

Living With Dementia During a Public Health Emergency: An Examination of the Silent Pandemic

Paul Arthur, PhD, OTR/L¹, Chih-Ying Li, PhD, OTR²

¹Florida Gulf Coast University, Ft Myers, Florida, United States; ²University of Texas Medical Branch, Galveston, Texas, United States

DOI: [10.5014/ajot.2023.77S2-PO156](https://doi.org/10.5014/ajot.2023.77S2-PO156)

Date presented: April 22, 2023

Primary Author and Speaker: Paul Arthur, paulbf@gmail.com

PURPOSE: There are more than 6 million Americans living with dementia that predominantly reside in their communities with the support of their familial caregivers (Alzheimer's Association, 2022). Persons living with dementia and their caregivers are among society's most vulnerable, a condition exacerbated by the COVID-19 pandemic. Throughout the pandemic, persons living with dementia were asked to isolate from support systems, change routines, and decrease service utilization (Wong et al., 2021). As a result, they were less likely to adhere to precautions and were nearly twice as likely than peers to experience an infection leading to mortality. Caregivers were dually faced with significant care challenges and lessened availability of support services. There is an important role for occupational therapy practitioners in support and prevention for persons living with dementia and their caregivers during public health emergencies. Primary research questions were (1) what was the effect of the COVID-19 pandemic on the cognitive, behavioral, and motor abilities of persons living with dementia in the US, and (2) what was the effect on dementia caregiver wellbeing during the public health emergency.

DESIGN: A cross sectional survey design was utilized for quantitative data collection in the Spring of 2022. Inclusion criteria were (1) identification as a caregiver of someone with dementia during the COVID-19 public health emergency, (2) over the age of 18, and (3) residing in the United States. Participants were recruited through targeted/paid social media (Facebook/Instagram) advertisement.

METHOD: Caregivers completed informed consent prior to a 54-question survey including the Clinical Dementia Rating Scale (Morris et al., 1997) and a semi-structured questionnaire developed by Rainero et al. (2021). Primary outcomes focused on changes (yes/no) in cognitive, behavioral, and motor systems during the pandemic. Secondary outcomes focused on caregiver well-being. We used logistic regression to identify person-level protective factors for primary and secondary outcomes.

RESULTS: 113 dementia caregivers (95% female) from 30 states participated in the survey. The average caregiver age was 63 (SD=9.9) while the average age of persons living with dementia was 80 (SD=9.4). More than 80% of the caregivers (n=88) reported declining cognition in the person living with dementia during the pandemic. They also reported worsening behavioral and psychological symptoms of dementia in nearly 78%, and decreased motor abilities in 80% of persons living with dementia. Greater than 57% of caregivers reported belief that the pandemic accelerated decline in the person living with dementia rather than being a part of the disease's natural course. More than 41% of caregivers reported a significant lack of assistance (receiving no help) during the pandemic; the highest endorsed caregiver symptoms included feelings of isolation (65%), overwhelmed (61%), and anxiety (58%). Persons living with dementia's prior-pandemic level of community mobility (as reported as ability to leave the house with/without assistance) served as a protective factor for behavioral symptom change during the pandemic (odds ratio 0.20 [95% CI 0.00-0.29]).

CONCLUSION: The impact of the COVID-19 pandemic on persons living with dementia and their caregivers is substantial in comparison to society at large and does not express difference in regional location.

IMPACT STATEMENT: A marked public health and preventative role signals a great opportunity for occupational therapy practitioners to fill the void and prepare for future public health emergencies and isolation periods to care for societies most vulnerable.

References

- Alzheimer's Association. (2022). 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 18(4), 700-789. <https://doi.org/10.1002/alz.12638>.
- Morris, J. C., Ernesto, C., Schafer, K., Coats, M., Leon, S., Sano, M., et al. (1997). Clinical dementia rating training and reliability in multicentre studies: the Alzheimer's Disease Cooperative Study experience. *Neurology* 48, 1508-1510. <https://doi.org/10.1212/wnl.48.6.1508>
- Rainero, I., Bruni, A. C., Marra, C., Cagnin, A., Bonanni, L., Cupidi, C., ... SINDem COVID-19 Study Group. (2021). The impact of COVID-19 quarantine on patients with dementia and family caregivers: A nation-wide survey. *Frontiers in Aging Neuroscience*, 12, 507. <https://doi.org/10.3389/fnagi.2020.625781>
- Wong, B. P. S., Kwok, T. C. Y., Chui, K. C. M., Cheng, T. S. T., Ho, F. K. Y., & Woo, J. (2021). The impact of dementia daycare service cessation due to COVID-19 pandemic. *International Journal of Geriatric Psychiatry*. <https://doi.org/10.1002/gps.5621>