

Research Brief

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DEMENTIA CAREGIVERS' PERSPECTIVES ON DISASTER PREPAREDNESS: BARRIERS, RESOURCES, AND RECOMMENDATIONS

Keywords: caregiving, dementia, disasters, hurricanes

Purpose of the Study: To better understand the experiences of caregivers for people with dementia during disasters, such as hurricanes.

Key Findings:

- ✓ Caregivers mentioned the importance of preparing for the unique needs of people with dementia during disasters, and their sense of responsibility to their care recipients.
- ✓ Caregivers discussed both barriers to and facilitators for preparing for disasters and executing disaster plans.

Major Policy/Practice Implication: Caregivers provide unique and actionable insights into their concerns and challenges regarding disaster preparation with people with dementia, as well as things that have worked for them during previous disasters. They highlight the critical need for evacuation shelters that are dementia friendly.

IMPORTANT BACKGROUND INFORMATION

Disasters, such as hurricanes and wildfires, can cause more than flooding and structural damage. They disrupt access to basic services and supports, such as food, shelter, and health care, and they provoke fear and anxiety that continues after the event.

Effects are magnified for the 6 million Americans with dementia and their caregivers. People living with dementia may struggle with routine daily tasks due to challenges with memory, language, and executive and cognitive function. The pressure to comprehend or carry out a disaster plan and the disruption of routines and environments that occur during a disaster can heighten their confusion and anxiety.

STUDY METHODS

Researchers conducted focus groups and phone interviews with 52 caregivers of people with dementia between April and September of 2021 to better understand experiences of caregiving during disasters. Specifically, they used the stress process model as a guide in identifying disaster experiences, the need for disaster preparation and the factors that can encourage or discourage a caregiver from adequately preparing. Researchers used a semi-structured interview approach to prompt conversation, yet allow the caregivers to speak openly about topics important to them. They used a number of research techniques to ensure that data collection was rigorous. ATLAS.ti 9 software aided them in the management of the process.

KEY FINDINGS

- ✓ Caregivers spoke about the **importance** of preparing for the unique needs of people with dementia in disasters.
 - They discussed **fulfilling a sense of caregiver responsibility**. Some caregivers were the only safety nets for their care recipients, and some felt unprepared for disasters.
 - They discussed the importance of **remaining calm during crises**. Some caregivers mentioned anxiety-inducing triggers, such as rushing to gather supplies, putting up window shutters, losing electrical power, and evacuating to unfamiliar places.
- ✓ Caregivers shared that **barriers** to disaster preparations are intertwined with the daily challenges of caregiving.
 - Many caregivers **felt overloaded** by the responsibilities of preparing for the disaster, while keeping calm/providing attention to care recipients.
 - They discussed **limitations in preparing for/responding to disasters**. Specifically, they worried the care recipients may have difficulty executing disaster plans due to cognitive limitations, and they felt alone in disaster preparation.
 - Many participants mentioned **limited options for evacuation**, given their worries about whether those in their care would act out, try to elope, or react in other negative ways to unfamiliar environments. They specifically discussed their fears around disaster shelters not being appropriate environments for people with dementia.
- ✓ Caregivers also discussed factors that could **facilitate preparedness**, such as dementia-specific preparedness information.

“They need your attention, and then you have to give your attention to getting things ready for them. So, it’s a double whammy there.”

- They want **usable information** in simple formats (e.g., bullet points) and large print. They also want information in multiple languages that uses positive messaging to help limit panic, such as real caregivers sharing what worked well for them during disasters.
- They desire **strong supports**, such as networks to assist with care and support, and safe dementia-friendly evacuation locations.

PRACTICE AND POLICY IMPLICATIONS

An unintended benefit of this study was that caregivers who had experienced disasters shared what they learned with the other caregivers in their focus groups. Caregiving for individuals with dementia can be stressful and overwhelming, especially in emergency situations. Caregivers could gain critical advice through targeted support groups.

The study also provides clear policy directives concerning the development and dissemination of guidance for caregivers, including information using plain language and large print. The study highlights a critical need for dementia-friendly shelters. Some caregivers said they would stay in unsafe conditions before risking a shelter that was not dementia-friendly.

ORIGINAL ARTICLE

Peterson, L.J., Hackett, S.E., Dobbs, D., & Haley, W.E. (2024). Dementia Caregivers’ Perspectives on Disaster Preparedness: Barriers, Resources, and Recommendations. *The Gerontologist*, 64(3), 1-8. Doi: 10.1093/geront/gnad076

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