

Research Brief

August 2023

“WE DID MORE DAMAGE”: HOW COVID-19 COLLAPSED THE CARE CONVOYS OF RESIDENTS LIVING WITH DEMENTIA

Keywords: care networks, long-term care, dementia, social support, COVID-19

Purpose of the Study: To understand how COVID-19 policies impacted the care networks and quality of life of long-term care residents with dementia.

Key Findings:

- ✓ Many residents did not understand the COVID-19 limitations on family visits, which seemed to instigate physical, emotional, and cognitive decline in some residents.
- ✓ Staff struggled to maintain a balance between a comforting and safe environment for both residents and themselves.

Major Policy/Practice Implication: Policymakers need to create emergency regulations that consider specific needs of residents with dementia, such as their cognitive abilities to adhere to regulations and the socioemotional impact of regulations.

IMPORTANT BACKGROUND INFORMATION

Nearly half of the 2 million US residents in long-term care (LTC) communities have dementia, and are especially vulnerable in emergencies. While early COVID-19 regulations were designed to minimize exposure, policymakers did not consider the impact that regulations, such as limited family visits, would have on residents' overall socioemotional, mental, and physical health outcomes. Residents with dementia often depend on complex care networks of family, formal staff, and comforting environments, all of which were strained in the pandemic. This research investigates the impact of COVID-19 regulations on care networks of residents with dementia.

STUDY METHODS

Researchers interviewed 43 long-term care administrators in 2021 about the impact of COVID-19 regulations on residents with dementia, particularly their care networks. A few interview topics included participants' perspectives on COVID-19 regulations, how the pandemic had impacted residents with dementia, and what they had done to cope/facilitate communication with outside family. Researchers individually and collectively reviewed interview transcripts using ATLAS.ti software to identify patterns in the interviews. They also used the care convoy model (shown below) to guide data analysis.

KEY FINDINGS

✓ **Residents did not understand limitations placed on family visits, which caused mental and physical decline.**

- Limited visits, short visits, and less personal visits (e.g., through a window) often confused residents
- Residents lacked reassuring physical touch (e.g., hand hold, hug)
- Families grieved because residents seemed to decline more rapidly between infrequent visits

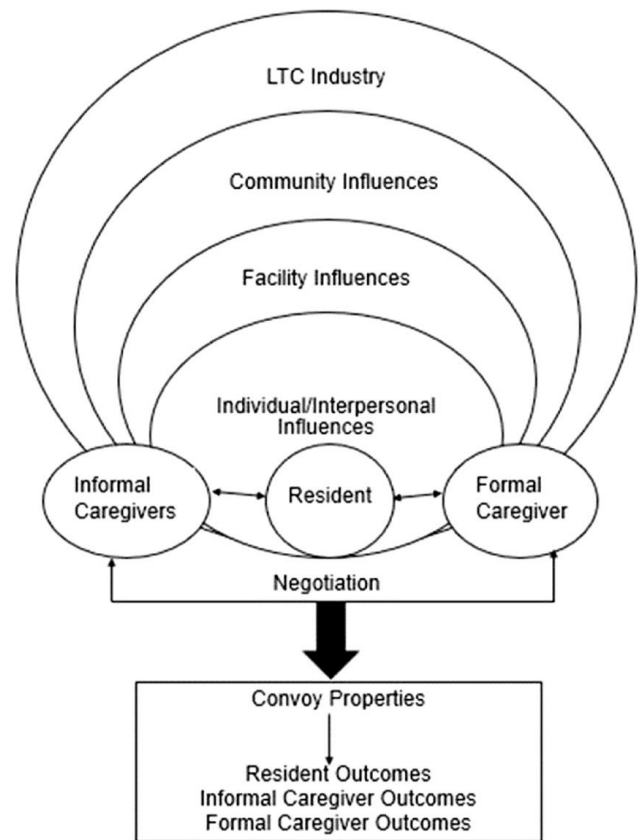
“Not being able to see family, not being touched, the fear, all of that, did tremendous damage to their mental health. And I truly believe it killed quite a few of our residents because the depression was so severe.”

✓ **Staff were pressured to overcompensate for lack of family care, and residents’ limited understanding of regulations.**

- Residents did not always understand safety measures, such as masking. Staff overcompensated with PPE to protect themselves and residents
- Staff were charged with comforting residents in the absence of family, but struggled due to safety protocols that made their environments feel clinical. Participants reported touching residents for reassurance, and removing masks to help residents read their body language

✓ **Administrators struggled to adhere to regulations that did not consider the real needs of residents with dementia.**

- Participants were frustrated that regulations did not consider the reality of residents with dementia
- Many participants defied protocols (e.g., isolation in rooms) because they viewed the nursing home as a home environment
- Some participants feared citations/fines as they struggled to adhere to regulations



PRACTICE AND POLICY IMPLICATIONS

Policymakers should seek provider input when creating emergency policy. While safety is important, socioemotional and cognitive needs are also critical contributors to health outcomes of residents with dementia.

ORIGINAL ARTICLE

Hackett, S.E., Peterson, L.J., Vogel, C.E., Dobbs, D. (2023). “We Did More Damage”: How COVID-19 Collapsed the Care Convoys of Residents Living with Dementia. *Journal of Applied Gerontology*, 42(7). doi: 10.1177/07334648231162360

This policy brief was written by Chelsea Goldstein, MGS and Lindsay Peterson, Ph.D. of the University of South Florida, School of Aging Studies and Florida Policy Exchange Center on Aging. For further information contact the study author, Sara Hackett, Ph.D. at sehackett@usf.edu.