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The role of symptom presentation in dementia caregiver burden and self-esteem

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Dementia caregiving can incur both negative (such as burden) and positive (such as higher self-esteem) reactions. Burden is a predictor of caregiver morbidity and mortality, while self-esteem reduces anxiety and promotes well-being. The comparative impact of caring for varying behavioural problems, cognitive impairments, declines in daily living abilities (ADL) and of care-recipient depression on caregiver reaction is unclear. This study asked: does the care-recipient's behaviour, cognition, ADL, or mood contribute most to caregiver burden and self-esteem? Caregivers were recruited through referral as part of a larger provincial research program in B.C., Canada. Caregivers provided 3+ hours of care over 3 days/week and care-recipients were on cholinesterase therapy for 6-months. 906 caregivers (n=613 spouses) were interviewed in-person and cared for persons with Alzheimer's (58.9%), vascular (11.6%), Lewy body (5.4%), Parkinson's (1.2%) and other/mixed dementia (22.9%). 81% of care-recipients were community-dwelling. Stepwise multiple regression models revealed greater ADL dependence and care-recipient depression ($P < 0.005$, $R^2 = 0.10$) predicted burden. Only care-recipient depression directly predicted self-esteem ($P = 0.013$, $R^2 = 0.02$). Providing care for ADL and care-recipient mood contribute to burden; however, managing care-recipients' mood had the greatest impact on caregivers' positive reactions. Care-recipient mood significantly influences caregiver reactions; recent frailty literature suggests this may result from the inability to manage depression and/or find meaning in new caring-relationship roles. While reactions to caregiving are diverse, healthcare providers should aim to increase satisfaction of caring and provide clinical and community support for managing depression in care-recipients. Findings highlight the clinical importance of mood symptoms to both patient outcomes and caregiver well-being.

Biography

Kaitlyn P Roland completed her PhD at the University of British Columbia in 2012 (Canadian Institutes for Health Research and Parkinson Society Canada funded). Her PhD work helped understand Parkinson-related changes to daily muscle activity (electromyography), and consequences for physical function and frailty, especially in females. She is currently completing postdoctoral studies at the University of Victoria's Centre on Aging (Canadian Institutes for Health Research and Michael Smith Foundation for Health Research funded). Her most recent work has focused on categorizing the physical, cognitive and neuropsychiatric symptoms that influence care needs and well-being in dementia caregivers across disease groups (i.e., Alzheimer's disease, Dementia with Lewy Bodies and especially Parkinson's disease related Dementia). Overall, her research program aims to support independent living, and reduce distress and healthcare utilization, which may have significant public health implications.

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