Stroke Rehabilitation: Taking Care of the Caregiver

What We Know

› Worldwide, in 2012, strokes were responsible for 6.7 million deaths worldwide and were the second leading cause of death and a primary source of disability.\(^{33}\) In the United States, in 2013, 6.8 million people were living after having experienced a stroke\(^6,11\)
› In the United States there are 34.2 million unpaid, nonprofessional caregivers (e.g., family, friends) providing care to an adult over the age of 50. Nearly 1 in 10 of these caregivers is over the age of 75. 23% of the caregivers are providing more than 40 hours of care a week. These nonprofessional caregivers are often the primary caregiver for individuals who have had a stroke\(^{23}\)
› An individual who has experienced a stroke will typically move from having 24-hour medical care and an intensive therapy program to being at home with little or no professional support and the expectation that family or friends will provide any needed supportive care. These nonprofessional caregivers will often describe the experience of a transition to home as being difficult or traumatic\(^{34}\)

- Preparing caregivers (e.g., in using medical equipment, providing mouth care, feeding, managing medication) before the stroke survivor is discharged from the hospital helps prepare them to deal with the physical, emotional, and cognitive needs of the stroke survivor and improves the caregiver’s self-efficacy\(^{20,30}\)
› In recognition that excessive caregiver burden can affect not only stroke survivors but also the caregivers’ quality of life (QOL), increasing attention has been drawn to the needs of nonprofessional caregivers, or individuals who care for disabled individuals\(^1,2,10,12,13,17,18,21,26,27,31,32\)

- Because stroke often results in persistent functional and cognitive deficits, survivors often require comprehensive assistance from caregivers. Individuals who become caregivers may find their social lives, occupational and financial situations, and emotional health threatened by their new roles and responsibilities\(^2,9,10,26,27\)

– The majority of caregivers (62%) are nonprofessional caregivers (typically the spouse and other family members) who lack medical or nursing experience yet provide challenging physical care for stroke survivors who need day-to-day assistance with eating, bathing, dressing, ambulation, and transfer from one place to another (e.g., bedroom, bathroom, doctor’s appointments). Caregivers may also face the burden of handling their loved one’s financial and legal matters\(^10,27,31\)

- Because stroke is a sudden, unanticipated event, caregivers are thrust into their new roles with little preparation, training, or support. As a result, caregivers often face high levels of stress, burden, and feelings of helplessness and hopelessness\(^1,20,24,27,28,30\)

- The impact of stroke reaches beyond functional outcomes for affected clients. Caregivers report feeling particularly overwhelmed by emotional, cognitive, and behavioral changes that may persist after the stroke client regains physical functionality\(^12,13,26\)

- Stroke survivors typically need the most assistance during their first year of recovery; thus, caregivers often are most burdened during this time period\(^26,31\)
An early hospital discharge poststroke is associated with improved functional ability in clients but may result in increased caregiver burden. There are specific factors that can influence the success of care at home and ease the stress on the caregiver. These include the strength of the caregiver–client relationship, the caregiver’s understanding of and willingness to provide care, the caregiver’s preexisting health issues, pre-stroke roles and responsibilities, accessibility of the home, availability of informal support resources for the caregiver, financial resources, pre-stroke caregiver experiences, a sustained ability to provide care over the long term, and having strategies for self-care.

The ability of caregivers to adapt and cope with their caregiving role is important to both their own well-being and the well-being of the stroke survivor. The coping style of the caregiver (active or passive) is a predictor of increased/decreased QOL for the caregiver. An active coping style, or using problem solving and information gathering to deal with a stressful life event, is associated with positive outcomes for the caregiver. Passive coping, also referred to as avoidance or escape coping, is a negative predictor of caregiver QOL.

Formal interventions for caregivers often include structured courses on improving coping ability; assistance with daily tasks, including housekeeping, meal preparation, and grocery shopping; respite for the caregiver; and emotional support via telephone, the Internet, nurse-led support groups and/or nurse home visits, and psychological counseling.

Investigators who processed a systematic review found that psychosocial interventions alone often failed to reduce the burden on caregivers because the impact on the caregiver is physical, emotional, social, and financial.

For persons newly assuming the role and responsibilities of caregiver, the Internet has become a primary means of education and informal help and support.

Internet discussion groups, blogs, message boards, social networking sites, and educational websites have become widely used resources that provide avenues for caregivers to share their feelings, glean practical advice, and receive social support, which has been cited by caregivers as their greatest need.

There are various conceptual theories and models that are related to caregiver stress and stroke survivors and affect the interventions that are provided.

Family systems theory presumes that a change in any part of the family system alters the entire system. Therefore, the changes experienced by the stroke survivor have an impact on all the members of the family, especially the caregiver.

The stress and coping theory suggests that stressful events will trigger a coping process to try to restore balance. This theory also incorporates the concept of contextual factors (e.g., background, socioenvironmental factors, illness) that can affect coping processes and outcomes.

The psychoeducational model will combine providing information on stroke and caregiving while also taking a psychological approach to any survivor or caregiver stress.

Although caregivers face numerous challenges in providing care and assistance for stroke survivors, evidence shows that most caregivers are less likely than survivors to be depressed or to focus on the survivors’ functional deficits (e.g., limited mobility, difficulty with self-care, speech).

Stroke survivors often exhibit emotional, behavioral, and cognitive impairment that can alter the relationship between themselves and their caregivers. Yet evidence shows that although survivors tend to perceive a loss of intimacy with their caregivers, caregivers tend to perceive their relationship as strengthened despite increasing challenges.

Stroke survivors tend to feel uncomfortable with their need for assistance and may equate dependence with inadequacy. Conversely, caregivers generally are comfortable in their role and are willing to provide more assistance with tasks than care recipients are willing to accept.

Researchers in the Netherlands found that when stroke survivors were anxious and had lower life satisfaction, there was an increase in the strain on the caregivers.

Research indicates that the QOL of the care recipient is in part dependent upon the QOL of the caregiver. Depression in caregivers is associated with poor stroke survivor function, communication, and social participation.

In Canada, the healthcare community has released guidelines for physicians, nurses, and any other allied health professionals to screen for depression for all clients who are living with stroke and those clients’ caregivers.
• If the caregivers have high levels of mastery in their caregiving skills, are in good physical health, and provide higher levels of assistance to the survivor, they typically report improved mental health and quality of life. These caregivers may feel needed and appreciated and sense that there is a positive outcome to providing care(4)

**What We Can Do**

› Learn about the challenges faced by caregivers to better evaluate their needs and provide support; share this information with your colleagues
› Develop an awareness of your own cultural values, beliefs, and biases and develop knowledge about the histories, traditions, and values of your clients. Adopt treatment methodologies that reflect the cultural needs of the client(3,14,22)
› Provide a family-centered approach that includes the caregiver as a client; schedule a conference with a multidisciplinary team, the patient, caregivers, and family members to discuss goal planning; provide education to help caregivers feel competent in the caregiving role(9,18,21)
› Social work professionals need to identify conflicts within the family and gaps in services during the ongoing assessment and provide better transitions of care and care coordination(15)
› Provide support to caregivers by
  • recognizing and acknowledging the emotional, physical, and financial stress of caring for a loved one who has experienced a stroke
  • evaluating the extent and quality of available social support(21-27)
  • taking sufficient time to assess the individual needs of each client and caregiver by listening actively and answering their questions(31)
  • offering practical advice on how best to provide assistance with activities of daily living and other day-to-day care activities (e.g., transportation)(10,27,31)
  • encouraging the caregiver to resume involvement in his or her own hobbies, activities, and spiritual practices(1,28)
› Based on the needs of the individual client and caregiver, request referrals to a licensed clinical social worker, vocational and rehabilitation counselor, physical and/or occupational therapist, and state or federal disability programs(10,27,31)
› Recognize the link between the well-being of caregivers and care recipients. Assess caregivers for depression and request a referral to a mental health clinician, if indicated(17,31)
References


Coding Matrix

References are rated using the following codes, listed in order of strength:

- **M** Published meta-analysis
- **SR** Published systematic or integrative literature review
- **RCT** Published research (randomized controlled trial)
- **R** Published research (not randomized controlled trial)
- **C** Case histories, case studies
- **G** Published guidelines
- **RV** Published review of the literature
- **RU** Published research utilization report
- **QI** Published quality improvement report
- **L** Legislation
- **PGR** Published government report
- **PFR** Published funded report
- **PP** Policies, procedures, protocols
- **X** Practice exemplars, stories, opinions
- **GI** General or background information/texts/reports
- **U** Unpublished research, reviews, poster presentations or other such materials
- **CP** Conference proceedings, abstracts, presentation
