

*Short Report*

## **Research Survey Series Shows Effects of COVID-19 Shutdowns on Alzheimer's Community, with Especially High Stress on Caregivers**

**Theresa Frangiosa \*, Virginia Biggar \*, Meryl Comer \*, Amber Roniger \***

UsAgainstAlzheimer's, PO Box 34565, Washington, DC 20043, USA

\* Correspondence: Theresa Frangiosa, tfrangiosa@usagainstalzheimer.org;

Virginia Biggar, vbiggar@usagainstalzheimer.org;

Meryl Comer, mcomer@usagainstalzheimer.org;

Amber Roniger, aroniger@usagainstalzheimer.org.

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### **ABSTRACT**

The specific objective of the COVID-19 Survey series is to understand the “real time” burdens and challenges of people living with dementia in this new restrictive environment. Overall, the main purpose of the Study is to develop an understanding over time, through multiple research projects, about “what matters most” to individuals with and/or affected by Alzheimer's disease and other dementias, including caregivers, and those concerned about brain health.

**KEYWORDS:** Alzheimer's disease; dementia; COVID-19; coronavirus; caregiver

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### **INTRODUCTION**

The COVID-19 pandemic and related restrictions have created severe stress for Alzheimer's and dementia caregivers, with increasing impacts on care for their loved ones, based on the findings of a series of four surveys of the Alzheimer's community by the UsAgainstAlzheimer's A-LIST® [1].

The four A-LIST COVID-19 surveys were conducted in March [2], April [3], May [4] and June [5] 2020 at a time when business closures, stay-at-home orders and fear of COVID-19 infection forced many family caregivers to care for their loved ones at home 24/7, with little or no help from home health aides, day support programs or extended family support. During this time, most caregivers with loved ones in long-term care were restricted from visiting and assessing the health of their family members firsthand.

The survey results shine a light on the enormous challenges and concerns of the broad Alzheimer's community of patients, caregivers and others from the COVID-19 coronavirus pandemic. The first survey was conducted when widespread social distancing, quarantine orders, and business closings were imposed amidst the growing numbers of cases throughout the United States. By the June survey, many of the restrictions

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were in the fourth month, providing an opportunity to assess possible cumulative effects over time.

## **OBJECTIVES**

The specific objective of the COVID-19 Survey series is to understand the “real time” burdens and challenges of people living with dementia in this new restrictive environment. Overall, the main purpose of the Study is to develop an understanding over time, through multiple research projects, about “what matters most” to individuals with and/or affected by Alzheimer’s disease and other dementias, including caregivers, and those concerned about brain health.

## **PATIENTS and METHODS: A REAL-TIME PULSE OF THE ALZHEIMER’S COMMUNITY**

The A-LIST is an online, research-ready community of more than 8000 people who self-identified with (or at risk for) Alzheimer’s disease, another dementia, or Mild Cognitive Impairment, current and former care partners, and people concerned about brain health. The A-LIST is a convenience sample that has been recruited through partnerships with Home Instead Senior Care, the Alzheimer’s Prevention Registry, the Alzheimer’s Association, The Balm In Gilead and over a dozen other advocacy, health equity and caregiver support organizations.

The A-LIST What Matters Most Insights Series (The A-LIST WMM Insights Series) (Study) is overseen by an Institutional Review Board (IRB), and conducted in accordance with International Conference on Good Clinical Practice (ICH GCP) and applicable United States (US) Code of Federal Regulations (CFR). Surveys are conducted within Survey Monkey and individual data is stored in a HIPAA-compliant database.

Typically, when individuals are recruited to take a survey, they are asked to sign the informed consent and join the A-LIST. A-LIST members engage in surveys to share insights on the experience of living with Alzheimer’s and other dementias, and caring for loved ones.

The A-LIST, with its virtual cohort and rapid-response surveys, offers researchers and related technology start-ups the opportunity to pressure-test hypotheses and efficiently take the pulse of the Alzheimer’s community, both qualitatively and quantitatively.

Since March 2017, 36 A-LIST surveys have been conducted on topics including patient and caregiver preferences, patient-doctor relationships, clinical trials, caregiver health, and dementia symptoms. UsAgainstAlzheimer’s uses survey results to inform policy makers, researchers, drug developers, insurers and others who serve dementia patients and caregivers. A-LIST research also identifies emerging needs and trends and provides insights for UsAgainstAlzheimer’s programs and initiatives.

The A-LIST is part of the broader UsAgainstAlzheimer’s What Matters Most research program, AD-PACE, a groundbreaking patient and

caregiver-led collaboration of industry, academics, government agencies and advocates. The April, May, June and July surveys were fielded to 43,662, 6447, 28,524, and 6609 potential respondents, and answered by 807, 750, 652, and 682 people, respectively. It should be noted that the only between group differences that were analyzed were the number of individuals with one or more stress symptoms, where current and former caregivers experienced more symptoms; there were insufficient numbers of people by race/ethnicity or age to measure differences.

Demographics for respondents in the four surveys are noted in the Table 1 below:

**Table 1.** Demographics for respondents in the four surveys.

Demographic	Wave 1 (March 2020)	Wave 2 (April 2020)	Wave 3 (May 2020)	Wave 4 (June 2020)
<i>n</i>	807 (745 with demographics)	750 (724 with demographics)	652 (640 with demographics)	682 (682 with demographics)
#/% current caregivers	198/26.6%	197/27.2%	176/27.5%	190/27.9%
#/% of care-givers-loved one at home	146/73.7%	151/76.6%	140/79.4%	142/81%
#/% of caregivers-loved one in assisted-living community	52/26.3%	46/23.4%	36/20.6%	34/19%
#/% former caregivers	169/22.7%	173/23.9%	147/23.0%	161/23.6%
#/% with diagnosis	48/6.4%	53/7.3%	52/8.1%	50/7.3%
#/% at risk for MCI/AD/dementia	119/16.0%	139/19.2%	126/20.0%	130/19.1%
#/% interested in brain health	211/28.3%	162/22.4%	139/21.7%	151/22.1%
% age ≤ 50 years	7.5%	6.3%	5.5%	6.1%
% age 51–65 years	34.0%	35.3%	26.5%	36.5%
% age 65+ years	58.5%	58.4%	58.0%	57.4%
Female	71.7%	71.9%	70.0%	75.6%
Male	28.3%	28.1%	30.0%	23.9%
% Caucasian	92.6%	93.7%	92.4%	90.9%
% African Amer	2.4%	2.5%	2.4%	2.7%
% Latino/Hispan	3.1%	2.4%	2.4%	3.0%
% Asian	1.2%	0.3%	0.6%	1.0%
% other ethnicity	0.7%	1.1%	2.2%	2.4%

## FINDINGS

### COVID-19 Pandemic's Significant Effects on Current Caregivers

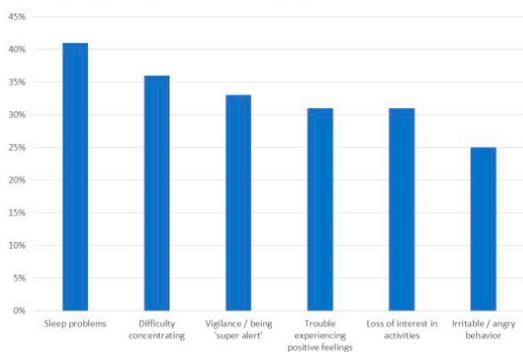
The A-LIST surveys found that caregivers of people living with Alzheimer's or another dementia experienced the highest levels of stress as a result of the COVID-19 closures. These respondents, the largest group of respondents to the surveys, consistently reported the highest stress levels, with 75% or more in each survey saying their stress levels were higher since COVID-19 coronavirus restrictions were put in place.

After seeing the increased stress levels among current caregivers in the March survey, questions were added to subsequent surveys to better characterize that stress, the symptoms and its effects.

The April, May and June surveys found that 80% or more of caregivers reported having one or more stress symptoms typically found in people experiencing severe stress. In June, the top-reported caregiver symptoms associated with stress included:

- Sleep problems (41%)
- Difficulty concentrating (36%)
- Vigilance/being 'super alert' (33%)
- Trouble experiencing positive feelings (31%)
- Loss of interest in activities (31%)
- Irritable/angry behavior (25%)

See Figure 1 below.



**Figure 1.** Percentage of individuals reporting symptoms as result of COVID-19 restrictions—June 2020 of  $n = 190$  current caregivers, 80% report one or more symptoms.

In a further effort to assess the impacts of these severe stress symptoms, a question was added to the May and June surveys about the effects on the caregiver's ability to care for their loved one. In May, 25% of caregivers said physical or mental health changes related to the COVID-19 pandemic and isolation have affected their ability to care for their loved one. This figure increased 6 points, to 31%, in the June survey.

In response to caregiver questions added (starting) in the May survey about unmet needs, more than a quarter (26% in May and 28% in June) of caregivers said they needed, but could not get, access to support

groups. In addition, 16% of respondents in May and 18% in June said they needed, but could not get, access to home health aides.

“On a daily basis, I feel more stress,” one caregiver wrote in an open-ended question in the June survey. “This mental condition sometimes manifests in less sleep; more eating; more crying; and more muscular pains.”

Because many people with dementia are in a higher risk category for COVID-19, concerns about the threat of coronavirus infection were high in the surveys. Throughout the first four surveys, more than 7 in 10 of the caregiver respondents who were caring for people with Alzheimer’s disease at home were unsure what would happen to their loved one *if they (the caregiver) got sick* with COVID-19. In addition, the surveys found that around 38% of caregivers were unsure what to do *if their loved one with Alzheimer’s became sick*.

### **Concerns about Care of Loved Ones in Assisted Living Facilities**

A subset of respondents—ranging over the four surveys from 52 respondents in March to 34 respondents in June, who reported having loved ones with Alzheimer’s or another dementia in nursing homes or other long-term care communities, had often experienced significantly higher stress (ranging from 68% to 84% over the four surveys) as a result of visitation restrictions and challenges getting information about their loved one.

Over the four A-LIST COVID-19 surveys, nine in 10 of these respondents (91%) were unable to see their loved one because of virus-related visitation restrictions at the facilities. The inability to know/accurately assess the health status of their loved one in a facility was the top stressor for these caregivers.

Throughout the four monthly surveys, between 35% and 44% of these caregivers were less confident about the level of care their loved one was receiving in these assisted living facilities than before the coronavirus restrictions were put into place.

“My mother feels abandoned, scared, and confused and I cannot be there to help,” a caregiver wrote.

With states and businesses expanding their phased re-openings, caregivers were asked in June about safeguards they would be willing to consider when visiting loved ones in long-term care communities. The June survey showed the following support for a range of safeguards: wearing personal protective equipment (94%), socially distanced visiting (74%), COVID-19 testing prior to visiting (59%), video visiting as an alternative to in-person visiting (59%), and paying for COVID-19 testing before visiting (41%).

Half (50%) said they had heard of cases of COVID-19 in the assisted living facility at the time of the June survey (June 9–14), up 19-points over the May survey, and 33 points more than the April survey.

### **Stress and Concerns of People Diagnosed with MCI, Alzheimer's or Another Dementia**

A subset of survey respondents—ranging from 48 to 53 over the four surveys—identified themselves as having been diagnosed with mild cognitive impairment, Alzheimer's or another dementia. More than half (52% in June) of these with a diagnosis had somewhat or significantly more stress than they did before coronavirus restrictions went into place, continuing a steady decline from the 76% level in the first survey in March.

In the June survey, about a third (34%) of individuals with a diagnosis wanted support, but could not get it, since the coronavirus crisis started, with the top three unmet needs including: pastoral care/religious services (13%), support groups (11%), and family support (11%).

### **DISCUSSION**

The COVID-19 pandemic and resulting closures caused major disruptions to economies, health systems and ways of life across the United States and the world.

UsAgainstAlzheimer's believes there is an urgent, unmet need for additional research to understand how the COVID-19 pandemic, and actions to stop its spread, impacted people living with Alzheimer's, other dementias, MCI, caregivers and their families. The A-LIST was able to rapidly respond with this series of four surveys to understand what matters most to our community during this crisis. The results provide valuable insights during this pandemic when the pace of in-person dementia research has reportedly slowed [6].

The A-LIST will continue fielding surveys to monitor the impacts of the evolving COVID-19 pandemic on this vulnerable population. UsAgainstAlzheimer's believes that the data points to an urgent need for action to ensure that: dementia caregivers receive needed support (both online and/or safely in-person), long-term care facilities permit caregivers to safely interact with their loved ones and consistently and openly share health information with family members, and that as a society, we plan much better for our collective future.

### **AUTHOR CONTRIBUTIONS**

All authors contributed to the intellectual design of the study and findings development; VB and AR fielded the study; TF oversaw initial data analysis, final versions of survey and publication and IRB interface in accordance with established protocol.

### **CONFLICTS OF INTEREST**

The authors declare that they have no conflicts of interest.

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