

ADVANCING STROKE RECOVERY THROUGH SOCIAL AND EMOTIONAL SUPPORT



American Stroke Association Advisory Committee

Post-Stroke Subcommittee:

D. Lombardi Hill, Lombardi Hill Consulting Group; M. Amatangelo, Brigham and Women's Hospital; J. Prvu Bettger, Duke University; K. Collins, Collins Collaboration, LLC; B. Jackson, AARP and Stroke Survivor; E. Miller, University of Cincinnati; M. Nguyen, American Stroke Association, L. Sadwin, The Torbot Group; K. Wait, American Stroke Association;



FINANCIAL DISCLOSURES

Debbie Lombardi Hill, Lombardi Hill Consulting Group – None

Mary Amatangelo, Brigham and Women's Hospital – None

Janet Prvu Bettger, Duke University – None

Karen Collins, Collins Collaboration, LLC – None

Barry Jackson, AARP, Stroke Survivor – None

Elaine Miller, University of Cincinnati – None

Meredith Nguyen, American Stroke Association – None

L. Sadwin, The Torbot Group – None

Kristina Wait, American Stroke Association – None



BACKGROUND

Post-stroke disability often disrupts family roles and responsibilities. Role reversal, in combination with the disabilities, is emotionally taxing and physically fatiguing for both the stroke survivor and the family caregiver. Depression can result and when left undermanaged can lead to poor health outcomes.

Research has shown social support is an important factor in recovery, post-stroke and caregiver depression.^{1,2} Studies have indicated high levels of social support are associated with faster functional recovery and more extensive recovery in stroke survivors.³

Also, that social support is independently associated with the presence and severity of post stroke depression and that positive social interaction is a significant contributor to variance in initial post stroke depression.^{4,5}

¹T. Bakas, P. Clark, M. Kely-Hayes, R. King, et al. *Stroke*, 2014; 45: 00-00

²T A Glass, D B Matcher, M Belyes and J R Feussner. *Stroke*, 1993; 24: 64-70

³R. King, C. Ainsworth, M. Ronen, R. Hartke; *J Neurosci Nurs*, 2010; 42 (6): 302.311

⁴R. Hartke, R. King; *Topics in Stroke Rehabilitation*, 2002; 9 (1): 16-33

⁵R Kammeyer, J K Daggy, L Williams. *Stroke*. 2015; 46: A147



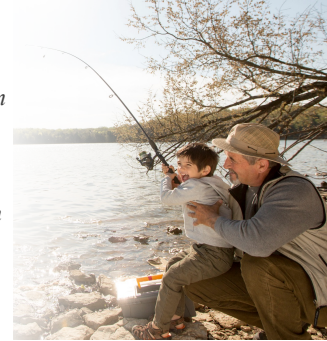
PURPOSE

The purpose of this critical review was to examine the research literature on the relationships of social support and coping strategies with health-related outcomes among stroke survivors and their family caregivers.



*"It's all overwhelming."
"How will I manage?"
"How can I remember all this?"
"There are too many decisions."
"It is so hard right now."
"I feel all alone."
"Who can I trust to help me do the right things?"*

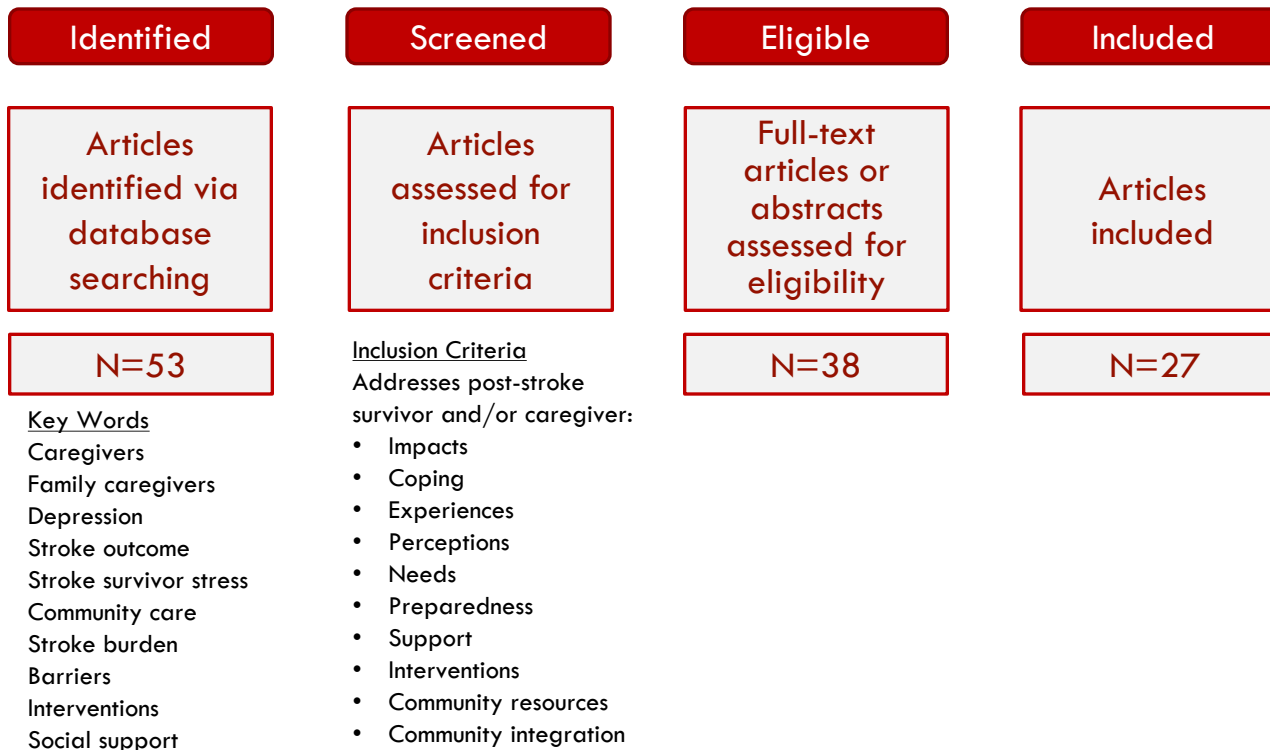
"Nothing has been the same since my stroke. It's like my whole world has been turned upside down. After 4 months I still have a lot of weakness on my left side. I'm in a foot brace and walk with a cane. I'm dealing with anger, anxiety, depression, comprehending, expressions and much more. I'm unable to return to work. I find it hard to motivate myself to wanting to do stuff. I'm wondering if things will get better....."





METHODS

Databases including PubMed, iMedPub, Medline Plus and AHA Journals were searched for articles published between 1996 and 2016. Key key terms were used and articles and/or abstracts were assessed to identify articles included.

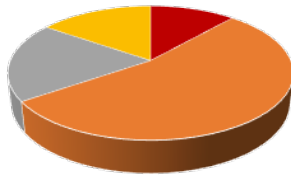




FINDINGS

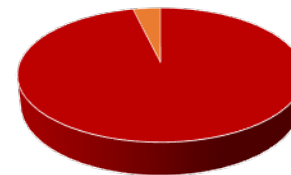
Twenty-seven articles identified by key terms related to stroke survivor and caregiver emotional and adjustment support needs, social support, depression and effective interventions, were included for review. The majority, 52%, were qualitative studies, 19% mixed (qualitative and quantitative) studies, 19% literature reviews and 10% quantitative studies. The articles were almost exclusively, 93%, found in peer-reviewed journals.

Research Type



■ Quantitative ■ Qualitative ■ Mixed ■ Lit Review

Journal Type



■ Peer-Reviewed ■ Professional, Not Peer Reviewed





RESULTS

Some specific findings include, but are not limited to, the following:

- There are significant differences across levels of social support¹
 - High levels of support associated with faster and more extensive recovery
- Having a small network size was independently associated with increased risk of incident stroke²
- Family caregivers rank emotional disturbances as their number one stressor³
- Positive social interaction was a **significant** contributor to variance in initial post stroke depression⁴
- Social support **was independently associated** with the presence and severity of post stroke depression⁴
- Early discharge to community rehab led to worse state of general health among caregivers even with a problem-solving approach⁵
 - Model of care focused on patient and too little on goal-setting for the caregiver
- In-person interventions not feasible for busy caregivers⁶
- Delivery of interventions via phone and Web may be beneficial approaches⁶

¹T A Glass, D B Matcher, M Belyes and J R Feussner. *Stroke*, 1993; 24: 64-70

²M. Nagayoshi, S. Everson-Rose, H. Iso, et al. *Stroke*, 2014; 45: 2868-2873

³W. Haley, J. Allen, J. Grant, O. Clay, et al; *Stroke* 2009; 40: 2129-2133)

⁴R Kammeyer, J K Daggy, L Williams. *Stroke*. 2015; 46: A147

⁵A. Meily, C. Heugten, M. Post, et al. *Patient Ed and Counseling*, 2005; 56: 257-267

⁶T. Bakas, P. Clark, M. Kelly-Hayes, et al, *Stroke*. E. 2014; 45:00-00



RESULTS

We found overwhelming evidence that attention to stroke survivor and caregiver social network can advance recovery and improve the health and well being of both stroke survivors and caregivers.

Knowledge gaps and focus on emotional and adjustment support needs are not being adequately met by community-based health services. This points to an important need for changes in practice to acclimate stroke survivors and their family caregivers to their new life roles, but also the need for more rigorous studies.



CONCLUSIONS

In addition to more research, there is a critical need for changes in facilitating transitions of care to meet the emotional and adjustment needs in the stroke population.

Emphasis on individual needs and providing information during transitions of care on managing stressors in the post-stroke journey is needed - especially information about community resources that offer opportunities to build and maintain social connections and enhance problem solving.

Current models of care focusing primarily on the stroke survivor, with little goal-setting for the caregiver, is a significant barrier to the overall health and well-being of both survivor and caregiver.

Encouraging health professionals to screen for social network presence and size and promoting support-seeking behavior may help advance recovery and improve the health and well being of stroke survivors and family caregivers.