

Care Demands and Well-Being of Primary and Secondary Non-Spousal Caregivers of Aging Adults

BACKGROUND

Informal caregivers are friends and family who provide unpaid, long- or short-term care to a person with disease or disability. It is common for multiple people in an aging adult's support network to share caregiving responsibilities. Usually, a "primary" caregiver assumes the greatest responsibility for care, while "secondary" caregivers provide supportive or supplementary care to the primary caregiver or care recipient. Relationship type is a predictor of who becomes the primary caregiver. Spouses are most often primary caregivers, followed by adult daughters. Friends are more likely to take on secondary roles but may become primary caregivers in the absence of family, or in emergencies.

Caregivers' experiences and well-being outcomes may vary based on primary caregiver status and relationship type. Yet research and intervention focus primarily on primary, spousal caregivers. The goal of this research was to characterize the care demands and well-being of primary and secondary caregivers of aging parents, other family, and friends.

STUDY METHOD

Measures. Analyses included 912 non-spousal caregivers of non-institutionalized recipients aged 50 and older. Data came from the National Alliance for Caregiving and American Association for Retired Persons' (AARP) Caregiving in the United States study. All variables were based on self-report. The primary caregiver was

identified by having respondents name the person who provided the most unpaid care to the care recipient. Care recipient relationship type was re-categorized for analyses as parent, other family, and friend. Care demands included average hours of care provision per week, duration of care provision in years, and the total number of activities of daily living (ADLs – e.g., bathing, dressing, feeding) and instrumental activities of daily living (IADLs – e.g., medication management, finance management) the caregiver assisted with. Well-being outcomes included emotional stress, physical strain, financial strain, self-rated health, and perceived impact on health. Emotional stress, physical strain, and financial strain were assessed with 5-points scales (excellent, very good, good, fair, or poor) ranging from "not at all stressful/a strain" to "very stressful/strenuous". Self-rated health was also rated on a 5-point scale ranging from "poor" to "excellent". Finally, caregivers' perceived impact of caregiving on health was dichotomized as "made it better or not affected" or "made it worse".

Analytic method. T-tests and chi-square tests of independence compared the demographics and care demands of primary and secondary caregivers. A two (primary, secondary) by three (parents, other family, friend) ANOVA assessed the independent and interactive effects of caregiving status and relationship type on stress, strain, and self-rated health. A binary logistic regression model examined the effects of primary caregiver status and relationship type on perceived impact of caregiving on health. Adjusted analyses considered how care demands (ADL/IADL

assistance, hours of care, duration of care) influenced these potential relationships.

FINDINGS

Primary caregivers provided more intense care for longer durations than secondary caregivers. Of all relationship types, caregivers of parents provided the greatest duration and intensity of care. Friends and non-parental family did not differ in intensity or duration of care. Primary caregivers of friends provided much more ADL/IADL assistance than secondary caregivers of friends.

Secondary caregivers reported as much emotional strain as primary caregivers and this effect was independent of the intensity of the care provided. Primary caregivers reported greater financial strain than secondary caregivers. And though their self-rated health did not differ, primary caregivers were more likely to report that caregiving had made their health worse. Primary caregivers of friends experienced greater physical strain than secondary caregivers of friends. Adjusted analyses indicated this was partially explained by their higher ADL and IADL assistance.

POLICY IMPLICATIONS

Non-spousal primary and secondary caregivers are commonly excluded from basic and applied research and have limited support from current policies and programs. However, our findings demonstrate the universal emotional stress of witnessing the suffering of a loved one and highlight the need for policies and programs to help secondary caregivers navigate their role.

Primary caregivers' greater financial strain may arise from ADL and IADL assistance that requires

financial resources (e.g. grocery shopping, paying bills) or from disruptions to occupational responsibilities (e.g. taking leave, reducing hours, forfeiting benefits, shrinking paychecks). Including financial health as a topic in psychoeducational interventions may be a necessary action to limit the financial strain experienced by primary caregivers.

Friends in this sample were primary caregivers at higher rates than previously reported in the literature. When assuming primary roles (instead of secondary ones), friends provided more ADL and IADL assistance, which contributed to their greater physical strain. These concerns promote the idea of having clinicians query their clients about the types and levels of assistance they might be providing to a friend and suggest potential resources and support. Future policies should focus on affording privileges accessible to family caregivers to caregivers of friends (e.g. ability to make health care decisions; absence of formal power of attorney designation).

Original Article

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