REVIEWS

Interventions for caregivers of stroke survivors: An update of the evidence

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ABSTRACT

Objective: The purpose of this systematic review was to summarize the latest evidence on the effectiveness of interventions for family caregivers of stroke survivors.

Methods: Using multiple databases, the search strategy included randomized controlled trials, published in English, between 2002 and 2013. Two independent reviewers extracted information and evaluated study quality.

Results: From an initial search of 120 studies, 18 were included. Most interventions were multi-faceted, including elements of information/education, support, and skill building. Skill building was defined as an intervention that equipped the caregiver with skills to provide care to the stroke survivor or skills to cope with the caregiving role. A variety of outcomes, most commonly psychological distress, caregiver burden, and quality of life, were measured with effectiveness of the intervention shown on at least one outcome in over 50% of studies. About half of the studies explicitly provided a theory that guided the intervention and outcomes. Interventions that included elements of skill building were more likely to show a significant effect. The majority of studies had insufficient power to detect significant differences and there was an under-representation of minority caregivers, limiting the generalizability of the review.

Conclusions: Interventions that deliver specific skills relative to performing the physical care needed by the stroke survivors and/or to manage the stroke survivor's emotional responses to the stroke as well as the caregiver's responses to the role seemed to be most effective in decreasing psychological distress and burden. Studies are beginning to examine technology as a mechanism for intervening with caregivers.

Key Words: Stroke, Caregivers, Interventions, Reviews

1. BACKGROUND

The majority of stroke survivors return to live in the community, relying on family members to meet their needs for care and support.^[1,2] This "informal care" can be substantial in scope, intensity, and duration.^[3,4] The sudden and unexpected nature of stroke leaves families with little time to prepare for the caregiving role. Furthermore, families are learning a new role while working through their own grief over the stroke event and all the losses a stroke usually implies. Shorter hospital stays result in stroke survivors returning home more quickly, with more limitations in their activities of daily living than any previous cohort of individuals with stroke.^[5]

The impact on the health of stroke caregivers has been wellestablished. Research has repeatedly described the effects of caregiving on caregivers' physical and psychological well-

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being as well as on their social relationships.^[6–9] In addition to the health-related effects, the financial effects are also significant. While at least 80% of stroke costs during the first six months post-stroke are health-system costs, families take on a greater proportion of stroke-related expenses over time.^[10] Ethnic minorities are at a higher risk for stroke and heart disease,^[11] yet few studies have specifically examined caregiving after stroke among non-White caregivers.^[12] The socioeconomic context including the family structure, cultural norms, living arrangements, and healthcare access may be very different for Black, Hispanic, and non-Hispanic White caregivers.^[13] This can lead to very different caregiver experiences and potentially impact on the types of interventions that may support caregivers from different cultural backgrounds.

Providing caregivers with support may not only improve their own health but may also improve outcomes for the stroke survivor.^[14-16] To address the negative impact of the caregiving role on the caregiver, a number of interventions including education, coping and problem-solving strategies, psychosocial support, and information provision have been tested. The evidence concerning effective interventions for family caregivers of stroke survivors has been summarized in several systematic reviews.^[17-21] Two reviews have focused on specific types of interventions, namely psychosocial interventions^[18] and information provision.^[20] While the provision of information has been significantly associated with caregiver knowledge acquisition (standardized mean difference of 0.74; 95% CI: 0.06, 1.43), there has been no effect on caregiver mood. Lee *et al.*^[19] summarized the results of 4 studies, an educational program (n = 2 studies) and a support program (n = 2 studies), in their review of interventions impacting the health-related quality of life of caregivers, measured with the Short Form Health Survey. Overall, the interventions improved the caregiver's mental health. The small number of studies included in the review and its very specific focus, however, limits the generalizability of the findings from this review. Two further reviews, including studies between 1990 and 2003^[21] and 1988 and 2005,^[17] summarized interventions for family caregivers. Both reviews described the generally low quality of the trials and reported the need for further research to support evidence for effective interventions. Given that the most recent summary of interventions, not limited to a specific type of intervention or outcome, included studies only to 2005, there is a need to update the evidence. Furthermore, there is a need to specifically examine the mode of intervention delivery, given the growing trend of using health information technology in our interactions with patients and their families. The purpose of this systematic review was to provide an update to the

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evidence for interventions for family caregivers of stroke survivors, summarizing intervention studies published since early 2000.

2. METHODS

A literature search for articles published from 2002 to 2013 was conducted using PubMed, CINAHL, Ovid Medline, Cochrane, Embase, and Web of Science databases. The keywords "stroke AND caregiver AND interventions" and "stroke AND carer AND interventions" were used. Two reviewers screened the databases and selected the articles based on the title and the abstract. In cases of uncertainty, the entire text of the article was reviewed. Reference sections of articles meeting the inclusion criteria were also searched for additional articles. The following inclusion criteria were applied: (1) intervention and outcomes for caregivers of stroke patients; (2) intervention for stroke patients and their caregivers, if the intervention and outcomes for caregivers were described; (3) randomized controlled trial; and (4) article written in English. Studies were excluded if they were not randomized controlled trials and if the intervention focus was primarily on the stroke survivor.

The setting and sample characteristics, the intervention including the mode of delivery, outcome domains, and the reported effects were abstracted from the selected studies by two reviewers working together using data extraction forms. Interventions were mostly complex in nature, including several elements such as information about resources, emotional support, and problem-solving strategies. The team reviewed all interventions and developed a list of all the elements included in each intervention. Similar elements were then grouped into categories that reflected the specific dimensions of the intervention. The three broad categories of interventions included: (1) education and information provision about stroke and resources; (2) emotional support and/or counseling; and (3) skills training specific to providing physical and emotional care to the stroke survivor and/or skills training related to active coping and problem-solving. An attempt was made to identify an association between the specific intervention component and outcomes reported by the investigators as statistically significant.

The methodological quality of each study was independently reviewed by two team-members using the Rapid Critical Appraisal Checklist for randomized clinical trials.^[22] This is a 9-item checklist addressing components important to the design and execution of clinical trials including randomization, blinding of intervention or blinded outcomes assessment, description of losses to follow-up and drop-outs, use of an intent-to-treat analysis, use of an appropriate control group, reliability and validity of measures, and duration of followup. We added an additional item to address study power. Each item was equally weighted and scored 1 point if present and a total score was obtained by summing the items. Each study was scored from a low of 0 to a high of 10. In cases where there was disagreement about the quality rating, the article was reviewed by the other two team-members and discussed until a consensus could be reached.

3. RESULTS

The details of study identification and selection can be seen in Figure 1. There were 18 studies, all published in English, included in the final review. Selected studies were from 5 countries, with 39% published in the United States. Over half (55%) of the reviewed studies were published in the early years of the review period (2002-2007) with only 6 eligible trials published since 2010.



Figure 1. Flow scheme of inclusion process

3.1 Description of samples

Table 1 provides an overview of the studies included in the review. Sample size across studies ranged from 20 to 300 caregivers and one cluster randomized trial included 928 patient/caregiver dyads.^[23] Several studies were designed as pilot studies and were not powered for efficacy.^[24–27] In about one-third of the studies, stroke survivor/caregiver dyads were recruited.^[23,27–31] The demographic characteristics of the caregivers reflect those reported in other studies with approximately 75% female, around 65 years of age, and the majority of caregivers identified as the spouse of the stroke survivor. Several studies included only spousal

caregivers.^[25, 28, 31, 32] The youngest caregivers were seen in the two studies that utilized internet technology to deliver the intervention.^[31, 33] Limited information was provided on the race/ethnicity composition of the samples but in those few studies that provided this information, the majority was non-Hispanic White (75%), followed by Black (20%), and "other" (5%) which was not defined. The only study with a focus on Hispanic caregivers (65%) was conducted in the Southwestern United States and Puerto Rico.^[27]

3.2 Quality ratings

Methodological quality using the 10-item checklist varied across the studies with a median score of 6. The majority of studies scored between 5 and 7, rated as medium quality. In all studies, participants were randomized to an intervention or control group as this was a criterion to be included in the review. In the majority of the studies there was no blinding to the intervention group, which would be difficult given the nature of the interventions. A number of studies, however, utilized blinded outcomes assessment. Instruments with sound psychometric properties among caregivers of stroke survivors were used in most studies. The majority of studies did not provide justification for their sample size or information on study power.

3.3 Description of the interventions

A variety of interventions was provided to family caregivers, with most defined as a complex intervention as several components were included (see Table 2). Most studies delivered information and education as one element of the intervention, but only one study included this as the sole component.^[34] Education/information-giving focused on the nature of stroke, recovery, and secondary stroke prevention along with information about community resources. Interventions that provided support for the caregiver were offered in the form of peer support through group activities, professional support and information on tips for caregiving and resources for seeking assistance. A number of interventions included elements of skill-building or training that encompassed skills for providing physical care to the stroke survivor, coping with the emotional aspects of stroke, and caregiver training related to problem-solving and active coping skills.^[23-25,27,30,31,35-38]

3.4 Timing and mode of delivery of interventions

The majority of interventions were delivered face-to-face (75%), although several investigators initiated the intervention protocol in person with telephone follow-up. Only four recent studies utilized technology to deliver interventions, with two studies using the internet^[31,33] and a third using videophone technology to connect with caregivers in their home,^[27] while a fourth study used a computer to tailor

the education package to the stroke survivor and caregiver's needs.^[29] Most interventions were delivered one-on-one to the individual caregiver (and stroke survivor, if included) and only 25% of the interventions utilized a group format to deliver the intervention. Interventions ranged in length from four weeks to one year, with most delivered over approximately 8 to 12 weeks. Two studies utilizing a family support organizer individualized the number of contacts with the caregiver to the identified needs.^[39,40] As there was variability in the length of the interventions, there was also variability both

within and between studies in the time of the intervention relative to the stroke event. Most interventions, however, were aimed at those newly in the role at the time of stroke survivor discharge from hospital. Almost all interventions were delivered by professionals specifically trained in stroke care including nurses, physical therapists, social workers and psychologists. The family support organizers were lay workers trained in poststroke care.^[39,40] Approximately 50% of the interventions were supported by theory, most commonly a stress process model, such as the Pearlin Stress Model.^[41]

Table 1. Overview	of interv	rention	studies
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First author, Year	Sample & Setting	Time poststroke	Intervention	Length of intervention	Time of outcome measurement	Measures
Grant, 2002 [33]	74 CGs recruited from rehabilitation facility	Within one month of stroke	 Social problem solving intervention; 2) Sham intervention; Control group 	12 weeks	One week after end of intervention	HRQL, problem-solving abilities, satisfaction with health care, depression, caregiver preparedness, caregiving burden
Van Den Heuvel, 2002 ^[39]	257 CGs recruited from inpatient and outpatient facilities	6 months to 3 years	Information and active coping strategies delivered via: 1) Group program or 2) Home visit; 3) Control group	8-10 weeks	1 and 7 months after completion of program	Confidence in knowledge, coping strategies, HRQL, social support, assertiveness
Clarke, 2003 [25]	68 CGs recruited from rehabilitation units	6 months	 Information and counseling; Control group 	5 months	One month after completion of program	Family functioning, HRQL, depression, anxiety, mastery
Hartke, 2003 [22]	124 CGs recruited from rehabilitation units	> 1 month	1) Telephone support group intervention; 2) Usual care	8 weeks	Immediately after program and 4 months later	Depression, loneliness, competence, burden, stress
Lincoln, 2003 [36]	250 SSs and CGs recruited from acute care hospital	Within one month of stroke	 Family support organizer (information and emotional support); Standard care 	Up to 9 months	4 months after starting program and at completion of program	Knowledge and satisfaction with information, anxiety, depression, caregiver strain
Kalra, 2004 [27]	300 SSs and their CGs recruited from rehabilitation units	Within one month of stroke	1) CG training; 2) Conventional care	3-5 sessions, delivered in hospital and one home session	3 and 12 months poststroke	Caregiver burden, anxiety, depression, functional status, quality of life
Smith, 2004 [31]	97 CGs recruited from rehabilitation unit	Within one month of stroke	 Stroke information manual and education meetings; 2) Control group 	Not documented	3 and 6 months poststroke	Knowledge of stroke, carer mood, satisfaction
Larson, 2005 [29]	100 CGs recruited from hospital	Approx. three months	 Support and education program; Control group 	Monthly sessions for 6 months	Immediately after program and 6 months later	Quality of life, life situation, general well-being, perceived health state
Tilling, 2005 [37]	151 CGs (at 3-month follow-up)	Approx. three months	1) Assistance from family support organizer; 2) Control group	Not documented	3 and 12 months after randomization	Caregiver strain, anxiety, depression, social life, satisfaction with stroke care
Draper, 2007 [32]	39 CGs of SSs with aphasia recruited from rehabilitation hospitals	Up to 12 months since stroke	 Treatment group that included elements of education, support, and communication skills; Delayed treatment control group 	4 weeks	Immediately after program and 3 months later	Quality of life, social support, satisfaction with support
Bakas, 2009 [21]	50 CGs recruited from rehabilitation and acute care hospitals	Not documented	1) Telephone Assessment and Skill-Building Task; 2) Attention control group	8 weeks	Immediately after program and 1 month later	Caregiver optimism, perceived difficulty with tasks, threat appraisal, depression, caregiver life changes, HRQL
Pierce, 2009 [30]	103 CGs recruited from rehabilitation centers	Up to 12 months since stroke	1) Web-based assistance called Caring-Web; 2) Control group	12 months	3, 6, 9, and 12 months during program	Depression, life satisfaction,
Marsden, 2010 [23]	20 CGs recruited in 3 rural communities	Mean of 38 months	 Community living after stroke (physical activity and education); Control group 	7 weeks	1 week after completion of program	HRQL, caregiver strain
Perrin, 2010 [24]	61 CGs recruited from rehabilitation units	Within one month of stroke	1) Transition assistance program providing education, skill development, and problem solving; 2) Control group	6 weeks	1 month (during program) and 6 weeks after program ended	Caregiver strain, depression, satisfaction
King, 2012 ^[34]	255 CGs recruited from rehabilitation units	Within one month of stroke	1) CG problem-solving intervention; 2) Wait-list control group	10-12 weeks	3, 6, and 12 months post-intervention	Depression, perception of life change, caregiver preparedness, anxiety, family functioning, perceived health, resources and stressors, appraisal of caregiving, social problem solving
Smith, 2012 [28]	88 CGs recruited through advertisements on websites and key organizations	Not documented	 Knowledge, resources, and skills intervention; 2) Information –only control group 	11 weeks	Immediately after program and 1 month later	Depression, mastery, self-esteem, social support
Eames, 2013 [26]	61 CGs recruited from 2 tertiary hospitals	Within one month of stroke	 Tailored education and support package in addition to usual care; Control group 	12 weeks	At end of program	Knowledge of stroke, self-efficacy, anxiety, depression, caregiver burden
Forster, 2013 [20]	928 SS and CG dyads	Within one month of stroke	1) CG training program to provide the knowledge and skills essential for management of stroke survivor; 2) Control group	Based on the London Stroke Carers Training Course (3-5 sessions, delivered in hospital and one home session)	6 and 12 months after program	Caregiver burden, depression, quality of life

Note. CGs (caregivers); SSs (stroke survivors); HRQL (health-related quality of life)

3.5 Measurement of outcomes

Studies measured a variety of outcomes including depression, caregiver burden, psychological distress, life satisfaction and well-being, health-related quality of life (HRQL), caregiving mastery, and family functioning. A number of different scales were used to measure these constructs, making it difficult to compare across studies. Most studies measured several outcomes but did not identify primary or secondary outcomes. Further, in those studies that provided informa-

tion for sample size calculation, they did not identify which outcome was used for estimating sample size. The most commonly measured outcomes were depression and caregiver strain, both measured in over half of the studies. Caregiving mastery and problem-solving skills were included in about 45% of the studies. Despite the importance of HRQL as an outcome, a measure of HQRL or overall quality of life was included in less than half the studies.^[23,24,28,30,32,35,36,42]

Table 2. Interventions and outcomes

First author, Year	Elements of intervention	Outcomes
Grant, 2002 ^[33]	Skill-building and problem solving around the caregiving situation; support	Increase in problem-solving abilities, greater caregiving preparedness, and decreased depression; no differences for satisfaction with health care and caregiver burden
Van Den Heuvel, 2002 ^[39]	Education, support, skill building	Increase in knowledge about patient care and in use of the coping strategy seeking social support; no differences in quality of life, confidence and self-efficacy
Clarke, 2003 ^[25]	Information and counseling	No differences between groups on physical, mental health (depression and anxiety), family functioning and quality of life
Hartke, 2003 ^[22]	Education, support, and skill-building	Significant decrease in burden and increase in competence; no difference in depression, loneliness, or stress
Lincoln, 2003 [36]	Information and emotional support	Increased knowledge of stroke and secondary prevention; no differences between groups in psychological distress, caregiver strain, and satisfaction
Kalra, 2004 ^[27]	Skill-building around caring for the stroke survivor	Significant decrease in burden, anxiety, and depression and increase in quality of life; no difference in satisfaction
Smith, 2004 [31]	Education	No differences between groups in knowledge of stroke, caregiver mood/anxiety, and satisfaction
Larson, 2005 [29]	Education and support	No difference between groups on quality of life, general well-being, and life satisfaction
Tilling, 2005 [37]	Information and emotional support	No differences between groups in anxiety, depression, caregiver strain, and satisfaction
Draper, 2007 ^[32]	Education, psychological support, and skill training for caring for stroke survivors with aphasia	No differences between groups on caregiver burden, psychological distress, and communication skills
Bakas, 2009 ^[21]	Information about stroke and skill-building around care and responses to care	Increase in optimism at 4, 8, and 12 weeks; no differences between groups for depression, life changes, perceived difficulty with tasks, threat appraisal and general health
Pierce, 2009 [30]	Information and support	No differences between groups in depression or life satisfaction
Marsden, 2010 ^[23]	Physical activity, education/provision of information and support	No differences between groups in physical-activity scales, health-related quality of life, or caregiver strain
Perrin, 2010 [24]	Skill development, education, and supportive problem-solving	Significant decrease in caregiver strain and depression and increase in satisfaction
King, 2012 ^[34]	Education and information about resources, support, and skill-building around problem-solving	Significant decrease in depression and increase in positive life changes at post-intervention but no changes at 6 and 12 months; no difference in caregiver preparedness, anxiety, and family functioning
Smith, 2012 [28]	Support and skill-building to help reduce personal distress and provide optimal care	Decrease in depression post-intervention and at one-month follow-up; no differences in self-esteem, mastery, and social support
Eames, 2013 ^[26]	Education and support	Significantly better self-efficacy for accessing stroke information, feeling informed, and satisfaction with information received; no differences between groups in stroke knowledge or caregiver burden
Forster, 2013 ^[20]	Education about stroke and skill-building around day-to-day management of disabled stroke survivors	No differences between groups on caregiver burden at 6 months (primary outcome) or depression and quality of life (secondary outcomes at 6 or 12 months

Note. Outcomes in bold indicate statistically significant outcome

3.6 Impact of interventions on caregiver outcomes

There were no studies where the intervention demonstrated positive effects across all measured outcomes (see Table 2). While some interventions showed an early effect, this had diminished by the final assessment, suggesting the intervention dose may have been insufficient to sustain a positive effect or that the intervention needs to change as the trajectory of care to a stroke survivor changes. Studies that included a multi-faceted intervention were more likely to demonstrate a positive effect on outcomes. As can be seen in Table 3, those studies that included all 3 components in the intervention were more likely to show at least one statistically significant outcome (4 of the 5 studies that included 3 components) as compared with those that included two components (4 of the 11 studies).

ings provide support for the importance of including a skill-

building component in interventions directed towards this

population. Studies that included this component, aimed

either at teaching the caregiver specific skills to care for

the stroke survivor or to assist them with problem-solving

and coping, were more likely to show a positive effect on

at least one outcome. It is not possible, however, to draw

conclusions about the active ingredient(s) or the nature of the

skill-building since the intervention was operationalized in

different ways across the studies. Furthermore, the intended

effect of skill building is not clear as few studies provided a

Of note, the skill-building intervention tested in a single site

by Kalra *et al.*^[30] showed a significant decrease in caregiver burden, anxiety, and depression, and an increase in quality

of life. Further testing of this intervention, however, in a cluster randomized controlled trial among 928 patient and

caregiver dyads at 36 stroke units failed to find differences

conceptual basis linking the intervention to outcome.

Table 3. Association between components of intervent	tion and significant outcomes
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First Author, Date	Education/Information about stroke and resources	Provision of emotional support and/or counseling	Skills training (specific to patient care and teaching caregiver about problem solving)
Grant, 2002 [33]*		Х	Х
Van Den Heuvel, 2002 [39]*	Х	Х	Х
Clarke, 2003 [25]	Х	Х	
Hartke, 2003 [22]*	Х	Х	Х
Lincoln, 2003 [36]	Х	Х	
Kalra, 2004 [27]*			Х
Smith, 2004 [31]	Х		
Larson, 2005 [29]	Х	Х	
Tilling, 2005 [37]	Х	Х	
Draper, 2007 [32]	Х	Х	Х
Bakas, 2009 [21]*	Х		Х
Pierce, 2009 [30]	Х	Х	
Marsden, 2010 [23]	Х	Х	
Perrin, 2010 [24]*	Х	Х	Х
King, 2012 [34]*	Х	Х	Х
Smith, 2012 [28]*		Х	Х
Eames, 2013 [26]*	Х	Х	
Forster, 2013 [20]	Х		Х

* Indicates that at least one outcome was reported as statistically significant

Interventions that were focused on providing the caregiver with information about stroke and available resources were less likely to have an impact on caregiver outcomes. Most studies that provided information and/or education did not show an impact on knowledge acquisition with the exception of Lincoln *et al.*^[39] who reported a significant increase in knowledge about resources associated with information provision. Interventions that included specific training related to caring for the stroke survivor and/or training on problemsolving techniques and active coping skills were more likely to be associated with significant positive caregiver outcomes. Of the 10 studies where the intervention included a focus on skills training, 8 studies showed a significant effect on at least one caregiver outcome.

4. DISCUSSION

This review provides an update to the evidence on interventions for family caregivers of stroke survivors. The findbetween the intervention and usual care groups on any of the assessed outcomes.^[23] These differences highlight the importance of understanding the practice context where the research is conducted and intervention fidelity.

The timing of the intervention is important to consider when examining caregiver outcomes. The time when the intervention was delivered relative to the stroke event varied within and across the reviewed studies, from in-hospital to the inclusion of participants that had been in the caregiving role for three years. Although most interventions were initiated within one month of stroke, there is insufficient evidence to draw conclusions relative to the ideal time of delivery. It is most likely that different interventions are needed over time to respond to the changing needs of caregivers. Cameron et al.^[43,44] have described the "timing it right" framework that highlights caregiver changing experiences and corresponding support needs across the continuum of care. Utilizing a more targeted approach in terms of the timing and nature of the intervention is more likely to be successful. The stroke survivor recovery trajectory and the consequent implications for the caregiver suggest that caregivers need more than an inpatient or early after discharge intervention and will require monitoring over time to support them in the role.

Few studies in the review reported on the race/ethnicity composition of their sample and in those that did,^[24, 25, 33, 37] with one exception^[27] the vast majority were non-Hispanic White. Interventions designed and tested among White middle-class caregivers may not be responsive to the needs of caregivers from different cultures and socioeconomic backgrounds. Perrin and colleagues^[27] developed a culturally sensitive educational and supportive problem solving intervention for strokes caregivers (65% Hispanic) in Puerto Rico and the United States. While stroke incidence rates have decreased in high income countries, they have increased by more than 100% in low and middle income countries,^[45] underscoring the necessity of developing and testing culturally sensitive interventions to support caregivers.

Successful interventions may require a shift in the paradigm of how we have traditionally interacted with caregivers. Most studies in this review (75%) relied on face-to-face communication to deliver support, education, or information. This can lead to low adherence to the program and attrition, understandable given the demands of the caregiving role. There is some support for utilizing the telephone to deliver interventions.^[46] Patients are utilizing internet and mobile technology at an increasing rate to seek health information with recent data showing 66% of patients searching for evidence online versus 15% from their physicians.^[47] Furthermore, there is an increase in the number of young adults experiencing stroke,^[48] implicating younger caregivers who may be more comfortable using technology. It is imperative to capitalize on these societal trends relative to expanding technology use as a way to support caregivers with much greater frequency, in real-time, and most importantly, over the long-term.

Use of technology may allow a better operationalization of the "timing it right" framework.^[43,44] This review reports on some early progress in this direction not presented in previous systematic reviews. Pierce and colleagues have developed Caring Web, an education and support intervention.^[33] Although testing of the web support showed no difference in well-being, there was a decrease in number of emergency room visits and hospital readmissions for their recipients of care. Smith *et al.*^[31] utilized the internet to deliver an intervention designed to provide the caregiver with knowledge, skills, and resources to help them reduce personal distress and also provide emotional care to their spouse with stroke. They reported a decrease in caregiver depression at post-intervention and one month later.

There are limitations to this review which reflects the findings from only those studies published in English. Differences in the interventions and the dose of the intervention (length of time it was delivered) across studies limited a more comprehensive comparison of the outcomes. The inclusion of studies with varying time periods relative to stroke for the delivery of the intervention limits conclusions about what works and when, owing to the heterogeneity of the studies. Despite the limitations, this systematic review has addressed a need for an updated review of the evidence for caregiver interventions, particularly with the emerging focus on different delivery options including the utilization of health information technology.^[49] Important contributions relate to developing culturally sensitive interventions and also an increasing use in technology to deliver interventions and support caregivers.

There are currently more than 6.8 million stroke survivors in the United States and an estimated 33 million worldwide.^[50] Without significant changes in primary and secondary prevention practices, the prevalence and consequent costs of stroke are anticipated to increase substantially over the next two decades.^[51] This increase in stroke survivors also implicates more family caregivers in the caregiving role. Thus it is imperative to continue to build the evidence about interventions that support caregivers in this essential role. As shown by the studies reviewed here, given the complexity of the caregiving situation, a simple intervention is not likely to impact on caregiver health. The findings support the inclusion of multiple components, in particular the skills to take on the caregiving role.

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CONFLICTS OF INTEREST DISCLOSURE

REFERENCES

- [1] Han B, Haley WE. Family caregiving for patients with stroke. Review and analysis. Stroke. 1999; 30: 1478-85. PMID:10390326. http://dx.doi.org/10.1161/01.STR.30.7.1478
- [2] Salter K, Zettler L, Foley N, et al. Impact of caring for individuals with stroke on perceived physical health of informal caregivers. Disability & Rehabilitation. 2010; 32: 273-81. PMID:20055566. http://dx.doi.org/10.3109/09638280903114394
- [3] Brouwer WB. Too important to ignore: informal caregivers and other significant others. Pharmacoeconomics. 2006; 24: 39-41. PMID:16445301. http://dx.doi.org/10.2165/0001905 3-200624010-00003
- [4] Rodgers H, Francis JJ, Brittain K, et al. Who cares? caring for the carers of stroke patients. Disability & Rehabilitation. 2007; 29: 425-7. PMID:17364796.http://dx.doi.org/10.1080/09638280600 834369
- [5] White CL, Korner-Bitensky N, Rodrigue N et al. Barriers and facilitators to caring for individuals with stroke in the community: the family's experience. Canadian Journal of Neuroscience Nursing. 2007; 29: 5-12. PMID:18240626.
- [6] Gaugler JE. The longitudinal ramifications of stroke caregiving: a systematic review. Rehabilitation Psychology. 2010; 55: 108-25. PMID:20496966. http://dx.doi.org/10.1037/a0019023
- [7] Low JT, Payne S, Roderick P. The impact of stroke on informal carers: a literature review. Social Science & Medicine. 1999; 49: 711-25. http://dx.doi.org/10.1016/S0277-9536(99)00194-X
- [8] Pierce LL, Thompson TL, Govoni AL, et al. Caregivers' incongruence: emotional strain in caring for persons with stroke. Rehabilitation Nursing Journal. 2012; 37: 258-66. PMID:22949279. http://dx.doi.org/10.1002/rnj.35
- [9] Simon C, Kumar S, Kendrick T. Cohort study of informal carers of first-time stroke survivors: profile of health and social changes in the first year of caregiving. Social Science & Medicine. 2009; 69: 404-10. PMID:19520471. http://dx.doi.org/10.1016/j.soc scimed.2009.04.007
- [10] Mittmann N, Seung SJ, Hill MD, et al. Impact of disability status on ischemic stroke costs in Canada in the first year. Canadian Journal of Neurological Sciences. 2012; 39: 793-800. PMID:23041400. http://dx.doi.org/10.1017/S0317167100015638
- [11] Cruz-Flores S, Rabinstein A, Biller J, et al. Racial-ethnic disparities in stroke care: the American experience: A statement for healthcare professionals from the American Heart Association/American Stroke Association. Stroke. 2011; 42: 2091-116. PMID:21617147. http://dx.doi.org/10.1161/STR.0b013e3182213e24
- [12] Pierce LL. Caring and expressions of spirituality by urban caregivers of people with stroke in African American families. Qualitative Health Research. 2001; 11: 339-52. PMID:11339078. http: //dx.doi.org/10.1177/104973201129119145
- [13] Perrin PB, Heesacker M, Uthe CE, et al. Caregiver mental health and racial/ethnic disparities in stroke: implications for culturally sensitive interventions. Rehabilitation Psychology. 2010; 55: 372-82. PMID:21171796. http://dx.doi.org/10.1037/a0021486
- [14] Cameron JI, Cheung AM, Streiner DL, et al. Stroke survivor depressive symptoms are associated with family caregiver depression during

the first 2 years poststroke. Stroke. 2011; 42: 302-6. PMID:21164124. http://dx.doi.org/10.1161/STROKEAHA.110.597963

- [15] Grant JS, Clay OJ, Keltner NL, et al. Does caregiver well-being predict stroke survivor depressive symptoms? A mediation analysis. Topics in Stroke Rehabilitation. 2013; 20: 44-51. PMID:23340070. http://dx.doi.org/10.1310/tsr2001-44
- Klinedinst NJ, Gebhardt MC, Aycock DM, et al. Caregiver character-[16] istics predict stroke survivor quality of life at 4 months and 1 year. Research in Nursing & Health. 2009; 32: 592-605. PMID:19722169. http://dx.doi.org/10.1002/nur.20348
- Brereton L, Carroll C, Barnston S. Interventions for adult fam-[17] ily carers of people who have had a stroke: a systematic review. Clinical Rehabilitation. 2007; 21: 867-84. PMID:17981846. http: //dx.doi.org/10.1177/0269215507078313
- Eldred C, Sykes C. Psychosocial interventions for carers of sur-[18] vivors of stroke: a systematic review of interventions based on psychological principles and theoretical frameworks. British Journal of Health Psychology. 2008; 13: 563-81. PMID:17708832. http://dx.doi.org/10.1348/135910707X236899
- [19] Lee J, Soeken K, Picot SJ. A meta-analysis of interventions for informal stroke caregivers. Western Journal of Nursing Research. 2007; 29: 344-56. PMID:17420524. http://dx.doi.org/10.1177/0 193945906296564
- [20] Smith J, Forster A, Young J. Cochrane review: information provision for stroke patients and their caregivers. Clinical Rehabilitation, 2009: 23: 195-206. PMID:19218295. http://dx.doi.org/10.1177/0 269215508092820
- [21] Visser-Meily A, van Heugten C, Post M, et al. Intervention studies for caregivers of stroke survivors: a critical review. Patient Education & Counseling. 2005; 56: 257-67. PMID:15721967. http: //dx.doi.org/10.1016/j.pec.2004.02.013
- [22] Melnyk B, Fineout-Overholt E. Evidence-Based Practice in Nursing & Healthcare: A Guide to Best Practice. 2nd ed. Philadelphia: Wolters Kluwer Health; 2011.
- [23] Forster A, Dickerson J, Young J, et al. A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis. Lancet. 2013; 382: 2069-76. http://dx.doi.org/10.1016/S0140-673 6(13)61603-7
- [24] Bakas T, Farran CJ, Austin JK, et al. Stroke caregiver outcomes from the Telephone Assessment and Skill-Building Kit (TASK). Topics in Stroke Rehabilitation. 2009; 16: 105-21. PMID:19581197. http://dx.doi.org/10.1310/tsr1602-105
- [25] Hartke RJ, King RB. Telephone group intervention for older stroke caregivers. Topics in Stroke Rehabilitation. 2003; 9: 65-81. PMID:14523701. http://dx.doi.org/10.1310/RX0A-6E2Y-B U8J-WOVL
- [26] Marsden D, Quinn R, Pond N, et al. A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial. Clinical Rehabilitation. 2010; 24: 328-41. PMID:20176772. http: //dx.doi.org/10.1177/0269215509344268
- [27] Perrin PB, Johnston A, Vogel B, et al. A culturally sensitive Transition Assistance Program for stroke caregivers: examining care-

giver mental health and stroke rehabilitation. Journal of Rehabilitation Research & Development. 2010; 47: 605-17. PMID:21110257. http://dx.doi.org/10.1682/JRRD.2009.10.0170

Clinical Nursing Studies

- [28] Clark MS, Rubenach S, Winsor A. A randomized controlled trial of an education and counselling intervention for families after stroke. Clinical Rehabilitation. 2003; 17(7): 703-12. PMID:14606735. http://dx.doi.org/10.1191/0269215503cr6810a
- [29] Eames S, Hoffmann T, Worrall L, et al. Randomised controlled trial of an education and support package for stroke patients and their carers. BMJ Open. 2013; 3: e002538. PMID:23657469. http: //dx.doi.org/10.1136/bmjopen-2012-002538
- [30] Kalra L, Evans A, Perez I, et al. Training carers of stroke patients: randomised controlled trial. BMJ. 2004; 328: 1099. PMID:15130977. http://dx.doi.org/10.1136/bmj.328.7448.1099
- [31] Smith GC, Egbert N, Dellman-Jenkins M, et al. Reducing depression in stroke survivors and their informal caregivers: a randomized clinical trial of a Web-based intervention. Rehabilitation Psychology. 2012; 57: 196-206. PMID:22946607. http://dx.doi.org/10.10 37/a0029587
- [32] Larson J, Franzen-Dahlin A, Billing E, et al. The impact of a nurseled support and education programme for spouses of stroke patients: a randomized controlled trial. Journal of Clinical Nursing. 2005; 14: 995-1003. PMID:16102151. http://dx.doi.org/10.1111/j.1 365-2702.2005.01206.x
- [33] Pierce LL, Steiner VL, Khuder SA, et al. The effect of a Webbased stroke intervention on carers' well-being and survivors' use of healthcare services. Disability & Rehabilitation. 2009; 31: 1676-84. PMID:19479528. http://dx.doi.org/10.1080/09638280902 751972
- [34] Smith J, Forster A, Young J. A randomized trial to evaluate an education programme for patients and carers after stroke. Clinical Rehabilitation. 2004; 18: 726-36. PMID:15573828. http: //dx.doi.org/10.1191/0269215504cr790oa
- [35] Draper B, Bowring G, Thompson C, et al. Stress in caregivers of aphasic stroke patients: a randomized controlled trial. Clinical Rehabilitation. 2007; 21: 122-30. PMID:17264106. http://dx.doi.o rg/10.1177/0269215506071251
- [36] Grant JS, Elliott TR, Weaver M, et al. Telephone intervention with family caregivers of stroke survivors after rehabilitation. Stroke. 2002; 33: 2060-5. PMID:12154263. http://dx.doi.org/10.1161/01. STR.0000020711.38824.E3
- [37] King RB, Hartke RJ, Houle T, et al. A problem-solving early intervention for stroke caregivers: one year follow-up. Rehabilitation Nursing Journal. 2012; 37: 231-43. PMID:22949276. http: //dx.doi.org/10.1002/rnj.039
- [38] van den Heuvel ET, de Witte LP, Nooyen-Haazen I, et al. Shortterm effects of a group support program and an individual support program for caregivers of stroke patients. Patient Education & Counseling. 2000; 40: 109-20. http://dx.doi.org/10.1016/S0738 -3991(99)00066-X
- [39] Lincoln NB, Francis VM, Lilley SA, et al. Evaluation of a stroke family support organiser: a randomized controlled trial. Stroke. 2003;

34: 116-21. PMID:12511761. http://dx.doi.org/10.1161/01. STR.0000047850.33686.32

- [40] Tilling K, Coshall C, McKevitt C, et al. A family support organiser for stroke patients and their carers: a randomised controlled trial. Cerebrovascular Diseases. 2005; 20: 85-91. PMID:15976500. http://dx.doi.org/10.1159/000086511
- [41] Pearlin LI, Mullan JT, Semple SJ, et al. Caregiving and the stress process: an overview of concepts and their measures. Gerontologist. 1990; 30: 583-94. PMID:2276631. http://dx.doi.org/10.1093 /geront/30.5.583
- [42] van den Heuvel ET, Witte LP, Stewart RE, et al. Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: which caregivers benefit the most? Patient Education & Counseling. 2002; 47: 291-9. http://dx.doi.org/10.1016/S0738-3991(01)00230-0
- [43] Cameron JI, Gignac MA. Timing It Right: a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. Patient Education & Counseling. 2008; 70: 305-14. PMID:18155388. http://dx.doi.org/10.10 16/j.pec.2007.10.020
- [44] Cameron JI, Naglie G, Silver FL, et al. Stroke family caregivers' support needs change across the care continuum: a qualitative study using the timing it right framework. Disability & Rehabilitation. 2013; 35: 315-24. PMID:22686259. http://dx.doi.org/10.31 09/09638288.2012.691937
- [45] Feigin VL, Lawes CM, Bennett DA, et al. Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. Lancet Neurology. 2009; 8: 355-69. http://dx.doi.org/10.1016/S1474-4422(09)70025-0
- [46] Hoffmann T, Worrall L, Eames S, et al. Measuring outcomes in people who have had a stroke and their carers: can the telephone be used? Topics in Stroke Rehabilitation. 2010; 17: 119-27. PMID:20542854. http://dx.doi.org/10.1310/tsr1702-119
- [47] Institute of Medicine. The Learning Health System and its Innovation Collaboratives, Update Report. 2011.
- [48] Kissela BM, Khoury JC, Alwell K, et al. Age at stroke: temporal trends in stroke incidence in a large, biracial population. Neurology. 2012; 79: 1781-7. PMID:23054237. http://dx.doi.org/10.12 12/WNL.0b013e318270401d
- [49] Lutz BJ, Young ME. Rethinking intervention strategies in stroke family caregiving. Rehabilitation Nursing Journal. 2010; 35: 152-60. ht tp://dx.doi.org/10.1002/j.2048-7940.2010.tb00041.x
- [50] Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. Lancet. 2014; 383: 245-55. http://dx.doi.org/10.1016/S0140-6736(13)61953-4
- [51] Heidenreich PA, Trogdon JG, Khavjou OA, et al. Forecasting the future of cardiovascular disease in the United States: a policy statement from the American Heart Association. Circulation. 2011; 123: 933-44. PMID:21262990. http://dx.doi.org/10.1161/CIR.0 b013e31820a55f5