

Preliminary results from the COVID caregiving project

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Abstract

Background: In the United States, family caregivers are the cornerstone of the support system for persons living with dementia (PLWD). This study examined how the coronavirus disease 2019 (COVID-19) pandemic challenged caregivers' capacity to deliver long term care services and supports to PLWD.

Method: Participants (expected N=40) in this qualitative study are family caregivers for PLWD who reside in either the community or a long-term care facility. Family caregivers participate in semi-structured, hour-long telephonic interviews covering: (1) adequacy of caregiving supports; (2) social, emotional, physical, financial, and other effects of caregiving during the COVID-19 pandemic on the caregiver; and (3) effects of the COVID-19 pandemic on the person with dementia. Interviews are audio-recorded, transcribed, and coded in NVivo. The University of Pennsylvania IRB approved this study.

Results: Preliminary results show that social distancing measures disrupted services and supports for PLWD (e.g., closure of adult day centers). Efforts to minimize the risk of COVID-19 disease or death for the person with dementia increased caregiver work and feelings of burden. Many caregivers described making difficult tradeoffs. Some reduced their utilization of supports (e.g., forgoing having paid aides come into the home, limiting visits from other family members), but this has increased workload and limited opportunities for respite. Other caregivers reduced work hours or left the workforce entirely (e.g., because they deemed their risk of SARS-CoV-2 exposure on the job too high), but this has increased financial vulnerability and social isolation. A majority of caregivers expressed concern that social distancing has negatively affected the person in their care; many perceive a hastening of cognitive decline and feel their time with the person with dementia has been limited by the pandemic. Caregivers for long-term care facility residents reported frustration with limited visitation opportunities as well as a perceived decrease in quality of care and lack of transparency.

Conclusion: Our results will help characterize the impact of the COVID-19 pandemic on PLWD and their caregivers. They will inform ethical guidelines and policies to improve the delivery of services and supports for PLWD and the ability of people to perform the work of caregiving.