

# Studying long-term caregiver health outcomes with methodologic rigor

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*Neurology*® 2015;84:1292–1293

In an insightful critique of the stroke caregiving literature, Gaugler<sup>1</sup> observed that over-reliance on small, clinic-based samples and cross-sectional designs, short time periods for follow-up assessments, and few studies beyond the initial caregiving year compromise our current understanding of caregiver adjustment. We could achieve a more complete picture of caregiver adjustment, essential for informed policies and strategic services, with more rigorous methodologic designs and stronger theoretical models to guide our understanding of relationships found among important variables and aspects of adjustment.

In this issue of *Neurology*®, the research by Haley et al.<sup>2</sup> meets the challenge for methodologic rigor by obtaining an epidemiologically derived sample of stroke survivor and caregiver dyads, following them for 36 months poststroke, and comparing them to a matched noncaregiving group. They used advanced statistical analyses to elucidate differences between caregiving and noncaregiving samples. As a result, Haley et al. substantially advance our understanding of poststroke care and its influence on caregiver health outcomes.

Previous studies of stroke caregivers began after the stroke had occurred.<sup>3</sup> Thus, this work cannot determine whether the caregiving situation or issues that existed prior to the caregiver role primarily influence negative caregiver outcomes. To address this limitation, we have 2 options: (1) identify possible future caregivers in the population and follow them until a family member has a stroke to identify prestroke to poststroke changes in health outcomes or (2) compare a sample of caregivers to a matched noncaregiving sample. The first option requires a substantial investment of resources and time to obtain a large number of stroke events and sample of stroke caregivers. Haley et al. utilized the second option by creating a comparison group of noncaregivers from the Caring for Adults Recovering from the Effects of Stroke (CARES) project of the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study.<sup>4</sup> They matched the sample on stroke survivor (age, sex, race, and relationship with a potential caregiver) and caregiver (sex, race, age  $\pm$  5 years, coresidence, and relationship) characteristics, and

they excluded individuals providing care to any family member with a disability. Baseline comparison of the caregiving and noncaregiving groups demonstrates similarities in characteristics but differences in health status (e.g., hypertension rates). Findings suggest that stroke caregivers are also at risk for poor health outcomes (like stroke) and may benefit from primary prevention strategies.

The use of a caregiver sample derived from an epidemiologic study designed to understand the risk factors and incidence of stroke enhances the generalizability of the Haley et al. study.<sup>2,4</sup> Consequently, their caregiving sample is more representative of the general population than caregiver studies using convenience, clinic-based samples (e.g., recruited from a rehabilitation center). They then used 2 advanced statistical methods to (1) examine changes in caregiver outcomes over time compared to a noncaregiving sample (i.e., mixed effects modeling) and (2) quantify the magnitude of differences between caregiving and noncaregiving groups (i.e., effect size estimates). Using these approaches, Haley et al.<sup>2</sup> demonstrate medium-sized differences between caregivers and noncaregivers in depression, mental component score of the Short Form–36, and leisure time satisfaction; these differences remained through 22, 31, and 36 months poststroke, respectively. Unlike the majority of prior studies, this study examines caregiver adjustment during the months following return to the community, where caregivers are learning the ropes and then adjusting to long-term caregiving poststroke.<sup>5</sup> Starting data collection 9 months poststroke has the potential of missing initial caregiving stress related to the early period of adjusting to their new caregiving role.

The Haley et al.<sup>2</sup> study does not necessarily help us anticipate who among caregivers are at risk for maladjustment over time, or how certain characteristics may facilitate adjustment for some and not for others. But the pattern observed over the 3-year period in caregiver depression, life satisfaction, and leisure time satisfaction raises intriguing theoretical possibilities for further examination. Restrictions in social and leisure activities are associated with increased risk of depression among the chronically ill and their caregivers.<sup>6</sup> Participation in

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rewarding personal and social leisure activities may provide caregivers with opportunities to experience positive emotions that are essential to personal resilience.<sup>7</sup> For example, caregivers to traumatically disabled family members, who are able to maintain positive emotions, may retain more resilience in their caregiving role.<sup>8</sup> Cognitive behavioral interventions designed to reduce stroke caregiver depression can also promote their leisure time satisfaction.<sup>9</sup> Finding ways to help caregivers participate in social and leisure activities may promote stroke caregiver well-being and could, in turn, facilitate stroke survivor adjustment.<sup>10</sup>

Haley et al. have made an important contribution to the stroke caregiving field by addressing common methodologic limitations<sup>1</sup> in a way that should be emulated in future studies of caregivers of stroke and other neurologic disorders (e.g., traumatic brain injury). Beginning longitudinal studies of stroke caregivers from an earlier time point (e.g., within the first month poststroke) and following them for more than 1 year will inform our understanding of caregivers' initial and long-term adjustment to the caregiving role and may inform the timing of specific types of caregiver supports and services.<sup>5</sup> Future work should attempt to characterize caregivers who do and do not adjust to the caregiving role over time. These findings can assist health and social care systems to target interventions to support those at increased risk for negative outcomes as they provide care and assistance. These findings also highlight the importance of considering caregivers' engagement in leisure time activities and their link to caregiver adjustment over time. Future interventions for family caregivers poststroke should consider the complex implications of providing care including the influence it has on caregivers' everyday life and participation in valued activities.

## STUDY FUNDING

No targeted funding reported.

## DISCLOSURE

The authors report no disclosures relevant to the manuscript. Go to [Neurology.org](http://Neurology.org) for full disclosures.

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