

Exploring Changes in Caregiver Burden and Caregiving Intensity due to COVID-19

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Abstract

This study explored self-reported changes in caregiving intensity (CI) and caregiver burden (CB) among informal caregivers due to the COVID-19 pandemic overall and by gender. Informal caregivers for someone age 50+ completed a survey via Amazon's MTurk in June 2020. Participants reported changes in CI and CB due to COVID-19 and provided demographic information. Multinomial logistic regression models assessed changes in CI and CB attributed to the COVID-19 pandemic overall and by gender. The sample ($n=835$) was 68.5% male and had an average age of 34 years (SD 9.8); 55.7% had increased CI, and 53.1% had increased CB attributed to the pandemic. Increased CB due to COVID-19 was associated with increased CI (OR 5.67, 95% CI 3.92–8.00). Male caregivers with decreased CI due to COVID-19 were nearly seven times as likely as those with no change in CI to have reduced CB due to COVID-19 (OR 6.91, 95% CI 3.29–14.52). Women with decreased CI due to COVID-19 were over eight times as likely to have reduced CB due to COVID (OR 8.30, 95% CI 2.66–25.91). Results indicate that many caregivers experienced increases in CI and CB since the start of the COVID-19 pandemic, and that these changes are complex and vary by gender.

Keywords

informal caregiving, COVID-19, caregiver burden, gender disparities

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Introduction

The 2020 COVID-19 pandemic has impacted daily life across the globe on a scale never observed in modern history, including the closing of public venues, implementation, and adherence to stay-at-home orders, social distancing, economic hardship, and high levels of mortality across the population directly impacting millions of households (Chakraborty & Maity, 2020; Douglas et al., 2020; Xiong et al., 2020). Besides the direct health impacts of COVID-19, the pandemic has caused substantial impacts on mortality (Sharma, 2020), mental health (Pfefferbaum & North, 2020; Pierce et al., 2020) and other aspects of health-related quality of life across the lifespan (Adbelli & Sümen, 2020; Bryson, 2020), particularly for older adults (Shahid et al., 2020).

Research from previous global disease outbreaks, such as SARS in 2003 (Maunder et al., 2003) and H1N1 in 2009 (Elizarrarás-Rivas et al., 2010), have shown that infectious disease outbreaks and pandemics are associated with increases in mental distress, anxiety, and

depression in the general population (Wheaton et al., 2012; Wu et al., 2009). The negative impacts of the ongoing COVID-19 pandemic may be especially problematic for marginalized and vulnerable populations (Solis et al., 2020), including women and racial and ethnic minorities (Gray et al., 2020; Macias Gil et al., 2020), older adults (Krendl & Perry, 2020), and those in poverty (Martin et al., 2020). However, few studies have focused on the direct or indirect effects of these prior outbreaks or the current pandemic on informal caregiver health and wellbeing. Informal caregivers, those who provide unpaid care to family and friends with

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long-term illnesses, chronic conditions, or disabilities, are an essential but often-overlooked component of the US healthcare system.

The effects of COVID-19 may have impacted caregiving intensity (CI), which is defined as the amount and type of care provided by informal caregivers (Jacobs et al., 2014) among informal caregivers. It also may have affected informal caregiver's caregiver burden (CB), which is defined as the impacts on physical and mental health, and health-related quality of life may also have changed due to the pandemic (Lightfoot & Moone, 2020). CB is an important concept in research on informal caregivers as increased CB impacts multiple aspects of health and quality of life among informal caregivers (Pucciarelli et al., 2017), including increased depression and anxiety (Gallagher et al., 2011), increased social isolation (Robison et al., 2009), and decreased frequency of preventive health behaviors (Mochari-Greenberger & Mosca, 2012). Women are more likely than men to be informal caregivers, and among informal caregivers themselves, women are more likely to provide higher intensity care and experience greater CB than their male counterparts (Bauer & Sousa-Poza, 2015; Cohen et al., 2019).

The few existing studies exploring potential changes to informal caregiving for older adults during the COVID-19 pandemic suggest that caregiving does impact overall CB. One study found that CB increased among informal caregivers to people with dementia during the pandemic (Canevelli et al., 2020). Another study compared changes mental and physical health status during the pandemic and found that caregivers, particularly long-term caregivers, had a greater likelihood of many physical and mental health issues than non-caregivers during the first several months of the COVID-19 pandemic (Park, 2020). Due to the combination of social distancing recommendations, stay-at-home orders, limitations on gatherings, and the disproportionate impact of COVID-19 itself on mortality and morbidity among older adults, there is a critical and immediate need to understand the specific challenges and changes to the type and intensity of caregiving, as well as to CB (Lightfoot & Moone, 2020). Therefore, the objectives of this exploratory study were to explore self-reported changes in CI and CB due to the COVID-19 pandemic and to identify socioeconomic, demographic, and health-related factors associated with changes in CI and CB overall and by gender.

Methods

Study participants were recruited using Amazon's Mechanical Turk (MTurk) (Simons & Chabris, 2012) between June 4 to 15, 2020. Interested individuals accessed a link to Qualtrics, provided informed consent, and completed questions assessing eligibility. The data were checked to ensure there was only one record per participant by checking IP addresses prior to analysis. If

duplicate IP addresses were detected, only the first response was used for the analysis. Respondents answered the eligibility questions and only those who were eligible could access the survey. Eligibility was based on being an informal caregiver for an individual 50 years of older with some health condition, disability, or cognitive decline, living in the United States (U.S.), and being able to read English. Respondents received \$1.50 as compensation for participating.

Main outcome variables of interest were change in CI and CB attributed to the COVID-19 pandemic. To assess changes in CI, participants were asked "Would you say the amount of hours that you provide care or assistance has (increased a lot, increased somewhat, about the same, decreased somewhat, decreased a lot) since the COVID-19 pandemic?" Similarly, changes in CB were assessed by the participant's response to a single item that asked "How do you feel your caregiver burden has changed since the COVID-19 pandemic?" with the same possible responses as the previous question. For analytic purposes, responses for both CI and CB were categorized into three level variables—increased, no change, decreased—due to small sample sizes in the "decreased a lot" categories for CI ($n=27$) and CB ($n=31$), which would have left empty cells using multivariable regression models.

Overall CB was assessed through the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989), a 22-item multidimensional scale used to estimate the amount of burden caregivers experience due to caregiving. In this sample, reliability of the components was excellent ($\omega=.93$), and the validity was assessed through an exploratory factor analysis that revealed a three-factor structure. The CBI was positively associated with the 21-item Depression, Anxiety and Stress Scale (DASS-21) (Antony et al., 1998) subscales of anxiety ($r=0.36$, $p<.001$), depression ($r=0.37$, $p<.001$) and stress ($r=0.35$, $p<.001$). For all three of the DASS subscales, the validity was strong ($\omega=.91$). Other characteristics of interest included respondents' age in years, gender (male/female), whether caregiver has been diagnosed with COVID-19 (yes/no), and care recipient's age, race/ethnicity and whether the caregiver lives with the care recipient (yes/no).

Descriptive statistics were obtained for all study variables: means and standard deviations for the continuous and discrete measures, and frequencies for ordinal and nominal variables. Bivariable and multivariable multinomial logistic regression models assessed the associations between each of the main study measures and the outcome measures of change in CB attributed to the COVID-19 pandemic overall, controlling for key covariate and confounders, including gender, race/ethnicity, and co-residence with care recipient, based on the best-fitting overall model. We then repeated the analysis using the same covariates (race/ethnicity and co-residence with care recipient) stratifying by gender to

determine if the potential associations changed based on gender. The “no change” response option was the reference category in all multinomial regression models, which means that odds ratios represent the likelihood of either increased CB or decreased CB compared to “no change” from a one-unit increase in each exposure. SPSS version 26.0 (Armonk, NY) and SAS version 9.4 (Cary, NC) were used for all statistical analyses and statistical significance was established at $p < .05$. The study was approved by the University of Rhode Island’s Institutional Review Board (study # 1606088-2).

Results

Table 1 shows the percent of the sample that experienced a change in CI and CB (increase, decrease, or stayed the same) and, within each of those groups, the descriptive statistics and frequencies of the exposure variables. The majority of the sample was male (68.5%) and respondents’ average age was 34 years (SD 9.8), and most respondents reported an increase in CI (55.7%) and CB (53.1%) since the COVID-19 pandemic began. There were no significant differences in changes to CI due to the pandemic by baseline CB, age, gender, or race/ethnicity. The most common primary health conditions and disabilities for which caregivers provided care were diabetes (22%), infectious diseases (15%), asthma (17%), Alzheimer’s disease and related dementias and conditions (11%), and heart disease and hypertension (6%), with the remaining 29% being other conditions. Most of the care recipients (53%) lived in their own house or apartment, 40% lived with the informal caregiver, and 6% lived in assisted living or nursing homes.

Caregivers who experienced an increase in CB had significantly higher levels of CB ($M=38.9$, $SD=14.4$) compared to those who did not experience a change in CB during the pandemic ($M=36.1$, $SD=12.8$) ($p=.002$). Furthermore, respondents with increased CI were more likely to have been diagnosed with COVID-19 (57%) than those not experiencing a change in CI (50%) or those with decreased CI during the pandemic (42%, $p < .001$).

The results of the multinomial regression models predicting changes (increased or decreased vs. no change) in CB due to COVID-19 are shown in Table 2. The odds ratios shown represent the one-unit change in odds from multinomial regression models of either increased CB or decreased CB compared to the “no change” in CB category. Among all respondents, increased CB due to COVID-19 was associated with an increase in CI due to COVID-19 (OR 5.67, 95% CI 3.92, 8.00). Model-adjusted probabilities of increased CB due to COVID-19 are shown in Figure 1. For the whole sample, 53% were predicted to have increased CB, and female caregivers had a significantly higher likelihood of increased CB due to COVID-19 (56.0%) than male caregivers (52%) ($p=.02$). There were significant differences ($p < .001$) among the three groups of CI changes (decreased, increased, and stayed the same) due to

COVID-19 on the likelihood of increased CB (17%, 72%, and 35%, respectively). Among caregivers with decreased CI, there were no significant differences by gender in the likelihood of increased CB due to COVID-19. However, women were significantly more likely than men to have increased CB due to the COVID-19 pandemic among caregivers who report an increase or the same amount of CI during the pandemic.

Similar results were observed among men. Male caregivers with decreased CI due to COVID-19 were nearly seven times as likely as those reporting no change in CI due to COVID-19 to have a reduction in CB due to COVID (OR 6.91, 95% CI 3.29, 14.52). Those with increased CI were nearly five times as likely as those with no change in CI due to COVID-19 to have an increase in CB due to COVID-19 (OR 4.62, 95% CI 2.96, 7.21). For female caregivers, the associations were more complex. Women with decreased CI due to COVID-19 were more than eight times as likely as those who reported no change in CI to reported reduced CB due to COVID (OR 8.30, 95% CI 2.66, 25.91). However, female caregivers with increased CI due to COVID were more likely than female caregivers with no change in CI to have a significant reduction in CB (OR 2.76, 95% CI 1.34, 5.69) or a large, significant increase in CB (OR 10.14, 95% CI 5.06, 20.30).

Discussion

The results of this exploratory study indicate that many caregivers experienced increases in CI and CB during the first several months of the COVID-19 pandemic. Study results show that changes in CI and CB due to the COVID-19 pandemic are complex and vary somewhat by gender. These findings are similar to previous research conducted prior to the pandemic that has shown that female caregivers experience greater levels of CB (Akpınar et al., 2011; Kahn et al., 2016), even after controlling for other aspects of caregiving, including CI (Rosdinom et al., 2013). Furthermore, women more likely than men to be informal caregivers to an older adult, and among the population of informal caregivers themselves (Bauer & Sousa-Poza, 2015), females often take on more emotionally and physically intensive aspects of caregiving compared to their male counterparts (Cohen et al., 2019; Navaie-Waliser et al., 2002).

However, the current study found that men with higher initial levels of CI were more likely to have an increase in CB due to the pandemic, but the association was not significant for women. There is no clear explanation for this finding, although it may be due to gender differences in resilience among informal caregivers (Schränk et al., 2016). Female caregivers may be more resilient than male caregivers (Gaugler et al., 2007), and this resilience may become magnified under periods of extreme stress and uncertainty, such as the COVID-19 pandemic. An Italian study of COVID-19-associated changes in care recipient needs and caregiver burden

Table 1. Descriptive Statistics for Informal Caregiver Sample.

	N	Baseline CBI		Age (mean, SD)	Female N (%)	White N (%)	COVID diagnosis		CR Lives with CG N (%)	CI decreased		CI stayed same		CI increased	
		(mean, SD)	(14.2)				(mean, SD)	N (%)		N (%)	N (%)	N (%)	N (%)	N (%)	
Overall	834	38.1 (14.2)	34.0 (9.8)	263 (31.5)	455 (54.8)	442 (53.0)	330 (39.6)	124 (14.9)	245 (29.3)	465 (55.8)					
CI change						abc	b								
Decreased	124	39.5 (16.3)	35.3 (9.9)	33 (26.6)	72 (58.1)	52 (41.9)	37 (29.8)	—	—	—	—	—	—	—	
Stayed same	245	38.5 (11.0)	33.3 (9.6)	83 (33.9)	140 (57.1)	123 (50.2)	84 (34.3)	—	—	—	—	—	—	—	
Increased	465	37.4 (15.0)	33.9 (9.7)	146 (31.5)	243 (52.6)	267 (57.2)	209 (44.9)	—	—	—	—	—	—	—	
CB change		c			b	bc	bc	ab	ac	bc					
Decreased	111	39.8 (16.0)	34.8 (9.9)	35 (31.5)	69 (62.2)	50 (45.0)	37 (33.3)	57 (51.8)	24 (21.8)	29 (28.4)					
Stayed same	281	36.1 (12.8)	34.2 (10.1)	83 (29.5)	156 (55.7)	126 (44.8)	102 (36.3)	45 (16.0)	135 (48.0)	101 (35.9)					
Increased	442	38.9 (14.4)	33.6 (9.4)	145 (32.9)	230 (52.3)	266 (60.2)	190 (43.0)	22 (5.0)	85 (19.2)	335 (75.8)					

Note. Significant differences ($p < .05$) between

(a) "Decreased" and "Stayed the Same"

(b) "Decreased" and "Increased"

(c) "Stayed the same" and "Increased".

Table 2. Multivariable Odds Ratios* of Changes to Caregiver Burden (Decreased or Increased) Due to COVID-19 from Multinomial Regression Models Overall and by Gender.

	All		Males		Females	
	Decreased	Increased	Decreased	Increased	Decreased	Increased
Initial caregiving intensity	0.99 (0.74, 1.33)	1.17 (0.94, 1.44)	1.15 (0.80, 1.65)	1.33 (1.02, 1.72)	0.71 (0.41, 1.21)	0.92 (0.63, 1.36)
Initial caregiver burden index	1.36 (0.93, 1.99)	1.36 (1.03, 1.79)	1.33 (0.85, 2.10)	1.37 (0.99, 1.89)	1.46 (0.72, 2.97)	1.27 (0.72, 2.23)
Change in CI due to COVID						
No change (ref)	—	—	—	—	—	—
Decreased CI	6.92 (3.76, 12.75)	0.85 (0.46, 1.55)	6.91 (3.29, 14.52)	0.93 (0.46, 1.86)	8.30 (2.66, 25.91)	0.50 (0.13, 2.02)
Increased CI	1.76 (0.95, 3.26)	5.67 (3.92, 8.20)	1.40 (0.66, 2.98)	4.62 (2.96, 7.21)	3.08 (1.03, 9.25)	10.14 (5.06, 20.30)
COVID-19 diagnosis	1.05 (0.63, 1.76)	1.70 (1.19, 2.44)	1.01 (0.55, 1.85)	1.46 (0.95, 2.24)	1.18 (0.42, 3.36)	2.76 (1.34, 5.69)
Age	0.99 (0.97, 1.02)	0.99 (0.98, 1.01)	0.99 (0.96, 1.02)	0.99 (0.97, 1.01)	1.00 (0.95, 1.05)	1.01 (0.98, 1.05)
Race						
White (ref)	—	—	—	—	—	—
Black	1.21 (0.61, 2.43)	1.57 (0.91, 2.69)	0.93 (0.41, 2.12)	1.69 (0.91, 3.13)	2.37 (0.63, 8.88)	0.91 (0.29, 2.88)
Asian	0.36 (0.18, 0.80)	0.89 (0.58, 1.37)	0.46 (0.19, 1.12)	0.89 (0.54, 1.47)	0.12 (0.01, 1.08)	0.95 (0.40, 2.27)
Other	0.87 (0.37, 2.01)	0.69 (0.38, 1.26)	0.82 (0.31, 2.14)	0.59 (0.31, 1.16)	0.92 (0.13, 6.36)	1.44 (0.35, 5.92)
Caregiver lives with recipient						
No (ref)	—	—	—	—	—	—
Yes	0.88 (0.53, 1.49)	1.13 (0.80, 1.60)	0.83 (0.45, 1.54)	1.06 (0.70, 1.61)	0.98 (0.35, 2.71)	1.41 (0.70, 2.83)

Comparison group = "no change".

*Boldface = $p < 0.05$.

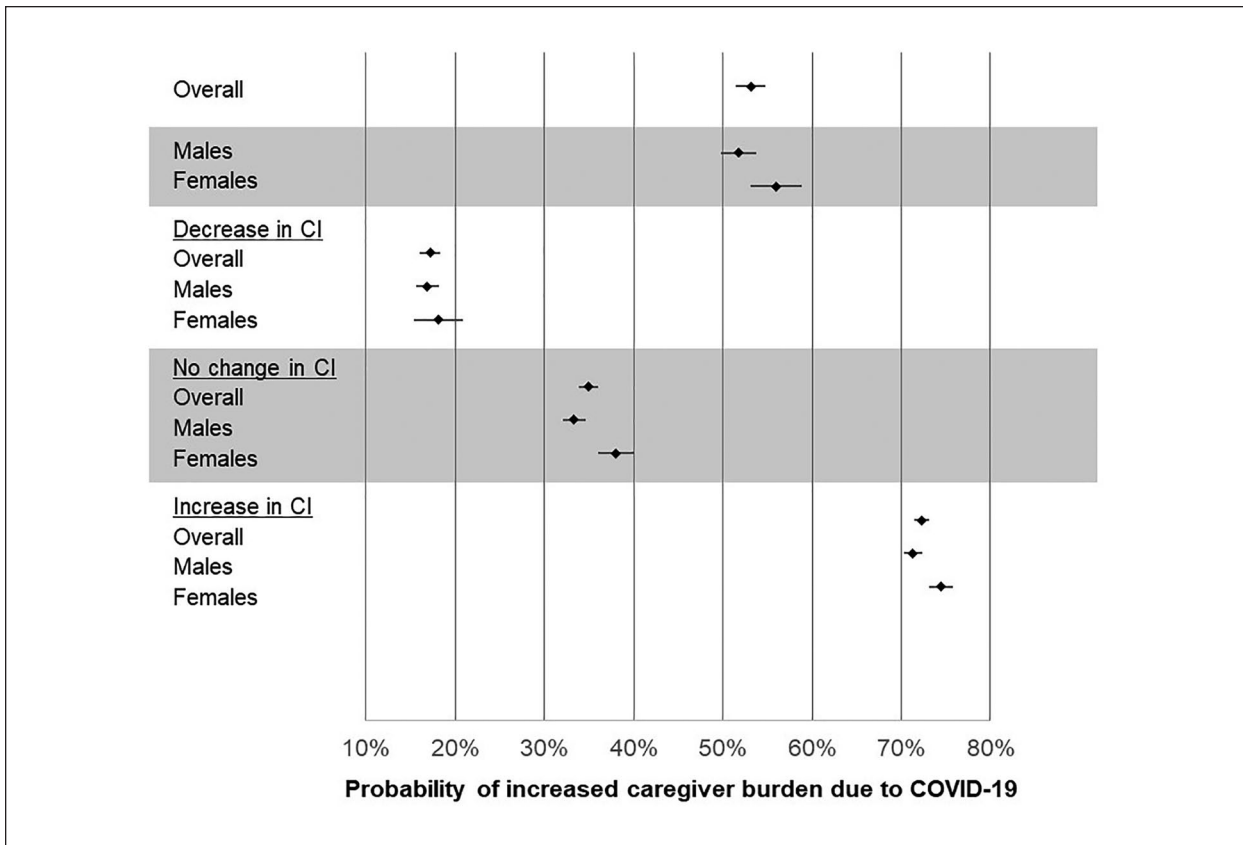


Figure 1. Multinomial logistic regression model-adjusted probabilities of increased caregiver burden due to COVID-19.

suggests that informal caregivers providing care to older adults may be subjected to intense levels of stress because they had to manage, with reduced social support and availability of formal care, the complexities of caregiving during the pandemic (Canevelli et al., 2020). A previous study of formal (paid) caregivers suggested that women may be better able to cope with the extreme stress (Merlani et al., 2011). Potential gender differences in coping strategies during the extreme stress that the COVID-19 pandemic among informal caregivers may partially explain the findings. That said, research on gender differences in caregiving experiences during the COVID-19 pandemic is limited. Furthermore, in the present study, female caregivers who were diagnosed with COVID-19 were more likely to experience increases in CB due to COVID-19, while the same association was not found for male caregivers. The reasons for this finding are not clear but may be due to the higher levels of initial CI among female caregivers than male caregivers. Future research is needed in this area to understand and interpret these findings.

A notable study finding is that higher initial CB as assessed by the CBI was associated with a higher likelihood of increased CB during the COVID-19 pandemic. This finding may be counterintuitive, as one could expect that there is a potential for a ceiling effect of CB—in other words, CB could not increase substantially due to the pandemic simply because it was already

high (Hagell et al., 2017). One possible explanation for this finding is that the extra burdens of the pandemic, whether due to increased anxiety or other stressors, magnified the effects of caregiving on those with an already high level of CB. More detailed research on highly burdened caregivers would be necessary to elucidate the potential mechanisms behind this finding.

Limitations

Study limitations include the cross-sectional study design, use of a convenience sample, and reliance on self-reported measures. As such, it was not possible to verify reported information, including the demographics of the caregivers or care recipients. The sample was limited to individuals with internet access as participants were recruited via MTurk, although research suggest that MTurk respondents are more representative of the U.S. population than traditional in-person convenience samples such as college undergraduate students (Behrend et al., 2011) while other research suggest that MTurk respondents tend to be younger, have lower incomes and are less likely to be Black (Berinsky et al., 2012; Krupnikov & Levine, 2014). Nonetheless, some studies suggest that online convenience samples tend to provide valid results for experimental research (Berinsky et al., 2012; Weinberg et al., 2014). Additionally, the majority of the sample was male (68.5%) and prior

research indicates that women are more likely to be informal caregivers than men, and among all informal caregivers, women provide greater levels of care than men (Bauer & Sousa-Poza, 2015; Cohen et al., 2019). Most (91%) of the care recipients were not institutionalized, and instead lived independently or with the caregiver. Caregiving in a nursing home or assisted living facility poses unique challenges for both the formal caregivers employed by the institution, as well as informal family caregivers (Van Houtven et al., 2020). Furthermore, although it was possible to validate established measures such as the CBI it was not possible to validate individual measures not previously used in research, such as changes in CB or CI due to the pandemic. Data were collected during the fourth month of the pandemic, and it is likely that CB and CI have remained high or increased as the pandemic has continued. It also is possible that the availability and use of support services for informal caregivers may have changed during the pandemic. Longitudinal studies on changes in CB and caregiving in general throughout the pandemic would be beneficial to understanding the evolution of informal caregiving and its impacts on informal caregivers as the pandemic continues. Notably, this sample reported a substantially higher cumulative incidence (53%) of having COVID-19 than the public, especially considering the data were collected during the early months of the pandemic (June 2020). One potential explanation is that people who had COVID-19 may have been more interested in participating in the study since the word “COVID-19” was part of the title of the study shown to the MTurk users. However, the reasons for this remain unclear and merit further study of potential differences in susceptibility of COVID-19 based on caregiver status.

Most respondents reported high levels of overall CB, and this finding supports the need for greater assistance and need for respite care for individual providing care for older adults. An important finding, although perhaps not surprising, is that caregivers who experienced increased CB before the pandemic reported greater overall CB. Similar results have been identified among a sample of caregivers of patients with dementia in Greece (Tsapanou et al., 2020). The increase in CB and CI attributed to the pandemic indicate that informal caregivers have insufficient resources to draw from in case of an emergency. Although the ongoing pandemic is a unique historical event, it is possible that other emergencies such as floods and hurricanes also increase CB and CI.

Conclusion

As of 2021, the COVID-19 pandemic continues to impact nearly every aspect of living, and those impacts continue to evolve over time. Understanding the specific impacts of the pandemic has on the population of over 40 million informal caregivers in the U.S. (American

Association of Retired Persons [AARP], 2020) is of critical importance to maintaining this critical component of the U.S. healthcare system. CB, one of the most important and widely used measures of impacts from caregiving, is a multidimensional measure and includes factors such as mental and physical health, social involvement, and quality of life. The findings of this study suggest that changes to CB due to the COVID-19 pandemic were not uniform across gender groups of informal caregivers. Therefore, understanding and addressing the needs of individual caregiver subgroups as the pandemic evolves is critical to protecting caregiver health and wellbeing. Future research should examine the mechanisms and specific components of CB and related factors to inform policies, programs, and interventions tailored to the individual needs of caregivers designed to mitigate the negative impacts of CB exacerbated by the pandemic.

Declaration of Conflicting Interests

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