

Dementia care research (research projects; nonpharmacological)/Family/Lay caregiving

“I just glove up and do what has to be done”: A mixed-methods exploration of dementia care challenges and care management strategies

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Email: leggetta@med.umich.edu**Abstract**

Background: Most family caregivers for persons living with dementia (PLwD) don't receive training for their role and therefore adopt a variety of care management strategies, some of which may be harmful. The current study utilizes a mixed-methods design to integrate family caregiver's qualitative and quantitative descriptions of recent care challenges (e.g. cognitive, functional, and behavioral symptoms of dementia), and the strategies utilized to manage these symptoms.

Method: Participants included 100 primary family caregivers for PLwD who were 74% female, 18% non-White, and on average 64 years old. Participants were interviewed qualitatively about their management of a recent care challenge and with the Caregiver Assessment of Function and Upset, Neuropsychiatric Symptom Inventory, Dementia Severity Rating Scale, and Dementia Management Strategies Scale (subscales: criticism, active management, encouragement). Care challenges and care management strategies are compared across qualitative analysis and T-tests.

Result: The most common type of qualitatively reported care challenge was BPSD (45%) followed by symptoms of cognitive decline (18%). Quantitatively caregivers reported the most stressful ADL to be toileting and BPSD as aggression. Caregivers providing ADL/IADL care ($r=.34, p<.01$) and with PLwDs with more severe cognitive symptoms ($r=.30, p<.01$) had significantly higher use of active management care strategies, relative to caregivers not assisting with those tasks. In contrast, caregivers providing care for PLwDs with greater BPSD burden ($r=.34, p<.001$) and particularly challenging symptoms of aggression ($t=-4.0, p<.001$), agitation ($t=-3.4, p<.001$), irritability ($t=-2.4, p<.05$) and hallucinations ($t=-2.3, p<.05$) reported more use of criticism as a management strategy.

Conclusion: Mixed-methods assessment of care challenges provides a more nuanced understanding of how caregivers manage care stressors. Active management or other straightforward assistive approaches may be required when the severity of dementia increases, yet critical strategies seem to emerge with greater severity of BPSD. Encouragement strategies, on the other hand, were independent of any care challenges and may be used to support the PLwD, not address an underlying symptom. As crit-

icism tends to be associated with more negative care outcomes (burden, potentially harmful behavior), intervention approaches may help caregivers identify more adaptive responses to prepare for stressful challenges such as BPSD.