FROM THE EDITORS’ DESK

Caregiver Factors in Stroke: Are They the Missing Piece of the Puzzle?

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Abstract

Stroke is a major global health problem and a leading cause of long-term disability. As health care professionals working with these patients, we work closely with their caregivers because we recognize the crucial role they play in our patients’ recovery. Increasingly, the effect of patient factors on caregiver outcomes is being studied. However, the effect of the reverse relationship of caregiver factors on patient outcomes has received much less attention, although there is evidence that social and family support can positively (and sometimes negatively) affect patient outcomes. A better understanding of this relationship may have implications for rehabilitation research, professional practice, and policy directions in terms of resource allocation.

Archives of Physical Medicine and Rehabilitation 2016;97:1223-5
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The importance of the role of caregivers in stroke and other chronic diseases is increasingly being recognized and studied.1-6 Caregivers play a crucial role in enabling patients to return and remain in the community, and provide much needed social support to patients.7 At present, most work has focused on the impact of caregiving and patient factors on the caregiver. Far less attention has been devoted to the impact of caregiver factors on the patient’s recovery. Does it matter who provides the care? Is more caregiving better? What makes the difference, if any? How and why is it different? As governments adapt health care–related policies to meet growing health care demands, the answers to these questions may provide us with a better appreciation of the impact of these changes on stroke recovery and on our future practice.

Studies on the relationship of caregiver factors and outcomes in stroke survivors are limited, with somewhat mixed findings. Intuitively, caregiver availability and their involvement in care could allow for more informal practice of exercises to occur and therefore, contribute to better patient recovery.8 Positive associations have been reported in several studies including one focused on upper limb rehabilitation in the subacute phase of stroke recovery,9 and another in patients beyond the first 6 months of stroke.10 However, the findings from studies done in Singapore were to the contrary. In a study11 of 2810 stroke patients undergoing subacute inpatient rehabilitation, having a caregiver was actually associated with poorer rehabilitation effectiveness (change in Barthel Index score divided by the maximum potential change) and efficiency (change in Barthel Index score divided by number of days between the first and last scoring). This association was maintained even after accounting for confounding factors such as patient demographics, type of stroke, and functional level on admission. In a separate study,12 patients were followed up from admission to an inpatient rehabilitation unit until 1 year after discharge. Surprisingly, having a caregiver was associated with less participation in supervised (formal) therapy in the community. This study, however, did not directly examine the impact of having a caregiver on patient participation in unsupervised therapy, or on actual functional outcome as did the other 3 studies.9-11 Nevertheless, none of these 4 studies9-12 evaluated the effect of caregiver availability on other important outcomes such as the ability for the patient to return home, and none of these studies took place at the acute phase of recovery.

What could account for the contradictory findings? There are several possibilities. First, these studies had methodological differences and limitations. Study designs were different: the ones with positive results were intervention based,9,10 while the other 2 were observational studies.11,12 Studies that found a negative association had larger study samples (281011 and 21512 vs 509 and 5110), which allowed for greater accounting of confounding factors such as patient demographics and baseline functional level. However, because of the nature of the study design and the

Disclosures: none.
population sampled, there was considerable disparity between patients with and without caregivers in these studies (<6% without\textsuperscript{11,12}). Therefore, these negative associations should be interpreted with caution.

Second, apart from study design differences, there could also have been an interplay of other caregiver and noncaregiver factors that were not included and considered in these 4 studies.\textsuperscript{9,12} For example, it is possible that who the caregiver is makes a difference. Results from work done on patients with heart failure suggest that the identity of the caregiver does matter. Spousal caregiver—patient dyads (compared with other family caregiver—patient dyads) have been found to report better care partnership and communication, which contributed to better patient outcomes in terms of self-care.\textsuperscript{13} Similar studies in the stroke population appear to be lacking. Therefore, at present, we are exploring this area of research. Preliminary findings from our analysis concur with those of Seber and Riegel.\textsuperscript{13} We found that the degree of closeness in relationships may affect patient outcomes: the closer the relationship (ie, spouse vs children/parent vs foreign domestic workers [FDWs]), the better the outcomes in terms of rehabilitation effectiveness and efficiency.\textsuperscript{14}

FDWs are unique to certain parts of the world such as Asia, the Middle East, and some parts of Europe.\textsuperscript{4,6,15-19} The services they provide differ from those of formal home-based services in that they are unskilled, live-in foreign workers employed on a full-time basis to provide help in a broad range of tasks including care for the elderly, care for children, domestic duties, or some combination of these.\textsuperscript{1} The impact of their care on patient outcomes compared with that of family caregivers is an important area of study given the current issues of population ageing and declining fecundity rates in these countries.\textsuperscript{6} Their presence is becoming increasingly common in our society.\textsuperscript{14} As a matter of fact, FDWs constitute more than 40% of the caregivers of stroke survivors in Singapore.\textsuperscript{14}

Aside from caregiver availability and identity, there is also the possible factor of caregiver numbers—is more better? From the patient’s perspective, having more available caregivers may provide a greater sense of perceived support, which has been associated with better patient recovery.\textsuperscript{20} However, that may not be the case. In a 2-year longitudinal study\textsuperscript{11} of war veteran stroke survivors, a greater number of caregivers and a greater amount of care provided were associated with poorer recovery in a multi-variable linear model. Nevertheless, this result needs to be interpreted with caution because the authors did not account for baseline function or stroke severity. Therefore, it is possible that those who required more help and more caregivers were those who were poorer functioning, which could explain their slower recovery. Yet, preliminary findings from our current study\textsuperscript{14} suggest a similar result—more caregivers were associated with poorer outcomes in terms of rehabilitation effectiveness and efficiency, even after adjusting for various confounding factors including admission functional level. Thus, further inquiry of such patient-caregiver relationships is still needed.

Similarly, the interaction between ethnicity and caregiver factors is another area that needs to be further examined. Caregivers from different ethnic groups are known to provide care differently and have different filial obligation beliefs.\textsuperscript{22} In our prior study\textsuperscript{14} and that of Hinojosa et al,\textsuperscript{21} ethnicity was a significant confounder of the caregiver factor—patient outcome relationship. Its possible role as an effect modifier was not explored, although there has been some evidence that ethnicity modifies the association between the level of support received and the progression of disability.\textsuperscript{23} The authors of that study\textsuperscript{23} suggested that this could be due to differences in what is deemed normal and accepted in terms of providing and accepting support, as well as different degrees in filial piety in different cultures. Furthermore, the concept of illness and illness behavior also differs between cultures.\textsuperscript{24-27} This may have a profound effect on the way patients and their caregivers view what is essential for recovery, and therefore, their response to the need for rehabilitation.

In addition, the severity of disease and the phase of recovery should also be considered when studying the relationship of caregiver factors and patient outcomes. The 4 studies\textsuperscript{9,12} presented in the second paragraph of this editorial were heterogeneous in terms of these 2 factors. A study by Glass et al\textsuperscript{20} illustrated the interaction between time, self-perceived level of social support, and stroke severity, but no studies to our knowledge have looked at actual caregiver factors.

In conclusion, the effect of caregiver factors on patient recovery is an understudied area, even though there is evidence that social and family support positively (and sometimes negatively) affects patient outcomes.\textsuperscript{5,20,23,28} A better understanding of this relationship has implications for rehabilitation research, professional practice, and policy directions. Perhaps future research on stroke outcomes needs to include and examine more patient-caregiver dyads, rather than patients alone. In line with this, as health care professionals, it may also be important for us to take into account caregiver factors and cultural issues when managing our patients. And as we gain more understanding through research, resources should be allocated to support the persons providing care for our patients. But as a first step, more well-designed studies with a greater homogeneity of outcome measures are needed to understand how and what caregiver factors affect patient outcomes.

Keywords
Caregivers; Rehabilitation

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References

List of abbreviations:
FDW foreign domestic worker