Percent	Percent
Caregiving Characteristics				
Any		51.6	31.7	19.7
Caring for:				
Spouse	58.0	36.8***	41.9	28.1**
Parent	22.5	31.6**	28.8	36.3
Child	23.4	21.1	25.7	14.2**
Grandchild	11.0	27.4***	21.1	37.9***
Other	8.70	11.4	8.50	16.3*
Coresident	69.9	54.6***	67.2	33.6***
Multiple recipients	17.1	22.7	22.5	23.5
Descriptive Characteristics				
Age	67.9	64.5***	64.8	64.0
Female	50.8	65.0***	58.5	75.5***
Non-Hispanic White	76.7	59.6***	55.8	66.0*
Non-Hispanic Black	7.6	11.7	13.7	8.60
Hispanic	10.9	18.0**	18.2	17.5
Married	69.6	66.8	67.0	66.5
College degree	28.6	30.3	27.4	35.4
Number of health conditions	87.1	1.05*	1.08	1.01
Previously diagnosed with depression	12.0	18.0*	16.6	19.9
Previously diagnosed with anxiety	13.9	23.2***	23.4	22.8

Table 2: Characteristics of caregivers age 55 + in the US, by type of caregiving disruption, April 17th to May 15th,2020

Employment Characteristics				
Employed (any)	30.8	39.8**	39.5	40.3
Retired	49.9	38.2***	40.3	34.4
County-level COVID 19 burden				
Cases per 1,000	2.20	3.28***	3.14	3.56
Deaths per 1,000	0.11	0.17***	0.16	0.19

Source: Authors' calculations using data from the COVID-19 Coping Study and the New York Times COVID-19

database

Notes: All percentages are weighted using survey weights. All variables are binary except age, the number of health conditions (which ranges from 0-8), and COVID-19 cases per 1,000 and deaths per 1,000.

^a Statistical significance is reported for differences in percentages or means relative to the reference group of caregivers with no disruptions.

^b Statistical significance is reported for differences in percentages or means relative to the reference group of caregivers providing more care.

* p<0.10, ** p<0.05, *** p<0.01

 Table 3: Associations between pre-COVID-19 caregiver status, COVID-19-related caregiving disruptions, and

 mental health and self-rated health in a national sample of Americans age 55+ between April 17th and May

 15th, 2020

	Depression	Anxiety	Loneliness	Poor/fair self- rated health
	(1)	(2)	(3)	(4)
Caregiver pre-COVID (vs. non-caregiver)	-0.004	-0.017	-0.018	-0.006
	(0.026)	(0.027)	(0.026)	(0.027)
Caregiving disrupted by COVID (vs. non-caregiver)	0.181***	0.195***	0.161***	0.011
	(0.048)	(0.036)	(0.040)	(0.032)
P-value for difference in coefficients for caregivers with				
no disruptions and caregivers with disruptions	0.010	0.000	0.004	0.769
Proportion of non-caregivers with each outcome	26.1%	23.4%	26.1%	18.2.5%
Ν	2438	2438	2438	2438

Source: Authors' calculations using data from the COVID-19 Coping Study and the New York Times COVID-19 database Notes: Sample includes all survey respondents. Results based on regressions of mental health outcome on caregiving status as described by Equation (1). All models adjusted for the following covariates: age, age², marital status, race/ethnicity, education, housing tenure, pre-pandemic employment status, previous chronic condition diagnoses (high blood pressure, diabetes, heart disease, asthma, chronic obstructive pulmonary disease, cancer, depression, anxiety, other medical condition), use of mobility aids, a pre-pandemic social isolation index, average county-level COVID-19 cases/1000 and deaths/1000, own COVID-19 diagnosis. All models included state fixed effects and robust standard errors are clustered at the state level. Weighted proportions of the noncaregiver sample reporting each symptom are reported at the bottom of the table, as well as p-values from linear tests for the quality of the coefficient for disrupted vs non-disrupted caregivers.

* p<0.10 ** p<0.05 *** p<0.01

		Employment Affected			
		Reduced			
		Job Loss or	Hours or	Working	
	Any	Furlough	Earnings	from Home	
	(1)	(2)	(3)	(4)	
Caregiver pre-COVID-19	-0.092*	-0.131**	0.103*	-0.034	
	(0.051)	(0.049)	(0.051)	(0.038)	
Caregiving disrupted by COVID-19	0.139*	0.145***	-0.066	0.069	
	(0.069)	(0.053)	(0.063)	(0.077)	
P-value for difference in coefficient between caregivers with no					
disruptions and caregivers with disruptions	0.043	0.006	0.071	0.301	
Despertion of non-conscious with each outcome	72 60/	22.50/	22.50/	20.2%	
Proportion of non-caregivers with each outcome	73.6%	23.5%	22.5%	30.2%	
N	800	800	800	800	

 Table 4: Associations between pre-COVID-19 caregiver status, COVID-19-related caregiving disruptions, and

 employment outcomes in a national sample of Americans age 55+ between April 17th and May 15th, 2020

Source: Authors' calculations using data from the COVID-19 Coping Study and the New York Times COVID-19 database Notes: Sample includes respondents employed prior to COVID-19. Results based on regressions of employment outcomes on on caregiving status as described by Equation (1). All models adjusted for the following covariates: age, age², marital status, race/ethnicity, education, housing tenure, previous chronic condition diagnoses (high blood pressure, diabetes, heart disease, asthma, chronic obstructive pulmonary disease, cancer, depression, anxiety, other medical condition), use of mobility aids, a pre-pandemic social isolation index, average county-level COVID 19 cases per 1000 and deaths per 1000. All models included state fixed effects and robust standard errors are clustered at the state level. Weighted proportions of the non-caregiver sample reporting each employment disruption are reported at the bottom of the table, as well as p-values from linear tests for the quality of the coefficient for disrupted vs non-disrupted caregivers.

* p<0.10 ** p<0.05 *** p<0.01



Percentage point change relative to non-caregivers (reference group)

Figure 1: Associations between pre-COVID-19 caregiver status, types of COVID-19-related caregiving disruptions, and mental and self-rated health in a national sample of Americans age 55+ between April 17 and May 15th, 2020. Source: Authors' calculations using data from the COVID-19 Coping Study and the New York Times COVID-19 database Notes: Sample includes all survey respondents. Each color corresponds to a single regression model of health outcomes on indicator variables representing non-caregivers (reference category), caregivers without disruptions, and caregivers with disruptions by type, as described by Equation (1). The models adjusted for the following covariates: age, age², marital status, race/ethnicity, education, housing tenure, pre-pandemic employment status, previous chronic condition diagnoses (high blood pressure, diabetes, heart disease, asthma, chronic obstructive pulmonary disease, cancer, depression, anxiety, other medical condition), use of mobility aids, a pre-pandemic social isolation index, average county-level COVID 19 cases/1000 and deaths/1000. All models included state fixed effects. Robust standard errors are clustered at the state level. Error bars represent 95% confidence interval



Figure 2: Associations between pre-COVID-19 caregiver status, COVID-19-related caregiving disruptions by type, and employment outcomes in a national sample of Americans aged 55+, April 17th to May 15th, 2020. Source: Authors' calculations using data from the COVID-19 Coping Study and the New York Times COVID-19 database Notes: Sample includes respondents employed prior to COVID-19. Each color corresponds to a single regression model of employment outcomes on indicator variables representing non-caregivers (reference category), caregivers without disruptions, and caregivers with disruptions by type, as described by Equation (1). The models adjusted for the following covariates: age, age², marital status, race/ethnicity, education, housing tenure, previous chronic condition diagnoses (high blood pressure, diabetes, heart disease, asthma, chronic obstructive pulmonary disease, cancer, depression, anxiety, other medical condition), use of mobility aids, a pre-pandemic social isolation index, average county-level COVID 19 cases/1000 and deaths/1000. All models included state fixed effects. Robust standard errors are clustered at the state level. Error bars represent 95% confidence intervals.



Figure 3: Association between pre-COVID-19 caregiver status, COVID-19-related caregiving disruptions by type, and employment outcomes in a national sample of Americans aged 55+ April 17th to May 15th, 2020, excluding health care and personal care workers. Source: Authors' calculations using data from the COVID-19 Coping Study and

the New York Times COVID-19 database

Notes: Sample includes respondents employed prior to COVID-19 and excludes 106 respondents working in health, health support or personal care industries. Each color corresponds to a single regression model of employment outcomes indicator variables representing non-caregivers (reference category), caregivers without disruptions, and caregivers with disruptions by type, as described by Equation (1). The models adjusted for the following covariates: age, age2, marital status, race/ethnicity, education, housing tenure, previous chronic condition diagnoses (high blood pressure, diabetes, heart disease, asthma, chronic obstructive pulmonary disease, cancer, depression, anxiety, other medical condition), use of mobility aids, a pre-pandemic social isolation index, average county-level COVID 19 cases/1000 and deaths/1000. All

models included state fixed effects. Robust standard errors are clustered at the state level. Error bars represent 95% confidence intervals.