

Caregiving Involvement and Self-Care of Dementia Caregivers

Subjects: Behavioral Sciences

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Caregivers often prioritize the needs of the care recipient and neglect their own health needs. It is imperative to understand the factors related to their self-care practices and engagement in self-care activities.

Keywords: caregiving ; Alzheimer

1. Caregiving Involvement and Self-Care of Dementia Caregivers

1.1. Dementia Caregivers and Health

According to the Alzheimer's Association, about 6.7 million Americans are living with dementia, and this number is projected to more than double by 2060 with the growth of the aging population ^[1]. Individuals with dementia rely heavily on the care provided by family caregivers (e.g., spouse, adult child), with 30% of individuals with dementia receiving care from three or more family caregivers ^[2]. The current study refers to family caregivers (e.g., adult child, spouse) of individuals with dementia as "dementia caregivers", who provide unpaid care.

Due to the high caregiving demands, dementia caregivers report having worse physical (e.g., chronic conditions) and psychological health compared to the caregivers of patients with other conditions. In fact, 74% of dementia caregivers report that they are concerned about their own health ^[3]. Dementia caregivers are at a higher risk for developing chronic health conditions (e.g., heart diseases, diabetes, stroke) compared to non-dementia caregivers and the non-caregiving population ^{[3][4]}. According to the Stress Process Model and other empirical research, dementia caregivers face stressors from heavy caregiving tasks and demands, a fact which is related to a high prevalence of anxiety, depression, cognitive decline, burden, caregiver-related stress and strain, and social isolation ^{[5][6][7][8]}. The Stress Process Model emphasizes the importance for interventions to address dementia caregivers' stressors from caregiving and to promote self-care ^[7]. Unfortunately, caregivers often place the needs of the care recipient above their own, despite their own high prevalence of poor health. Thus, it is imperative to identify strategies that support dementia caregivers in prioritizing their own health and engaging in behaviors that promote their physical and psychological well-being. The present study examined the extent to which dementia caregivers engaged in self-care activities, how this varied based on the caregivers' characteristics, and whether self-care engagement mediated the relationship between social support and caregiver outcomes.

1.2. Self-Care

Engaging in self-care activities enables dementia caregivers to maintain their own health while effectively caring for their loved ones. Self-care is conceptualized by Orem's self-care theory as activities that individuals engage in to improve their physical and psychological health and well-being ^[9]. The Theory of Self-Management Behavior complements this idea by emphasizing the multifaceted nature of individuals' actions to manage health conditions effectively ^[10]. Past studies have identified caregivers' self-care needs to include health-promoting behaviors (e.g., sleep), leisure activities for stress management (e.g., reading), and resources for their own physical care (e.g., medication management, regular doctor visits) ^{[11][12][13]}. Although these studies investigated the components of self-care, they did not assess the actual level of engagement in self-care activities among dementia caregivers. The current study builds on the Caregiver Health Model, which emphasizes caregiver-health-promoting behavior as one of the crucial determinants of caregivers' health ^[14]. To better understand dementia caregivers' self-care profile and practices, the current study examined the extent to which dementia caregivers engage in self-care activities and the extent to which factors such as a caregiver's background characteristics, level of involvement in caregiving, and social support influence their engagement in self-care.

1.3. Caregiving Involvement and Self-Care

Dementia caregivers provide more intense care compared to caregivers of older adults with other conditions [8]. Dementia caregiving involvement includes the following: assisting with daily living activities (ADL: e.g., bathing, feeding) or with instrumental activities of daily living (IADL: e.g., transportation, chores, managing financial affairs); managing behavioral symptoms (e.g., agitation, nighttime disturbance) or other health conditions and comorbidities of the care recipients (e.g., diabetes, cancer); arranging formal services (e.g., paid in-home care); and providing overall management and emotional support. Moreover, caregiving demands are time-intensive, with dramatic increases in caregiving hours as dementia progresses [15].

Studies have shown that caregiver involvement (e.g., time spent caregiving, use of formal services) varies based on age, gender, race/ethnicity, caregiver relationship, and employment status. Dementia caregivers are more likely to be older adults, over 65 years or older, women, and the adult, child, or spouse of the individual with dementia who report spending more caregiving time compared to their counterparts [1][16]. People who are not working are more likely to use formal support services [17]. Compared to White, Non-Hispanic caregivers, African American, Hispanic, and Asian American dementia caregivers report providing more care in terms of the number of hours per week, using less formal help and services, and having more caregiving demands. Caregiving involvement may affect a caregiver's ability to engage in self-care activities [18]. The current study expands the literature by investigating whether self-care activity varies according to a caregiver's background characteristics.

The level of involvement in caregiving can also cause the caregiver to prioritize their loved one's needs over their own, which results in worsened health over time for the caregiver and increased risks of chronic disease, morbidity, and mortality [8][19][20]. Despite the potentially adverse relationship between caregiving involvement and caregivers' health, few studies have investigated whether caregiver involvement (e.g., ADL/IADL help and formal use of care and services) is related to self-care activity engagement [18].

1.4. Social Support, Self-Care, and Caregiving Outcome

Available social support has been shown to promote health and well-being in dementia caregivers [21][22][23][24]. Further, both observational and intervention studies have shown that social support (e.g., social interactions, received support, satisfaction with support) from family and friends is positively related to caregivers' engagement in self-care behaviors such as physical activity and sleep [21][22]. In addition, social intervention studies aimed at increasing health-promoting behaviors have shown improvements in caregiving outcomes such as burden [23][24]. However, to date, these interventions often focus solely on health behaviors rather than the holistic concept of self-care that consists of both physical and behavioral activities. Moreover, studies have not tested self-care as a mechanism in the relationship between social support and caregiving outcomes, despite evident associations between these factors. The present study addresses these gaps by comprehensively assessing self-care activities and including activities such as physical health check-ups, restorative activities, and sleep. To our knowledge, the current study is also the first to examine self-care as a mediator in the relationship between social support and caregiving outcomes.

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