Supporting the Needs of Stroke Caregivers Across the Care Continuum

Barbara J. Lutz, PhD, RN, CRRN, APHN-BS, and Michelle Camicia, MSN, CRRN, CCM

ABSTRACT

Objectives: To describe issues faced by stroke family caregivers, discuss evidence-based interventions to improve caregiver outcomes, and provide recommendations for clinicians caring for stroke survivors and their family caregivers.

Methods: Literature review.

Results: Caregiver health is linked to the stroke survivor’s degree of functional recovery; the more severe the level of disability, the more likely the caregiver will experience higher levels of strain, increased depression, and poor health. Inadequate caregiver preparation contributes to poorer outcomes. Caregivers describe many unmet needs including skills training; communicating with providers; resource identification and activation; finances; respite; and emotional support. Caregivers need to be assessed for gaps in preparation to provide care. Interventions are recommended that combine skill-building and psycho-educational strategies; are tailored to individual caregiver needs; are face-to-face when feasible; and include 5 to 9 sessions. Family counseling may also be indicated. Intermittent assessment of caregiving outcomes should be conducted so that changing needs can be addressed.

Conclusions: Stroke caregiving affects the caregiver’s physical, mental, and emotional health, and these effects are sustained over time. Poorly prepared caregivers are more likely to experience negative outcomes and their needs are high during the transition from inpatient care to home. Ongoing support is also important, especially for caregivers who are caring for a stroke survivor with moderate to severe functional limitations. In order to better address unmet needs of stroke caregivers, intermittent assessments should be conducted so that interventions can be tailored to their changing needs over time.

Key words: stroke; family caregivers; care transitions; patient-centered care.

Stroke is a leading cause of major disability in the United States [1] and around the world [2]. Of the estimated 6.6 million stroke survivors living in the US, more than 4.5 million have some level of disability following stroke [1]. In 2009, more than 970,000 persons were hospitalized with stroke in the US with an average length of stay of 5.3 days [3]. Approximately 44% of stroke survivors are discharged home directly from acute care without post-acute care [4]. Only about 25% of stroke survivors receive care in inpatient rehabilitation facilities [4] even though the American Heart Association (AHA) stroke rehabilitation guidelines recommend this level of care for qualified patients [5]. Regardless of the care trajectory, when stroke survivors return home they frequently require assistance with basic and instrumental activities of daily living (BADL/IADL), usually provided by family members who often feel unprepared and overwhelmed by the demands and responsibilities of this caregiving role.

The deleterious effects of caregiving have been identified as a major public health concern [6]. A robust body of literature has established that caregivers are often adversely affected by the demands of their caregiving role. However, much of this literature focuses on caregivers for persons with dementia. Needs of stroke caregivers are categorically different from caregivers of persons with dementia in that stroke is an unpredictable, life-disrupting, crisis event that occurs suddenly leaving family members with insufficient time to prepare for the new roles and caregiving responsibilities. The patient typically transitions from being cared for by multiple providers in an acute care, inpatient rehabilitation facility, or skilled nursing facility (SNF)—24 hours a day, 7 days

From the School of Nursing, University of North Carolina- Wilmington, Wilmington, NC (Dr. Lutz), and the Kaiser Foundation Rehabilitation Center, Kaiser Permanente, Vallejo, CA (Ms. Camicia).
a week—to relying fully on one person (most often a spouse or adult child) who may not be ready to handle the overwhelming demands and constant vigilance required for adequate care at home. Studies have repeatedly demonstrated the damaging health effects of caregiving. Caregivers describe feeling isolated, abandoned, and alone [7–9], and what frequently follows is a predictable trajectory of depression and deteriorating health and well-being [7,10–13]. The purpose of this article is to describe difficulties and issues faced by family members who are caring for a loved one following stroke, discuss evidence-based interventions designed to improve stroke caregiver outcomes, and provide recommendations for clinicians who care for stroke survivors and their family caregivers post-stroke.

Difficulties and Issues Faced by Caregivers

With an aging population and increasing incidence of stroke, it is imperative that we identify and address the ongoing needs of stroke survivors and their family caregivers in the post-stroke recovery period. Multiple studies acknowledge that stroke is a life-changing event for patients and their family members [9,14] that often results in overwhelming feelings of uncertainty, fear [15], grief, and loss [9]. Stroke also can have long-term effects on the health of stroke survivors and their family caregivers. Studies have identified the effects of caregiving on the health of caregivers and subsequent links between stroke survivor and caregiver outcomes over time [12,16,17]; the ongoing needs of stroke caregivers post-discharge [18,19]; and the importance of assessing caregiver preparedness and subsequent caregiving outcomes [5,20].

Effects of Caregiving on the Health of Caregivers and Stroke Survivors

Research on stroke caregiving consistently indicates that caregiver health is inextricably linked to the stroke survivor’s degree of physical, cognitive, psychological, and emotional recovery. The more severe the patient’s level of disability, the more likely the caregiver will experience higher levels of strain, increased depression, and poor health outcomes [21]. Studies also indicate that certain caregiver characteristics, such as being female or having lower educational level, pre-existing health conditions [7,22,23], poor family functioning, lack of social support [22,24], or lack of preparation [25], are all risk factors for poorer caregiver outcomes.

Stroke family caregivers often experience overwhelming physical and emotional strain, depressive symptoms, sleep deprivation, decline in physical and mental health, reduced quality of life, and increased isolation [7,10,11,14,26,27]. Perceived burden has been positively associated with caregiver depressive symptoms [12,14,28,29]. Depressive symptoms in caregivers, with a reported incidence of 14% [30] to 33% [31], may persist for several years post-stroke. In a study of the long-term effects of caregiving with 235 stroke caregivers when compared with non-caregivers, researchers found that caregivers had more depressive symptoms and poorer life satisfaction and mental health quality of life at 9 months post-stroke, and many of these differences continued for 3 years post-discharge [23].

Lower stroke survivor functioning and higher depressive symptoms are correlated with higher caregiver depressive symptoms and burden, and poorer coping skills and mental health [12,21]. A review of stroke caregiving literature by van Heugten et al [32] indicated that long-term caregiver functioning was influenced by stroke survivor physical and cognitive functioning and behavioral issues; caregiver psychological and emotional health; quality of family relationships; social support; and caregiver demographics. Caregivers of stroke survivors with aphasia may have more difficulties providing care, increased burden and strain, higher depressive symptoms, and other negative stroke-related outcomes [33].

Gaugler [34] conducted a systematic review of 117 studies and reported that caring for stroke survivors who were older, in poorer health, and had greater stroke severity increased the likelihood of poorer emotional and psychological family caregiver outcomes. Caregivers who had “negative problem orientation and less social support” were more likely to have depressive symptoms and poorer self-rated health at 1-year post-stroke. One of the best predictors of caregiver stress and poor health in the first year post-stroke was lack of caregiver preparation [25,34].

Research also suggests that stroke survivor outcomes are influenced by the ability of the family caregiver to provide emotional and instrumental support as well as assistance with BADL/IADL [6,35]. As the caregiver’s health decreases, the stroke survivor’s health and recovery will also likely suffer and ultimately may result in re-hospitalization or nursing home placement. For example, Perrin et al. found a consistent reciprocal relationship between caregiver health and stroke survivor functioning,
such that the quality of caregiving may be affected by caregiver burden and depressive symptoms, which in turn can impair the functional, psychological, and emotional recovery of the stroke survivor [21]. Studies have also linked poorer caregiver well-being to increased depressive symptoms in stroke survivors [36,37].

In a review of 27 studies with data from approximately 6000 patients and 3000 caregivers, 5 post-stroke problem areas and ranges of prevalence were identified (Table 1). The authors noted a need for “a longer-term holistic approach to the rehabilitation of stroke patients and support for carers” [38].

Positive effects of caregiving have also been reported, including a feeling of confidence, satisfaction in providing good quality care [30,39,40], an improved relationship with the care recipient [30,40,41], having greater life appreciation, and feeling needed and appreciated [40]. In a systematic review of 9 studies, improvements in the stroke survivor’s condition was a source of positive caregiving experiences [40]. In 2 studies, two-thirds of caregivers surveyed affirmed all survey items related to positive aspects of caregiving [40]. Additionally, studies have demonstrated that caregivers who engaged in emotion- and problem-focused coping strategies had positive caregiving experiences [40]. Haley et al found that by 3 years post-stroke many of the ill effects of caregiving had resolved, suggesting that some caregivers may be successful in adapting to their “new” post-stroke lives [23].

Understanding the difficulties and issues faced by caregivers throughout the trajectory, from immediately following the stroke through the transition home and, ideally, the adaptation of the caregiver to this new life, provides an opportunity for health care professionals to intervene with strategies to support this major life change.

### Table 1. Prevalence of Problems for Stroke Survivors and Their Caregivers [38]

<table>
<thead>
<tr>
<th>Problem Area</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional problems</td>
<td>19%–62%</td>
</tr>
<tr>
<td>Social problems</td>
<td>18%–46%</td>
</tr>
<tr>
<td>Service issues</td>
<td>13%–77%</td>
</tr>
<tr>
<td>Poor communication with rehab providers</td>
<td>18%–88%</td>
</tr>
<tr>
<td>Transfer of care</td>
<td>33%–100%</td>
</tr>
<tr>
<td>Other areas</td>
<td>10%–73%</td>
</tr>
</tbody>
</table>

Caregiving Trajectory and Ongoing Needs of Stroke Caregivers

Stroke survivors and their family caregivers rapidly move from intensive therapy and nursing case management while in a facility to little or no assistance following discharge. Despite case management and discharge planning services received while in an institutional setting, the transition from inpatient care to home can be a crisis point for caregivers [9]. They describe having to figure things out for themselves with little or no formal support after discharge [9,43,44], leaving them feeling overwhelmed, exhausted, and abandoned once they return home [9].

These family members rarely make an active choice to become caregivers; rather, they take on the role because they are unable to perceive or access any other suitable alternatives [8,45]. Whatever their circumstances, these devoted family members are particularly vulnerable as they transition into the caregiving role without an adequate support system for assessing and addressing their needs [7–9,46]. Without this assistance, caregivers develop their own solutions and strategies to meet the needs of the care recipient after discharge [47,48]. Unfortunately, these strategies are often ineffective and may result in safety risks for patients (eg, falls, skin breakdown, choking), and care-related injuries (eg, falls, muscle strains, bruises) and increased stress and anxiety for caregivers [48–50].

Caregivers have described unmet needs in many domains including skills training, communicating with providers, resource identification and activation, finances, respite, and emotional support [35,44,48,51,52]. Bakas et al found that in the first 6 months post-discharge, stroke caregivers had needs and concerns related to information, emotions and behaviors, physical care, instrumental care, and personal responses to caregiving [48], and that their information needs change during the course of the patient’s recovery [53]. In a study by Lutz et al [44], caregivers identified multiple areas where they felt they were unprepared to assume the caregiving role post-discharge. These included identifying and activating resources; making home and transportation modifications to improve accessibility; developing skills in providing physical care and therapies; managing medications and behavioral issues; preventing falls; coordinating care across settings; attending to other family responsibilities; and caring for themselves.

In a study of interactions between rehabilitation providers and stroke caregivers, Creasy et al [52] noted...
that caregivers have needs, which were often not recognized, in the following areas: information; providing emotional support for the stroke survivor and having their own emotional support needs met; being involved in treatment decisions; and being adequately prepared for discharge home. Caregivers’ interaction styles with providers, which ranged from passive to active/directing, affected their abilities to have their needs recognized and addressed. These findings highlight the importance of recognizing the caregiver’s interaction style and tailoring communication strategies accordingly.

Cameron et al [54] noted that caregiver support needs change over time, with needs being highest during the inpatient phase as they prepare for discharge home. Moreover, caregivers who are providing care for stroke survivors with more severe functional limitations need more support over a longer period of time. Recognizing the needs of stroke caregivers, the 2016 Canadian Stroke Best Practice Recommendations on Managing Transitions of Care Following Stroke includes recommendations related to assessing, educating, and supporting stroke family caregivers [55].

### Assessing Caregiver Readiness and Related Outcomes

A major contributing factor to poorer caregiver outcomes is inadequate preparation for the caregiving role. Several authors have identified specific assessment domains that must be considered when evaluating caregivers. The Family Caregiver Alliance Caregivers Count Too! Toolkit (www.caregiver.org/caregivers-count-too-toolkit) includes 7 assessment domains [56]. These domains are similar to those included in the Nursing Standard of Practice Protocol: Family Caregiving by the Hartford Institute for Geriatric Nursing [57] (Table 2).

Young et al [58] recommend specific domains for a comprehensive readiness assessment of stroke family caregivers. Caregiver domains include strength of the caregiver/care recipient relationship; caregiver willingness to provide care; pre-existing health conditions, previous caregiving experience, home and transportation accessibility, available resources, emotional response to the stroke, and ability to sustain the caregiving role. This type of readiness assessment should be completed early in the care trajectory, while the stroke survivor is receiving inpatient care, so that care plans can be tailored to address gaps in caregiver preparation prior to discharge. It is especially important for new caregivers and those caring for stroke survivors with significant functional limitations [44]. Currently there are no tools designed to assess a family member's readiness to assume the caregiver role.

Validated instruments have been developed to assess caregiving outcomes, including preparedness, with caregivers who have been providing care for a period of time. For example, the Mutuality and Preparedness Scales of the Family Caregiver Inventory was developed with caregivers 6 months post-discharge [59] and has been validated with stroke caregivers at 3 months post-discharge [60].

Several validated tools are available to assess the caregiver’s changing needs and the effects of care provision on well-being [8,45,61]. For example, the Caregiver Strain Index [62] has been validated in studies with stroke family caregivers [11,28]. Bakas developed 2 scales to specifically assess stroke caregivers post-discharge. The Bakas Caregiving Outcomes Scale assesses caregiver

<table>
<thead>
<tr>
<th>Table 2. Caregiver Assessment Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregivers Count Too! Toolkit [56]</strong></td>
</tr>
<tr>
<td>1. Background on the caregiver and the caregiving situation</td>
</tr>
<tr>
<td>2. Caregiver’s perception of health and functional status of the care recipient</td>
</tr>
<tr>
<td>3. Caregiver’s values and preferences with respect to everyday living and care provision</td>
</tr>
<tr>
<td>4. Health and well-being of the caregiver</td>
</tr>
<tr>
<td>5. Consequences of caregiving on the caregiver</td>
</tr>
<tr>
<td>6. Care-provision requirements (skills, abilities, knowledge)</td>
</tr>
<tr>
<td>7. Resources to support the caregiver</td>
</tr>
<tr>
<td><strong>Nursing Standard of Practice Protocol: Family Caregiving [57]</strong></td>
</tr>
<tr>
<td>1. Caregiving context—including relationship to patient, roles and responsibilities, physical environment, resources, and cultural background;</td>
</tr>
<tr>
<td>2. Caregiver’s understanding of the patient’s health and functional limitations;</td>
</tr>
<tr>
<td>3. Level of preparation for and knowledge about the caregiving role;</td>
</tr>
<tr>
<td>4. Quality of family relationships;</td>
</tr>
<tr>
<td>5. Pre-existing issues, such as marital discord, poor management of finances; and</td>
</tr>
<tr>
<td>6. The caregiver’s physical, mental, and emotional health</td>
</tr>
</tbody>
</table>
life changes [63] and the Needs and Concerns Checklist assesses post-discharge caregiver needs [48]. There are many other instruments designed to assess general caregiving outcomes, including depressive symptoms, burden, anxiety, and well-being. For a list relevant tools see Deeken et al [61] and The Selected Caregiver Assessment Measures from the Family Caregiver Alliance [64].

While these scales are helpful for assessing caregivers who are already providing care, they do not capture the gaps in caregiver readiness prior to patient discharge from the institutional setting. Taken together, these studies suggest that assessing readiness and implementing interventions to improve caregiver preparation prior to discharge and assessing and addressing their changing needs over time, from inpatient care to community reintegration, may be important strategies for improving both caregiver and stroke survivor outcomes. These strategies may also facilitate sustainability of the caregiver role over time.

**Interventions to Improve Caregiver Outcomes**

In a review of 39 articles representing 32 caregiver and dyad intervention studies, researchers from the AHA made 13 evidence-based recommendations. Recommendations with the highest level of evidence indicated that (1) interventions that combined skill-building with psycho-educational programs were better than psycho-educational interventions alone; (2) interventions that are tailored to the individual are preferred over “one-size-fits-all” interventions; (3) face-to-face interventions are preferred, but telephone interventions can be useful when face-to-face is not feasible; and (4) interventions with 5 to 9 sessions are recommended [65]. In a review of 18 studies, Cheng et al confirmed the recommendation that psychoeducational interventions that focused on skill building improved caregiver well-being and reduced stroke survivor health care utilization [66].

Studies also recommend that families may need family counseling to help them develop positive coping strategies and adjust to their lives after stroke [66]. Stroke survivors and their families experience grief and loss as they begin to realize how the stroke has changed their relationships, roles, responsibilities, and future plans for their lives (eg, work, retirement). While many inpatient rehabilitation facilities may provide services from a neuro-psychologist to discuss post-stroke changes in the brain and possible behavioral and emotional manifestations, referrals for family counseling to address the impact of stroke on the family and community reintegration are seldom provided [9].

Recent interventions have shown promise in improving stroke caregiver outcomes. For example, Bakas et al. completed a randomized controlled trial of an 8-week, nurse-delivered, Telephone Assessment and Skill-Building Kit (TASK) intervention [67]. Caregivers in the intervention group with moderate to severe depressive symptoms at baseline demonstrated significant improvements in depressive symptoms and life changes at 8, 24, and 52 weeks. The TASK shows promise because it can reach caregivers in rural and urban areas at a relatively low cost [67].

Recognizing the need to improve post-acute care for stroke survivors and their family caregivers, several large funded clinical trials are being tested in the US and globally. For example, the ATTEND Trial in India is testing a home-based, caregiver-led rehabilitation intervention [68]. The Comprehensive Post-Acute Stroke Services (COMPASS) study in North Carolina, is a state-wide pragmatic, randomized controlled trial testing a comprehensive community-based patient-centered post-acute care intervention with stroke survivors and their caregivers (www.nccompass-study.org). Results of these and other studies will continue to identify evidence-based strategies to improve care coordination, quality of care, and post-stroke outcomes for stroke survivors and their caregivers.

**Recommendations for Clinicians**

Based on this review we have identified strategies that clinicians can implement across the care continuum that may help reduce caregiver strain and burden, and improve outcomes for family caregivers and the stroke survivors for whom they provide care. The evidence suggests that caregivers need assistance in building skills, not only in providing the care needed by the stroke survivor but also in solving problems as they arise; navigating the multiple systems of care, including understanding options for post-acute care; accessing community resources; communicating effectively with health care and social support providers; and dealing with the emotional effects of stroke [44,52].

Caregivers need help in navigating the multiple providers and systems of care to get the services the stroke survivor needs as well as to secure support services. They need information from trusted sources about stroke prevention and available community resources. Providing a list of resources is often insufficient, especially in the
first few weeks or months post-stroke; these caregivers are already overwhelmed with the enormity of the tasks and responsibilities that they have taken on as a caregiver. Instead they need someone who can advocate for them and connect them with the appropriate resources at the right time.

They also need assistance developing and maintaining self-care strategies so they can sustain the caregiving role long-term. Identifying opportunities for respite and helping them activate informal and formal resources, such as other family members, friends, church groups, neighbors, and services from local senior centers, independent living centers, or area agencies on aging can help them identify assistance with the breadth of duties including care of the stroke survivor, meal preparation, transportation, or a supportive listening ear. It is important for the caregiver, in addition to any other close support person as available, to have a facilitated discussion with the healthcare team to brainstorm activities where assistance may be provided and who might be approached to help.

Online resources can also be helpful for information and support. Table 3 includes a list of current websites that may be of assistance. Providers must be familiar with the content to direct the caregiver to the websites that best meet their specific needs. If the caregiver has access to a computer, providers can facilitate skill building for online searches during this process.

The timing of providing support and resources is also critical. Becoming a caregiver is a process and often family members who are new to the role need more intense direct assistance and support when the stroke survivor first comes home, but many may need ongoing support over time. Research suggests it can take caregivers up to 3 years to figure out how to manage the new responsibilities, learn to navigate the multiple systems for care and services, establish confidence in their abilities, deal with the emotional upheaval, and to adapt to their new lives [23].

Research indicates the 44% of stroke patients receive no post-acute care. Clinicians also need to advocate for patients to get the most appropriate level of organized, coordinated, and inter-professional post-acute care [5]. This requires that they understand the different levels of post-acute care, including the criteria for admission, the scope and intensity of nursing, therapy, physician and other services provided in each setting, and the associated clinical outcomes. This knowledge is also necessary to enable clinicians to educate stroke survivors and their caregivers on post-acute care so that they understand the process and can effectively self-advocate for the provision of appropriate services as needed.

Approximately 45% of stroke survivors in the US are discharged either to an inpatient rehabilitation facility or SNF for rehabilitation [4]. Patients discharged to an inpatient rehabilitation facility receive a minimum of 3 hours of therapy per day and are cared for 24 hours/day by a staff led by registered nurses (RNs) with rehabilitation expertise. SNFs do not have minimum requirements for hours of therapy, 24-hour RN staffing, nor a requirement for nurses with specialty training in rehabilitation. Pressure to reduce the length of stay in acute care often results in providers transitioning stroke survivors to the post-acute care setting that accepts the patient first. Because SNFs have fewer criteria for admission, they are more likely to rapidly accept a patient for care when compared to an inpatient rehabilitation facility. Providers must determine and make recommendations for the most appropriate level of post-acute care to ensure the stroke patients’ rehabilitation needs can be met in the recommended setting [5,69]. It is also essential that family caregivers have the knowledge and skills to advocate for the appropriate level of post-acute care based on the stroke survivor’s expected recovery trajectory. Research has demonstrated that that stroke survivors admitted

---

**Table 3. Online Stroke Caregiving Resources**

<table>
<thead>
<tr>
<th>Website</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Heart Association</td>
<td><a href="http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/ForFamilyCaregivers/ForStroke-Family-Caregivers_UCM_308560_SubHomePage.jsp">www.strokeassociation.org/STROKEORG/LifeAfterStroke/ForFamilyCaregivers/ForStroke-Family-Caregivers_UCM_308560_SubHomePage.jsp</a></td>
</tr>
<tr>
<td>American Association of Retired Persons</td>
<td><a href="http://www.aarp.org/home-family/caregiving">www.aarp.org/home-family/caregiving</a></td>
</tr>
<tr>
<td>Elder Care Services</td>
<td><a href="http://www.aoa.gov/elderpage/locator.html">www.aoa.gov/elderpage/locator.html</a></td>
</tr>
<tr>
<td>Family Caregiver Alliance</td>
<td><a href="http://www.caregiver.org">www.caregiver.org</a></td>
</tr>
<tr>
<td>National Alliance for Caregiving</td>
<td><a href="http://www.caregiving.org">www.caregiving.org</a></td>
</tr>
<tr>
<td>National Family Caregiver Association</td>
<td><a href="http://www.nfcacares.org">www.nfcacares.org</a></td>
</tr>
<tr>
<td>National Stroke Association</td>
<td><a href="http://www.stroke.org/we-can-help/caregivers-and-family/careliving-guide">www.stroke.org/we-can-help/caregivers-and-family/careliving-guide</a></td>
</tr>
</tbody>
</table>
to an inpatient rehabilitation facility, when compared to similar patients in a SNF, have better outcomes, including improved function [70] and lower re-hospitalization and death rates [71,72]. The Association of Rehabilitation Nurses provides resources for health care professionals and patients regarding rehabilitation. For more information for professionals about levels of post-acute care, see www.rehabnurse.org/uploads/files/healthpolicy/ARN_Care_Transitions_White_Paper_Journal_Copy_FINAL.pdf [73]. For information for patients and caregivers, see www.restartrecovery.org.

Providers must also be knowledgeable about community resources in order to provide connections to services and agencies that are relevant to the changing needs of the caregiver over time. Initially, caregivers may need assistance in meeting the stroke survivor’s BADL/IADL, and later needs may expand to include support groups, respite, and opportunities for a greater community engagement.

Training in time management provides room in the busy caregiving schedule for self-care for the caregiver. Providers must assist with determining routines that meet the needs of both the caregiver and stroke survivor, as the health of each is dependent on the other. Assistance in developing a wellness program that is feasible for the caregiver to maintain will improve adoption of health promoting practices.

As discussed above, the needs of both the stroke survivor and caregiver vary along the post-stroke trajectory. Therefore, both caregivers and stroke survivors should be assessed intermittently over time: caregivers for evidence of effective coping strategies and confidence in the sustaining the caregiving role, and stroke survivors for improvement in their functional abilities and compensatory strategies in BADL/IADL. The opportunity for the stroke survivor to assume household tasks that decrease the caregiver burden, in addition to providing a greater sense of purpose for the stroke survivor, must be explored. For example, the stroke survivor may be able to assist with activities such as meal planning and components of meal preparation or light housekeeping utilizing adaptive devices as needed.

Additional research is necessary to understand how the needs of caregivers change over time, the appropriate timing of reassessment, and the evaluation of interventions to facilitate the transition into this role, while preventing the adverse effects of caregiving on the health of the caregiver and stroke survivor during this transition period.

**Conclusion**

There is clear evidence that stroke caregiving can have detrimental effects on the physical, mental, and emotional health of caregivers, and that these effects are sustained over time. Evidence also indicates that caregivers who are not well-prepared to assume the caregiving role are more likely to experience negative outcomes. Studies suggest that the time of transition from inpatient care to home is a time of crisis for caregivers and that their support needs are high during this time. However, research also indicates that while needs may change over time, caregivers need ongoing support, especially if they are providing care for a stroke survivor who has moderate to severe physical, cognitive, and/or communication limitations.

In order to better understand the needs of stroke caregivers, a pre-discharge assessment of their readiness to provide care should be conducted so that interventions can be tailored to address their needs to minimize negative effects of a poorly planned transition [69]. Currently, there are assessment tools that can be used with caregivers post-discharge to assess their self-reported needs (after they have an understanding of the role) and caregiving outcomes. Research is needed to develop a valid and reliable tool that pre-emptively assesses the gaps in caregiver readiness that can be utilized prior to the transition from the institutional setting to home. This will enable the identification and evaluation of primary prevention strategies to improve caregiver preparation so that the adaption to the new caregiving role can be expedited, minimizing the adverse health effects on both the caregiver and stroke survivor.

Providers must be aware of the changing needs of stroke survivors and tailor plans of care accordingly, using evidenced-based interventions. Policy makers must consider research on the long term effects of caregiving and consider legislation to support the health and respite needs of the growing population of caregivers. This will contribute to attaining the 3 aims of the National Quality Strategy: improving quality of care, improving health, and reducing health care system costs [74].

**Corresponding author:** Barbara J. Lutz, PhD, 601 S. College Rd., Wilmington, NC 28403, lutzb@uncw.edu.

**Financial disclosures:** None.

**References**

1. Mozaffarian D, Benjamin EJ, Go AS, et al. on behalf of the American Heart Association Statistics Committee & Stroke


51. Cameron JI, Gignac MA. “Timing It Right”: a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. Patient Educ Couns 2008;70:305–14.
69. Camicia M, Lutz B. Nursing’s role in successful transitions...


72. Bettger JP, Liang L, Xian Y, et al. Inpatient rehabilitation facility care reduces the likelihood of death and rehospitaliza-
tion after stroke compared with skilled nursing facility care [abstract]. Stroke 2015; A146.
