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## Clinical Implications of Family-Centered Care in Stroke Rehabilitation

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### Abstract

**Background and Purpose**—Most stroke survivors will be cared for at home by family caregivers with limited training. Families actively involved in rehabilitation feel more prepared for the new responsibilities of caring for the stroke survivor. The focus of this article is to highlight the relevant concepts of a family-centered model of care and provide general guidance on how integrating a family-centered mindset may be clinically applicable.

**Family-Centered Care**—Family-centered care is a model of healthcare that encourages collaboration and partnership among patients, families, and providers with respect to the planning, delivery, and evaluation of health care. Care provided within such a model can expand providers' knowledge of the impact of illness and any issues that may affect eventual transition back home.

**Clinical Relevance and Conclusion**—Rehabilitation nurses should view stroke patients and family caregivers as a unit. Using family-centered strategies can help nurses provide appropriate, individualized care during rehabilitation.

### Keywords

stroke family caregiver; family-centered care

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The need for assistance varies greatly among stroke survivors (Kelly-Hayes, et al., 2003), most of which is provided by family members who are 'non-professional' caregivers with limited training (Lutz, Young, Cox, Martz, & Creasy, 2011; Sumathipala, Radcliffe, Sadler, Wolfe, & McKeivitt, 2012). Unfortunately, the abrupt nature of stroke and shortened lengths of stay in both acute and rehabilitation care settings allows little time to prepare families for the emotional, physical, and psychological demands of caregiving (Hafsteinsdóttir, Vergunst, Lindeman, & Schuurmans, 2011; Lutz, Young., Cox, Martz, & Creasy, 2011).

Current clinical practice guidelines endorse the inclusion of stroke patients and their families throughout the care continuum by recommending shared decision making with regard to goals and treatment planning (Davidson et al., 2007; Duncan et al., 2005; Lindsay, Gubitz, Bayley, & Phillips, 2012; Miller et al., 2010). Similarly, experts have long advocated for the consideration of families in stroke rehabilitation and treatment (Lutz et al., 2011; Lutz & Young, 2010; Evans, Connis, Bishop, Hendricks, & Haselkorn, 1994; Lindsay et al., 2012; Miller et al., 2010; Visser-Meily et al., 2006). Despite this, families continue to experience a low rate of involvement in care planning (Monaghan, Channell, McDowell, & Sharma, 2005) often resulting in a wide variety of unmet needs – such as a lack of information about the recovery process, residual disabilities, and strategies for meeting the patients’ post-discharge needs. Such unmet needs and lack of preparedness have potential negative consequences for the mental health of family caregivers, such as risk for depression (Grant, Weaver, Elliott, Bartolucci, & Giger, 2004) and anxiety (Greenwood & Mackenzie, 2010a). Caregivers are also at risk for physical injury, with research showing that caregivers with various educational needs may be four times more likely to report an injury (Hinojosa & Rittman, 2009).

Recent studies found that stroke family caregivers rely on their interactions with health care providers to identify and address their needs as they prepare for the caregiving role (Cameron, Naglie, Silver, & Gignac, 2013; Creasy, Lutz, Young, Ford, & Martz, 2013). Research has also shown that both patients and families generally want to be involved in multiple aspects of care, and that such care should be individualized to their unique needs (Cott, 2004; Young, Rogers, Dent, & Addington-Hall, 2009). Studies with caregivers who were more actively involved in the discharge planning process through partnering models or more detailed needs assessments found that families felt more prepared and had increased levels of satisfaction with care (Bull, Hansen, & Gross, 2000a&b; Shyu, Chen, Chen, Wang, & Shao, 2008). Unfortunately, research has also shown that providers are oftentimes hesitant to include family members, concerned that this may lead to conflict in the patient-provider relationship among other issues such as a lack of time and insufficient staffing (Frampton et al., 2008; Levack, Siegert, Dean, & McPherson, 2009).

From frustrated caregivers who acknowledged that “no one’s talked to us” (Creasy, Lutz, Young, Ford, & Martz, 2013, p. 93) to those who explained away the lack of information shared by providers by noting that “they probably assume that everybody knows what’s going on,” (p. 93) it is apparent from the literature that family-centeredness and inclusion in care planning is not currently consistently practiced within the rehabilitation setting (Creasy, Lutz, Young, Ford, & Martz, 2013; Monaghan, Channell, McDowell, & Sharma, 2005). Because of the impact stroke has on the survivor and on the family members who will provide most of the post-discharge care, providers must be committed to assessing how these caregivers are and will be affected. Whereas family members are often viewed as resources for the patient, family-centeredness draws attention to the family as an entity that itself needs support and care (Institute for Patient- and Family-Centered Care [IPFCC], 2010). The focus of this article is to extend the findings from previous studies by highlighting the relevant concepts of a family-centered model of care and how they can be applied to stroke rehabilitation. The purpose of this discussion is to provide rehabilitation

nurses general guidance on how integrating a family-centered approach to care is clinically applicable.

## **Traditional Healthcare: Patients and Families as Passive Recipients of Care**

Stroke survivors and family members have historically found themselves treated in a healthcare system that is driven by a biomedical – or illness-oriented – model of care (Balint, 1969). Even today, healthcare is often based in scientific empiricism, is reductionist, reactive, and disease-centered (Giroux & Farris, 2008; Siebens, 2011). Patients treated within this type of care model have little to no contribution or responsibility. They are often relegated to the role of passive, compliant recipients of care with little to no consideration for families (Allen & Petr 1998; Lutz & Bowers, 2000).

Not until the 1970s, with the articulation of the biopsychosocial model in the classic work by Engel (1977), did medical care formally incur a blending of the classic biological, psychological, and social factors. This was a major step toward holistic care (Stineman, 2011); by inviting consideration of more than just a patient’s symptom status, providers would be led to greater understanding of the illness. Other ‘conditions of life,’ such as social context, were organized within a hierarchical system ranging from the individual patient, through the provider-patient relationship, family systems, ethnic beliefs, and the political economy (Yamada, Greene, Bauman, & Maskarinec, 2000). Patients were treated as “human beings” (Engel, 1981, p. 103) whose experiences and behaviors shaped not only disease manifestation, but confidence in and adherence to medical care. Patients and families were further acknowledged as important in treatment and in influencing the outcomes of health and disease (McCollum & Pincus, 2009).

Despite the positive evolution of biomedicine toward the inclusion of psychosocial factors, care based upon the biopsychosocial model continued to be primarily provider-driven. While patient contributions were acknowledged with respect to treatment adherence and outcomes, collaborations and partnerships among providers and patients rarely existed. Within the biomedical model of care, families were not actively involved in care beyond the extent that their relationships with the patient informed providers about family issues that might impact the health of the patient (Engel, 1981; Weiss & Lonquist, 2012).

## **Family-Centered Model of Care: Collaborative Healthcare**

First advocated for by parents of hospitalized children in the 1960s and 70s and supported by experts in pediatric and family nursing (Beatty, 1972; Bell, 2013; Jolley & Shields, 2009; Shelton & Stepanek, 1994), the application of family-centered systems of care has slowly gained popularity in adult populations (Bamm & Rosenbaum, 2008). True to its earliest roots in the client-centered therapies of Carl Rogers (1951), family-centered care is not merely focused on increasing family presence and patient autonomy while decreasing medical paternalism. Instead, it encourages collaboration and partnership among patients, families, and providers with respect to the planning, delivery, and evaluation of health care (IPFCC, 2010); this type of care is not only “*about* patients...[but] *by* and *for* them” (Grob, 2013, p. 463). Such a model shifts the focus from care of patients to care for and with

consumers (Lutz & Bowers, 2000). Thus, family-centered care is not proposed as the goal of treatment, but rather the framework by which care may be provided.

### **Conceptual Framework**

Family-centered care has evolved beyond simply allowing the presence of families in care settings (Dokken & Ahmann, 2006). Although there is still no consensus for a singular conceptual framework for these paradigms, both patient- and family-centered care models call for the consideration of biopsychosocial factors as well as individualized and collaborative efforts (IPFCC, 2010; Mead & Bower, 2000). In one conceptualization of patient-centeredness, six interactive dimensions are proposed – the illness experience, person-as-a-whole, common ground, health promotion, enhancing relationships, and ‘being realistic’ (Stewart et al., 2003). Hutchfield (1999), in another conceptual analysis, identified various antecedents and attributes of family-centered care, including the need for respectful, collaborative relationships between providers and families.

Consideration that families have varied needs (i.e. more concerns than just the hospitalized individual) has become an important dimension of family-centered health care (IPFCC, 2010). Other dimensions of family-centered care include broadening the explanatory perspective of illness beyond the biomedical; giving consideration to the personal meaning of illness for patients; encouraging greater patient and family involvement through the sharing of responsibility and power in decision making; supporting a therapeutic alliance and valuing the relationship between providers, patients, and their family members; and acknowledging the unique perspective and influence of individual providers within these partnerships (Mead & Bower, 2000). While such models promote consumer empowerment, they primarily encourage partnerships and collaborations among patients, family members, and providers. Families’ dynamics and strengths, coping and adaptation strategies, experiences and expectations are illuminated through interactions with providers in attempts to provide support and promote an increased quality of life (Bamm & Rosenbaum, 2008). In practice, a two-way interaction between families and providers is the centerpiece that moves the collaborative process along (An & Palisano, 2013). Our own study further highlighted the importance of interactions between stroke caregivers and healthcare providers in identifying and managing issues related to providing care for the stroke survivor after discharge (Creasy, Lutz, Young, Ford, & Martz, 2013). While some caregivers actively engaged with providers to obtain information and resources, those who were more passive relied on providers to initiate these critical exchanges. When these vital conversations were not initiated by the healthcare team, caregivers were often left either feeling frustrated and unsure of how to proceed, or complacent, assuming that everything was being taken care of by the rehabilitation staff (Creasy, Lutz, Young, Ford, & Martz, 2013).

### **Patient- or Family-Centered Care?**

With core concepts and dimensions that are undeniably related to one another in the literature, it is unclear whether absolute distinctions exist or should exist between patient-, family-, client- or person-centered care, collaborative care, or patient-partnership models (IPFCC, 2010). However, in all cases, conceptualizations of ‘patient-centered’ call for involvement of the family in the care process (Charmel & Frampton, 2008; Frampton, et al.,

2008). The term ‘family’ is meant to acknowledge consideration for patients’ supportive networks; family caregivers are those who are designated by either the healthcare team or the patient as the family members who will be primary in providing care and support to the stroke survivor post-discharge. Because ‘family’ is defined by each individual patient, family caregivers may be spouses, siblings, adult children, other family members, or a close non-related person (IPFCC, 2010).

Being patient- and family-centered does not indicate a role-reversal among providers and consumers (Frampton, et al., 2008). While some patients and families may desire absolute control over all aspects of care (Berwick, 2009), this is the rare and extreme case; most families are interested in collaboration with, not control over, healthcare providers. Instead, family-centeredness calls for respect, interdependence, partnership, and negotiation (Falardeau & Durand, 2002), with family members – who have traditionally been relegated to more passive roles – included as allies in care (IPFCC, 2010).

## **Family-Centered Care with Stroke Patients and Caregivers**

### **Family Benefits and Clinical Implications**

Because stroke affects more than just the patient’s biology – such as relationships (Thompson & Ryan, 2009) and mental well-being (West, Hill, Hewison, Knapp, & House, 2010)) – a clinical picture encompassing the home environment as well as the social and psychological context would help expand providers’ knowledge of the impact of illness and any issues that may affect rehabilitation (Galland, 2006). Stroke patients and their family caregivers would benefit from a collaborative, dynamic treatment process that includes an understanding of the social and environmental context of the family. In our previously published study, for example, families wanted providers to understand the context of the patient’s life and tailor treatment goals and care decisions based on the patient’s individual preferences (Creasy, Lutz, Young, Ford, & Martz, 2013). Unfortunately, not all caregivers are proactive in providing this information to the rehabilitation team, and often, team members do not seek this information. Considering that less than 25% of stroke caregivers are currently involved in patients’ rehabilitation goal setting (Monaghan, Channell, McDowell, & Sharma, 2005), implementation of a family-centered model of care would encourage shared responsibility for these mutually beneficial interactions. When a truly interactive partnership exists, it is possible to attenuate barriers associated with conflicting treatment goals. Patients, families, and providers who collaborate and negotiate – as opposed to being strictly client-, family-, or doctor-focused – have a better chance of reaching a common goal for care (Falardeau & Durand, 2002).

Making family-centeredness part of the rehabilitation process would ensure that all patients and families are given the opportunity to participate in and contribute to treatment planning; for family caregivers of stroke survivors, active participation and engagement is especially crucial considering the large and diverse needs during this time (Cameron, Naglie, Silver, & Gignac, 2013). Without such a model in place, caregivers must often manage their needs and experiences on their own; those who take more passive roles may not receive the necessary preparation as they wait for providers to initiate critical interactions (Creasy, Lutz, Young, Ford, & Martz, 2013). As one caregiver stated, “It’s hard to ask questions about things when

you don't know [what to ask]" (p. 93). Because family members are often experts on the patient and 'constants' in care time spent evaluating and educating families may also benefit individual providers. Use of a familiar caregiver may help individualize care and address any patient resistance; family caregivers who are involved in care may also free up providers for other important aspects of recovery (Horwitz, Horwitz, Orsini, Antoine, & Hill, 1998).

Family-centered care would further benefit this population with respect to visitation issues and provider rounds. Directed more toward a pediatric care population, Griffin's (2003) discussion of visitation issues and family-centered benefits is nonetheless applicable to stroke patients and their caregivers. While some facilities endorse strict visitation hours or discourage family presence during some procedures, a family-centered approach recognizes the constant role of the family in patients' lives. Considering that an estimated 80% of stroke survivors are discharged home and most will be cared for by a family member following discharge from inpatient rehabilitation (Eldred & Sykes, 2008), families need to be involved in all aspects of care as early as possible. Further, allowing families – to the extent desired by patients and families – to be present during provider rounds would provide additional information for and engagement with families. Confidentiality and privacy issues may be circumvented by holding rounds in private patient rooms (IPFCC, 2010) and previous studies have found that patients generally want their family members actively involved in rounds (Rotman-Pikielny et al., 2007; Sisterhen, Blaszak, Woods, & Smith, 2007). It should also be acknowledged that family caregivers may have other responsibilities outside of the caregiving role such as preparing the home for discharge, work, or other family or personal needs. Therefore, providers must be aware that these caregivers' inability to be present at the facility every day does not necessarily translate to uninvolved or uncommitted caregivers (Lutz, Young, Cox, Martz, & Creasy, 2011).

Transitioning home is possibly one of the most critical times for stroke patients and caregivers, as caregivers often feel unprepared for survivors' post-discharge limitations and are frequently surprised by the discharge date itself (Lutz et al., 2011). Providers may "face a fundamental ethical dilemma. There is an imperative to discharge, but many families need more time and support to adjust" (Hokenstad, Hart, Gould, Halper, & Levine, 2005, p. 392). Despite the known benefits of increased satisfaction and feelings of preparedness (Bull, Hansen, & Gross, 2000b), current systems of care do not encourage active family participation in discharge planning (Almborg, Ulander, Thulin, & Berg, 2009). Family-centeredness and partnership could increase families' participation in discharge planning and may mediate some of the negative post-discharge experiences of some caregivers, such as depression and anxiety (Berg, Palomäki, Lönnqvist, Lehtihalmes, & Kaste, 2005; Greenwood & Mackenzie 2010b). Some caregivers feel exhausted and overwhelmed before the patient is even discharged (Lutz et al., 2011). Involving families throughout the trajectory of care and incorporating assessments of the unique needs of this population may help providers assist families in developing routines for the self-care and respite that will be crucial to the long-term health of the dyad (Steiner, Pierce, Drahuschak, Nofziger, Buchman, & Szirony, 2008).



## Barriers and Ethical Considerations

Clinical-level barriers to a family-centered model of care for stroke rehabilitation involve a complex mixture of interpersonal or attitudinal factors as well as ethical considerations. Even if the family is considered the 'basic unit of care', providers must remain vigilant that the competent, individual patient's rights are not superseded by the family's preferences (Allen & Petr, 1998). Providers may be faced with the dilemma of who the actual patient is – the individual or the family unit – in addition to responsibility issues that arise when tasks are delegated to family members. Coyne (2013), for example, found that some providers working within a family-centered model over-relied on families; while this study focuses on nurses caring for children, the implication that caregivers legitimately feel that they had to be 'present constantly' is applicable to caregivers in stroke settings as well.

Provider-specific barriers also exist, indicating a need for provider buy-in prior to any successful implementation of a family-centered approach. Most providers are comfortable with biomedical model and may have insufficient knowledge of patient- or family-centered models of care, for instance thinking that family and patient inclusion will take up too much time (Sumsion & Smyth, 2000). Other barriers include possible mismatch between provider and patients' needs and goals for treatment (Irwin & Richardson, 2006) and inconsistent communication about the roles and expectations of caregivers in the clinical setting (Coyne, 2013). Adopting a true family-centered model of care not only requires collaborative partnerships among providers, families, and patients, but also organizational support and the provision of resources (Cott, 2004). Without such system redesign, providers may be faced with difficulty in changing their practice.

As with other clinical models, patient- and family-centeredness may also not be important to all patients. Consistent with findings from an earlier review of patient preferences (Benbassat, Pilpel, & Tidhar, 1998), Swenson, Zettler, and Lo (2006) found that patient values and expectations affected their preference for biomedical versus patient-centered communication. Age also affected patients' desires for participation in care, with older generations less interested in collaboration – a concerning implication for stroke patients and their caregivers since almost 75% of strokes occur in persons aged 65 or older (Roger, et al., 2012). Additionally, the perception and definition of family and the appropriateness of family members' involvement in care may vary across cultures, requiring rehabilitation nurses to remain sensitive to these differences when defining what family-centeredness entails (Bamm & Rosenbaum, 2008; IPFCC, 2010). The only sure way to establish patients' and families' preferences is through direct inquiry, which itself espouses the tenants of family-centeredness through the provision of respectful, dignified, and personalized care (McClimans, Dunn, & Slowther, 2011; Rosewilliam, Roskell, & Pandyan, 2011).

## Recommendations for Rehabilitation Nurses

In order to provide care that is family-centered, rehabilitation nurses must ensure that stroke patients and family caregivers are engaged in ways consistent with the conceptual framework of this care model. The planning and delivery of care should be determined through collaborative partnership among providers, patients, and families (IPFCC, 2010). Working with stroke patients and their family caregivers with a family-centered approach

requires that nurses be constantly attentive to the following questions: What are the expectations this family has for recovery and life after discharge? Are these realistic and, if not, how can we work together to develop a plan that is realistic and acceptable to all? Can this person do what we are asking them to do regarding caring for the stroke survivor? Does the family caregiver have the knowledge, needed skills, resources, and capacity to provide the care for the stroke survivor? Is this family caregiver committed to and accepting of this new role? We recognize that to fully integrate family-centered care into practice changes in the organizational culture and structure of our health care systems are needed. However, we have identified some strategies that may be implemented by individual rehabilitation nurses working in rehabilitation settings.

One strategy would be to conduct a thorough assessment of caregivers' strengths, capacity to provide care, and gaps in their needs and ability to perform the caregiving tasks that are expected of them. Recommendations already exist for caregiver assessment and the need for case management (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Lutz & Young, 2010; Young, Lutz, Creasy, Cox, & Martz, 2014), and research shows that the needs of stroke caregivers change throughout the trajectory of care (Cameron, Naglie, Silver, & Gignac, 2013; Lutz, Young, Cox, Martz, & Creasy, 2011). Therefore assessment is not a one-time event, but rather a continual process. One strategy for identifying caregivers' needs is to simply ask them. Providers must also assess patients' and caregivers' expectations about rehabilitation outcomes and life post-discharge. This knowledge may help providers work with patients and caregivers to identify the needs and resources required to meet these expectations, or to help families develop realistic goals for recovery and post-stroke life. Close collaboration among all rehabilitation healthcare providers – including nurses, physicians, and occupational, physical, and speech therapists – is necessary to gain a complete picture of families' post-discharge needs. In addition to patient assessments conducted within the inpatient rehabilitation setting, an assessment of the home environment to identify other needs would be beneficial. This type of assessment is recommended in several stroke rehabilitation guidelines (Lindsay, Gubitz, Bayley, & Phillips, 2012; Miller, et al., 2010).

Engaging caregivers in meaningful ways that address issues identified through the caregiver assessment is another strategy that nurses can use to begin to implement family-centered care in rehabilitation settings (Young, Lutz, Creasy, Cox, & Martz, 2014). It is not enough to assess patients and caregivers' expectations and needs; providers must work with these families to address these issues and activate the appropriate resources. Various resources are already available to assist nurses and other rehabilitation healthcare providers in the assessment of and engagement with stroke patients and their family caregivers.

For example, the Agency for Healthcare Research and Quality (2013) provides a free, online, evidence-based toolkit, "Guide to Patient and Family Engagement in Hospital Quality and Safety", that suggests strategies to improve family engagement. These include recruiting patients and family members to be members of advisory committees to help improve quality, and implementing strategies to improve continuity of care across shifts and communication with all stakeholders. The toolkit also includes a basic tool for discharge planning. While the toolkit was developed to be used in acute care institutions, the tools



could be easily revised for application to inpatient rehabilitation and skilled nursing settings. For example, nursing staff could recruit family members of stroke patients for a focus group to get feedback on issues and concerns that family members identified during a past stay on a rehabilitation unit. Following the focus group, an advisory panel that includes staff, family members, and previous patients could be convened to develop strategies to address concerns. Nurses working on the unit could also initiate bedside shift reports that include family members and patients to help improve continuity of care.

The “Patient-Centered Care Improvement Guide” developed by Planetree, Inc. and The Picker Institute also provides many detailed suggestions and ideas for providing a more patient and family-centered approach to care (Frampton, et al. 2008). The guide includes an excellent “self-assessment” tool that rehabilitation nurses could adapt their settings to identify strengths and areas for improvement in providing family-centered care (pp. 10–16). The AHRQ toolkit and the patient-centered care guide are available online.

Finally, anticipatory guidance strategies may be helpful to help prepare caregivers for the transition home and changes they might expect. Even thorough assessments cannot identify all potential needs that these families may face. Nurses and other rehabilitation providers should work with patients and families to help them anticipate post-discharge needs and provide information and support resources for issues that may be identified after discharge. This may include information about mental health issues (i.e., anticipated personality changes in the survivor, grief and depression in both patients and caregivers, resources for family counseling), respite needs and resources (i.e., available adult day care programs), and information on community resources (i.e., food banks, financial assistance). Another strategy is for providers to educate caregivers on the importance of self-care and to provide them with realistic information and resources for this.

## Conclusion

When stroke survivors are discharged home, most of the care provided will be by family members; the inclusion of family caregivers in treatment planning and needs assessments in the rehabilitation setting should therefore be implemented. Despite this, families are not generally included as integral within the trajectory of stroke care. Why is this? One reason may be due to the challenges and obstacles discussed, notably individual provider attitudes and organizational barriers. It is also possible that families of adult stroke patients do not see themselves as integral to the treatment of their loved ones’ health care.

Our colleagues in pediatric and family nursing recognized the importance of implementing the components of family-centered care into the care of children several decades ago (Harrison, 2010; Jolley & Shields, 2009). In 1994, Shelton and Stepanek identified eight elements of family-centered care for children with special needs which continue to be supported by research and have been recently incorporated into intergenerational family-centered care models (IPFCC, 2010). As rehabilitation nurses, we should become familiar with these elements of family-centered care and identify ways to implement them with adult stroke patients and their family members.

One approach would be to convene family advisory groups to help prioritize the elements of family-centered care and develop implementation strategies. The Agency for Healthcare Research and Quality (2013) and the “Patient-Centered Care Improvement Guide” (Frampton, et al., 2008) are excellent resources that provide specific strategies and ideas for implementing a more family-centered approach to care.

While we have provided recommendations for rehabilitation nurses to implement family-centered care, ultimately implementation of this approach to care needs to be addressed at a systems level and should include all members of the rehabilitation team. Family-centered care needs to be part of the vision, commitment, culture, & infrastructure of the organization.

Family-centered care is also an issue of ethics (Hirschfeld & Wikler, 2003; Levine & Zuckerman, 1999). Just as bioethics have evolved toward patient autonomy, self-determination, and beneficence, so, too, must they evolve to incorporate the interests and preferences of the millions of family caregivers currently providing hundreds of thousands of hours and dollars of care each year. Functional independence measures notwithstanding, providers know that certain stroke patients will require extensive home-based care following discharge; they know family caregivers will ultimately be the providers of this care. “Family well-being is jeopardized if caregiving demands exceed a threshold unique to that family system, and the collapse of the family system will in turn harm the patient who has sustained the stroke” (Brashler, 2006, p. 14). Providers therefore have a duty and an obligation to assess, prepare, and support such caregivers as much as possible – both for the patient and family’s sake – prior to the inevitable discharge. Nurses and other rehabilitation providers should view stroke patients and family caregivers as a unit. While caregiver assessment tools exist, their purpose is generally to evaluate the family member’s ability to provide care and be a resource for the patient (Feinberg, 2003; Lutz & Young, 2010). We must think about how to involve families more collaboratively in the stroke rehabilitation process; assessment of need should not just stop with the patient but should also include the needs of the family. After all, without the family, the patient could not go home.

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