Common Caregiver Issues and Nursing Interventions After a Stroke

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After rehabilitation, most stroke survivors return to the community and continue with their daily lives, despite stroke-related functional, cognitive, and behavioral changes.1 Caregivers are the primary support system for these survivors after discharge and an integral part of the healthcare team that contributes to survivors’ rehabilitation and recovery.2,3 However, caregiving is stressful, and caregivers often experience a variety of interrelated individual, interpersonal, and organizational issues in managing stroke-related deficits. These issues and potential nursing interventions for addressing them will be discussed in this article.

Individual Issues and Nursing Interventions

Individual caregiver issues commonly relate to insufficient knowledge and skills to understand and manage stroke survivors’ physical, cognitive, emotional, and behavioral problems.4 Initially, caregivers request information about the stroke diagnosis, prognosis, complications, and predicted recovery.5 As stroke survivors begin the transition to home care, caregivers require information about ensuring their safety, including fall prevention, medications, and prescriptions; adequate nutrition; and management of physical, instrumental, psychological, and behavioral problems.5 Empirical data support caregivers who also require information and support about how to manage complex feelings and interactions with stroke survivors who experience memory problems, depression, anxiety, frustration, withdrawal, and are argumentative.6-8

Empirical literature also indicates that caregivers feel uncertain and unprepared in the caregiving role.9 Caregivers need open and honest communication about their role and stroke survivors’ abilities,9,10 while also offering hope. Conducting a comprehensive predischarge nursing assessment of caregiver physical and psychological health and social, financial, and spiritual needs initially and during follow-up is essential.11 This assessment is vital to understand how caregivers’ skills, abilities, and resources match stroke survivors’ needs for follow-up care better. On the basis of this assessment, nurses should develop a highly individualized case management plan to help caregivers attain skills and services necessary to facilitate success and seamless postdischarge transition.2

Although nurses provide important information, stroke- and caregiving-related information commonly is not remembered by overwhelmed caregivers. Therefore, basic information should be provided throughout acute and chronic care in both oral and written formats, with frequent reinforcement of specific information in the caregiving trajectory.12 Caregivers also request that more extensive services be offered during rehabilitation, especially on weekends13 because competing work and other responsibilities (family, home, and church) make attending rehabilitation therapy difficult during the week.4 Furthermore, although guidelines exist, some resources suggest there is no consensus about what caregivers need in rehabilitation and the guidelines are not consistently applied in practice.10 Although caregivers report being invited to observe rehabilitation therapy and care, fewer opportunities may be available to practice these important caregiving skills adequately.4 Household environments also differ from rehabilitation settings (eg, logistics of bathrooms and hallways), making it difficult to transfer these skills to home settings.

These findings suggest that caregivers need tailored nursing interventions that develop and reinforce requisite information and skills (including handling techniques and assisting with activities of daily living), while being attentive to caregiver responses during teaching and allowing time for return demonstration of skills and care.8,10 More comprehensive services offered on weekends and during all phases of recovery (eg, acute care, rehabilitation, and after rehabilitation) is important. Realistic simulated environments that better mimic caregivers’ homes during rehabilitation also may be valuable in transferring skills to the home setting.

Multicomponent nursing interventions that provide caregivers skills to cope and manage physical, cognitive, emotional, and behavioral stroke-related problems are essential beginning with initial treatment and continuing throughout stroke recovery.3 Furthermore, caregivers may question how they will manage caregiving long term and report feelings of physical and emotional strain, being worried about themselves and care recipients, extreme tiredness, and losing self to caregiving.14 Telephone follow-up by nurses to monitor how caregivers are coping with physical and emotional aspects of caregiving is important.7 Furthermore, caregivers need suggestions for setting realistic goals to improve their physical (time to exercise, eating a heart healthy diet) and psychological (time alone
to do enjoyable activities, such as reading, church, or social activities) well-being.

Skills training to offer support and teach effective coping skills, such as relaxation techniques and problem-solving techniques, are useful in lessening negative caregiver outcomes. Empirical data that support these skills can be taught by nurses via the telephone, in conjunction with written materials. Counseling to address caregivers’ feelings and strategies to address their own personal care needs is also useful.

**Interpersonal Issues and Nursing Interventions**

Caregiver interpersonal issues commonly relate to changes in relationships between stroke survivors and their caregivers and differences in roles and social activities from stroke-related deficits. After stroke, the reciprocal relationship between partners is disrupted and a more 1-sided relationship may ensue from physical, cognitive, emotional, and behavioral stroke deficits. Intimacy issues are also stressful. Therefore, nurses should assess the quality of relationships between survivors and caregivers early in the caregiving period to determine potential problems. Caregivers and stroke survivors who previously had ineffective communication and relationships before the stroke commonly continue these patterns. Nurses should routinely coach and model effective communication skills between stroke survivors and their caregivers to minimize interpersonal conflicts and ascertain personal preferences and values. Caregivers also need information about interpersonal relationships and sexuality.

Caregivers also feel overwhelmed in attempting to perform their usual roles, as well as those previously assumed by the stroke survivor. Therefore, nurses should facilitate open discussion about changes in both stroke survivors’ and caregivers’ roles and how each contributes valuable but perhaps different roles within the family. Because survivors’ and caregivers’ perceptions may differ, the discussion must clearly identify stroke survivors’ expectations for caregivers and caregivers’ expectations for survivors. Realistic goal setting in conjunction with the survivor, caregiver, and other family members is essential. Assessing and facilitating proactive relationships among caregivers, stroke survivors, and other family members in performing roles associated with caregiving are important to avoid conflicts. Family counseling may be valuable.

Caregivers experience restricted or missed valued social activities, such as performing family rituals, visiting family and friends, attending religious services, participating in social events or classes, and going out for enjoyment. Many restrictions are for a limited time, but caregivers report a loss of friends because of inadequate social contact with these friends. Therefore, nurses should assist caregivers to identify strategies for maintaining these contacts, both separately and together with the stroke survivor (adapting activities around stroke survivors’ deficits). Providing information about caregiver self-help groups to socialize with others and to express feelings and emotions is also important. Web-based and telephone support seem to be useful in addressing caregiving issues and providing emotional support. As such, these support programs should address caregivers’ self-efficacy and mastery, active coping strategies, and social support.

Stroke deficits and caregiving sometimes changes intimacy between survivors and partners or spouses. Stroke survivors and caregivers should participate in collaborative communication to redefine intimacy into a mutually satisfying and sustaining relationship. Emotional support can be provided through hugging, touching, holding, and other intimate behaviors. Stroke survivors and caregivers should be counseled by nurses to avoid focusing on the past but rather maximizing the present.

Stroke nonadherence to medical and therapy regimens may be present during stroke recovery, creating stress between stroke survivors and their caregivers. Caregivers should be taught to enhance survivors’ independence by allowing them to do as much of their own care as possible. In addition, nurses should encourage open communication about caregiver needs, feelings, and concerns related to stroke survivor adherence to treatment regimens.

**Organizational Issues and Nursing Interventions**

Organizational issues of stroke caregiving often relate to identifying and using resources and community services that will assist both them and stroke survivors. Caregivers may feel abandoned and want other family members to offer assistance rather than waiting to be asked to assist them. Initially, caregivers need assistance in identifying potential sources of support that are valuable in the caregiving role, including other family members and friends, caregiver support groups, and religious and community organizations. Caregivers, family members, and other support groups (eg, religious groups and friends who offer assistance) also should be engaged (ideally as a group) early after stroke therapy about outpatient services and treatment regimens and their valuable role in the rehabilitation process. Family and friends benefit from a list of potential caregiving tasks for which they can volunteer their services. Nurses can discuss the value of developing a monthly calendar of caregiver and survivor needs and required assistance (eg, travel to therapies, prescription pickup, caregiver relief time for personal activities, and meal provision), with methods to identify commitments by each group member.

Interdisciplinary collaboration programs that offer telephone and in-home after discharge follow-up is important for caregivers. Empirical data support the value of these contacts being offered more intensively initially, followed by routine follow-up over time. Caregivers also suggest the importance of navigating patient care services, including medical benefits and insurance claims. Many caregivers are technology savvy, so information about how to access support resources via both the telephone and the Internet is important.

Support services change and nurses can provide important information about cost-effective interventions, such as occupational and physical therapy assistants who collaborate with occupational and physical therapists to develop and implement treatment plans when reimbursed physical, occupational, and speech therapy ends. Because financial issues are another common concern for caregivers, social services should be initiated early and continued throughout recovery.
Respite care is important in providing physical and psychological time away from caregiving. Although caregivers are focused primarily on the well-being of the stroke survivor rather than themselves initially, caregivers need to understand the importance of taking care of themselves to provide optimum care to the stroke survivor. Therefore, nurses can provide valuable information on available stroke rehabilitation day respite programs for caregivers. The Access to Respite Care and Health National Respite Network and Resource Center is one resource that provides information for professionals and caregivers to locate respite and crisis care services in their communities.

In conclusion, caregivers experience individual, interpersonal, and organizational issues during stroke recovery. Nursing intervention programs based on empirical literature and stroke rehabilitation patient care guidelines that address these stroke caregiver issues are essential in improving caregivers’ well-being and quality of life. Furthermore, intervention programs that span time and include core skills of providing stroke-related information, caregiver skill training, stress-coping strategies, and problem-solving seem valuable.

TAKE-HOME POINTS

- Caregiving is stressful and caregivers often experience a variety of individual, interpersonal, and organizational issues in managing stroke-related deficits. Nurses can provide useful interventions to assist stroke survivors, caregivers, and others to manage these issues.
- Caregivers experience individual issues related to insufficient knowledge and skills to understand and manage stroke survivors’ physical, cognitive, emotional, and behavioral problems.
- Caregivers face interpersonal issues about changes in relationships between stroke survivors and themselves and differences in roles and social activities from stroke-related deficits.
- Caregivers encounter organizational issues of stroke caregiving about identifying and using resources and community services that will assist both them and stroke survivors.

Disclosures

None.

References


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