


# Caregiving in Quarantine: Evaluating the Impact of the Covid-19 Pandemic on Adult Child Informal Caregivers of a Parent

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## Abstract

Informal caregivers form a shadow workforce projected to become even more essential as the U.S. population ages. Most are untrained in the role and manage caregiving with competing life demands that compound burden and threaten the welfare of the older adults in their care. The 12-item Zarit Burden Interview measure was employed to investigate differences in subjective burden before and during the Covid-19 pandemic among adult children who are primary informal caregivers of a parent. Additionally, this study explored family composition to determine if the presence of siblings or dependent children affected burden scores. A convenience sample ( $N=77$ ) reported significantly more burden since the onset of the Covid-19 pandemic when compared to pre-pandemic burden. Since the pandemic began, those with living siblings reported less burden than those without siblings, while there was no difference in burden between sandwich generation caregivers and those providing care only for a parent. This study's results point to the role family plays in resilience during a crisis and emphasizes the need to promote efficient supports and networks to alleviate caregiver burden.

## Keywords

informal caregiver, burden, Covid-19, caregiving, caregiver burden

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## Introduction

The prevalence of informal caregivers in the community is underappreciated because they are often invisible and undertake a role not characterized by a salary, title, or defined by specific duties. Around 41.8 million Americans provide unpaid care to an adult age 50 or older, and a majority of the 89% who are related to the care-recipient are caring for a parent (American Association of Retired Persons [AARP] & National Alliance for Caregiving [NAC], 2020). A distinct source of caregiver burden arises specifically from the awkward role reversal of parenting one's own parent (Avioli, 1989), and informal caregivers report higher incidence of compassion fatigue than formal caregivers (Thorson-Olesen, 2018). The U.S. healthcare system is so reliant on informal caregiver labor, that they are considered an essential shadow workforce (Bookman & Harrington, 2007) often substituting for long-term care and hospital stays (Houtven & Norton, 2004). Caring for a parent

while juggling competing life demands can generate role overload that dismantles family and social relations (Conway, 2019). High levels of caregiver burden lead to a depletion of emotional reserves or burnout (Gérain & Zech, 2019), which predicts institutionalization of the care-recipient (Gaugler et al., 2009) and abusive caregiver behaviors (Alves et al., 2019).

The economic shutdown and quarantine policies enacted across the U.S. since March 2020 in the wake of the Covid-19 pandemic have no parallel in modern history. Since the pandemic began, adult-child primary caregivers (hereafter referred to as “informal

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caregivers”) face the additional burden of protecting high-risk parents from an invisible virus. The threat of severe illness and death increases with age with the vast majority, 8 out of 10, of Covid-19 fatalities in the U.S. being among those aged 65 and older in September 2020 (Centers for Disease Control and Prevention, 2020). Broad scale stressors caused by the pandemic have created compounding sources of burden for informal caregivers who now may need to provide care at a distance, but also worry their parent may die if infected (Lightfoot & Moone, 2020). Often overlooked is the fact many caregivers also have co-morbidities (Schmaderer et al., 2020), that put them at heightened risk of Covid-19 mortality. Shuttered by quarantine measures enacted to slow viral spread, critical in-person respite offered by community-based adult services are mostly no longer available. This loss may be offset by online support groups, which have been effective at sharing information and maintaining social connection (Leszko, 2020) and the advent of remote telehealth and telemedicine that delivers remote professional care.

Family dynamics create unique stressors that can irrevocably alter relationships, especially during times of stress. Siblings are called upon to communicate with one another in decision-making and negotiating informal care for a parent, which can ignite family conflict (Kwak et al., 2012) even in the best of times. One sibling can alienate the others by asserting undue influence on a parent or dominating parental affairs for personal gain (Lashewicz & Keating, 2009) or be so focused on blame, guilt, or self-pity they ruin the carefully laid care plans of another (Miller & Berger, 2020). Long-term patterns of real or perceived parental favoritism also have substantial impact on sibling relationships (Con et al., 2018). Decades of personal backstory may be a source of comfort but may also impede cooperation in the provision of care. Attempts to resolve an imbalance in care distribution between siblings causes more stress when an expected amount of help is asked for, agreed upon, and is not received (Ingersoll-Dayton et al., 2003). It is unclear how the fallout from the Covid-19 pandemic has affected sibling cooperation or communication, which may, in turn, impact the burden of the sibling who is the primary informal caregiver of their parent.

Likewise, it is unclear how the presence of dependent children may be affecting the burden of informal caregivers during the pandemic. Long-term demographic trends have birthed a dramatic rise in adults responsible for the care demands of their parents and their dependent children or grandchildren (Wiemers & Bianchi, 2015). Among family caregivers, 28% have dependent children at home (AARP & NAC, 2015). These “sandwich generation” caregivers are already likely to experience extreme difficulty balancing the demands of caring for a parent, their own children, and managing work (Yin et al., 2002). During the Covid-19 pandemic, the older adult is at elevated risk for infection when the informal

caregiver works outside their home (Stokes & Patterson, 2020) and possibly when coming into regular contact with their grandchildren, who may be silent vectors (Kelvin & Halperin, 2020). In a recent study, major factors increasing caregiver burden were identified as financial issues and caring for additional others (Schmaderer et al., 2020). During a time of economic and social upheaval, burden is more likely to negatively impact sandwich generation caregivers, especially if there are multiple dependent children or they provide care for both parents. The pandemic-inspired increase in people working from home may, however, offer a crucial lifeline. Intergenerational caregiving as an arrangement can come with its own benefits, which can include financial or babysitting transfers, and resource sharing (Bookman & Kimbrel, 2011). The study aimed to address three main objectives:

1. To examine differences in informal caregiver subjective burden before and during the Covid-19 pandemic.
2. To compare differences in subjective burden scores since the Covid-19 pandemic between informal caregivers who have siblings and those who do not.
3. To compare differences in subjective burden scores since the Covid-19 pandemic between informal caregivers who have dependent children at home and those who do not.

## Methodology

### Sample

This study’s convenience sample consisted of adults who identify as primary informal caregiver for one or both community-dwelling parents aged 65 or older. Additional inclusion criteria were to provide a minimum of 6 hours of care weekly, and to have been in the caregiving role since before 2020 (prior to the Covid-19 pandemic). Respondents who reported being children-in-law, or whose parent resided in a skilled nursing facility were excluded from this study. Further, two participants were rejected for failure to complete the study surveys.

### Measures

The Zarit Burden Interview (ZBI) was the first to measure subjective caregiver burden and remains a popular, reliable tool with a Chronbach’s alpha of 0.92 (Hébert et al., 2000) and a test-retest reliability score of 0.89 (Seng et al., 2010). To avoid survey fatigue, the present study used a short version of the ZBI featuring 12 items taken from the 22-item version, also with an impressive Cronbach’s alpha of 0.88 with correlations between the two versions ranging from 0.92 to 0.97 (Bédard et al., 2001). On the ZBI, respondents rate each item on a

5-point Likert scale from 1 (Never) to 5 (Nearly Always) with higher scores indicating higher levels of burden. Sample questions include “Do you feel you should be doing more for your parent?” and “Do you feel you don’t have as much privacy as you would like because of your parent?” The 12-item ZBI scores were combined to create the total subjective burden score, which could range from 12 to 60. For objectives 2 and 3, the change in subjective burden score (pre and during Covid) was calculated as the dependent variable.

For a snapshot of the sample, a demographic survey, created by the researcher, was also administered. Questions included gender, age, relationship status, existence of siblings, children at home, location of the care-recipient, and choice in taking on the caregiving role. An additional three items specifically addressed primary sources affecting burden identified in the literature (navigating health systems, lack of social support, and problem behavior of the care-recipient) and how these variables may have changed since the onset of the Covid-19 lockdown measures.

### Procedure

After obtaining approval from the University’s IRB, permission was obtained from two community-based adult service programs in Southern California to recruit volunteer participants from their databases via targeted emails. Participants were also sourced through personal and professional contacts, and social media outreach. Those eligible were provided a link to the confidential Qualtrics survey. The first page described the study, inclusion and exclusion criteria, potential risks and mitigation, and confidentiality protocols. Participants digitally signed informed consent before filling out the 12-item ZBI survey twice, first to report their burden before March 2020 (prior to the pandemic) and again to report their burden since that time (during the pandemic). Finally, participants completed the demographic survey.

### Data Analysis

Descriptive statistics were generated for sample characteristics. For Objective 1, a paired samples *t*-test compared overall scores looking for differences in informal caregiver subjective burden before and during the Covid-19 pandemic. For Objective 2, two separate independent samples *t*-tests compared changes in subjective burden between informal caregivers who have siblings and those who do not. For Objective 3, two separate independent samples *t*-tests compared changes in subjective burden between informal caregivers who have dependent children at home and those who do not. For objective 2 and 3, the change score was calculated (pre and during Covid) to measure change in subjective burden score. Data were analyzed using SPSS, significance at  $p \leq .05$ .

## Results

Of a total of 77 respondents, 28.6% reported the presence of dependent children at home and 83.1% reported having living siblings. As expected and noted in the literature, an overwhelming majority of caregivers in this study were female (77.9%). Participant demographic characteristics are outlined in Table 1.

1. A significant difference was found between pre-pandemic subjective burden ( $M=32.87$ ,  $SD=8.48$ ) and subjective burden during the pandemic ( $M=35.66$ ,  $SD=9.04$ );  $t(76)=-3.75$ ,  $p=.000$  among the population of primary adult child caregivers of a parent. Burden has increased significantly in this population since the onset of the pandemic. See Figure 1.
2. Since the Covid-19 pandemic, a significant difference was found in subjective burden scores between caregivers with living siblings ( $M=1.92$ ,  $SD=6.24$ ) and those without siblings ( $M=7.08$ ,  $SD=6.54$ );  $t(75)=-2.70$ ,  $p=.009$ . Since the onset of the pandemic, informal caregivers with siblings experience significantly less burden than those who do not have living siblings. See Figure 2.
3. Since the Covid-19 pandemic, no difference was found in subjective burden scores between adult child caregivers of a parent who have dependent children at home and those who do not. Since the onset of the pandemic, informal caregivers with dependent children experience no more burden than those who do not have dependent children. See Figure 3.

## Discussion

Significantly increased burden during a global health crisis was perhaps to be expected. As caregivers rise to meet daily crises and challenges under constantly changing conditions, informal caregiver burden is consistently high, but this study showed the pandemic significantly increased that burden. Several factors specific to Covid-19 inform these results.

Ongoing social distancing and lockdown measures enacted to prevent the spread of infection have fundamentally disrupted daily life. The most common stressors identified by older adults during this time are confinement and lack of freedom (Whitehead & Torossian, 2020). There is also concern that quarantine measures will cause a backlash of stigma and discrimination of older adults due to their inherent vulnerability (Bruns et al., 2020). These pressures combined with the threat of mortality may account for stress reactivity resulting in disruptive behavior of the care-recipient. Descriptive data reveal most of this study’s respondents,  $n=53$  (68.8%) said their parent’s problem behavior worsened since the onset of lockdown measures, with

**Table 1.** Sample Characteristics.

Demographics	N=77	Percentage (%)
Gender		
Female	60	77.9
Male	16	20.8
Other	1	1.3
Age		
18–29	1	1.3
30–39	7	9.1
40–49	27	35.1
50–59	20	26
60+	22	28.6
Gender of parent receiving care		
Female	50	64.9
Male	10	13
Care for both parents	17	22.1
The parent resides		
In their own home	43	55.8
With me	32	41.6
Other	2	2.6
Relationship status		
Single	25	32.5
Married	40	51.9
Live-in partner	7	9.1
Partner lives elsewhere	5	6.5
Dependent children at home		
Yes	22	28.6
No	55	71.4
Caregiver has living siblings		
Yes	64	83.1
No	13	16.9
Do you feel you had a choice in becoming the caregiver?		
Yes	21	27.3
No	56	72.7
Parental behavior since Covid-19 has been		
Better	4	5.2
Worse	53	68.8
Does not apply	20	26
Navigating health systems, access, info, and appointments since Covid-19 has been		
Easier	11	14.3
Harder	58	75.3
Does not apply	7	9.1
Social support since Covid-19		
More social support	8	10.4
Less social support	35	45.5
Same amount of social support	33	42.9
Does not apply	1	1.3

Variable	N	Mean	SD	t-value	p
Pre-pandemic burden	77	32.87	8.48	-3.75	.000*
During pandemic burden	77	35.66	9.04		

**Figure 1.** Subjective burden scores before and during the pandemic among primary adult child caregivers of a parent.

Note. \*Significant at  $p \leq .05$ .

Variable	N	Mean	SD	t-value	<i>p</i>
Siblings	64	1.92	6.24	-2.70	.009*
No siblings	13	7.08	6.54		

**Figure 2.** Difference in subjective burden scores since the pandemic between adult child caregivers who have living siblings and those who do not.

Note. \*Significant at  $p \leq .05$ .

Variable	N	Mean	SD	t-value	<i>p</i>
Dependent Children	22	3.00	6.40	1.75	.861
No Dependent Children	55	2.71	6.65		

**Figure 3.** Difference in subjective burden scores since the pandemic between adult child caregivers with dependent children at home and those without.

only  $n=4$  (5.2%) saying it had improved. The increase in problem behaviors factors into the increase in burden as caregiver resilience is at its lowest when dealing with behavioral problems, which are also directly associated with larger degrees of distress (Haro et al., 2014; Joling et al., 2016; Verbakel et al., 2018).

Distancing guidelines to slow viral transmission appear to be correlated to a decrease in social support and frustration with health delivery. In this study, 45.5% of respondents reported receiving less social support since Covid-19 lockdown measures began, yet 10.4% reported having more social support. Additionally, 75.3% said navigating healthcare systems, access, and appointments was more difficult, yet 14.3% said it was easier. These results suggest that online social supports and telehealth delivery have yet to prove effective at relieving burden among informal caregivers. It is unclear if remote forums can ever adequately replace in-person supports and services, but further research may offer direction on implementing age-friendly adaptations to make technology networks more convenient, accessible, and engaging for care-recipients.

Since the Covid-19 pandemic began, informal caregivers who have living siblings report significantly less caregiver burden change than those without siblings. The existence of siblings may reduce stress on the sibling who is primary caregiver. A study by AARP and NAC (2020) reported that those who feel they had no choice in becoming the caregiver reported a higher incidence of strain than those who did not feel so obliged. In opposition to the AARP and NAC study, and despite the fact that 72.7% in this current study claimed they had no choice in taking on the caregiver role, those with living siblings reported significantly less caregiver burden. This finding may suggest that siblings circle the wagons and offer a measure of relief to the informal caregiver, perhaps by sharing additional care duties, or offering financial, moral, or other supports. These findings share similarities with another study (Lin & Wolf, 2019) that

found most parents receive care from only one child but as their frailty rises so does the tendency for other adult children to step up and help out. Likewise, siblings in this study may insulate informal caregivers from the extra burden of the Covid-19 crisis; a resource unavailable to those without living siblings who report significantly more burden, underscoring the negative impact of social isolation on resilience and the need for effective interventions.

Interestingly, those who care for both their parent and dependent child(ren) show no statistical difference in change in subjective burden from those who have no dependent child(ren). It is unclear how pandemic work-from-home policies may have affected both populations, but quarantine measures appear to have made functioning in the role as manageable, or rather just as burdensome, for those with and without children at home. These findings are somewhat surprising given that sandwich generation caregivers are charged with multi-tasking the care demands of two generations. This extra work can be a source of satisfaction when sandwich generation caregivers feel a sense of mastery in competently managing many varied roles (Hammer & Neal, 2008), which implies intergenerational caregivers may be better trained for pandemic response. Conversely, they may be more apt to discount or under-report their own burden. For example, sandwich generation caregivers did not report more burden despite most of their children's schools having closed because of it.

Carragher and Ryan (2020) found a sense of belonging to other people, to family, activates resilience in older adults and this appears true for their informal caregivers as well. Perhaps the rate of intergenerational transfers and help from children or partners has increased and they are assisting with caregiving responsibilities. Future research may shed light on the question, but what seems apparent from these results is the importance of family to cushion burden during a time of widespread fear and disturbance.

## Limitations

Limitations of this study include the self-reporting nature of the survey and the fact that self-reported burden scores prior to the Covid-19 pandemic were answered after the fact and are therefore vulnerable to time effects. Eligible participants recruited from community-based adult service programs may have reported higher post-pandemic burden because those specific supports were no longer available in the same format. Informal caregivers who are more burdened, harder to locate, and/or from different cultural, socioeconomic, or racial backgrounds may not have been adequately represented in this study as this study used a convenience sample. Further, additional demographic questions on health, support services, and family dynamics could shed light on caregiver burden.

## Conclusions

This study evaluated how the interplay of family composition and burden has been impacted in the wake of a once-in-a-lifetime global pandemic. Informal caregivers wear many hats while deftly juggling unexpected moving parts on any given day, and a majority say the role gives them a sense of meaning or purpose (AARP & NAC, 2020). When that purpose becomes protecting a high-risk parent from a highly infectious lethal outbreak, findings show they experience significantly higher burden levels.

The unprecedented, ongoing disruptions, fears of mortality, and accompanying stressors make the Covid-19 pandemic a perfect storm for burden. Since its onset, informal caregivers report higher burden, more difficulty in the role, and less social support. And while social distancing is not social isolation, for many this may be a distinction without a difference.

Despite managing competing care demands, sandwich generation caregivers do not report higher burden in the midst of a pandemic than those without dependent children. Informal caregivers who have living siblings experience significantly less burden during the pandemic than those without. In this way, siblings can be considered a form of social support, highlighting the role of family in offsetting burden in the context of a crisis. An expanded study on family dynamics and burden could dive into variables like ethnicity, employment (or work from home) status, varying levels of care needs, and specific living arrangements. Future research may also give insight into whether or how family composition affects informal caregiver burden at unremarkable times, or if Covid-19 has uniquely inspired family members to rally together around a vulnerable parent.

As the population continues to age, the increasing numbers and workload of informal caregivers must be met with effective interventions to alleviate burden. Prioritizing development of streamlined remote supports and age-friendly social policies to bolster resilience is

essential in order to sustain the U.S. healthcare system and safeguard the welfare of informal caregivers and the older adults in their care.

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