

Factors Associated With Participation Restriction in Mid-Life Caregivers and Implications for OT Intervention

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PURPOSE: Mid-life caregivers comprise roughly 50% of the 43.5 million unpaid caregivers providing care to a friend or family member in the US (AARP/NAC, 2020); maintaining their health and preventing future disability is critical to supporting our aging population. Mid-life caregivers (aged 45-64) are vulnerable to poor health and disability in later life due to competing demands associated with mid-life, including work, social, financial, and familial responsibilities (Gomez-Bernal et al., 2019). When caregivers experience restricted participation in meaningful activity, quality of care for care recipients decreases and caregiver burden increases (Beach & Schulz, 2017), contributing to chronic poor health and associated disability. Intervening to prevent participation restrictions among mid-life caregivers requires clear understanding of the complex set of factors contributing to restricted participation in meaningful social and community activity. We used the International Classification of Functioning, Disability, and Health as a framework to understand how caregiving dyad personal factors, caregiving contextual factors, and environmental factors are related to participation restriction in mid-life caregivers.

DESIGN: This was a cross-sectional study using data from the 2015 cohort of the National Health and Aging Trends Study (NHATS) and the companion National Study of Caregiving (NSOC). We included 1,019 mid-life caregivers of older adults. Our independent variables were caregiver personal factors (health, depression/anxiety, gender, children under 18, and employment status), care recipient factors (health, depression/anxiety, and dementia status), caregiving contextual demands (number of days per month, positive and negative aspects of caregiving, relationship to care recipient, and living with care recipient), and environmental factors (respite use, caregiver training, and social support). Our dependent variable was whether or not caregivers have restricted participation in meaningful activity.

METHODS: We used multivariate logistic regression to understand the impact of our predictors on participation restriction. To further investigate the contribution of individual items from the positive and negative aspects of caregiving scales to participation restriction, we used these items as predictors in a second multivariate logistic regression.

RESULTS: More caregiving days per month (OR = 1.04, $p = .05$) and higher negative aspects of caregiving (OR = 1.42, $p < .001$) were risk factors for participation restriction, while higher positive aspects of caregiving (OR = 0.85, $p = .03$), using respite (OR = 0.36, $p < .001$), female gender (OR = 0.48, $p = .01$), and caregiver relationship spouse vs. child (0.51, $p < .03$) were protective factors. When we examined individual items from the positive and negative aspects of caregiving scales, we found that frequent changes to the caregiving routine (OR = 1.94, $p < .001$) and having no time for self (OR = 1.85, $p < .001$) increased risk for participation restriction, while feeling closer to the care recipient (OR = 0.51, $p < .001$) was protective.

CONCLUSION: We identified that daughters providing care to a parent are most at risk for participation restriction. Aiding caregivers to reconfigure and stabilize habits and routines, improve communication and closeness with care recipient, and use respite services are interventions that can allow caregivers to engage in revitalizing, meaningful activity. Impact Statement. Mid-life caregivers are at a critical juncture for developing disease and disability; participation in meaningful activity is key to prevention efforts. Our research identified occupational therapist-driven intervention targets to improve participation in mid-life caregivers

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