



Extension

UNIVERSITY OF WISCONSIN-MADISON

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RESEARCH BRIEF – JUNE 2022

FAMILIES UNDER STRESS

ASSESSING CAREGIVERS' ADAPTATION, COPING AND RESILIENCE THROUGH THE COVID-19 PANDEMIC

The COVID-19 pandemic brought many changes to the daily lives of families around the world. Significant emerging research documents the negative impact of COVID-19 and surrounding circumstances on families' mental health and well-being. School and childcare closures have placed parents in dual positions of teacher and caregiver as they balance working remotely, economic insecurity, and their own stress. Meanwhile, caregivers of those with illnesses or disabilities have taken on increasing responsibility for care tasks due to social distancing and quarantine guidelines. Changes in routine, stress, and social isolation are impacting families of all types across the state and globally. In order to best support families both during and after the pandemic, it is critical to understand how COVID-19 has affected Wisconsin families.

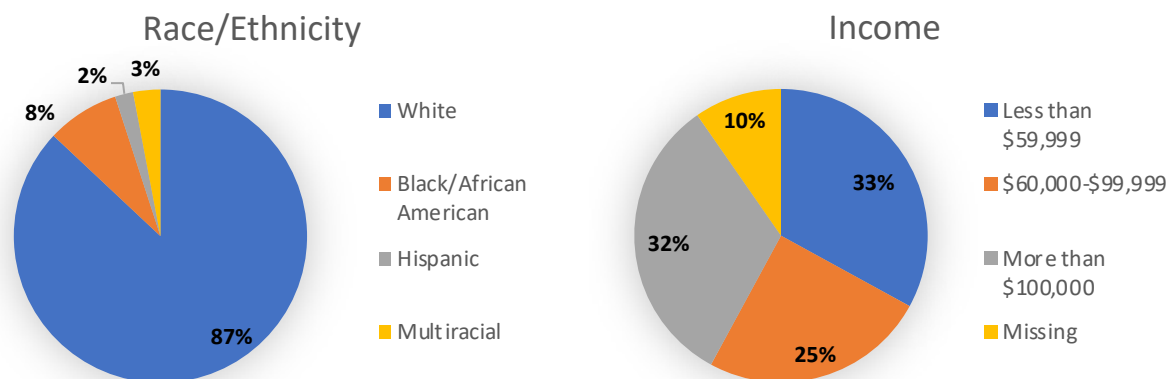
METHODS AND APPROACH

Data were from the COVID-19 Community Impact Survey collected by the Survey of the Health of Wisconsin (SHOW). The SHOW is a population-based health examination survey designed to collect data on health and health determinants from a representative sample of Wisconsin residents. In May of 2020, SHOW launched a statewide online/phone survey of early impacts of COVID-19 on health and well-being across diverse families. The second wave was collected in December 2020 and the third wave was collected in June 2021 to examine the ongoing impact of COVID-19.

A total of 1,403 adults participated at Wave 1; 1,889 adults participated at Wave 2; and 1,615 adults participated at Wave 3. Participants reported on 1) COVID-19 perceptions, beliefs, behaviors; 2) economic well-being; 3) food security, diet, and housing; 4) personal, social, and community context; 5) health and healthcare access; 6) mental and emotional health; 7) information sources and literacy; 8) lifestyle behaviors; and 9) caregiving.

■ SUMMARY OF SAMPLE DEMOGRAPHICS ■

Participants self-reported their age, gender, race/ethnicity, annual income, educational attainment, medical conditions, type of health insurance, caregiving status, and the number of adults and children in the household. The mean age of participants at Wave 1 was 55.1 years (SD = 15.8). Thirty-six percent of the sample identified as male and 64% identified as female. The majority (86%) reported being non-Hispanic white race/ethnicity. Over 26% of participants reported an annual income greater than \$100,000 per year, and about 30% of participants reported living with children under 17 years of age. Most participants had at least one medical condition (80%), had health insurance (96%), and were well-educated, with 82% of participants reporting they attended at least some college.



In this report, we focused on experiences of caregiving during the COVID-19 pandemic. Caregivers were defined as participants who reported that they were currently providing care for an individual in their household who was older than 18 years old. We aggregated the data to understand how families with and without caregiving roles perceived and adapted to the pandemic on average, as well as which characteristics were associated with better well-being over time.¹

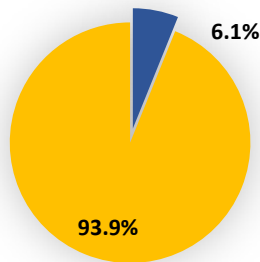
¹ Chi-square and t-tests were performed to determine if there were significant differences between caregivers and non-caregivers using an alpha level of 0.1.

CAREGIVING FOR ADULTS

DEMOGRAPHIC CHARACTERISTICS AND SITUATIONAL CHANGES DUE TO COVID-19

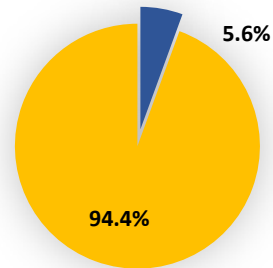
At Wave 1 (May 2020), 6% of the sample (n = 71) reported being a caregiver. Caregiver responsibilities appeared to shift over time – among those with data at both waves, nearly 50% of Wave 1 caregivers reported not being a caregiver at Wave 2, while many new caregivers were identified. At Wave 2 (December 2020), 6% of the sample (n = 89) reported currently being a caregiver.

Caregiving at Wave 1



■ Caregivers ■ Non-caregivers

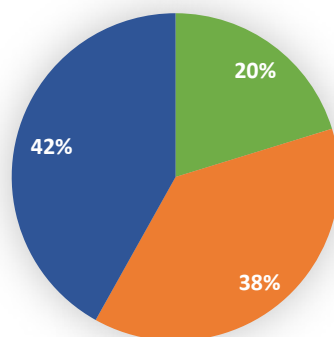
Caregiving at Wave 2



■ Caregivers ■ Non-caregivers

The mean age at Wave 1 was 58 years for caregivers and 53 years for non-caregivers. Caregivers and non-caregivers were similar in employment status with about 50% employed within both groups in the beginning of COVID-19, and nearly 60% experienced some change in employment status due the pandemic. However, caregivers were less likely to have children in the household (20% compared with 28% for non-caregivers) and reported lower incomes than caregivers, with 38% reporting an annual income of less than \$59,999 compared to 31% of non-caregivers. On average, caregivers reported having more medical conditions than non-caregivers (2.8 compared with 2.4) and were more likely to report not having any health insurance (6% compared with 3% for non-caregivers). Caregivers were also more likely to have been using benefits, including WIC, FoodShare, and unemployment insurance prior to the pandemic (21% compared with 13%) but were no different from non-caregivers in benefit use due to the pandemic.

Change in Caregiver Status at Wave 2 among Caregivers at Wave 1

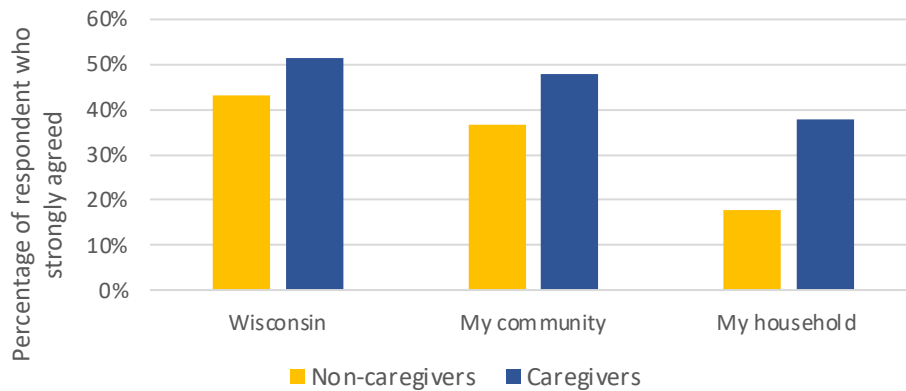


■ New Caregiver
■ Stopped Caregiver
■ Ongoing Caregiver

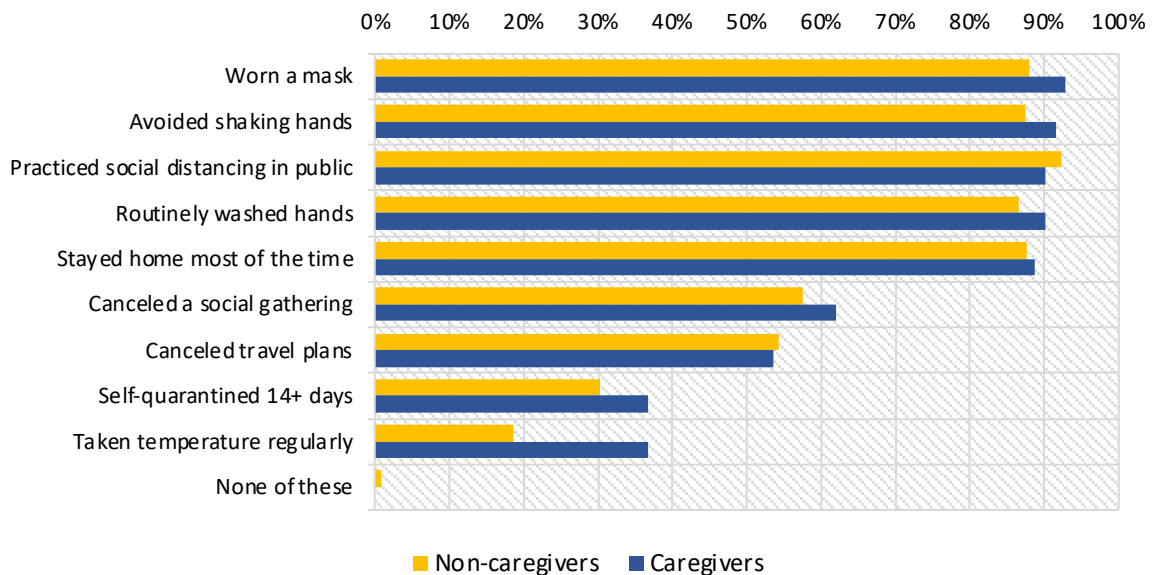
COVID-19 PERCEPTIONS, BELIEFS, AND BEHAVIORS

During the early stages of the pandemic (May 2020), there were several notable differences in how caregivers perceived and reacted to the pandemic compared to non-caregivers. Caregivers were significantly more likely to report that they have been contacted by a health professional about potential exposure to COVID-19 than non-caregivers (9% compared with 4%) and reported greater levels of perceived threat of COVID-19 than non-caregivers. Caregivers were also more likely to report that they strongly agree that COVID-19 is a threat to their communities (48% compared with 37%) and households (38% compared with 18%) than non-caregivers.

In May 2020, COVID-19 is a threat to...



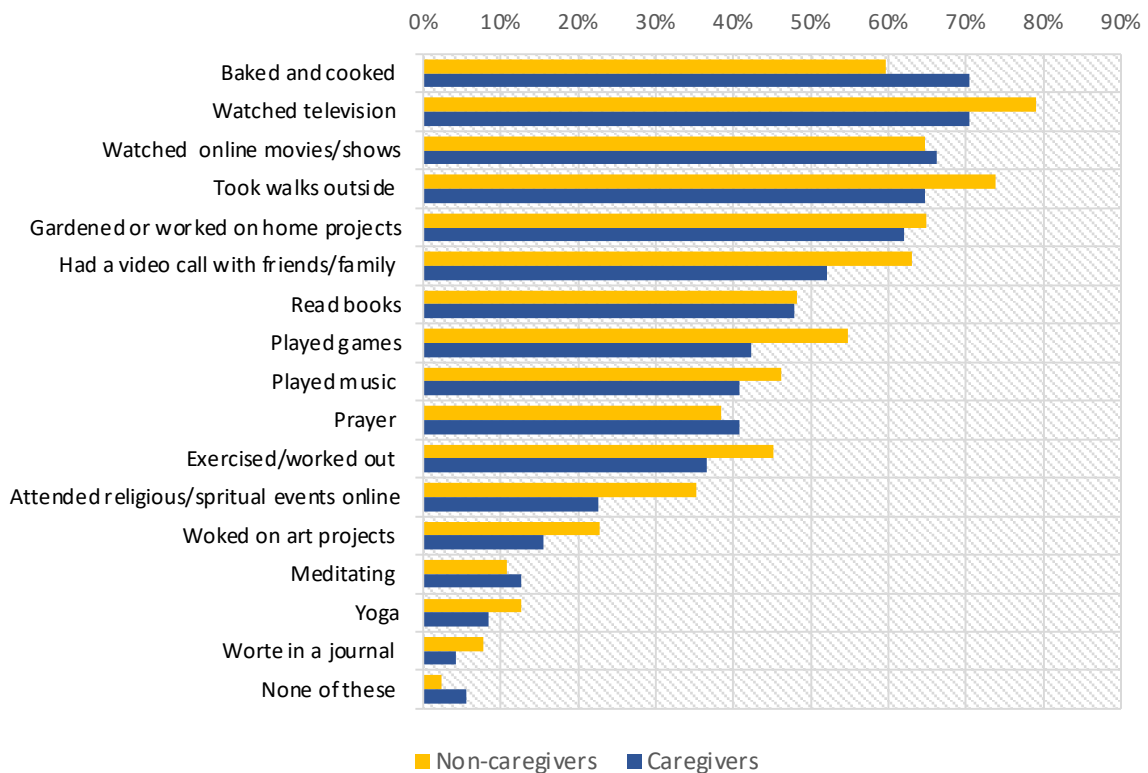
Precautionary Behaviors in May 2020



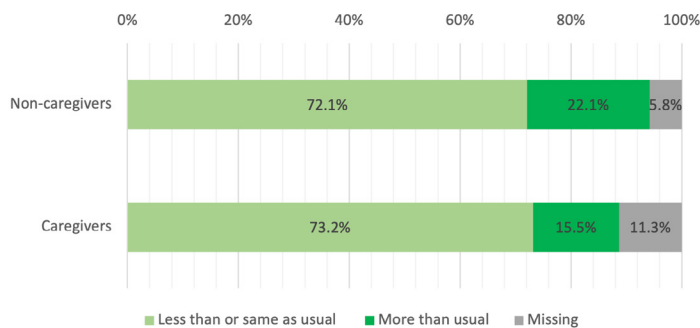
■ COPING STRATEGIES DURING COVID-19 ■

Caregivers also used different approaches to dealing with change, stress, and anxiety during the pandemic. On average, caregivers endorsed fewer of the listed coping behaviors than non-caregivers in May 2020 (mean of 6.6 coping behaviors in caregivers versus 7.3 in non-caregivers). Specifically, caregivers were less likely than non-caregivers to take walks outside, watch television, play online, card, or board games, have video calls with family and friends, or attend religious or spiritual events online as ways to cope with COVID-19. In contrast, caregivers were more likely than non-caregivers to report baking or cooking as a coping strategy. About 6% of the caregivers, but only 2% of non-caregivers, reported that they did not engage in any of the listed coping behaviors. Caregivers and non-caregivers also differed in alcohol use and physical activity: non-caregivers were more likely than caregivers to report having increased their alcohol use during the pandemic (16% for caregivers versus 22% for non-caregivers), but were also more likely to report being more physically active than usual (10% of caregivers versus 25% of non-caregivers).

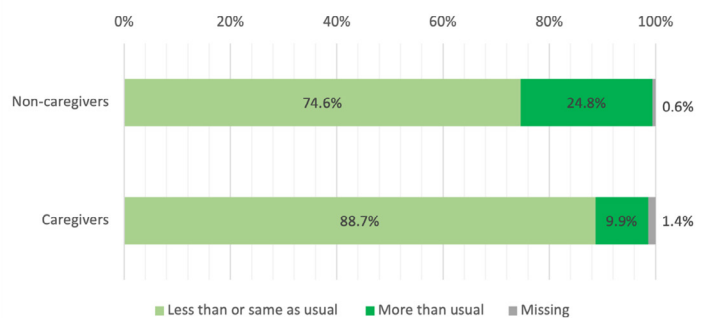
Engagement in Coping Strategies in May 2020



Change in Alcohol Use in May 2020



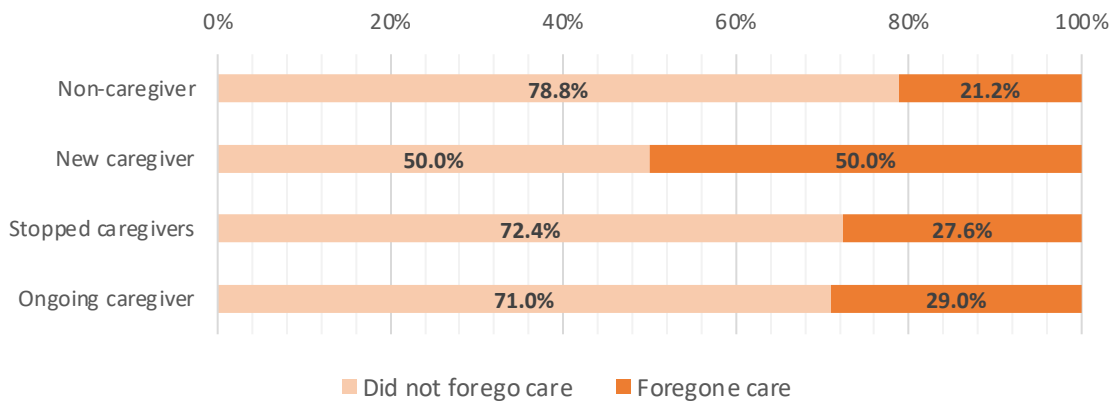
Change in Physical Activity in May 2020



HEALTH AND HEALTHCARE

Caregivers, particularly new caregivers, were more likely than non-caregivers to forego healthcare during the pandemic. In particular, new caregivers who started caregiving during the winter peak of the pandemic were the most likely to forego mental health counseling in December 2020. Both caregivers and non-caregivers experienced some delayed healthcare. In both groups, about 9% reported delaying healthcare because they were afraid of getting COVID, and 35% reported postponing or cancelling healthcare due to COVID.

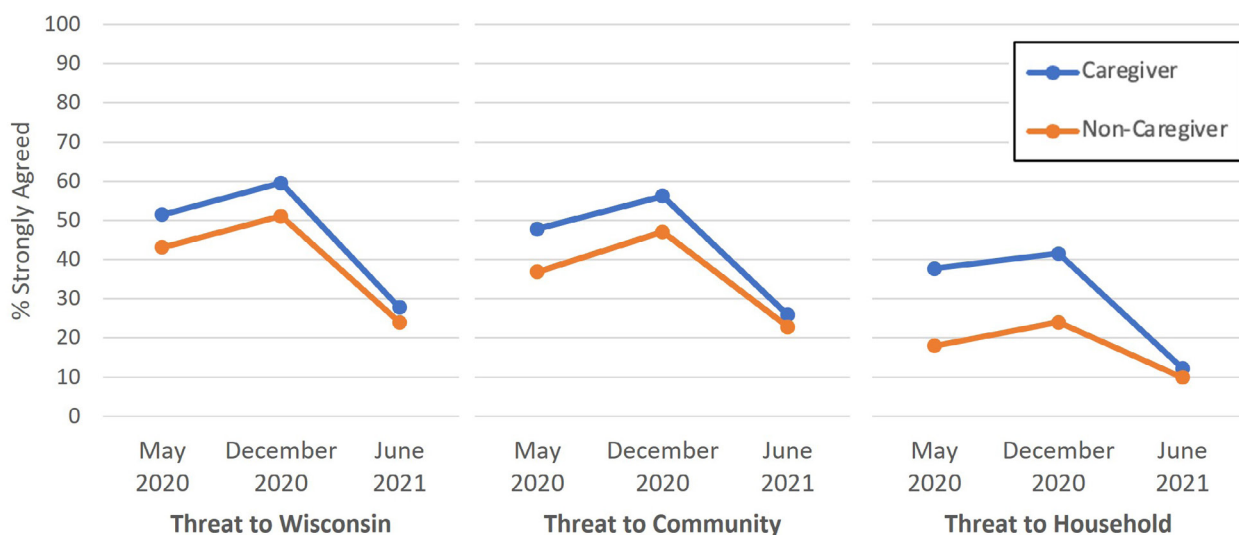
Foregone Healthcare due to COVID-19 in May 2020



CHANGES OVER TIME

As the pandemic intensified into the winter, caregivers continued to strongly perceive COVID-19 as a threat to their household, above and beyond the rates reported by non-caregivers (42% versus 24%). Nevertheless, caregivers and non-caregivers both took fewer precautions (5.7 on average) than they had in May 2020. Caregivers were more likely to rely on unofficial sources (i.e., friends, families, and coworkers) for information about COVID-19 compared to non-caregivers.

COVID Threat Perception Over Time



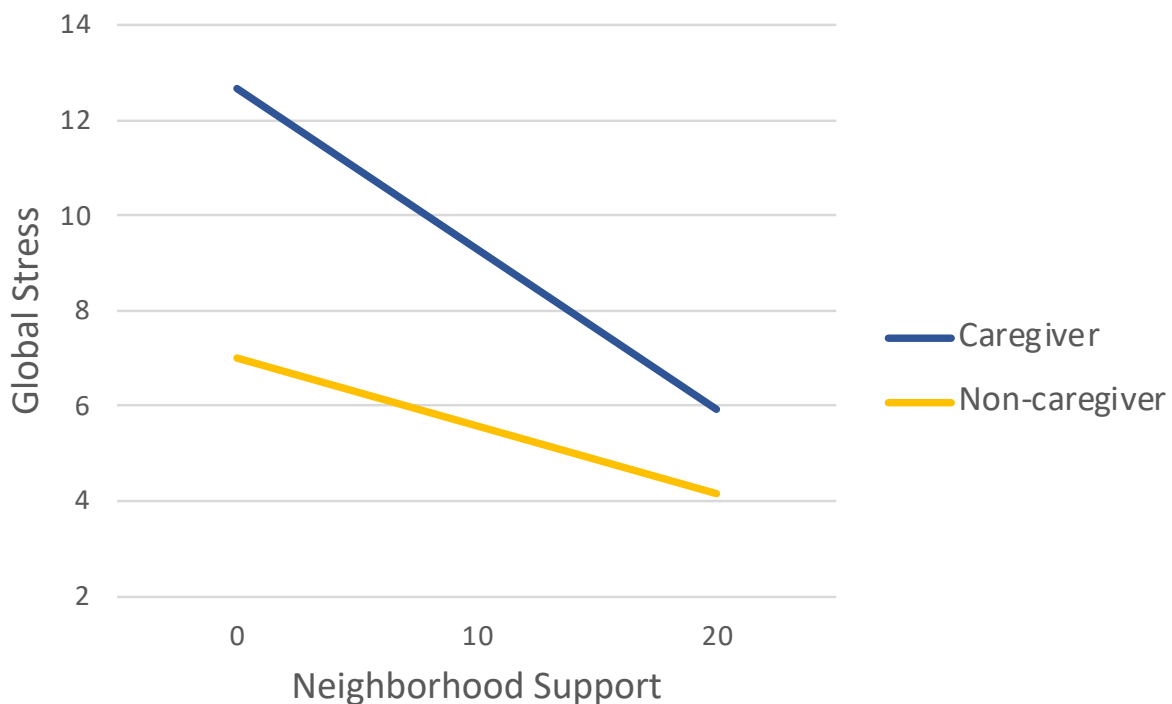
As the pandemic eased in spring and summer 2021, the perceived threat of COVID was much lower for both caregivers and non-caregivers. Caregivers and non-caregivers alike took even fewer precautions (4.5 on average), consistent with the lower levels of community spread and the widespread availability of the vaccines at that time. Caregivers were more likely than non-caregivers to postpone or cancel healthcare because of being afraid of getting COVID-19, and were more likely to forego getting prescription medications.

■ SOCIAL SUPPORT DURING COVID-19 ■

ROLE OF THE NEIGHBORHOOD IN SUPPORTING CAREGIVERS

In the early pandemic (May 2020), neighborhood sense of community - feelings of belonging to one another and to the community - was particularly impactful for caregivers. Caregivers answered seven questions about their sense of community (for example, "I belong in my neighborhood", "I have a bond with others in my neighborhood", and "I have a say about what goes on in my neighborhood"). Caregivers reporting low sense of community had greater stress and traumatic distress than non-caregivers. However, these differences were minimal among caregivers with high sense of community, suggesting that community-based support was critical in mitigating adverse psychosocial outcomes for caregivers during the pandemic.

Neighborhood Support Moderates the Association between Caregiving and Stress during COVID-19

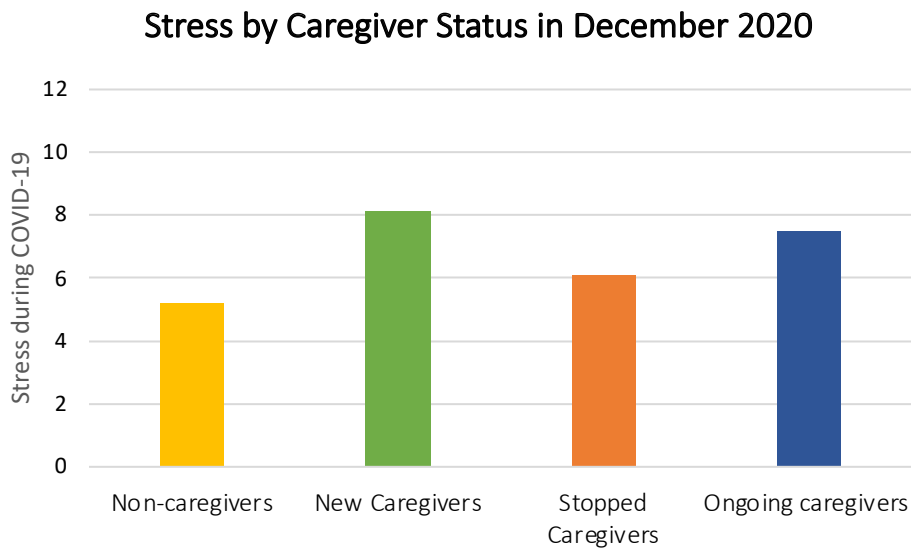
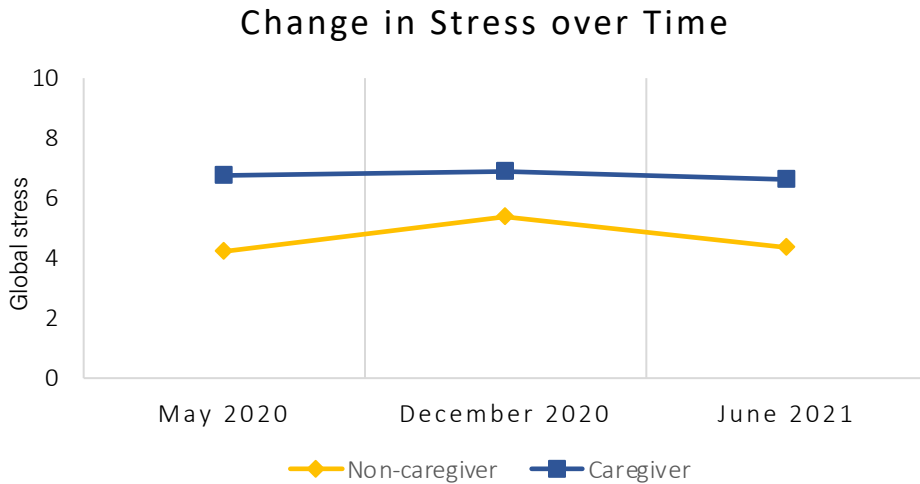


MENTAL AND EMOTIONAL HEALTH

STRESS AND ADAPTATION

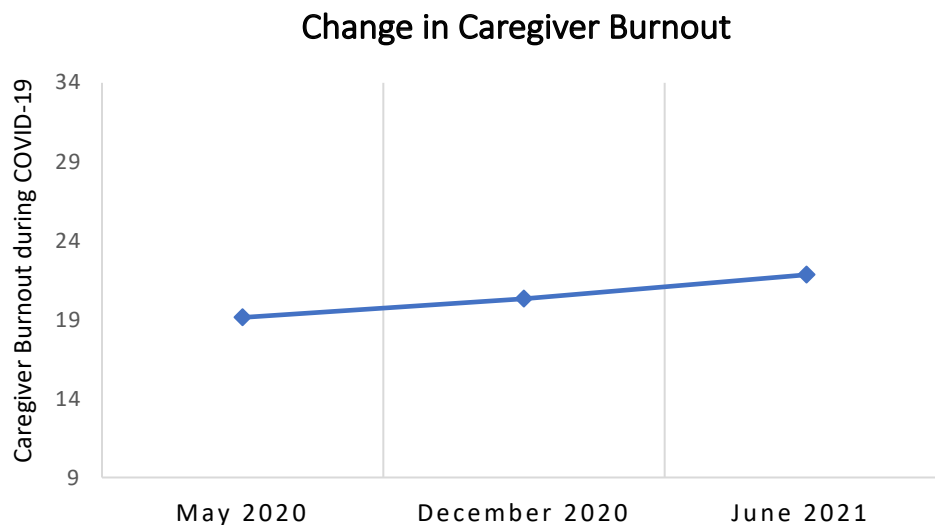
Throughout the pandemic, caregivers reported significantly higher levels of stress than non-caregivers. While the average level of stress for non-caregivers increased considerably during the peak of the COVID wave in December 2020 and then declined by June 2021, the levels of stress for caregivers remained elevated throughout that entire period. Across all timepoints, caregivers were more likely than non-caregivers to report experiencing stress related to caring for others, medical problems, and meeting basic needs.

Caregivers' transitions into and out of caregiving were also reflected in their average stress levels. Among participants who responded to the survey in both May 2020 and December 2020, new caregivers (who took on their caregiving role between May 2020 and December 2020) reported the greatest increase in stress over that timeframe, while non-caregivers reported the lowest levels of stress.



CAREGIVER BURNOUT

Caregivers also reported on their feelings and thoughts about caregiving during the pandemic. Caregivers answered seven questions about their emotional state on a 5-point scale: “I am in survival mode”, “I am in control”, “I feel completely run down”, “I have more energy for things”, “My resources are being all used up”, “I have a sense of purpose” and “Some things are going well, while other things are falling apart”. In the beginning of the pandemic, the mean score was 19 on a range from 5 to 35 indicating that caregivers experienced moderate levels of burnout with caregiving responsibilities. Negative feelings and thoughts about caregiving steadily increased throughout the pandemic, despite the rise and fall in community spread and perceptions of COVID threat.



IMPLICATIONS AND TAKE-AWAYS

The COVID-19 pandemic upended daily life, placing caregivers in unexpected and stressful circumstances. During the pandemic, caregivers of adults were more likely to report that COVID-19 was a threat to their communities and household, take more precautionary behaviors, use fewer coping behaviors, and forego healthcare than non-caregivers. Caregivers also had significantly greater levels of stress than non-caregivers and continued to report an increase in feelings of burnout over the course the pandemic. However, this trend was less pronounced for caregivers who had greater sense of community, suggesting the importance of community-based support in mitigating distress of caregiving during the pandemic.

LIMITATIONS TO CONSIDER

The number of survey respondents who reported being a caregiver is lower than we would expect based on the prevalence of caregiving in Wisconsin and nationally. It is possible that many caregivers were too busy, stressed, or overwhelmed to respond to the survey. In addition, the majority of the respondents identified as non-Hispanic white (86%). The COVID-19 pandemic has disproportionately affected underserved and minority populations and may have differentially affected caregiving experiences of caregivers from diverse racial/ethnic backgrounds. The information in this report should be interpreted with caution given the low percentage of caregivers and the lack of racial and ethnic diversity represented in the sample. It may be possible some caregivers might have experienced even greater challenges and/or benefits than we know. Policies and programs should be tailored to reflect the various needs of caregivers and better support them during stressful times, such as the COVID-19 pandemic.

RESOURCES FOR CAREGIVERS AND FAMILIES

Many resources are available to support caregivers and families, both during the pandemic and as we begin to recover and return to a new sense of normalcy.

Local Aging and Disability Resource Centers throughout Wisconsin (<https://www.dhs.wisconsin.gov/adrc/index.htm>) are an excellent first stop for connecting with information and learning about programs, services, and opportunities that are available to support caregivers, older adults, and people with disabilities.

Caregivers in need of respite care (a short break that allows caregivers to run errands or take time to themselves, and can help lower caregivers' stress and prevent burnout) can also reach out to the Respite Care Association of Wisconsin (<https://respitewi.org/>).

Family caregiving often comes with significant financial concerns. To learn more about local financial support options and grants, visit <https://coveringwi.org/caregiver>.

Extension programming can support the well-being of caregivers and their families. Program examples include Powerful Tools for Caregivers (often taught through an Aging and Disability Resource Center or other local partner), Aging Mastery Program, and local programming specifically designed for caregiver needs. Take a look at the Extension calendar of events (<https://extension.wisc.edu/events/>) or your local Extension homepage (<https://counties.extension.wisc.edu/>), or contact your local Extension offices to learn more about programs that might meet your needs.



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