Family Caregivers of Stroke Survivors

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Stroke is one of the leading causes of disability in the United States (Rosas and et al., 2007). Many stroke survivors subsequently experience persistent impairments that can include cognitive and neuromuscular dysfunction (ranging from memory problems to paralysis, hemiplegia, and weakness), vision problems, communication deficits (e.g., aphasia), emotional liability, and depression (Hackett, Yap, Parag, & Anderson, 2005; Lai, Studenski, Duncan, & Perera, 2003), making them dependent on care and help in their daily living. Family members provide the majority of care and assistance received by stroke survivors. The burden and distress experienced by many of these caregivers has been recognized for some time. A sizeable amount of literature documents many of the problems experienced by these caregivers and the characteristics of those who are at risk for depression, distress, and poor health.

In this chapter we provide an overview of the issues and problems encountered by many caregivers of stroke survivors, and we describe some of their unique needs and challenges. We then review studies of caregiver interventions that appeared in the peer-reviewed literature from 2000 to 2013. We also attend to existing, major reviews of the intervention literature that were published during this time frame. We consider these interventions from the perspective of a chronic care model, evaluating the implementation and effectiveness of community and home-based programs. We close with brief case studies that illustrate elements of evidence-based practice.

STROKE CAREGIVER NEEDS, ISSUES, AND CHALLENGES

Consistent with caregivers for other health conditions, women are more likely than men to assume the role of caregiver after a stroke by a family member; wives

Mayo, Hanley, & Wood-Jahnsen, 2003). Although distress after stroke is a common and understandable occurrence among caregivers, caregiver adjustment is best understood as a dynamic process over time. Despite this understanding, only a few studies have examined the adjustment of family caregivers of stroke survivors beyond the initial year of caregiving (Gaugler, 2010). For our purposes, it is helpful to consider the varying caregiver needs that occur in five phases following stroke: (a) event/insurance, (b) stabilization during acute care, (c) preparation during acute care and in-patient rehabilitation, (d) implementation during the first few months after the patient returns home ("learning the ropes"), and (e) long-lasting adaptation in the home and community (Cameron & Cigan, 2008). Much of the extant literature concerns the issues and needs family caregivers face during acute and postacute care, during rehabilitation, and upon return to the community. These are critical periods during which family members assume a caregiver role while simultaneously having considerable interaction with health and rehabilitation staff as they provide prescribed services.

Event, Diagnosis, Stabilization, and Rehabilitation

For many stroke caregivers, hospitalization and the first few months after hospitalization are the most difficult time during in the first 2 years of caregiving. Early stroke caregiving stress often consists of uncertainty, new responsibilities, and dealing with the stroke survivor's impairments and emotions. Information about the patient's health is very important to stroke caregivers during the acute rehabilitation phase, perhaps more so than during the postacute rehabilitation phase (King & Senn, 2006). Stroke caregivers need information, support, and accessibility to the patient and the healthcare professional. Stroke caregivers need healthcare professionals to take the time to answer their questions honestly, having consistent access to a specific "contact" person is also valued (i.e., it is important to talk to the same nurse each time; Hafst adjust, Vergaust, Lindeman, & Schramka, 2013). In the acute and postacute setting, caregivers want information about stroke in general, as well as resources that provide information on preventing recurrent strokes, communicating problems, coping with problems, preventing the physical and emotional deterioration of the stroke survivor, and handling the stroke survivor's changing needs.

Unmet psychosocial needs often concern issues with the healthcare team. In one study, a majority of caregivers wanted written information about stroke, its comorbidities, and caregiving while their care recipient was hospitalized, but of those caregivers studied, less than half received any written information (Zoffin, McKenna, Worrall, & Badd, 2004). Family members report they were inadequately prepared for caregiving and their role as a caregiver was taken for granted by the healthcare staff regardless of their age, health, and other characteristics (Smith, Lawrence, Kerr, Langhorno, & Lees, 2004). One study found that stroke caregivers experienced difficulties speaking with the


healthcare team when needed and were concerned that their input was not considered by the healthcare team. However, 90% of stroke caregivers reported being satisfied with the support they received from family and friends. The emotional needs of stroke caregivers included dealing with stress and anxiety, sadness and grief, and fear of another stroke. Practical needs consisted of caring for the stroke survivor and changing their usual routine and lifestyle (MacIlsaac, Harrison, Buchanan, & Hopman, 2011). Stroke caregivers may be more satisfied with their community network support and their familial support during the postacute rehabilitation phase than they are during the acute rehabilitation phase (Kim & Moon, 2007).

Caregivers’ needs vary with treatment settings. A South Korean study found that caregivers whose stroke survivors are being treated in inpatient facilities find health information more important than caregivers whose stroke survivors are being treated in outpatient clinics or in a geriatric day hospital (Kim & Moon, 2007). Caregivers whose stroke survivors are being treated in a geriatric day hospital report greater satisfaction with health information, emotional information, instrumental information, professional information, community network support, and familial support than caregivers whose stroke survivors are being treated in inpatient facilities or outpatient clinics (Kim & Moon, 2007).

Studies relying on a liberal indicator of depression suggest that more than one third of family caregivers may be at risk for major depression disorder within days of discharge from rehabilitation (Grant, Bartolucci, Elliott, & Giger, 2000; Grant, Weaver, Elliott, Bartolucci, & Giger, 2004b). Depression observed during hospitalization and rehabilitation may be the best single indicator of caregiver depression 6 months and 18 months after discharge (Berg, Palomaki, Lonnqvist, & Kaste, 2005).

Return to the Community and Initial Adjustment

For most caregivers, the first month after hospital discharge is the most stressful period as the limitations of the stroke survivor become salient at home (Grant, Glandon, Elliott, Giger, & Weaver, 2004a). The main issues and challenges that stroke caregivers face during the first month after hospital discharge are concerns about safety of the stroke care recipient (e.g., potential for falling as a result of stroke survivor impulsivity, weakness, dizziness), functional deficits of the stroke care recipient (e.g., dressing, bathing, walking, transferring), and managing cognitive, behavioral, and emotional changes in the stroke care recipient (Grant et al., 2004a). These three issues and challenges continue to be salient throughout the second and third months after hospital discharge. It is important to note that caregivers have reported experiencing improvements in these areas by the end of the second month and into the third month (Grant, Glandon, Elliott, Giger, & Weaver, 2006b).

A systematic review of educational needs after hospitalization found that stroke caregivers wanted information about preventing future strokes, dealing
with communication problems, coping with problems, preventing the physical and emotional deterioration of the stroke survivor, and handling the stroke survivor's changing moods. Other needs included information about preventing falls, maintaining adequate nutrition, staying active, managing stress, and dealing with emotions and mood changes (Hafsteinsdóttir et al., 2011). Qualitative research has found that, during this time, caregivers experience an array of problems with a care recipient, including dealing with interpersonal issues, managing mood and behavioral disturbances, and assisting with activities of daily living (e.g., bowel incontinence [Grant et al., 2004a; Haley et al., 2009; King, Ainsworth, Ronen, & Hartke, 2010]). Despite the well-known difficulties caregivers have with these problems, caregivers in the study conducted by Smith and colleagues (2004) believed healthcare staff often choose to ignore these issues during hospitalization.

After the return to the community, a substantial percentage of caregivers are unable to maintain employment outside the home (Ko, Aycock, & Clark, 2007). Those lacking in social support who also possess a pessimistic view of solving problems are more likely to have more depressive symptoms during the first 13 weeks postdischarge (Grant, Elliott, Weaver, Glandon, & Giger, 2006a). However, the same study also found that a more optimistic approach to solving problems was associated with positive changes in personal health during this period. Indeed, in a review of the available literature concerning stroke caregiver adjustment over time, Gaugler (2010) observed that few studies actually examine changes in adjustment over an extended time period, and there may be unique characteristics of those who do and do not experience adjustment problems over time. Research concerning positive adjustment over time is lacking, but those at risk for increased burden, stress, and poor adjustment should be identified as early as possible before discharge as well as after their return to the community.

Stress levels for stroke caregivers and stroke survivors have been correlated positively throughout the first year after hospital discharge. Stress levels for both members of the caregiving dyad were at a moderate level and had decreased by the end of the first year, but stroke survivors experienced a greater decrease in stress than stroke caregivers. Predictors of lower levels of stroke caregiver stress during the first year after hospital discharge include being older, a greater number of people in the caregiver's support network, greater caregiving preparedness, use of a reframing coping style, and higher functioning of the stroke survivor. Predictors of higher levels of stroke caregiver stress during the first year after hospital discharge include being female, using a passive coping style, and having a lower self-rated health status at the time the stroke survivor is discharged from the hospital (Ostwald, Bernal, Cron, & Godwin, 2009).

Other studies suggest a complementary—if not reciprocal—relationship of caregiver distress and well-being to stroke survivor emotional adjustment and functioning (Grant et al., 2013; Perrin, Heesacker, Stidham, Rittman, & Gonzalez-Rothi, 2008). Although causal effects are difficult to disentangle, these studies indicate that stroke survivors have more emotional difficulties, physical impairments, and isolation as caregiver distress increases during the first year.
after discharge. Of the various factors that predicted stroke survivor adjustment significantly after return to the community, Klinedinst and colleagues (2009) found caregiver depression at baseline was the only clinical predictor that could be considered potentially modifiable.

Long-Term Adjustment

Stroke caregiving stress later during the stroke disease trajectory consists of a plateau in the survivor’s functioning, caregiver and survivor health problems, finances, and dealing with the caregiver’s emotions. Balancing work and caregiving is a stressor that is present in both the early and later stages of stroke caregiving; but, overall, the specific difficulties of stroke caregiving change over time and there is individual variation in needs as well (King & Semik, 2006). Stroke caregivers report greater burden and lower overall quality of life when compared with age- and sex-matched population norms during the first 2 years of caregiving (White et al., 2003). White et al. (2003) found caregivers experienced an average of four to five physical symptoms each month. The most frequently reported of these physical symptoms were feeling tired, headaches, stiff joints, and trouble falling asleep. Although other evidence indicates that burden may decrease during the first 3 years of caregiving, this work also found caregiver-care recipient dyads experienced steady and significant decreases in interpersonal and social relations (Visser-Meily et al., 2009). A recent study found a population-based sample of family caregivers had significantly poorer adjustment on several psychosocial dimensions at nine months post-stroke than a matched non-caregiving control group, but by three years these differences dissipated (Haley, Roth, Hovater, & Clay, 2015). This work illustrates the value of longitudinal studies of population-based samples in understanding the long-term adjustment of family caregivers.

Cultural influences on caregiver adjustment range from the subtle to the obvious throughout the literature. Across cultures and nations, financial issues loom prominently in the burden reported by caregivers (Lurbe-Puerto, Leandro, & Baumann, 2012; Mak, Mackenzie, & Lui, 2007). Deteriorations in personal health can vary by nationality (Lurbe-Puerto et al., 2012), and by corresponding disparities and differences in health care and support services. Caregiver needs vary over time among caregivers of different nationalities, consistent with findings from studies of American samples. Cultural values such as familismo, the value of placing family over the individual, may account for differences observed in time spent in caregiving, support received from other family members and a larger social network, and emotional reactions to care-recipient adjustment in comparisons of Puerto Rican caregivers with white and black caregivers (Finojosa & Rittman, 2007; Perrin, Heesacker, Utne, & Rittman, 2010). Collectively, the available literature indicates that individually tailored, culturally sensitive interventions and services for caregivers are warranted.
SYSTEMATIC REVIEWS AND META-ANALYSES OF THE INTERVENTION RESEARCH

Several systematic reviews of the intervention literature concerning family caregivers of stroke survivors have appeared during the past 13 years, and several of these are listed in the evidence table (Table 3.1). In one of the more influential reviews (cited 123 times to date, according to Google Scholar), Visser-Meily and colleagues examined the effectiveness of different types of interventions for caregivers of stroke survivors: provision of specialist services, psychoeducation, counseling, and social support from peers (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005). Of the 22 studies reviewed, 10 reported positive results on one or more of the outcome measures used, including a significant reduction in depression, improvement of knowledge, improvement in satisfaction with care, improvement in family functioning, improvement in quality of life, better problem-solving skills, more social activities in daily life, more social support, and less burden. Four of the six psychoeducation studies had positive results, three of the four counseling studies had positive results, and the only study that concerned social support from peers study had no positive results. These researchers concluded that they could not recommend a specific type of intervention that is most beneficial for stroke caregivers. However, they suggested that future research base interventions on the needs of caregivers according to a caregiver needs assessment, as opposed to providing a “prepackaged” intervention. They also asserted that counseling interventions seem to be promising because they have been shown to be effective and because they focus on the needs of caregivers specifically, as opposed to focusing on the needs of both stroke survivors and stroke caregivers.

A substantive review by Liu and colleagues specifically examined interventions for caregivers that tried to improve their problem-solving skills across a variety of formats, including training, education, and support (Liu, Ross, & Thompson, 2005). Eleven studies met the criteria for review, six of which were randomized controlled trials (RCTs). Although the authors concluded the overall evidence supported the use of problem-solving approaches to treat caregiver depression, this literature was plagued by a lack of theoretical grounding, poor operational definitions of “problem solving,” and lack of diversity in the samples. Moreover, all the studies were confined to the early “poststroke” phase of caregiving.

Only two of the reviews listed in Table 3.1 featured meta-analytic procedures. The meta-analysis by Lee, Socken, and Picot (2007) was restricted to studies written in English that used the Short Form Health Study-36 (Ware & Sherbourne, 1992) to measure caregiver adjustment, resulting in only four studies for analysis. All four were RCTs; two were studies of education programs and two studied support programs. Although the effect sizes provided evidence for efficacy, the strict criteria for inclusion and the small number of studies limit the
<table>
<thead>
<tr>
<th>Author (Year)</th>
<th>Sample (Baseline)</th>
<th>Racial/Cultural Factors</th>
<th>Design</th>
<th>Interventions</th>
<th>Results</th>
<th>Evaluation</th>
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<tbody>
<tr>
<td>Bakas et al., 2009b</td>
<td>50 caregivers; phase 4</td>
<td>25% black, 73% white, 2% other</td>
<td>NR</td>
<td>RCT</td>
<td>TASK</td>
<td>Increased optimism, and decreased task difficulty and threat appraisal were noted.</td>
</tr>
<tr>
<td>Bakas et al., 2009a</td>
<td>40 caregivers; phase 4</td>
<td>NR</td>
<td>NR</td>
<td>Program evaluation</td>
<td>TASK</td>
<td>Content validity rated as 4.56 points on a scale of 1 to 5 points. Satisfaction with TASK rated as 4.41 points on a scale of 1 to 5 points.</td>
</tr>
<tr>
<td>Bjorkdahl et al., 2007</td>
<td>35 caregivers; phases 4 and 5</td>
<td>NR, but study took place in Sweden</td>
<td>NR</td>
<td>RCT</td>
<td>Home setting intervention; day rehabilitation</td>
<td>No statistically significant differences in caregiver burden between the two interventions were noted.</td>
</tr>
<tr>
<td>Grant et al., 2002</td>
<td>74 caregivers; phase 4</td>
<td>74% white, 26% black</td>
<td>NR</td>
<td>RCT, three-group, repeated-measures experimental design</td>
<td>Social problem-solving telephone intervention</td>
<td>Improved problem-solving skills, greater caregiver preparedness, and decreased depression were noted.</td>
</tr>
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**Table 3.1: Intervention Studies for Family Caregivers of Stroke Patients**
<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Sample Characteristics</th>
<th>Design</th>
<th>Intervention</th>
<th>Summary of Findings</th>
<th>Intervention Effectiveness</th>
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<tbody>
<tr>
<td>Hartke &amp; King, 2003</td>
<td>88 caregivers</td>
<td>81% white, 15% black, 4% other</td>
<td>NR</td>
<td>RCT</td>
<td>Structured psychoeducational telephone support group intervention</td>
<td>There was a statistically significant reduction in stress, but no statistically significant changes in depression, burden, loneliness, or competence. Intervention was effective in preventing accumulation of burden over time, but it was ineffective in reducing burden over time.</td>
</tr>
<tr>
<td>Kim et al., 2012</td>
<td>73 caregivers</td>
<td>NR, but study was conducted in South Korea</td>
<td>NR</td>
<td>Repeated-measures quasi-experimental design</td>
<td>Hospital-based group intervention, home-based individual telecare intervention</td>
<td>There was a statistically significant decrease in caregiver burden in the home-based individual telecare intervention group. Home-based individual telecare intervention was more effective in reducing caregiver burden than hospital-based group intervention.</td>
</tr>
<tr>
<td>King et al., 2007</td>
<td>30 caregivers</td>
<td>83% white, 10% Hispanic, 7% black</td>
<td>NR</td>
<td>Single-group repeated-measures design</td>
<td>CPSI</td>
<td>A statistically significant improvement in depression, preparedness, and anxiety was noted; however, caregiver burden and taking care of one's own needs declined over time. Effectiveness of intervention was attributed to it being tailored to each individual caregiver.</td>
</tr>
<tr>
<td>Klag et al., 2012</td>
<td>255 caregivers</td>
<td>64% white, 36% nonwhite</td>
<td>NR</td>
<td>RCT</td>
<td>CPSI</td>
<td>Statistically significant changes in depression, life change, and health were observed at 3 months, but faded by 6 months. A second round of intervention was recommended because caregiver needs change over time.</td>
</tr>
<tr>
<td>Ouapra et al., 2010</td>
<td>140 caregivers</td>
<td>NR, but study conducted in Thailand</td>
<td>NR</td>
<td>Two-group nonrandomized experimental design</td>
<td>SELF</td>
<td>The SELF group had a better quality of life and lower levels of strain than the control group. Providing education and support can reduce strain and improve quality of life.</td>
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<tr>
<th>Author</th>
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<tr>
<td>Perrin et al., 2010</td>
<td>89 caregivers; phases 3 and 4</td>
<td>Diversity of Study Sample: 16.3% African American/ black, 1.6% Asian American, 16.4% non-Hispanic white/white, 62.3% Hispanic/Latino Puerto Rican, 3.3% Hispanic/Latino Mexican</td>
<td>Yes primary tool of intervention is a guidebook with two different versions designed specifically for Mainland and Puerto Rican stroke caregivers</td>
<td>Experimental design with random assignment of participants to either the treatment group or the control group</td>
<td>TAP, consisting of skill development, education, and supportive problem solving. At 3 months, the treatment group had lower depression scores than the control group when controlling for baseline differences. A decrease in strain in the treatment group and an increase in strain in the control group were observed.</td>
<td>TAP may be an effective intervention during the transition from hospital to home. Caregivers in the treatment group were highly satisfied with the intervention; caregiver satisfaction was associated with reduced depression and strain.</td>
</tr>
<tr>
<td>Pfeiffer et al., 2014</td>
<td>122 caregivers; phase 5</td>
<td>Diversity of Study Sample: 82% native German, 8% ethnic German expatriates from Eastern European states, 10% of various European migration backgrounds</td>
<td>NR</td>
<td>NR</td>
<td>RCT</td>
<td>Problem-solving intervention</td>
</tr>
<tr>
<td>Schreiber et al., 2006</td>
<td>117 caregivers; phase 5</td>
<td>NR</td>
<td>NR</td>
<td>Program evaluation</td>
<td>Group program intervention, home visit program intervention</td>
<td>Overall, stroke caregivers expressed a preference for the group program intervention.</td>
</tr>
<tr>
<td>Shyu et al., 2010</td>
<td>158 caregivers; phases 4 and 5</td>
<td>NR, but study took place in Taiwan</td>
<td>NR</td>
<td>NR</td>
<td>RCT</td>
<td>Telephone call and home visit intervention</td>
</tr>
<tr>
<td>Study</td>
<td>Sample Size</td>
<td>Methodology</td>
<td>Intervention Description</td>
<td>Outcome Description</td>
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<tr>
<td>Shyu et al., 2010</td>
<td>NR</td>
<td>NR</td>
<td>Telephone call and home visit intervention</td>
<td>Intervention did not improve stroke caregivers’ quality of life.</td>
<td></td>
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</tr>
<tr>
<td>Smith et al., 2012</td>
<td>32</td>
<td>NR</td>
<td>Web-based psychoeducational intervention</td>
<td>Depression was significantly lower statistically for the intervention group than for the control group.</td>
<td></td>
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</tr>
<tr>
<td>Wilz &amp; Barskova, 2007</td>
<td>124</td>
<td>NR</td>
<td>Cognitive-behavioral group therapy (using different evidence-based therapeutic techniques)</td>
<td>A decrease in depression and anxiety, and an improvement in quality of life in the intervention group were noted.</td>
<td>Intervention targeted at stroke caregivers specifically, as opposed to stroke caregivers and survivors, was effective.</td>
<td></td>
</tr>
<tr>
<td>Brereton et al., 2007</td>
<td>8</td>
<td>NR</td>
<td>Systematic review of RCTs</td>
<td>All interventions had positive outcomes. Only training, problem solving, and support improved quality of life and well-being.</td>
<td>The quality of the included RCTs was low, thus it is not possible to draw conclusions on the effectiveness of the interventions because of the heterogeneity of the interventions and of the outcome measures.</td>
<td></td>
</tr>
<tr>
<td>Lee et al., 2007</td>
<td>4</td>
<td>NR</td>
<td>Meta-analysis of RCTs</td>
<td>There was a mean effect size of 0.27. Overall, the interventions were effective in improving caregiver mental health (as measured by the Short Form Health Study-36).</td>
<td>This study was limited by specific outcome measures. Future meta-analyses should study additional outcome variables and outcome measures.</td>
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<tr>
<td></td>
<td></td>
<td>Diversity of Study Sample</td>
<td>Cultural Diversity Training Received</td>
<td>Comparisons of Racial/Cultural Factors</td>
<td>Systematic review and meta-analysis of RCTs</td>
<td>Three intervention types: support and information, vocational training, psychoeducation</td>
</tr>
<tr>
<td>Legg et al., 2012</td>
<td>8 stroke caregiver intervention studies (N = 1,007 caregivers); phase(s) NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>Systematic review and meta-analysis of RCTs</td>
<td>Three intervention types: support and information, vocational training, psychoeducation</td>
</tr>
<tr>
<td>Lui et al., 2005</td>
<td>11 stroke caregiver studies, but only information pertaining to the six intervention studies is included here (N &gt; 1,400 caregivers; one study did not report sample size; phases 3, 4, and 5)</td>
<td>Only reported by two of the six studies: n = 30, with 60% of stroke caregivers black; n = 74, with 74% of stroke caregivers white and 26% black</td>
<td>NR</td>
<td>NR</td>
<td>Systematic review of RCTs</td>
<td>Problem-solving interventions</td>
</tr>
<tr>
<td>Visser-Meily et al., 2005</td>
<td>22 stroke caregiver intervention studies (N &gt; 2,300 caregivers; not all studies reported sample size; phases 1-5)</td>
<td>NR</td>
<td>NR</td>
<td>Systematic review of intervention studies (18 of the 22 studies were RCTs)</td>
<td>Four intervention types: provision of specialist services, psychoeducation, counseling, social support from peers</td>
<td>Ten of the 22 studies reported positive results on one or more outcome measures.</td>
</tr>
</tbody>
</table>

**NOTE:** CPSI, Caregiver Problem-Solving Intervention; NR, not reported; RCT, randomized controlled trial; SELF, Supportive Education Learning Program; TAP, Transition Assistance Program; TASK, Telephone Assessment and Skill-Building Kit.

*The five phases of caregiving after a stroke are (1) event/diagnosis, (2) stabilization during acute care, (3) preparation during acute care and in-patient rehabilitation, (4) implementation during the first few months after the patient returns home ("learning the ropes"), and (5) long-lasting adaptation in the home and community (Cameron & Cignac, 2008).*
generalizability of the results. However, a recent Cochrane review of nonpharmacological interventions for stroke caregivers restricted to RCTs—and with no restrictions on date of publication or language of publication—resulted in only eight studies for analysis (Legg et al., 2012). There was no evidence that these interventions were effective in reducing caregiver depression, anxiety, or quality of life. Understandably, these researchers observed the need for more intervention research because the evidence to date is insufficient (Legg et al., 2012).

RANDOMIZED CONTROLLED TRIALS

In our review of the literature, two RCTs published earlier this century, and subsequently included in some of the literature reviews discussed previously, warrant further attention in this chapter. In addition, several noteworthy RCTs have appeared in the current literature. All of these are listed in the Table 3.1. The two RCTs included in some of the published literature reviews that merit comment are the evaluations by Grant and colleagues (Grant, Elliott, Weaver, Bartolucci, & Giger, 2002) and Hartke and King (2003). Both studies relied on telephone contacts to interact with participants and both featured interventions that were informed by contemporary theories of coping and adjustment: the social problem-solving model (Grant et al., 2002) and the stress and coping model (Hartke & King, 2003). Both also had unique methodological features that stand out in contrast to other studies listed in Table 3.1. Grant and colleagues (2002) assigned participants to either a problem-solving “partnership” group (that provided training in problem-solving skills) or to one of two comparison conditions: a “sham” intervention group and a control group. In addition, Grant and colleagues (2000) were among the first to analyze intraindividual trajectories of response to the intervention over time with hierarchical linear modeling, in a manner congruent with most theoretical models of therapeutic changes in counseling (Kahn & Schneider, 2013). The study by Hartke and King (2003) stands out because it is among the few in the literature with a majority of participants who were beyond their second year in the caregiver role.

The results of these telephone-based, theory-driven interventions were also interesting. Grant and colleagues (2002) found that caregivers in the problem-solving group reported a significant decline in depression, and significant increases in problem-solving abilities and caregiver preparedness compared with those in the comparison groups. No differences were found, however, in burden between the groups during the 12 weeks of participation postdischarge. In contrast, Hartke and King (2003) found no differences during 6 months between the telephone “group conference” support group and the control group, but those in the control condition experienced a significant increase in their sense of burden compared with the treatment group. Although the reasons for this pattern are unclear, these results provide evidence that home-based interventions may benefit “experienced” caregivers despite clinical lore that they live with chronic, intractable problems. Grant and colleagues
suspected their results may be attributable, in part, to the way in which the intervention was tailored to address the specific problems identified by each caregiver at each contact. Collectively, both studies demonstrate the potential of long-distance, home-based technologies in providing strategic, theory-driven interventions for stroke caregivers.

Similar to the study by Grant et al. (2002), many recent RCTs focus almost exclusively on family caregivers identified during rehabilitation and use some variation of telephone contacts to provide or enhance the intervention upon return to the community. For example, Bakas and colleagues developed the Telephone Assessment and Skill-Building Kit (TASK), an 8-week intervention program that assesses caregivers’ unmet needs and then helps them obtain knowledge and skills after hospital discharge (Bakas et al., 2009b). The intervention was designed to meet caregivers’ needs in four areas: finding information about stroke, managing the survivors’ emotions and behaviors, providing personal care, and providing instrumental care. Caregivers in the TASK intervention group received tip sheets addressing needs and concerns, a stress management workbook, a brochure on family caregiving from the American Stroke Association, and eight weekly calls from a nurse who conducted assessments of needs and delivered individualized interventions. Caregivers in the TASK intervention group displayed statistically significant increases in optimism at 4 weeks, 8 weeks, and 12 weeks, and significant decreases in task difficulty at 4 weeks and in threat appraisals at 8 weeks and 12 weeks. These caregivers also had greater satisfaction with their experience in the intervention group than those assigned to the comparison group (Bakas et al., 2009a).

Other RCTs that featured telephone contacts after discharge include a study of an enhanced, home-based, postdischarge program that resulted in improved quality of care for stroke survivors at the 12-month follow-up, but no effects on quality of life (Shyu, Kuo, Chen, & Chen, 2010). Another study, building on positive results from an earlier, quasi-experimental pilot of a problem-solving intervention for caregivers (King, Hartke, & Denby, 2007), found caregivers receiving the intervention reported significant gains during the first 4 months of participation, but these were no longer present at the 6-month evaluation (King et al., 2012). The intervention included problem-solving and cognitive-behavioral therapy techniques individualized to each caregiver. The systematic nature of this research provides an excellent example of the kind of programmatic research that is needed to advance our understanding of interventions for stroke caregivers.

A novel application of a contemporary long-distance technology involved a Web-based psychosocial intervention guided by a stress process model to benefit caregivers and care recipients (Smith, Egbert, Dellman-Jenkins, Nanna, & Palmieri, 2012). The intervention consisted of five components: a professional guide, educational videos, online chat sessions, e-mail and message boards, and a resource room. In comparisons with those assigned to an education-only group, caregivers in the treatment group reported less depression postintervention and at the 1-month follow-up assessment. More caregivers and stroke
survivors in the intervention group showed at least a 50% decrease in Center for Epidemiologic Studies–Depression (Radloff, 1977) scale scores postintervention and at the 1-month follow-up than caregivers and stroke survivors in the control group. In addition, more participants in the intervention group than in the control group dropped below the clinical cutoff score for depression postintervention and at the 1-month follow-up. This work demonstrates the potential of other long-distance technologies to assist family caregivers in the community.

A recent RCT conducted in Germany for family caregivers of stroke survivors illustrates how long-distance technology and cognitive–behavioral interventions are integrated with beneficial effects (Pfüffer et al., 2014). This project differs from much of the work discussed previously because it focuses on the issues facing family members who have been caregivers for some time and who face the personal consequences of providing care, such as restrictions in social life, competing demands and roles in their lives, need for respite, increasing awareness of an uncertain future with regard to possible new adverse health events, and changes in their own health or ability to continue caregiving. To provide more information about this project, we have included two case studies that demonstrate how caregiver issues are assessed and how a problem-solving intervention (D’Zurilla & Nezu, 2006) based, in part, on Lazarus’ relational model of stress (Lazarus & Folkman, 1984) is provided in the context of an ongoing, collaborative partnership with a provider.

The components of the problem-solving intervention in this project were (a) problem definition and facts using a card-sorting procedure for problem identification, (b) optimism and orientation, (c) goal setting, (d) generation of alternatives, (e) decision making, and (f) implementation and verification. The card-sorting task was developed to identify problems of each caregiver. The essential element of this approach was a set with 40 cards marked with possible challenging issues in stroke caregiving. The card-sorting task included the following steps: (a) sorting out applicable cards (e.g., “My sleep is disturbed”), (b) labeling additional blank cards with problems that were not covered by the set, (c) allocating the selected and labeled cards to a 5-point scale ranging from “not at all burdensome” to “very burdensome,” and (d) grouping cards that belong to the same problem (optional step). This technique helped the caregiver, with minimal instruction by the therapist, to realize there are common problems in caregiving, to break down one’s own situation into specific challenges and problems, to identify one’s own resources and strategies of successful coping (cards that were allocated to the categories “not at all” or “little” burdensome), to think about how problems might overlap or share similar characteristics, and to select problems that need immediate attention.

The main intervention period in the experimental condition of this study included an initial in-home visit, five weekly (month 1), and four biweekly (months 2 and 3) telephone sessions. The following maintenance period (months 4–12) consisted of another in-home visit (month 4) and nine monthly telephone sessions, with the option of four additional telephone calls in case of crisis or severe symptomatology. The intervention was delivered by clinical psychologists.
Assessments were delivered at baseline, after 3 months, and after 12 months. Depressive symptoms were reassessed at 24 months and 36 months.

The following two case studies demonstrate the positive effect of the problem-solving approach on caregivers' depressive symptoms. Case study 1 (Mrs. V) is an example for an implementation according to the study protocol with regard to frequency and duration of contacts, as well as the numerous repetitions of the problem-solving steps accompanied by an improvement in social problem-solving abilities. Case study 2 (Mrs. W) is an example of a slow start of the intervention with short telephone contacts, low initial compliance, difficulties in implementing a selected solution, very few repetitions of the problem-solving steps, and no improvement of social problem-solving abilities during the 12 months of intervention, but one very effective solution implementation after 8 months.

Case Study 1: "Mrs. V"

Mrs. V, a 59-year-old retired pediatric nurse and former head of a daycare facility for children is the informal caregiver for her mother, who is 89 years old. In addition, Mrs. V has been caring for her mother-in-law, who has been living with Mrs. V and her husband for 10 years. Her mother has mild cognitive impairment as a result of a stroke that occurred 18 months before the caregiver intervention began. Mrs. V has four grown children. After her mother had the stroke, Mrs. V's husband wanted to place her in long-term care, but Mrs. V was very offended by this suggestion. The arrangement they agreed on was to have Mrs. V's mother live in their house 5 days a week and spend the other 2 days each week living in her own apartment in a house belonging to Mrs. V's cousin.

During the initial home visit of the interventionist, Mrs. V completed a card-sorting task to categorize caregiving aspects as either not burdensome at all or as very burdensome. Caregiving aspects that Mrs. V identified as not burdensome at all were housekeeping, lacking knowledge about disease and caring, being responsible for organization and finances, being responsible for caregiving, fear that something could happen to her mother (e.g., another stroke), and her mother's incontinence. Caregiving aspects that were burdensome or very burdensome for Mrs. V were change of life planning, conflicts and tensions, testy and aggressive interactions, feelings of guilt, divergences, her mother's negative attitude toward everything, difficulty communicating with her mother, and partnership problems that were written down on an additional blank card. Superior problem areas were sleep, interaction with her mother, partnership, and support.

A problem-solving telephone intervention was conducted for 12 months and consisted of 19 telephone calls, with a mean duration of 51 minutes, and two home visits. During these 12 months, several major events occurred in Mrs. V's life. Specifically, during the first month her third grandchild was born; in the third month, her mother experienced pulmonary
inflammation. During the fourth month her mother-in-law passed away; during the seventh month, her son and daughter-in-law separated. During the twelfth and final month of the intervention, her daughter-in-law became severely ill and, as a result, Mrs. V had to help her son and daughter-in-law care for their two young children.

The goals of the intervention were to improve Mrs. V's interactions with both her mother and her husband, to organize various responsibilities (e.g., children, grandchildren, mother), to cope with the death of her mother-in-law and the divorce of her son, to alleviate her insomnia, to organize her own leisure time, and to enhance self-care. The problem-solving steps were applied to one to five different problems at each contact. During the intervention, a wide range of problem- and emotion-focused goals were covered, and numerous selected solutions were implemented (e.g., clear and nonjudgmental communication with her husband, self-awareness, giving voice to own needs, being kind to oneself, asking cousin for support, dealing with own impatience and aggressions, integrating moments of respite during the day).

At the baseline, 3-month, and 12-month assessments, Mrs. V was above the cutoff score for depression, but her depression decreased to below the cutoff at a 24-month assessment (Table 3.2). Her satisfaction with her own

### Table 3.2 Baseline and Outcome Measures for the Case Studies

<table>
<thead>
<tr>
<th>Individual Case</th>
<th>Baseline</th>
<th>3 Months</th>
<th>12 Months</th>
<th>24 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CASE STUDY 1: MRS. V</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms (CES-D)</td>
<td>35</td>
<td>31</td>
<td>26</td>
<td>11</td>
</tr>
<tr>
<td>Physical complaints (GBB-24)</td>
<td>36</td>
<td>37</td>
<td>43</td>
<td>—</td>
</tr>
<tr>
<td>Satisfaction with own performance as caregiver (SCQ-subscale 2)</td>
<td>18</td>
<td>29</td>
<td>28</td>
<td>—</td>
</tr>
<tr>
<td>Social problem-solving abilities (SPSI-R(S))</td>
<td>63</td>
<td>69</td>
<td>81</td>
<td>—</td>
</tr>
<tr>
<td><strong>CASE STUDY 2: MRS. W</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms (CES-D)</td>
<td>21</td>
<td>18</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>Physical complaints (GBB-24)</td>
<td>33</td>
<td>25</td>
<td>20</td>
<td>—</td>
</tr>
<tr>
<td>Satisfaction with own performance as caregiver (SCQ-subscale 2)</td>
<td>39</td>
<td>44</td>
<td>44</td>
<td>—</td>
</tr>
<tr>
<td>Social problem-solving abilities (SPSI-R(S))</td>
<td>67</td>
<td>73</td>
<td>63</td>
<td>—</td>
</tr>
</tbody>
</table>

**NOTE:** CES-D, Center for Epidemiologic Studies—Depression scale (Radloff, 1977); GBB-24, Giessen Subjective Complaints List (Brehler, Hinz, & Scheer, 2008); SCQ, Sense of Competence Questionnaire Subscale 2 (Vernooij-Dassen, 1993); SPSI-R(S), Social Problem Solving Inventory—Revised: Short Version (D'Zurilla, Nezu, & Maydeu-Olivares, 2002).
performance as a caregiver increased from the baseline to the 3-month assessment and had remained relatively stable by the 12-month assessment. Mrs. V’s social problem-solving abilities increased from the baseline to the 3-month assessment and had increased again by 12 months. The intensity of her physical complaints increased from the baseline to the 3-month assessment and from the 3-month assessment to the 12-month assessment. Mrs. V was very satisfied with the total time of the intervention and with the telephone-based delivery of the intervention as well as the frequency and duration of the telephone calls, but she wished she had this kind of counseling earlier. Mrs. V perceived the intervention as very helpful (98 on an analogue scale from 0 to 100) and summarized her experience with the intervention after 12 months this way: “The talks helped me not to feel responsible for everything any longer and to let things slide from time to time ... and not to feel bad about this like before ... But it was an abyss to realize that I am completely at a loss what to do during the achieved leisure time ... that I have to relieve strain even in such moments ... Taken as a whole I can take things as they come much easier in the future ... I’m thankful about the received individual support.”

Case Study 2: “Mrs. W”

Mrs. W is a 69-year-old retired office assistant. She is the informal caregiver for her husband who is 82 years old and has been living with various severe diseases for the past 20 years. He had a stroke 23 months before the start of the caregiver intervention and has frontal temporal symptoms, such as lack of impulse control and depression. Although Mrs. W has one child from a previous marriage and her husband has four children from a previous marriage, none of their children are providing them with any support. They also are not receiving support from any other family members or friends and have no money for additional support. They maintain a range of sporadic to no contact with their family members and have lost nearly all their previous social contacts. Mrs. W can only leave the house during her husband’s afternoon nap. When talking about her life and her situation in her initial in-home face-to-face session, Mrs. W was very embittered and reported that the only relaxation she can actually experience is smoking.

Before the implementation of the caregiving intervention, Mrs. W completed the card-sorting task. Caregiving aspects that Mrs. W identified as little or not burdensome at all were inadequate recognition of her role as a caregiver, the inability to speak openly, her husband’s wish to die, lack of common activities, her husband’s incontinence, and the impossibility of having her intimacy and sexual needs met. Caregiving aspects that were burdensome or very burdensome for Mrs. W were being bothered by her husband’s misery and suffering, being responsible for caregiving, testy and
aggressive interactions, and the fact that she couldn't leave her husband alone. Superior problem areas include rumination, lack of time for her own interests, missing her husband as a partner, and being responsible for everything. Her major goal was to be free of any caregiving obligations for at least one afternoon per week. The selected possible solution was to contact one of the local volunteer services to arrange a first meeting.

A problem-solving telephone intervention was conducted for 12 months, consisting of 13 calls, with an average time per call of 15 minutes, and two home visits. The first three telephone contacts after the initial home visit were shorter than 10 minutes. With these brief calls we informed Mrs. W that we wanted to keep contact without putting any pressure on her and hoped to overcome her skepticism about the intervention. Her skepticism stemmed, in part, from her depressive attitudes and former negative experiences with the healthcare system. Even after establishing a more stable and confidential therapeutic partnership, Mrs. W was still not able to contact any volunteer service, but successfully organized an inpatient rehabilitation program for her husband after 4 months. However, instead of the wished-for relief, her husband lost a great amount of weight during rehabilitation and Mrs. W suffered burnout and exhaustion during this time. During the sixth month, Mrs. W experienced severe frustration, accompanied by suicidal ideation after her husband shouted at her relatives during the only family celebration in her home after many months. During this time the intervention goals were to find feasible solutions to deal with the aggressive behaviors of her husband (e.g., time out, cognitive strategies, contact a volunteer service to make some respite possible) and to agree on an emergency strategy in the case of repeated suicidal ideations. During the seventh month, she had severe hives. Finally, during the eighth month of the intervention, Mrs. W was able to contact a volunteer service despite the skepticism and refusal of her husband. The first volunteer who introduced herself was a couple years older than Mrs. W and was immediately declared to be unqualified by Mrs. W. The interventionist encouraged Mrs. W not to drop this solution at all, and practiced with her how to communicate her concerns openly to the volunteer service. Finally, Mrs. W organized two volunteers with weekly visits and experienced, as a consequence of this support, a relief of her burdensome situation. Despite his earlier skepticism, her husband looked forward to each volunteer visit and enjoyed the new contacts as well.

At the baseline and 3-month assessments, Mrs. W was above the cutoff score for depression, but her depression decreased to below the cutoff at the 12-month assessment (Table 3.2). Her satisfaction with her own performance as a caregiver increased from the baseline to the 3-month assessment and remained the same by the 12-month assessment. Mrs. W's social problem-solving abilities increased from the baseline to the 3-month assessment, but then declined by the 12-month assessment to below the baseline score. The intensity of her physical complaints decreased from the baseline to the 3-month assessment and from the 3-month assessment to the
12-month assessment. Mrs. W was very satisfied with the total time of the intervention and mostly satisfied with the telephone-based delivery of the intervention as well as the frequency and duration of the telephone calls. She perceived the intervention as very helpful (100 on an analogue scale from 0 to 100) and summarized her experience with the intervention after 12 months: "I liked the telephone calls. I felt well regarded and could talk about things nobody else is interested in .... Get on with it [this kind of intervention]. The talks helped me. Many thanks for your efforts."

ADDITIONAL INTERVENTION STUDIES

The more noteworthy quasi-experimental intervention studies also focused on caregivers during hospitalization and postdischarge, and used telephone contacts as part of the intervention. In one of these, a home-based individual telecare intervention, consisting of 14 phone calls over 3 months to provide emotional and social support and information specific to the family's needs, was examined (Kim et al., 2012). The home-based individual telecare intervention was more effective in reducing caregiver burden than a hospital-based group intervention. The significant decrease in caregiver burden in the home-based individual telecare intervention group was apparent 12 weeks after discharge.

A study conducted in Thailand examined the implementation and effectiveness of the Supportive Educative Learning Program (SELF) in reducing caregiver strain and improving caregiver quality of life, with stroke caregivers located in two different hospitals (Oupra, Griffiths, Pryor, & Mott, 2010). The SELF intervention consists of didactic education sessions, hands-on training for caregivers, a booklet describing stroke care, and three follow-up phone calls. Both the SELF intervention and the usual-care groups showed improvement in quality of life, but caregivers in the intervention group had better quality of life at the time of hospital discharge and 3 months after discharge. Both groups showed statistically significant declines in strain at the 3-month follow-up, but the caregivers in the control group reported greater levels of strain than the caregivers in the SELF intervention group at both discharge and at the 3-month follow-up.

COSTS

All the intervention studies discussed to this point were implemented in community and/or hospital settings. The types of interventions ranged from telephone calls to home visits, from hospital and rehabilitation settings to home settings, from individual to group interventions, from problem solving to supportive education, and from an in-person format to an online format. These studies demonstrate that community implementation of stroke caregiver interventions can be effective, but a potential barrier to continued community implementation is cost of the intervention per caregiver. For this reason, stroke caregiver intervention
cost templates have been developed. For example, after Bakas and colleagues created and implemented the TASK intervention for stroke caregivers (Bakas et al., 2009b), they developed a cost template to determine the cost of the intervention per caregiver (Bakas, Yong, Habermann, McLennon, & Weaver, 2011).

Bakas and colleagues (2011) developed the cost template by accounting for the costs of organizing and implementing the intervention, and the costs of the caregivers' time. The cost of the intervention included training the nurses to deliver the intervention, preparing for the intervention, delivering the intervention, supervising the delivery of the intervention, and wrapping up the intervention. The number of nurses and supervisors needed, as well as the number of hours spent preparing for and delivering the intervention, were measured. Caregiver time was measured as the amount of time it took to deliver the intervention and was valued at $10.39 per hour, which is the mean wage for home-care aides.

Because TASK is a telephone-based intervention, there were no travel costs, but costs were incurred when mailing printed materials to caregivers, which cost $43 per caregiver. The personnel cost was estimated to be $20/hour for nurses and $22/hour for supervisors. The two nurses who delivered the intervention spent 18 hours being trained by the supervisors, and for each intervention delivery the nurses spent 15 minutes preparing and 15 minutes wrapping up. For the caregivers who participated in the TASK intervention, they received, on average, 3.95 hours of intervention across eight phone calls. After intervention delivery, the nurses met with supervisors for 1.5 hours of evaluation after each phone call, creating a sum of 12 hours of evaluation per caregiver. Supervisors also held weekly meetings throughout the course of a year, totaling 26 hours. The mean cost per caregiver was calculated to be $421, which the researchers evaluated as low cost (Bakas et al., 2011).

Some of the costs of the intervention are fixed. For example, regardless of the number of caregivers receiving the intervention, the cost of training and supervision is fixed. Supervisory costs might be reduced with video or computer training resources. The researchers also suggest that costs can be reduced by streamlining the weekly meetings and by communicating the necessary information only. As stated earlier, the mean cost of $421 per caregiver is considered low cost; moreover, the cost also should be evaluated in terms of the effectiveness of the intervention (Bakas et al., 2011). The TASK intervention was shown to be effective in increasing stroke caregiver optimism and in decreasing stroke caregiver task difficulty and threat appraisal. Furthermore, stroke caregiver needs were met more quickly in the TASK intervention group than in the attention control group (Bakas et al., 2009b). Based on the effectiveness of the TASK intervention, the costs of delivering the intervention may be balanced by the lower subsequent costs as a result of the positive outcomes of the intervention. Ultimately, cost templates are important in developing and evaluating intervention programs (Bakas et al., 2011). The development of cost templates for other interventions can highlight their cost-effectiveness as well as denote areas in which cost reduction is possible.
CONCLUSION

Stroke is one of the most frequent and debilitating health conditions in modern society, and its deleterious effects on family functioning and family members are well documented. Therefore, the paucity of caregiver research in general and of high-quality research specifically is surprising. Although there are several interesting themes and trends in the literature, we understand why the Cochrane review adroitly observes that a critique of this work "highlights the opportunities for improvements" in the area (Legg et al., 2012; p. e31). There are several key themes apparent in the literature at this point. We understand that caregivers value information and want emotional support (Schure et al., 2006). When effects are found in response to interventions, they involve reductions in distress, negative moods, and depressive symptoms, but lack promotion of positive attributes (e.g., caregiver competence, life satisfaction). Long-distance technologies appear to be quite suitable for providing home-based interventions (and caregivers seem to appreciate them [Pfeiffer et al., 2014]). And the research to date has attended almost exclusively to interventions for caregivers in the transition from hospital to home.

There are interesting trends embedded in the literature as well that have not yet become as well developed as the aforementioned key themes. Information-only programs appear insufficient to help caregivers; some degree of counseling and "tailoring" of the intervention is required to address caregivers' emotional needs and unique problems. Interventions that attend to the specific problems reported by caregivers appear to be promising, and there is emerging evidence as caregivers benefit from an intervention, changes may also be observed in the care recipient. Yet, the lack of ethnic and racial diversity in the research poses a serious threat to its generalizability, and this must be remedied in future work. In addition, benefits of interventions provided in the weeks postdischarge may not persist throughout the remainder of the inaugural year of caregiving. Perhaps the trajectory of the caregiver career does, in fact, pose new problems and challenges over time that require ongoing support and training as needed.

In a comprehensive, integration of the cross-sectional, longitudinal, and qualitative studies of stroke caregiver adjustment, Gaugler (2010) observed that this research relied heavily on samples recruited from clinical settings. Studies of caregivers recruited from the community might reveal different patterns of adjustment. Indeed, a nationwide study of a matched sample of stroke caregivers (N = 3,503) and noncaregivers using an empirical, propensity score matching procedure found noncaregivers had significantly higher mortality rates over an average of 6 years (Roth et al., 2013). Although the study lacks information about the actual degree of assistance provided, and lacks detail about the psychological and physical health of the caregivers during the 6-year time frame, the findings illustrate dramatically the need to consider the possible benefits of the "caregiving career." The authors speculated that the positive psychological benefits of caregiving might facilitate personal health over time. A recent systematic review
of benefits reported by stroke caregivers concluded that individual differences may account, in part, for positive experiences such as increased self-esteem, feeling appreciated, and improved relationships (Mackenzie & Greenwood, 2012). Some of these benefits may be apparent within a year of assuming the caregiver role (Haley et al., 2009). Yet, the degree to which these experiences are amenable to psychosocial interventions is essentially unknown.

The mechanisms underpinning positive adjustment among caregivers are unclear, but it is reasonable, theoretically, to assume that these would operate in a manner anticipated by popular stress and coping process models in which cognitive appraisals influence coping behaviors (which can include positive reappraisals and spiritual beliefs) and subsequent emotional experiences ( Folkman, 2008). However, cognitive appraisal activity does not assume such a primary role in other compelling models of positive adjustment. For example, the broaden-and-build model of resilience maintains that experiences of positive affect facilitate increased flexibility, personal well-being, and an ability to integrate new information over time in times of stress (Fredrickson, 2013). Indeed, in a current student of family members during the initial year of caregiving for a relative with a traumatically acquired disability, resilient caregivers were distinguished significantly from distressed caregivers by their elevated experiences of positive mood throughout the year (Elliott, Berry, Richards, & Shewchuk, 2014). Resilient caregivers were not significantly different from other caregivers on measures of personal gain, positive comparisons, or caregiver competence. Furthermore, there is evidence that resilience among family caregivers may be an extension of a resilient personality, consistent with Block's (1993) ego resilience and control model that accounts, in part, for the lower levels of distress they experience in comparison with other caregivers (Elliott et al., 2014). Understanding the theoretical mechanisms that promote positive adjustment among caregivers is necessary for strategic, informed interventions that facilitate personal growth and meaning.

Historically, family caregivers are expected to operate as extensions of the healthcare system, performing complex medical and therapeutic tasks, and ensuring care recipient adherence to prescribed regimens (Shewchuk & Elliott, 2000). This is certainly true of family caregivers of stroke survivors. However, these caregivers do not receive adequate training, preparation, or ongoing support from the healthcare system. Although stroke caregivers often receive information and instruction during inpatient hospitalization or rehabilitation, it is illogical and unreasonable to assume this prepares them adequately for the challenges and problems that will evolve and appear over time. The complex and evolving issues faced by stroke caregivers cannot be addressed in brief, educationally based training during the inpatient rehabilitation program or in brief, infrequent outpatient visits arranged with the survivor’s care providers, who are concerned primarily with the medical care and therapeutic needs of the survivor.

Viewing caregiver needs from the lens of a chronic care model requires the development of interventions that prepare stroke caregivers to address the challenges they face and to “help them become more active and expert in their own
self-management and to operate competently as formal extensions of health care systems” (Shawchuk & Elliott, 2000, p. 561). This kind of partnership recognizes the active and essential role of the individual caregiver in health care; respects their needs for ongoing training, support, and assistance; and is responsive to problems often encountered by caregivers in general, and to those experienced specifically by the individual caregiver. Elliott and Parker (2012) recently argued that the success of these partnerships requires ongoing assessments of the needs, health, and capacity of the caregiver, and of the problems experienced by the dyad at any point in time, and sensitivity to changes to their status, challenges, and needs. For these reasons, many favor cognitive–behavioral interventions that address emotional issues and provide training in instrumental skills for coping with specific and unique problems. These interventions can be conducted by low-cost (i.e., nondoctoral-level) providers, they can address the specific issues identified and prioritized by the caregiver, and they can be delivered effectively to the home via long-distance technologies.

REFERENCES


