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The Science of Caregiver Health

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As more people are living longer with chronic conditions, the management of chronic illness is shifting from formal healthcare providers and settings to individuals, their families, and the communities in which they live. In 2009, approximately 30% of U.S. households (an estimated 36.5 million) identified one person who had served as an unpaid caregiver (National Alliance for Caregiving, in collaboration with AARP, 2009). There is increasing evidence that the responsibilities of caring for family members and friends can have a significant negative impact on the mental and physical health of informal caregivers, and that the decreased health status of the caregiver can translate to negative health outcomes in the care recipient. More research is needed on caregiver health and caregiver interventions because of the reciprocal impact on a large part of the population.

Stress, depression, and insomnia are cited as the most frequent, significant negative influences on caregiver health. Independent risk factors for poor physical health in caregivers include older age, lower income and education, and cohabitating with the care recipient (which can affect healthy sleep and eating habits). Younger caregivers and spouses report better physical health but higher levels of depression and caregiver burden in comparison with older caregivers. Estimates of the psychosocial and economic impact of providing care vary, with a 2009 survey finding that approximately 70% of caregivers were employed; 67% of these working caregivers adjusted their work schedules to accommodate caregiving duties, and 20% took leaves of absence to perform their caregiving duties (National Alliance for Caregiving, AARP, 2009). Hence, caregiver burden can lead to loss of income, benefits, job security, and career opportunities.

Factors affecting caregiver physical health include muscle strain and musculoskeletal injury from caregiving activities, and neglect of personal health-related activities, such as diet and physical exercise. Half of caregivers report living with at least one chronic condition, and approximately the same percentage report that their declining health affects their caregiving abilities.

The role of the caregiver varies, depending on the care recipient's age and illness. Managing complex, chronic conditions in children affects the entire family and becomes an integral part of family life. Major factors influencing family management in this circumstance

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include the presence of support networks, and specialized healthcare and education resources (Knafl et al., 2013).

Most caregivers of young and middle-aged adults are spouses of similar age who may experience severe disruption in their professional, family, and social lives. For example, caregivers of adult cancer patients may feel a lack of choice in their caregiving role that can have psychological repercussions (Longacre, Ross, & Fang, 2013).

Among older adults, the negative health impact of dementia caregiving has been studied extensively. These effects include an increased risk for depression, fatigue, sleep problems, hypertension, and, in extreme cases, death (National Alliance for Caregiving, AARP, 2009). Current practices keep dementia patients at home as long as possible before the transition to institutional residential care, with unpaid caregivers—primarily family members—shouldering the burden of care. A decline in caregiver health associated with dementia caregiving burden can lead to earlier placement of the care recipient in long-term institutional care.

The impact of the care provider–recipient interaction has been noted across a wide range of conditions and includes the negative influence of poor caregiver mental health on patient outcomes. In the transition from institutional to home care, informal caregivers are vulnerable to high levels of stress from feelings of inadequate knowledge about the disease or condition and resources for providing care, and lack of confidence and skills training in conducting post-discharge care. More research could improve coordination of care and caregiver education and preparation for home care responsibilities.

Caregivers from diverse populations may face additional barriers associated with implementation of interventions, such as poor knowledge of services, mistrust of healthcare systems, and literacy and language challenges. Hence, sensitivity to language, cultural, and social differences is an important factor in the development and delivery of effective caregiver interventions.

Hispanic and African American caregivers may see their efforts less as a burden and more as familial or societal fulfillment. Similarly, filial responsibility creates a natural and expected caregiving role for children of Chinese American dementia patients (Sun, Ong, & Burnette, 2012). However, cultural stigma around dementia and related behaviors can contribute to caregiver stress, due to shame and loss of social networks. Female Chinese American caregivers may experience additional burden related to intergenerational issues associated with Western acculturation.

Several effective interventions have been developed that improve informal caregiver knowledge, self-efficacy, physical health, and coping, and reduce burden, distress, anxiety, and depression. These beneficial outcomes are similar across many conditions such as dementia, cancer, stroke, and heart failure, indicating the potential for standard interventions that can be tailored to specific conditions and cultural backgrounds.

Interventions that target caregiver strain (i.e., time and effort to conduct disease-related caregiving tasks) and psychosocial health could also contribute to positive outcomes in care recipients' health and quality of life. Individual interventions for caregivers of older adults are more effective in improving caregiver well-being, whereas group interventions for caregivers of older adults yield better outcomes in developing supportive networks and improving care recipient symptoms (Sorensen, Pinquart, & Duberstein, 2002).

Despite the development of promising interventions to improve caregiver health, few effective interventions have undergone wide-scale implementation. Several interventions have been designed for telephone or face-to-face delivery in clinical or home settings. Some of these interventions have also been tested and validated for delivery by the Internet, opening the door for dissemination with other technologies, such as Skype and WebEx. However, sustainability requires adaptation to the rapid pace of change in technologies.

Several interventions have been implemented by nonresearchers or outside of the original research setting, with positive outcomes similar to the original research results. Nevertheless, implementation outside of the research setting presents challenges, including issues with completion of prescribed, multiple sessions and lengthy initial assessments. Practical concerns such as the number and intensity of sessions should be considered in future research; some interventions have yielded better overall outcomes with fewer sessions (Northouse, Katapodi, Song, Zhang, & Mood, 2010).

Because nursing professionals have had a long-term focus on improving the health and quality of life of caregivers, the nursing and nursing science communities are poised to design, test, and implement innovative caregiver health interventions in clinical and community settings.

Limitations of current research include the prevalence of cross-sectional studies and use of convenience samples, which often consist of more distressed, self-selected caregivers or highly motivated participants with adequate health status. Future research should emphasize the use of more longitudinal studies that track change over time, and more representative cohorts of the caregiver population.

Application of a variety of tools for measuring caregiver health complicates interstudy comparisons and meta-analyses. The use of standardized assessment tools, methods, and common data elements would allow more rigorous comparison of studies, facilitate the assembly of larger datasets, and bolster conclusions from studies of caregiver outcomes. Studies based on a common theoretical framework are also amenable to comparison, potentially allowing the development of similar interventions.

Caregiver health has a significant impact on a large part of our population, including the caregivers themselves and the care recipients. Further investigation is needed to identify the predictors of ill health among caregivers and strategies to attenuate those factors. The development and wide-scale dissemination of caregiver interventions will serve the dual purpose of improving the well-being of those providing care and advancing the health of those who need care to manage their chronic conditions.

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