

Promoting Caregiver Resilience During Medical Crises of Persons Living with Dementia

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USA

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Promoting Caregiver Resilience During Medical Crises of Persons Living with Dementia

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1

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Research Abstract

Background: Caring for a person (or persons) with dementia (PWD) requires knowledge, skill, and resilience in managing everyday health needs and responding effectively to crises caused by PWD acute illness and hospitalization. Such crises may cause lasting depletion of caregiver/caregivers (CG) physical, mental, and emotional reserves and lead to poor CG health and decisions to place a PWD in residential care. **Innovation:** CG crisis due to acute medical decompensation in a PWD is a neglected area of study. This study defines a new dimension in caregiving research by focusing on how CG manage the health of PWD under everyday circumstances, respond to sudden medical changes, and maintain – or sacrifice – their own wellness when a PWD illness creates a caregiving crisis. This new knowledge will provide a method to identify CG at risk for poor outcomes and guide development of a new intervention to support CG resilience and restore CG equilibrium after crisis. **Sample:** 100 CG of PWD recently hospitalized for an ambulatory care sensitive condition, a disorder that if well managed in an ambulatory setting may not require hospitalization. **Methods:** Triangulation of data from CG interviews and assessments and PWD medical records to inform the content of the intervention toolkit. **Aim 1.** To set intervention targets for resilience coaching by identifying gaps in CG self-care during day-to-day caregiving as well as PWD health crises; describing CG experiences, observations, decision making processes, and actions prior to a potentially preventable hospitalization of PWD; and identifying CG/PWD characteristics that suggest opportunities for mitigating future risk. **Outcome 1:** Create a CG self-care inventory to identify and monitor CG self-care practices and how they change during PWD health crises. **Outcome 2:** Map the chain of events leading to hospitalization, identify missed opportunities for preventive intervention, and create a repository of CG descriptions of early symptoms of conditions that lead to hospitalization of PWD. This map and symptom repository may assist providers in interpreting CG reports of illness in PWD. **Outcome 3:** Stratify CG into those with high vs. low risk for experiencing difficulties responding effectively to a PWD health crisis and identify intervention components that are most relevant for individual CG (e.g., enhanced self-care, knowledge/skills, engaging health system). **Aim 2.** To use data from Aim 1 to inform the design of a toolkit for CG resilience coaching focused on: A. enhanced self-care during times of crisis; B. Early recognition/response to signs/symptoms of acute worsening in PWD health; and C. Appropriate content and timing for reporting/advocating to clinicians. The toolkit will be tested in future studies as the foundation for a new generation of CG interventions focused on sustaining and promoting resilience through building CG knowledge and skills to care for the health of PWD and oneself. The aims of this study align with the goals of the National Alzheimer's Plan Act and the Healthy People 2020, because enhancing and maintaining CG self-care is a national priority for PWD, their CG, and long-term societal wellbeing.

Lay Summary

Enhancing and maintaining caregiver/caregivers (CG) self-care is a national priority – for people living with dementia, for their caregivers, and for long-term societal wellbeing. The National Alzheimer’s Plan Act recognizes widespread deficiencies in detecting and addressing the needs of CG of person/persons with dementia (PWD) and identified CG assessment and interventions as one of its five key goals. Additionally, CG who are better prepared to manage their care recipient’s health and to maintain personal wellness, may be more effective in preventing potentially avoidable hospitalizations, thereby meeting a key dementia-related objective of Healthy People 2020.

Further information available at:

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