



Rethinking Intervention Strategies in Stroke Family Caregiving

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KEY WORDS

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Stroke is a condition that affects both patients and family members who provide care and support. Because stroke is an unexpected traumatic event that suddenly forces family members into a caregiving role, caregivers often experience an overwhelming sense of burden, depression, and isolation; a decline in physical and mental health; and reduced quality of life. Caregiver health is inextricably linked to a stroke survivor's physical, cognitive, and psychological recovery. Evidence suggests that informational interventions alone are not as effective in meeting the complex needs of stroke caregivers as interventions that combine information with other support services. This article discusses issues related to stroke caregiving and proposes comprehensive strategies designed to meet the poststroke recovery needs of both patients and caregivers. Suggested strategies include a comprehensive assessment specific to caregiver needs, skills, and resources and case management services designed to provide continuity of care across the stroke-recovery trajectory.

In the United States in 2006, approximately 44 million adults, most often family members, provided unpaid assistance to community-living adults with disabilities at an estimated value of \$306 billion (Family Caregiver Alliance National Center on Caregiving [FCA], 2006). Long-term caregiving for family members with chronic disabling conditions has a significant impact on the health and well-being of caregivers. Informal (unpaid) caregiving often takes an enormous toll on these carers, resulting in a decline in physical and emotional health, increased depressive symptoms, and a decreased sense of well-being (FCA). As many as 70% of family caregivers have clinically significant depressive symptoms and of those, between one-quarter and one-half have major symptoms of depression (FCA). The impact on physical health also is profound. According to the FCA, family caregivers reported poorer physical health than their noncaregiving counterparts, and they also experienced higher mortality rates. Sixty percent of family caregivers report fair-to-poor health. These caregivers also experience high levels of frustration and stress, which may lead to harmful behaviors such as alcohol or drug abuse. Because they have less time to care for themselves, family caregivers also are less likely to engage in health promotion and prevention activities (FCA).

Research on family caregiving has led to recommendations for interventions designed specifically to prevent the ill effects of caregiving (Brereton, Carroll, & Barnston, 2008; Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; Pierce et al., 2004b). The FCA has identified preventive strategies to help maintain the health and well-being of family caregivers, which include

assessing caregiver needs and providing education, better respite services, and financial support (FCA, 2006).

With improved emergency and acute medical care, more patients are surviving adverse events such as a stroke, but they are recovering with physical and cognitive limitations that require long-term assistance from family members. This article provides an overview of family caregiving issues for people recovering from stroke and suggestions for future comprehensive interventions to address these issues.

Stroke Epidemiology and Sequelae

Stroke occurs suddenly, is traumatic, and leaves patients and their families unprepared for dealing with its aftermath. It is a complex, life-changing experience for both stroke survivors and their family caregivers. Stroke affects 795,000 people in the United States each year, with costs for new or recurring strokes at \$68.9 billion (Lloyd-Jones et al., 2009). Stroke is the leading cause of disability in the United States, with an estimated 4.8 million community-living stroke survivors who have some level of disability (American Heart Association, 2005). In a study of ischemic stroke survivors age 65 and older, approximately 50% had some hemiparesis, 30% needed assistance with walking, approximately 25% were dependent in their activities of daily living (ADLs), and approximately one-third had depressive symptoms. As a result, 26% were placed in nursing homes (Kelly-Hayes et al., 2003).

Stroke survivors who can return home are at increased risk for depression, injury due to falls, and decreased physical functioning (Lutz, Chumbler, & Roland, 2007). In one study, researchers found that

stroke patients with higher levels of disability were more likely to be depressed (Carota et al., 2005). Another study found that falls were a major postdischarge risk for ambulatory stroke patients (Yates, Lai, Duncan, & Studenski, 2002). Family caregivers often are ill-prepared to manage these and other multiple, complex problems of poststroke patients.

The Costs of Family Caregiving

Informal family caregiving has been a focus of nursing research for more than 25 years. Much of the nursing research in this area has explored the effects of providing care on the caregivers of patients with stroke and other disabling conditions (Grant, Elliott, Giger, & Bartolucci, 2001; Grant, Glandon, Elliott, Giger, & Weaver, 2004; Grant, Weaver, Elliott, Bartolucci, & Newman Giger, 2004; Scholte op Reimer, de Haan, Pijnenborg, Limburg, & van den Bos, 1998; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). Family caregivers of stroke patients often experience an overwhelming sense of burden and depression, a decline in physical and mental health, reduced quality of life (QOL), and isolation (Forster, 2005; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; van Exel, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004; van Exel, Koopmanschap, van den Berg, Brouwer, & van den Bos, 2005). Perceived burden has been positively associated with caregiver depression. In addition, caregivers who were better able to cope with stressors (as measured by the Sense of Coherence Scale) perceived less burden and were less depressed (Chumbler, Mann, Wu, Schmid, & Kobb, 2004; van Puymbroeck & Rittman, 2005).

Many of these deleterious outcomes are related to the patient's functional status (physical and mental) and associated caregiving tasks. For example, in one study, caregivers of patients with more severe stroke-related impairments were more likely to be depressed immediately poststroke and at 6- and 18-month follow-ups (Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005). In another study, feelings of burden were positively related to the number of caregiving tasks (van Exel et al., 2005). Bakas and Burgener (2002) discovered that high task difficulty and low self-esteem increased emotional distress in caregivers, while in a later study Bakas and colleagues found that the "tasks perceived as most time consuming and difficult, which also were predictive of mood and other negative caregiver outcomes, were managing finances, managing behaviors, and providing emotional support" (2004, p. 95). Tooth, McKenna, Barnett, Prescott, & Murphy (2005) found that patient motor and cognitive function and time spent in daily caregiving tasks were associated with caregiver

burden. A study of Japanese family caregivers revealed that those with a higher "mastery" of caregiver skills exhibited "fewer depressive symptoms" (Schreiner & Morimoto, 2003, p. 307).

In an analysis of 31 peer-reviewed studies assessing the effects on QOL for caregivers of stroke patients, Low, Payne, and Roderick (1999) found that most studies focused on the degree of psychological morbidity, and that caregiver QOL was significantly influenced by stroke-related cognitive and behavioral problems, physical disability and mobility impairment, the caregiver's own physical health and prestroke psychological status, and the quality of the relationship between the stroke patient and the caregiver. The few studies that focused on the physical and social health of those providing informal care indicated that stroke caregivers' lives are disrupted and they are socially isolated and experience exhaustion (Low et al.).

Systematic reviews of the literature are considered the highest level of evidence. Rombough and colleagues (2007) conducted a systematic review of the research on stroke caregiver QOL, with nine studies meeting their inclusion criteria. The authors concluded from their review that additional research was needed because QOL was not uniformly defined, different instruments were used to measure QOL, and none of the QOL instruments used were specific to stroke caregivers. However, they also found that caregiver QOL was positively correlated with improved functional status of stroke survivors.

In another review of 27 studies with data from approximately 6,000 patients and 3,000 caregivers, five poststroke problem areas and range of prevalence were identified (Table 1). Based on their review, the authors identified the need for "a longer-term holistic approach to the rehabilitation of stroke patients and support for carers" (Murray, Young, Forster, & Ashworth, 2003, p. 803).

Bhogal and colleagues (2003) conducted a systematic review of the literature between 1997 and 2002 to explore community reintegration issues for stroke survivors and their families. Their findings revealed that stroke caregivers "suffer from an alarming amount of depression and psychological morbidity, with estimates ranging from between one-third to one-half of caregivers" (p. 127), and patients with "well-functioning families" (p. 115) and strong social and emotional support have better outcomes.

This body of literature indicates that caregiver health is inextricably linked to the patient's degree of physical, cognitive, and psychological functional recovery. The more severe a patient's level of disability, the more likely the caregiver will experience higher levels of burden, increased depression, and

Table 1. Prevalence of Problems for Stroke Survivors and Their Caregivers (Murray, Young, Forster, & Ashworth, 2003)

Problem Area	Range of Prevalence
Emotional problems	19%–62%
Social problems	18%–46%
Service issues	13%–77%
Poor communication (with rehabilitation providers)	18%–88%
Transfer of care	33%–100%
Other areas	10%–73%

poor health outcomes. The research also indicates that stroke-patient outcomes are strongly influenced by the ability of the family caregiver to provide emotional and instrumental support and assistance with ADLs. As a caregiver's health declines, the patient's health and recovery also are likely to suffer. When assessing postdischarge needs and treatment plans for stroke patients, the needs of family caregivers must be considered (Visser-Meily et al., 2006).

Interventions for Caregivers

Based on the research exploring the effects of caregiving and the needs of stroke family caregivers, researchers have developed interventions to alleviate the negative effects of caregiving and better meet the needs of informal caregivers. Several nurse researchers have conducted intervention studies for stroke caregivers after discharge. Pierce and colleagues (2004a, 2004b) found that using a Web-based intervention to provide social support to caregivers of family members with stroke can be a useful strategy. Lutz and colleagues (2009) tested the feasibility of a home-telehealth intervention for veterans who are stroke survivors and their caregivers. They found that study participants "thought home-telehealth provided a 'safety net' and was a useful supplement to their poststroke recovery, especially if it was combined with real-time face-to-face or phone contact from a care coordinator" (p. 408).

Grant and colleagues used a telephone intervention to improve the problem-solving skills of stroke caregivers (Grant, 1999; Grant et al., 2001, 2002; Grant, Glandon, et al., 2004). Caregivers in the telephone-intervention group had better problem-solving skills; were more prepared and less depressed; and had improved vitality, social functioning, and mental health scores on the SF-36 Health Survey. They concluded that the telephone intervention may have been effective because the intervention nurse caller could tailor the session to the individual needs of each caregiver who was called (Grant et al., 2002).

Hartke and King (2003) conducted a telephone support group intervention for spouses caring for stroke patients after discharge from rehabilitation. They

found no significant differences in levels of stress between the control and intervention groups. The intervention group had increased competence in caregiving tasks, however, while the control group had increased burden over time. These findings suggest that while providing support is important, it may not be sufficient to meet the needs of caregivers over time.

In a study evaluating the effects of a training intervention for stroke caregivers, 300 patients and caregivers were randomized into intervention and control groups. The caregivers in the control group received standard information about stroke and were encouraged to attend rehabilitation sessions and be involved in discharge planning. In addition to the standard activities, caregivers in the intervention group received three to five training sessions in basic caregiving skills, such as providing assistance with ADLs and instrumental ADLs, and prevention and management of stroke-related problems. The caregivers in the intervention group had lower burden, anxiety, and depression. Patients in the intervention group also had lower anxiety and depression scores, reduced hospital costs, and improved QOL (Kalra et al., 2004).

There have only been a few systematic reviews of stroke-caregiving-intervention literature. Visser-Meily and colleagues (2005) conducted a critical review of stroke-caregiver-intervention studies. Their international sample included 22 studies from Europe, the United States, Canada, New Zealand, and Australia. They identified four types of interventions (educational, peer support, counseling, and specialist services) and nine outcome domains (QOL, emotional state, burden, family functioning, social activity in daily life, coping, satisfaction with care, knowledge, and social support). Only a few of the studies in the review focused specifically on the needs of caregivers; most focused on patient outcomes with caregiver outcomes as a secondary aim. The authors concluded that better research in intervention studies is needed after completing a caregiver needs assessment focusing on the nine outcome areas.

Brereton and colleagues (2008) conducted a systematic review of the stroke-caregiver-intervention literature. The inclusion criteria were that the study

had to be a randomized clinical trial (RCT) with the intervention and outcomes focused on the adult family caregiver and the caregiver was the primary research subject. The interventions in the eight papers reviewed included education, supportive counseling and support groups, in-home and telephone problem solving, and caregiver training while the patient was participating in inpatient rehabilitation. Because of the heterogeneity of the studies and the poor quality of the research designs, the authors concluded that while some interventions for family caregivers may be beneficial, the evidence was insufficient to make a recommendation about which interventions might be appropriate.

Smith and colleagues (2008) conducted a review of the effectiveness of informational interventions for stroke patients and their caregivers. They included 17 RCTs involving 1,773 patients and 1,058 caregivers in the review. They found evidence that informational interventions improve stroke-related knowledge and patient satisfaction and reduce patient depression scores, but this effect was small and “probably clinically insignificant” (p. 1). They concluded the evidence suggests that informational interventions that “actively involve patients and carers and include planned follow up for clarification and reinforcement have a greater effect on patient mood” (p. 1). Bhogal and colleagues (2003) found in their systematic review that there is “strong evidence...of a positive benefit of family education when an active educational counseling approach was taken” (p. 117).

Taken together, these studies indicate the need for additional intervention studies to determine the most effective interventions to improve the health of caregivers (Pierce & Lutz, 2008). All of the reviews commented on the lack of sufficient evidence and recommended additional research focusing on interventions to address the needs of caregivers. The literature also suggests that effective caregiver interventions should be individualized to the needs of the caregiver and patient, however. This could entail engaging patients and caregivers in intervention design, providing postintervention follow-up, or including a counseling component depending on the family structure. To tailor interventions to the individual needs of both patients and their family caregivers, rehabilitation nurses need to rethink how they provide services across the continuum of care from inpatient rehabilitation to discharge home.

Implications for Postdischarge Stroke Care

Stroke is a condition that affects not just the patient, but the family members who provide care and support to the person recovering from stroke. Nurses need to take a different approach to providing rehabilitation care

Key Practice Points

1. Stroke is the leading cause of disability in the United States; there are an estimated 4.8 million community-living stroke survivors with some level of disability.
2. Family caregivers are often ill prepared to manage the complex problems and postdischarge care needs of stroke patients.
3. Family caregivers of stroke patients often experience an overwhelming sense of burden and depression, decline in physical and mental health, reduced quality of life, and isolation.
4. Caregiver health is closely linked to the stroke patient's physical, cognitive, and psychological recovery.
5. Comprehensive caregiver assessment tools, case management interventions that support the needs and preferences of the caregiver as well as the patient, and systems that provide continuity of care across the stroke recovery trajectory are needed to improve care for stroke patients and their family caregivers.

to patients and their families affected by stroke. The first step in this approach would be to conduct a pre-discharge comprehensive assessment of caregivers. This would help in designing treatment plans that would meet the recovery goals of patients and the needs and skills of caregivers. In addition, nurses should explore care coordination and case management models that are tailored to the needs of the patient-family unit across the stroke-recovery trajectory through discharge home when patients and their caregivers are the most vulnerable. Current case management services are facility based and are not designed to provide assistance beyond the patient's length of stay.

Caregiver Assessment

The pre-discharge caregiver assessment should focus on the needs, capacities, capabilities, and resources of the primary family caregiver. Rehabilitation nurses need to view the patient and family caregiver as a unit. A successful discharge to the community often hinges on the expectation that family members or close friends (most often spouses/partners or adult children) will provide the necessary care. A systematic assessment of the needs and skills of those most likely to take on the primary caregiving role generally is overlooked, however (Feinberg, 2003). According to Feinberg, assessments of caregivers generally take one of two forms. In the first, the caregiver is assessed as part of the overall evaluation of the patient's needs. For example, a typical

rehabilitation admission assessment features questions related to the patient's marital status and social support, identifying who the caregiver will be upon discharge, whether there are stairs in the home, and pre-morbid living status. Questions that specifically evaluate caregiver needs and skills usually are absent from these assessments.

In the second type, formal assessments exclusively evaluate a caregiver's needs and effects of caregiving. These tools generally evaluate the effects of caregiving after a caregiver has provided care for some period of time. Tools have been designed to assess caregivers of patients with dementia and other long-term disabling conditions in the areas of burden, costs of caregiving, and information needs/knowledge (van Exel et al., 2004; Visser-Meily et al., 2005). For example, the Caregiver Appraisal Scale is designed to assess five dimensions of caregiving: satisfaction, impact, mastery, ideology, and burden (Struchen, Atchison, Roebuck, Caroselli, & Sander, 2002). The Patient-Caregiver Functional Unit Scale (PCFUS) evaluates the patient-caregiver dyad by assessing the physical and emotional difficulties experienced by a caregiver based on the patient's functional abilities (Fredman & Daly, 1997).

Several scales developed to assess caregiver burden have been validated with stroke caregivers, including the Zarit Burden Interview (Zarit, Orr, & Zarit, 1985), the Burden Interview/Index (Visser-Meily et al., 2005), and the Sense of Competence Questionnaire (SCQ; Scholte op Reimer, de Haan, Pijnenborg, Limburg, & van den Bos, 1998). The Bakas Caregiving Outcomes Scale is one of the few instruments designed specifically for caregivers of stroke, and it focuses on adaptation to caregiving. It was validated with caregivers of stroke patients with mean time since stroke of approximately 18 months (Bakas & Champion, 1999). All of these scales are designed to assess the impact of caregiving after informal caregivers have provided care for some period of time (not to assess caregiver needs before rehabilitation discharge).

Feinberg, a leading researcher on the needs of caregivers of patients with Alzheimer's disease, suggests that a baseline assessment is necessary to prioritize and tailor effective interventions for caregivers and improve the appropriate use of resources. The 12 domains important for caregiver assessment identified by Feinberg (2003) are listed in **Table 2**.

Feinberg also identified five important neglected areas of caregiving assessment: "(1) actual tasks performed by family caregivers beyond personal care functions; (2) skills necessary to provide the care; (3) quality of care provided; (4) values and preferences of the care recipient and the caregiver; and (5) positive aspects of caregiving" (2003, p. 28). Teel, Duncan,

Table 2. Twelve Potential Domains for Caregiver Assessment (Feinberg, 2003)

Caregiving context
Knowledge
Care recipient functional level
Care tasks and skills
Health
Social support
Financial, legal, and employment information
Coping strategies
Positive aspects of caregiving
Values and preferences
Confidence and competence in caregiving role
Strengths

and Lai (2001) suggested that a comprehensive assessment of stroke caregivers "should include determination of caregiver perceptions about the caregiving situation" (p. 59). Finally, several studies suggest the assessment of caregivers before patient discharge from rehabilitation is an additional neglected area for informal caregivers of stroke patients (Brereton & Nolan, 2000; Lutz, 2004; Smith, Lawrence, Kerr, Langhorne, & Lees, 2004). An assessment conducted early in the rehabilitation process that focuses on caregiver responsibilities, skills, values, and preferences could be used to help the rehabilitation team develop treatment plans to improve long-term outcomes for both patients and the family caregivers.

Case Management and Patient and Caregiver Postdischarge Needs

The second step to improving stroke care would be to design evidence-based comprehensive care coordination or case management services that are individualized to the needs of both patients and caregivers. Studies have described patients and caregivers as feeling "abandoned by services once they have returned home" (Rodgers et al., 1999, p. 2590). These patients and their informal caregivers transition from having intense therapy and nursing case management to having little or no assistance. Even with the case management and discharge planning services received during inpatient rehabilitation, they describe having to figure things out for themselves with little or no formal support after discharge (Lutz, 2004; Rodgers et al.). This finding is confirmed by Anthony and Hudson-Barr (1998), who found that families have "limited participation...in the discharge planning process" and are "unable to meet the needs of significant others after discharge" (p. 53).

Intervention studies focusing on the transitional needs of patients with other chronic conditions and their families after hospital discharge have employed nurse case management models. For example, Coleman and colleagues (2004) developed the "Care Transitions Intervention" (p. 1817), which was designed to promote communication across sites and encourage patients to take an active role in their care by asserting their preferences. Using a "Personal Health Record" (Coleman et al., p. 1818) and a nurse transitions coach, the intervention focuses on medication self-management, primary care and specialist follow-up, and knowledge of signs/symptoms of exacerbations. In this RCT, patients in the intervention group were "half as likely to return to the hospital as subjects" (Coleman et al., p. 1821) in the control group.

For more than a decade, Naylor and colleagues have been testing and refining an advanced nurse practitioner case management model to improve outcomes for patients with a variety of long-term conditions including diabetes, congestive heart failure, and high-risk pregnancy (Naylor, 1990, 2000; Naylor et al., 1999, 2004). In a large RCT, patients who were hospitalized with chronic conditions common to elderly patients (e.g., cardiovascular diseases, respiratory-tract infections, bowel procedures, and lower-extremity orthopedic procedures) were randomized to an experimental or control group ($N = 363$). Geriatric advanced registered nurse practitioners (ARNPs) followed the experimental group for 4 weeks. The control group received routine visits from a home health nurse. The protocol was implemented within 48 hours of hospital discharge. Patients in the experimental group had fewer rehospitalizations and lower costs at 24 weeks' postdischarge (Naylor et al., 1999). These researchers have consistently demonstrated the effectiveness of ARNP follow-up for frail elders to reduce costs and rehospitalization, but none of these transition interventions have been designed specifically for stroke patients and their informal caregivers. Also, these transition interventions focus on the patient and management of the chronic condition and not on caregiver needs.

Continuity of Care and Seamless Transitions

Typically, health care in the United States is site based and institutionally focused; care is delivered in discrete, independent healthcare systems and providers do not have access to patient care records across the continuum of care. When care is provided in independent "silos," it is more likely to be fragmented and patients are at higher risk for medical error and negative outcomes (Institute

of Medicine, 2001). The approaches to caring for stroke patients and others recovering from long-term disabling conditions needs to shift from a site-based, institutional focus to a family-centered focus that addresses patient and family needs across the illness recovery trajectory. This shift would allow for care coordination and case management services to cross sites and follow patients and families as they transition from acute care to rehabilitation to home. This type of transitional case management model has the potential to improve outcomes for both stroke patients and their family caregivers and reduce long-term health costs by preventing caregiver injury and morbidity and improving stroke-recovery outcomes.

This type of model is supported by Cameron and colleagues (2008). In their comprehensive review of the literature, they identified societal-, system-, and individual-level strategies to improve transitional care for stroke patients and their caregivers from acute rehabilitation to discharge home. At the individual level, these researchers argue for coordinated discharge planning and case management focused on patient and family needs. At the systems level, they encourage interdisciplinary coordination across the continuum of care, which includes electronic medical records systems that can be accessed by care providers across all levels of care. Finally, they encourage quality standards that transcend all levels of care. To achieve these strategies at the individual and systems level, they recommend flexible funding streams at the policy (societal) level of care.

Early supported discharge (ESD) models that have been tested in other countries offer promise for stroke rehabilitation. ESD consists of a comprehensive set of services delivered to patients in their homes. Patients and families are evaluated by the ESD team before discharge, and a comprehensive interdisciplinary treatment plan is developed. Services include rehabilitation therapies, primary care, nursing, and supportive services for both patients and family caregivers. By providing comprehensive coordinated care at home, health providers can work with patients and family members in their own environments to help patients recover and family members manage caregiving responsibilities. These models, when "appropriately resourced" (Langhorne et al., 2005, p. 501), show promise for improving outcomes and reducing costs for "selected stroke patients" (Langhorne et al., p. 501). However, these models must be implemented at the level and intensity—and with the broad array of necessary services—to ensure a successful transition and reintegration back into the community. Current funding mechanisms in the United States are not designed

to support the type and level of comprehensive home-based care that is recommended in the ESD models.

Discussion

This article provides an overview of the issues faced by family caregivers of patients recovering from stroke and potential intervention strategies. Family caregivers often experience increased burden, depression, and poorer health than their noncaregiving counterparts. Studies also indicate that stroke patients have better recovery outcomes if they have strong social support systems and well-functioning families to assist them with their post-discharge recovery needs. Some evidence suggests that professionally facilitated educational programs combined with other supportive interventions such as counseling improve outcomes for stroke patients and their family caregivers. However, there is evidence that rehabilitation nurses need to broaden their scope of care beyond focusing on the needs of patients to understanding the needs, preferences, and resources available to the patient-family unit across the stroke-recovery trajectory. Assessing the functional status of stroke (and other impaired) patients while they are in rehabilitation to determine their necessary level of care after discharge is a routine part of nursing care. Admissions protocols for patients need to be expanded to include a comprehensive assessment of the primary caregiver's health, needs, preferences, and resources.

Rehabilitation nurses also need to explore interventions that foster continuity of care and a seamless transition from inpatient rehabilitation to home. Interventions based on care coordination/case management models can be incorporated to facilitate continuity of care across sites and through the transition to home, where patients and their caregivers are at greatest risk for untoward outcomes. Establishing a case management model that tailors the plan of care to the needs of both patients and their family caregivers would improve discharge planning. This model should include a pre-discharge home assessment; assessment for and provision of postdischarge therapy needs for the patient; and educational, support, and advocacy services for the caregiver for a designated time period postdischarge. Caregiver support could include skill training, assistance with ADLs, and help with navigating complex disability services such as Social Security, Medicare, and Medicaid.

A first step toward a more seamless transition from inpatient rehabilitation to home for stroke survivors and their caregivers is to conduct a comprehensive pre-discharge assessment of the informal caregiver to better understand how the caregiver's skills, capacities, and resources match the patient's needs for

follow-up care. Based on this assessment, a highly individualized case management plan can be developed to help the caregiver attain the skills and services necessary to facilitate a successful and seamless postdischarge transition. In addition, follow-up post-discharge skill building and supportive counseling interventions individualized to the caregiver's needs (similar to the telephone intervention being tested by Bakas and colleagues (2009) could be implemented. Adding Web-based services (such as support groups and educational resources) and telehealth monitoring to measure long-term outcomes would make the intervention more comprehensive while minimizing resource use. Technology-based strategies have been successful with caregivers of stroke survivors and other chronically ill populations (Bass, McClendon, Brennan, & McCarthy, 1998; Lutz et al., 2009; Pierce et al. 2004a, 2004b; Rotondi, Sinkule, & Spring, 2005).

Conclusion

As we continue to improve the survival rates of patients who experience stroke, we must develop corresponding strategies to deal with the needs of family caregivers who are called upon to care for recovering stroke patients. We must shift our focus from the patient only to the patient, caregiver, and family. In many cases, the caregiver is viewed as a resource for the patient, not a separate entity in need of care and support. Until we develop comprehensive caregiver assessment tools, case management interventions that support the needs and preferences of the caregiver as well as the patient, and systems that provide continuity of care across the stroke care trajectory, we will continue to put both patients and caregivers at higher risk for injury, depression, decreased health and well-being, and even death.

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