CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Transitions of Care Following Stroke

Evidence Tables

Supporting Patients, Families and Caregivers through Transitions

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on Behalf of the Canadian Stroke Best Practice Recommendations
Transitions of Care Following Stroke Writing Group

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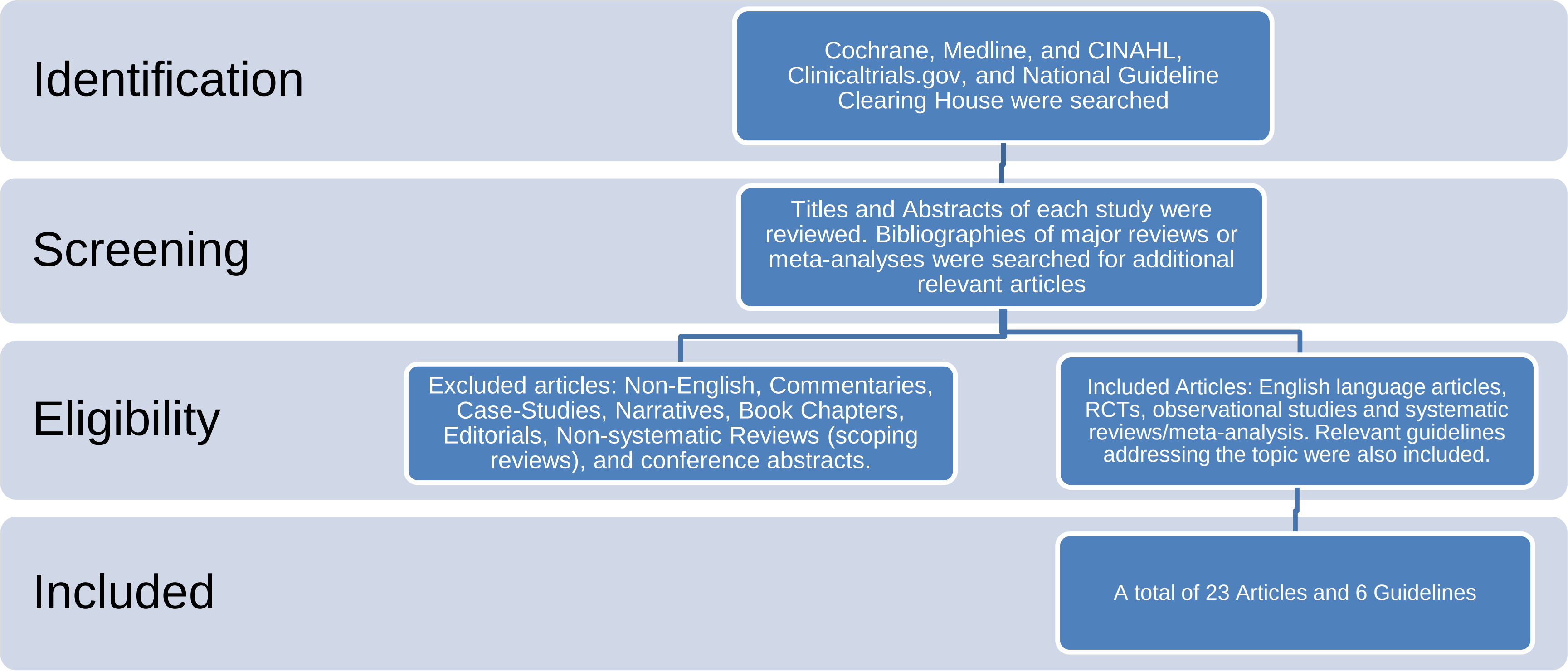
Search Strategy



Cochrane, Medline, and CINAHL, Clinicaltrials.gov, and National Guideline Clearing House were searched

Titles and Abstracts of each study were reviewed. Bibliographies of major reviews or meta-analyses were searched for additional relevant articles

Excluded articles: Non-English, Commentaries, Case-Studies, Narratives, Book Chapters, Editorials, Non-systematic Reviews (scoping reviews), and conference abstracts.

Included Articles: English language articles, RCTs, observational studies and systematic reviews/meta-analysis. Relevant guidelines addressing the topic were also included.

A total of 23 Articles and 6 Guidelines

Cochrane, Medline, and CINAHL, Clinicaltrials.gov, and National Guideline Clearing House were search using medical subject. Titles and abstract of each article were reviewed for relevance. Bibliographies were reviewed to find additional relevant articles. Articles were excluded if they were: non-English, commentaries, case-studies, narrative, book chapters, editorials, non-systematic review, or conference abstracts. Additional searches for relevant best practice guidelines were completed and included in a separate section of the review. A total of 23 articles and 6 guidelines were included and were separated into separate categories designed to answer specific questions.

Published Guidelines

Guideline	Recommendations
Bakas T, Clark PC, Kelly-Hayes M, et al. Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American Heart Association and American Stroke Association. *Stroke* 2014;45:2836-52	Recommendations for caregiver vs dyad interventions: Stroke caregiver interventions are probably recommended in preference to dyadic interventions when stroke caregiver outcomes are most desired. Class IIa; Level of Evidence A Stroke dyad interventions are probably recommended in preference to stroke: Caregiver interventions when survivor outcomes are most desired. Class IIa; Level of Evidence A Recommendations for types of interventions: Interventions that combine skill building (eg, problem solving, stress management, goal setting) with psycho-educational strategies should be chosen over interventions that only use psycho-educational strategies. Class I; Level of Evidence A Interventions that involve only psycho-education are not recommended and have the potential to jeopardize social functioning in some survivors and caregivers. Class III; Level of Evidence B Interventions that consist of support only or a combination of support and psycho-education are not well established and do not have sufficiently strong evidence. Class IIb; Level of Evidence B Recommendations for tailoring vs one-size-fits-all interventions: Interventions that are tailored or individualized on the basis of the needs of stroke caregivers should be chosen over nontailored one-size-fits-all interventions. Class I;Level of Evidence A Postdischarge assessments with tailored interventions based on changing needs should be performed to improve caregiver outcomes. Class I;Level of Evidence C Individual approaches are probably recommended over group interventions. Class IIa; Level of Evidence B Recommendations for mode of delivery for interventions: Interventions that are delivered face to face and/or by telephone are recommended. Class I; Level of Evidence A Interventions delivered completely by telephone can be useful, particularly when face-to-face access is not feasible. Class IIa; Level of Evidence B Interventions delivered by the Web might be considered for those with computer access. Class IIb; Level of Evidence B Recommendations for number of sessions for interventions: Interventions consisting of 5 to 9 sessions are recommended. Class I;Level of Evidence A Interventions with a wide range of sessions (eg, 0–60) delivered by a family support organizer are not as useful and may jeopardize social functioning in some survivors and caregivers. Class III; Level of Evidence B
Intercollegiate Stroke Working Party. National clinical guideline for stroke, 4th edition. National Institute for Health and Clinical Excellence London: Royal College of Physicians, 2012.	**A** Patients and their carers should have their individual practical and emotional support needs identified: • before they leave hospital • when rehabilitation ends or at their 6-month review • annually thereafter. B Health and social services personnel should ensure that: • any identified support needs are met • support services appropriate to the needs of the patient and carers are provided • patients are informed about organisations able to provide other relevant services, and how to contact them • patients and carers receive all the financial and practical support to which they are entitled.

Guideline	Recommendations
	C Patients should be provided with information tailored to their own specific needs regularly during the acute, rehabilitation and longer-term care phases of the illness.
Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning. A national clinical guideline. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network (SIGN); 2010 June.	**Information Needs of Patients and Carers** • Stroke patients and their carers should be offered information about stroke and Rehabilitation [Evidence Level D]. • Information should be available to patients and carers routinely and offered using active information strategies, which include a mixture of education and counseling techniques [Evidence Level A]. • Information should be tailored to the information needs of individual patients and carers, followed up to check understanding and ensure clarity, and repeated as appropriate [Evidence Level A]. • Information should be tailored to the communication needs and visual needs of individual patients and carers. Patients with aphasia should be provided with accessible and easy to read material, be given sufficient time for assimilation and be followed up by health professionals to ensure understanding [Evidence Level D]. • Information needs should be monitored and information should be provided at appropriate time [Evidence Level A] **Carer Support** • Where a carer is suspected of being clinically depressed or anxious, they should be encouraged to seek help by contacting the appropriate member of the general practice team [Good Practice Point]. **Stroke Liaison Workers** • NHS Board areas should consider developing specialist stroke nurse led support services that include education, information provision and liaison, in the community for people who have had a stroke and their carers [Good Practice Point].
Management of Stroke Rehabilitation Working Group. VA/DoD clinical practice guideline for the management of stroke rehabilitation. Washington (DC): Veterans Health Administration, Department of Defense; 2010. p.p.70-72	**Patient, Family Support, and Community Resources** 1. Recommend all stroke patients and family caregivers receive a thorough psychosocial assessment with psychosocial intervention and referrals as needed. 2. The psychosocial assessment of both the patient with stroke and the primary family caregiver should include the following areas: a. History of pre-stroke functioning of both the patient and the primary family caregiver (e.g., demographic information, past physical conditions and response to treatment, substance use and abuse, psychiatric, emotional and mental status and history, education and employment, military, legal, and coping strategies) b. Capabilities and care giving experiences of the person identified as the primary caregiver c. Caregiver understanding of the patient's needs for assistance and caregiver's ability to meet those needs d. Family dynamics and relationships e. Availability, proximity, and anticipated involvement of other family members f. Resources (e.g., income and benefits, housing, and social network) g. Spiritual and cultural activities h. Leisure time and preferred activities i. Patient/family/caregiver understanding of the condition, treatment, and prognosis, as well as hopes and expectations for recovery j. Patient/family/caregiver expectations of stroke-related outcomes and preferences for follow-up care 3. Families and caregivers should be educated in the care of patients who have experienced a severe stroke, who are maximally dependent in ADL, or have a poor prognosis for functional recovery; as these patients are not candidates for rehabilitation intervention. 4. Families should receive counseling on the benefits of nursing home placement for long-term care.

Guideline	Recommendations
	Discharge from Rehabilitation 1. Recommend patient and family are educated regarding pertinent risk factors for stroke. 2. Recommend that the family and caregivers receive all necessary equipment and training prior to discharge from rehabilitation services. [I] 3. Family counseling focusing on psychosocial and emotional issues and role adjustment should be encouraged and made available to patients and their family members upon discharge. **Long-Term Management** 1. Recommend post-discharge telephone follow-up with patients and caregivers be initiated and include problem solving and educational information. 2. If available, asynchronous and real-time tele-health, video, and web-based technologies, (e.g., web-based support groups, tele-rehabilitation), should be considered for patients who are unable to travel into the facility for care and services. 3. Patient and family should be educated regarding pertinent risk factors for stroke. 4. Provide patient information about, and access to community based resources. **Family/Community Support** 1. Patients and caregivers should be educated throughout the rehabilitation process to address patient’s rehabilitation needs, expected outcomes, procedures and treatment as well as appropriate follow-up in the home/ community. [B] 2. Patient and caregiver education should be provided in both interactive and written formats. [B] 3. Caregivers should be provided in a variety of methods of training based on their specific needs, cognitive capability, and local resources; Training may be provided in individual or group format, and in community-based programs. [B]
Clinical Guidelines for Stroke Management 2010. Melbourne (Australia): National Stroke Foundation; 2010 Sep. p. 81-82; 97-98.	**Safe transfer of care from hospital to community** • A documented post-discharge care plan is developed in collaboration with the patient and family and a copy provided to them. This may include relevant community services, self-management strategies (e.g. information on medication and compliance advice, goals and therapy to continue at home), stroke support services, any further rehabilitation or outpatient appointments, and an appropriate contact number for any queries [Grade GPP] **Carer Training** • Relevant member of the multidisciplinary team should provide specific and tailored training for carers/family before the stroke survivor is discharged home. This should include training, as necessary, in personal care techniques, communication strategies, physical handling techniques, ongoing prevention and other specific stroke-related problems, sage swallowing and appropriate dietary modifications, and management of behaviours and psychosocial issues [Grade B] **Community rehabilitation and follow-up services** • Contact with and education by trained staff should be offered to all stroke survivors and families/carers after discharge [Grade C]. • Stroke survivors can be managed using a case management model after discharge. If used, case manages should be about to recognize and manage depression and help to coordinate appropriate interventions via a medical practitioner [Grade C]. • Stroke survivors and their carers/families should be provided with contact information for the specialist stroke service and a contact person (in the hospital or community) for any post-discharge queries for at least the first year following discharge [Grade GPP].

Guideline	Recommendations
	Self-Management • Stroke survivors who are cognitively able should be made aware of the availability of generic self-management programs before discharge from hospital and be supported to access such programs once they have returned to the community [Grade C]. • Stroke-specific programs for self-management should be provided for those who require more specialized programs [Grade GGP]. • A collaboratively developed self-management care plan can be used to harness and optimize self-management skills [Grade GPP]. **Peer Support** • Stroke survivors and family/carers should be given information about the availability and potential benefits of a local stroke support group and/or other sources of peer support before leaving hospital and when back in the community [Grade GPP]. **Carer Support** • Carers should be provided with tailored information and support during all stages of the recovery process. This includes (but is not limited to) information provision and opportunities to talk with relevant health professionals about the stroke, stroke, team members and their roles, test or assessment results, intervention plans, discharge planning, community services and appropriate contact details [Grade C]. • Where it is the wish of the person with stroke, carers should be actively involved in the recovery process by assisting with goal setting, therapy sessions, discharge planning, and long-term activities [Grade GPP]. • Carers should be provided with information about the availability and potential benefits of local stroke support groups and services, at or before the person's return to the community [Grade C]. • Carers should be offered support services after the person's return to the community. Such services can use a problem-solving or educational-counselling approach [Grade C]. • Assistance should be provided for families/carers to manage stroke survivors who have behavioural problems [Grade GPP].
Duncan PW, Zorowitz R, Bates B, Choi JY, Glasberg JJ, Graham GD, Katz RC, Lamberty K, Reker D. Management of adult stroke rehabilitation care: a clinical practice guideline. Stroke, 2005;36:e117 -125	**Patient and Family/Caregiver Education** 1. Recommend that patient and family/caregiver education be provided in an interactive and written format. 2. Recommend that clinicians consider identifying a specific team member to be responsible for providing information to the patient and family/caregiver about the nature of the stroke, stroke management rehabilitation and outcome expectations, and their roles in the rehabilitation process. 3. Recognize that the family conference is a useful means of information dissemination. 4. Recommend that patient and family education be documented in the patient's medical record to prevent the occurrence of duplicate or conflicting information from different disciplines. **Educate Patient/Family, Reach Shared Decision About Rehabilitation Program, and Determine Treatment Plan:** 4. Recommend that patient and caregiver education be provided in an interactive and written format. Provide the patient and family with an information packet that may include printed material on subjects such as the resumption of driving, patient rights/responsibilities, support group information, and audiovisual programs on stroke. **Is Patient Ready for Community Living?** 1. Recommend that the patient, family, and caregivers be fully informed about, prepared for, and involved in all aspects of healthcare and safety needs. 2. Recommend that the family and caregivers receive all necessary equipment and training in moving and handling, in

Guideline	Recommendations
	order to position and transfer the patient safely in the home environment. 3. Recommend that the patient have appropriate vocational and income support opportunities. Stroke patients who worked before their strokes should be encouraged to be evaluated for the potential to return to work, if their condition permits. Vocational counseling should be offered when appropriate. 4. Recommend that leisure activities be identified and encouraged and that the patient be enabled to participate in these activities. 5. Recommend that case management be put in place for complex patient and family situations. 6. Recommend that acute care hospitals and rehabilitation facilities maintain up-to-date inventories of community resources, provide this information to stroke patients and their families and caregivers, and offer assistance in obtaining needed services. Patients should be given information about, and offered contact with, appropriate local statutory and voluntary agencies.

Evidence Tables

Impact of Stroke on Patients, Family and Informal Caregivers

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Cameron et al. 2014 **Canada**	NA	399 first-ever stroke survivors, identified during the acute hospital stay and their caregivers. In the year 1 sample, 69% of caregivers were female. Mean age was 58 years. 70% of caregivers were spouses and 86% lived with the stroke survivor.	Standardized measurements were obtained at 1, 3 6 and 12 months post stroke. Additional measurements were completed at 18 and 24 months in a subset of 80 dyads. Mixed effects modeling was conducted to examine factors related to caregiver psychological well-being of caregivers, assessed using the Positive Affect Scale, at 12 months and 2 years.	**Caregiver assessments:** SF-36 (physical health subscore), caregiver's perception of behavioural and psychological symptoms assessed using the Brain Impairment Behavior Inventory-Revised, (apathy, depression, memory/comprehension, irritability), Caregiver Assistance Scale, Caregiving Impact Scale, Caregiver mastery (Pearlin) **Survivor assessments:** Stroke Impact Scale, MMSE and Charlson index	In the full model, factors associated with psychological well-being of caregivers at 12 months included: increasing age, higher Caregiver Assistance Scale scores, lower Caregiver Impact Scale scores, higher Caregiver mastery scores, higher SF-36 (physical health domain) scores, higher Personal gain scores, lower survivor depression scores, higher Stroke Impact Scale scores (physical component) of the survivor, higher cognitive composite scores of the survivor and lower CNS scores. At 2 years, independent factors were higher mastery scores, higher SF-36 (physical health domain) scores, lower survivor depression scores, and lower CNS scores.
Gallacher et al. 2013 **UK** **Systematic review**	NA	69 qualitative studies, published from 2000 onwards that explored the adult patient experience of stroke management in any setting and provided information on patient burden.	Data were analyzed using framework synthesis, informed by Normalization Process Theory and organized into themes.	NA	**Treatment Burden** 4 areas of treatment burden were identified: 1) Making sense of stroke management and planning care. Example: In several studies, patients reported encountering barriers to receiving timely and complete information related to their recent stroke 2) Interacting with others. Example: Many patients reported a lack of time and empathy from therapists 3) Enacting management strategies across multiple care settings including 3a) institutional admission. Example: patients reported negative environmental circumstances such as inadequate support from staff during mealtimes; 3b) managing stroke in the community. Example: patients reported discharge services that are poorly coordinated, badly managed and inadequate; 3c)

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					reintegration into society. Example: Patients reported feeling unsupported by health services in their struggle to understand bans on driving; 3d) adjusting to life after stroke. Example: Patients report being unprepared for their slow pace of recovery. 4) Reflecting on management. Example: miscommunication can result in a patient making a treatment decision related to their care (e.g. to discontinue a medication) that contradicts the advice of their healthcare provider
Denno et al. 2013 **USA** **Cross-sectional study**	NA	153 informal caregivers included in the U.S. National Health and Wellness survey who were eligible and agreed to participate (2007-2009). Inclusion criteria were: ≥18 years, providing care for a stroke survivor with spasticity for at least 6 months. 70.6% of caregivers were women. Mean age: 52 years. 78% of caregivers were either the survivor's spouse or adult children	Participants completed a one-time online survey. Analysis to determine whether caregiver burden was an Independent predictor of self-reported anxiety and depression, using logistic regression.	**Measures of Caregiver Burden:** Oberst Caregiving Burden Scale (OCBS) (time and difficulty sub scores), Bakas Caregiving Outcome Scale (BCOS) **Measures of Anxiety and Depression:** Patient Health Questionnaire-9 (PHQ-9), reported categorically (none, mild, moderate, moderately-severe and severe) and self-report, based on physician diagnosis	Mean OCBS (time & difficulty) scores were 3.08±0.86 and 2.16±0.90, respectively. Mean BCOS score was 3.28±0.87. 21.6% and 22.2% of caregiving reported having anxiety and depression, respectively. PHQ-9: none or mild (64%), moderate (18.3% and moderately-severe and severe (17.7%) Increasing OCBS difficulty score was a significant predictor of: Self-report anxiety (OR=2.57, 95% CI 1.57-4.21, p<0.001) Self-report depression (OR=1.88, 95% CI 1.19-2.99, p=0.007) Higher PHQ-9 category (OR=2.48, 95% CI 1.72-3.56, p<0.001). Increasing OCBS time score was a significant predictor of being in a higher PHQ-9 category. (OR=1.96, 95% CI 1.35-2.83, p<0.001), but was not a predictor of either self-reported anxiety or depression. Increasing BCOS score was a significant predictor of: Self-report anxiety (OR=2.43, 95% CI 1.47-4.16, p<0.001) Self-report depression (OR=2.27, 95% CI 1.35-3.70, p=0.002)

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					Higher PHQ-9 category (OR=4.55, 95% CI 2.94-7.14, p<0.001).
Goodwin et al. 2013 **USA** **Longitudinal study**	NA	30 stroke survivors and their spousal caregivers who were living at home had who had participated in the 12-month CAReS study (2001-2005, n=159). 80% of stroke survivors were males. Mean age was 71 years. 80% of caregivers were women. Mean age was 65 years.	In the present study, data was collected on a single occasion using an in-home interview, 3-5 years following stroke. (baseline and 3, 6, and 12 month data had been collected previously) Changes in HRQoL for both the stroke survivor and their caregiver from baseline were assessed. Possible predictors of HRQoL were also examined. Mean HRQoL scores for survivor and caregiver were compared with normative means	**Measures of HRQoL:** SF-36, QoL (Stroke Impact Scale SIS) **Other Measures:** Depression (Geriatric Depression Scale GDS), Mutuality (Mutuality Scale), burden (Zarit Burden Interview)	Mean time since stroke onset was 4.7 years. Caregiver: There was a significant decrease in GDS scores from baseline to >2 years and no significant changes in mutuality Scale scores or ZBI Survivor: From baseline -12 months, GDS decreased significantly, but then increased significantly from 12 months to end of follow-up. SIS subscores: Despite significant improvements in physical and social participation, there were significant decreases in all SIS subscales from 12 months to end of follow-up. Older age and increasing number of illnesses were associated with significantly lower SF-36 physical domain subscore (p=0.004) for caregivers. Higher levels of depression were associated with significantly lower SF-36 mental domain subscores for survivors (p=0.003).
Perkins et al. 2013 **USA** ***REasons for Geographical and Racial Differences in Stroke (REGARDS)***	NA	Population-based, longitudinal study of 30,239 African Americans (41.5%) and Caucasian (58.5%) participants ≥45 years living in the US, with half the sample obtained from those living in the stroke belt (10 south-eastern states)	Data was obtained using telephone surveys and in-home examination. Data collection included: basic demographic and socioeconomic questions, whether participants were providing care to a family member with a chronic ongoing illness, and if so, how many hours per week and if they found the task to be mentally/emotionally stressful (no strain, some strain or a lot of strain). Information related to self-rated health (SF-36), depressive symptoms (CESD-4) and health status (diabetes,	**Primary outcome:** Effect of care-giver status on all-cause mortality (proportional hazards model)	12.3% of participants were family caregivers. After an average of 5.29 years follow-up, 258 (6.95%) had died. Compared with caregivers who were still alive, independent predictors of all-cause mortality were older age, male sex, worse self-rated health, high caregiver strain (a lot of strain vs. no strain: OR=1.55, 95% CI 1.06-2.26, p=0.02 and a lot of strain vs. some strain: OR=1.83, 95% CI 1.27-2.63, p=0.001). Education, income level, history of stroke, relationship with care receiver and the number of hours spent caregiving were not independent predictors.

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			hypertension, history of stroke or heart disease) were also obtained. Following enrolment data on all-cause mortality was collected every 6 months.		
Cameron et al. 2011 **Canada** **Longitudinal study**	NA	399 first-ever stroke survivors and their caregiver. 59% of stroke survivors were males. Mean age was 68 years. 70% of caregivers were women. Mean age was 58 years. (Same sample used in Cameron et al. 2014)	Telephone interviews were conducted at 1, 3, 6 and 12 months following stroke. Additional interviews were conducted at 18 and 24 months in a subset of 80 dyads. Mixed effects modeling was conducted to examine the relationship between survivor's physical disability and behavioural/psychological symptoms and caregiver's emotional distress.	**Caregiver assessments:** SF-36 (physical health subscore), caregiver's perception of behavioural and psychological symptoms assessed using the Brain Impairment Behavior Inventory-Revised, (apathy, depression, memory/comprehension, irritability), Caregiver Assistance Scale, Caregiving Impact Scale, Caregiver mastery (Pearlin), Centre for Epidemiological Studies Depression Scale **Survivor assessments:** Stroke Impact Scale, MMSE and Charlson index	5 different models are presented. In the full model (C), using the full cohort, the only survivor-related factor associated with increasing caregiver emotional distress was depression. Increasing levels of emotional distress were found among caregivers who were younger, female, in poorer physical health, who had experienced greater lifestyle interference, with a lower sense of personal control and who were caring for their spouse. In the simplest model (D), in addition to the same variables in model C, lower cognitive status was also associated with increasing caregiver emotional distress.
McPherson et al. 2011 **Canada** **Cross-sectional study**	NA	56 dyads (stroke survivors who had been admitted to a single hospital from 2007-200) and their spousal caregivers. 84% of caregivers were female. Their mean age was 62 years. 88% of stroke survivors were male. Their mean age was 65 years.	A postal survey was administered an average of 31.7 months post stroke. Univariate and multivariable analyses were conducted to explore the relationships between caregiver HRQoL and caregiver role, reciprocity, balance and relationship satisfaction	**Care recipient measures:** Stroke-Specific Quality of Life Scale (SS-QoL), **Caregiver assessments:** SF-36, Caregiver Reaction Assessment (CRA), Caregiver Reciprocity Scale II (CRS II), perceived equity in the relationship (single-item, 5-point scale), Quality of Marriage Index (QMI)	3 separate models were developed to assess HRQoL, which explained 24% to 39% of the variance. Independent predictors of SF-36 (physical domain) were care recipient's age (inverse) and CRA (negative dimension) (inverse) Independent predictors of CRA (positive domain) were QMI and CRS II (intrinsic) Independent predictors of CRA (negative domain) were CRS II (balance) and SS-QoL
Hayes et al. 2009	NA	275 veterans who had sustained a first-ever	Telephone surveys of survivors and their	Items from the National Alliance for Caregiving	66 (12.6%) of caregivers were injured. Caregivers who reported a

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USA **Cross-sectional study**		stroke (2000-2006), and their informal caregivers. 91% of caregivers were women. Their mean age was 61 years. 74% of caregiver's were the survivor's spouse.	caregivers were conducted on a single occasion. The association between caregiver characteristics and the development of injuries was explored.	(NAC) Survey, the Behavioural Risk Factors Surveillance Survey and the Centre for Epidemiological Studies Depression Scale (CES-D), were used. The 5-level classification system of the NAS was used to assess burden (1=low, 5=high)	physical injury were more likely to report higher levels of burden, provided more hours of care per week, exhibited more depressive symptoms and fewer healthy days per month compared to carers reporting no injury. The most common type of injury reported was a back injury and 53% of injured carers stated that the injury interfered with their ability to provide care. Significant predictors of injury were higher caregiver burden (OR=1.62, 95% CI 1.14-2.31, p=0.008) and depression (OR=1.10, 95% CI 1.04-1.17, p=0.001).
Ko et al. 2007 **USA**	NA	132 caregivers who participated in the Family Function, Stroke Recovery, and Caregiver Outcomes Study. The stroke survivors were participants of the EXCITE trial, examining constraint-induced movement therapy. Their ages ranged from 30-83 years. 64% were male.	In-person and telephone interview were conducted at 5 rehabilitation centres. Caregiver data were collected at baseline (3-9 months post stroke) and at 4 and 8 months, in conjunction with EXCITE evaluations. The characteristics of working vs. nonworking caregivers was examined using univariate and multivariable approaches	**Caregiver outcomes:** SF-36 (physical domain), Centre for Epidemiological Studies Depression Scale (CES-D), Piper Fatigue Scale (PFS), Family Assessment Device (FAD), Family Caregiver Conflict Scale for Stroke (FCCS)	52% of caregivers were working full time or part-time. The majority of working caregivers reported reducing their hours of paid work, or missing work. 9 caregivers retired or resigned. Working caregivers were younger on average (50 vs. 64 yrs) and were less likely to have major health problems (35% vs. 65%). There were no significant differences in mean scores between working and nonworking caregivers for the outcomes: CES-D), PSF, FAD, or FCCS. Working caregivers had significantly higher mean SF-36 (physical) scores (54.5 vs. 49.6, p<0.05) and had significantly more support from other family members. Independent predictors of working full time were: younger age (OR=1.13, 95% CI 1.07-1.19), better physical health (OR=1.09, 95% CI 1.00-1.18), increasing depressive symptoms (OR=1.12, 95% CI 1.02-1.24).
Rochette et al. 2007 **Canada** **Longitudinal study**	NA	54 spouses (not necessarily caregivers) of persons who had been admitted to an acute care hospital from 2001-2003 with first-ever stroke.	Data was collected at 2 weeks and 6 months following stroke by interview in the participant's home. Pre-stroke data was also collected during these	**Outcomes:** LIFE-H 3.0 (excluding education domain), Caregiver Strain Index (CSI), Beck Depression Inventory (BDI)	The stroke severity varied widely from 1.5-11.5, although the majority of stroke survivors had mild motor impairment. 6 months post stroke, 35.2% of spouses reported a high level of burden (CSI score ≥7) and 17% were identified with possible depression (BDI score

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		76% of spouses were female. Their mean age was 69 years.	interviews. Changes in participation-level outcomes (LIFE-H, perceived burden and presence of symptoms of depression) were examined over time.		≥10). From pre-stroke to 6 months post, the most significant changes (clinically and statistically) were in the social roles domains (personal relationships, employment and recreation). These changes were associated with increased caregiver strain, but not with depression.

Support Needs for the Caregiver and Family

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Cameron et al. 2014 **Canada** **Qualitative study**	NA	16 patients recruited from an inpatient rehabilitation stroke facility and 15 informal caregivers. 12 patients were female. Median age was 62 years. 13 caregivers were female. Median age was 41 years. 10 caregivers were parents. 20 health care professionals (HCP) were also included (occupational/physical therapists, social workers, nurses, pharmacists , nurses, SLPs, and others)	Information regarding participant's perceptions and experiences with weekend passes were obtained Data from patients and caregivers was collected during the first week following the first weekend pass and then 4 weeks following discharge home, through in-depth interviews. Data from HCP was obtained during a single focus group.	NA	3 key themes emerged: i) Preparing patients for safe return home. Patients discussed the need to feel safe in the home environment while caregivers discussed their need to feel supported. Assessing the patient for readiness was a key theme discuss by HCPs. ii) Gaining insight into what life would be like, and for the caregiver to evaluate their abilities to care for stroke survivor iii) The experiences of patients and caregivers during weekend passes. Patients and caregivers discussed the range of emotions they experienced and how their experienced changes before and after the weekend pass.
Cecil et al. 2013 **UK** **Qualitative study**	NA	30 first-ever stroke survivors and their informal caregivers. 23 caregivers were women, 19 caregivers were spouses. Stroke survivors ranged in age from 37-95 years.	Data were collected through semi-structured interviews, conducted 6 weeks following hospital discharge.	NA	9 themes across 3 categories emerged: 1) Impact of the stroke: issues were raised that were related to the changes in lifestyle, concerns and worries and mental health issues. 2) Extrinsic factors that support the caring scenario: issues were raised related to interactions with health professionals, information

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					and knowledge received and experiences with other family members in their caregiver role. 3) Intrinsic factors that help the caregiver cope: Issues raised were related to the caregivers own health and well-being, gratitude and faith and the nature of the dyadic relationship
Creasy et al. 2013 **USA** **Qualitative study**	NA	17 family caregivers (10 female) of first-ever stroke survivors. Mean ages of stroke survivor and caregiver were 69 and 65 years, respectively.	2 interviews were conducted, one close to the point of discharge from hospital and the other, within 4 months of discharge. Interview questions were loosely structured with a focus on pre-discharge expectations and post-discharge experiences.	NA	Caregivers expressed information needs related to their role as caregiver in preparation for discharge home. They expressed concerns for their own emotional support needs and their ability to provide emotional support. Caregivers discussed their experiences with caregiver-provider interactions, some of which were positive, others, negative. Caregivers discussed the interactive strategies they developed, from passive to active to manage their interactions with providers.
Cameron et al. 2013 **Canada** **Qualitative study**	NA	24 informal caregivers to stroke survivors recruited from inpatient rehabilitation, a community-based aphasia program and a rural-focused community-care organization and 14 health-care professionals (HCP) with primary stroke care responsibilities (nurses, occupational and physical therapists speech-language pathologists and case workers). 70.8% of caregivers were female. Mean age was 65.5 years.	One time interviews were conducted either in person or through telephone. The focus of the questions for caregivers was related to their emotional, informational and instrumental needs, while the focus of HCP was on the description of the caregiver supports they provided and the identification of needs that they perceived to be unmet. The data were analyzed using the “Timing it Right” framework (described below).	NA	3 caregiver themes emerged concerning: the type and intensity of support needed, who provides support and the method of providing support and the primary focus of care, which varied across the care continuum (i.e., as survivor transitioned from inpatient rehabilitation through community care). Caregivers and HCP described similar issues related to caregiver needs.
Cameron & Gignac 2008 **Canada** **Review**	NA	11 qualitative and quantitative studies that described the family caregiver support needs across the stroke event/care continuum	The results of the included studies were used to inform the “Timing it Right” framework	NA	5 phases with distinct caregiver needs, related to information provision, emotional support, training and feedback, were identified. The **event/diagnosis phase** is characterised by short duration during the acute inpatient period.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					Caregiver needs are related to information provision (diagnosis/prognosis) and emotional support The **stabilization phase** also occurs during the acute inpatient period. In addition to needs related to information provision (cause of event, current care needs) and emotional support, caregivers also need initial training to assist with ADL and rehabilitation therapies. During the **preparation phase** (acute or inpatient rehabilitation), caregivers require information related to accessing community resources , continued emotional support and feedback about ADL supporting activities During the first few months after the patient returns home (**implementation phase),** caregivers require information (availability of community resources), emotional support (issues of anxiety and the future), practice with ADL training and feedback related to their performance Over the long period of the **adaptation phase**, caregivers need information related to planning for the future, and helping the stroke survivor with issues related to community reintegration (work and leisure) and emotional support as the relationship with the stroke survivor changes.
Mackenzie et al. 2007 **UK** **Cross-sectional study**	NA	42 family carers of patients who had been admitted to an acute stroke unit and were discharged home. 69% of carers were women. 57% were spouses or partners. 45% of carers reported some degree of physical problem or disability. Their mean age was 62 years. 55% of survivors were	Surveys were conducted before discharge and 4-6 weeks after, to examine carer's needs, knowledge, satisfaction and competence in caring for stroke survivors. Surveys were completed over a 14-month period	**Carer assessments:** Carer Assessment Scale (CAS), + 1 open-ended question enquiring about additional items not on the scale, Knowledge of Stroke (KOS) scale (administered only at follow-up), Sense of Competence Questionnaire (SCQ)(administered only at follow-up), Satisfaction with Stroke Services (SSS) scale (administered only at follow-up)	The median CAS scores decreased from 10 (discharge) to 8 (follow-up), p=0.059. Possible scores range from 0-54 with higher scores=greater needs. Prior to discharge, carers were asked to anticipate and prioritize what their 3 most important problems would be. The most frequently cited issues were: 1st priority-elimination needs (24.4%), communication (14.6% and fluctuation in mood (12.2%) 2nd priority-ADL assistance (15.4%), fluctuation in mood (12.8%) and elimination needs (10.3%)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		women. Their mean age was 70 years. Median BI score at discharge was 14.		**Stroke Survivor assessment:** Barthel Index (BI)	3rd priority-inner conflict (17.2%), witnessing sick conditions (13.8%), getting information related to health and social services (10.3%). At 5-6 weeks follow-up, the 2 top priorities identified by caregivers previously had not changed. The 3rd priority had changed: getting equipment home, restriction of social life and feeling tired were identified by 20% of carers. The median KOS score was 24 and did not differ by sex. (Possible scores range from 0-30 with higher scores=greater knowledge) Median SCQ score was 50 (possible scores range from 27-108, with higher scores=greater burden). There was a significant inverse correlation with age (*r*=-0.62, p<0.001) Median SSS score was 50 (possible scores range from 12-48, with higher scores=greater satisfaction). Male carers reported greater satisfaction than women (32 vs. 28.5, p<0.011)
Smith et al. 2004 **UK** **Cross-sectional study**	NA	Caregivers of 90 patients who had experienced a stroke 3-11 months previously and who were livening in the community. 62% of the patients were male. The mean age was 68 years. 72% of the carers were female. The mean age was 58 years.	Semi-structured interviews lasting 1-2 hours with the caregiver were conducted on a single occasion at one-year post stroke in the participant's home. Key themes and issues were identified qualitatively.	NA	Key themes identified that were related to the post-hospital experience included: the caregiver's experience with the transition process from hospital-home, the changing nature of the relationship with the stroke survivor, adjusting to the carer role and lack of information. Carers reported delays and barriers waiting for applications/funding for alterations to make the home more accessible, having to provide care in the immediate post-discharge period with no skills training and lack of follow-up with GPs. Difficulties associated with transportation to follow-up appointments, financial difficulties and accessing benefits were also identified as concerns. Carers expressed difficulty coping with patients' quick anger and emotional lability. Lack of attention to the carer's physical and emotional ability to provide care was also noted.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					Carers reported lack of timely access to comprehensive information on all aspects of stroke

Interventions to Support Family Caregivers

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Steiner et al. 2008 **USA** **RCT**	CA: ☒ Blinding: Patient ☒ Therapist☒ Assessor☑ ITT: ☒	73 caregivers of patients who had sustained a first-ever stroke and were discharged home following inpatient rehabilitation. 75% of the caregivers were female. Caregivers included spouses (69%), adult children (19%0, and friends (19%). Mean age was 55 years.	Participants were randomly allocated to either the intervention group (n=36), which consisted of the use of "Caring Web", an online education and support including 4 components: "Ask the Nurse", "Caretalk", an online support group (email), "Tip of the Month" and educational links or a control (non-Web user) group (n=37).	Measures of emotional and physical support from family and friends (measured on a 3-point Likert scale) and caregiver health (measured on a 5-point Likert scale) were measured at baseline, 3, 6 and 12 months by telephone interviews.	At 12 months, there were no significant differences between groups for any of the outcomes of interest. Assessments at other time points were not conducted. At one year, 35.1% and 38.9% of participants in the non-web and web groups respectively, reported feeling a lot of emotional support. At one year, 16.2% and 11.1% of participants in the non-web and web groups respectively, reported receiving a lot of physical support. At one year, 32.4% and 27.8% of participants in the non-web and web groups respectively, reported their health as "very good".
Tilling et al. 2005 **UK** **RCT**	CA: ☑ Blinding: Patient ☒ Therapist☒ Assessor☑ ITT: ☒	340 patients with first-ever stroke (67% ischemic) admitted to hospital and their caregivers. Mean age of stroke patients was 77 years. 50% of patients were incontinent, 49% had dysphagia, 62% were dysarthric.	Patients (and their caregivers) were randomized to receive support from a family support organizer (FSO) (n=170) or standard outpatient care (control group, n=170). The FSO received training to provide emotional support, information and prevention advice to patients with stroke and their families.	**Primary outcome:** Patient satisfaction with services **Secondary outcomes:** Barthel Index (BI), Hospital Anxiety & Depression Scale (HADS), modified version of Reintegration to Normal Living Index (RNLI), Pound Satisfaction Scale **Caregiver outcomes:** Caregiver Strain Index, HADS Assessments were conducted at 3 months and 1 year after randomization	There was an average of 15 telephone or face to face contacts with the FSO (range 1-60). At 3 months, mean total RNLI scores were significantly lower in the intervention group (6 vs. 7, p=0.05). There were no significant differences in overall all patient satisfaction scores (7.6 vs. 7.4, p=0.80). Al one year there were no significant differences between groups except that fewer patients in the intervention group had been seen in hospital for stroke (21% vs. 38%, p=0.009). At one year there were no significant differences between groups for any of the caregiver outcomes, except that significantly fewer of the caregivers in the intervention group were satisfied with the information they received regarding applying for

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					benefit and social services.
Lincoln et al. 2003 **UK** **RCT**	CA: ☑ Blinding: Patient ☒ Therapist☒ Assessor☑ ITT: ☒	250 patients who had been admitted to hospital following acute stroke, with a pre-stroke Barthel Index score ≥10 and their informal caregivers. 65% of the stroke survivors were male. The mean age was 70 years. No demographic details were reported for the caregivers.	Participants were randomized to receive either the Stroke Family Support Organiser (FSO) service (n=126) which provided support, information to patients and carers and liaised with hospital or to standard care (n=124), for up to 9 months. The aim was to reach patients within 4 weeks of stroke	**Stroke Survivor & caregiver outcomes:** General Health Questionnaire-12 (GHQ-12), Barthel index (BI), Nottingham Extended ADL (EADL), stroke knowledge, satisfaction with information, overall satisfaction. Assessments were conducted at 4 and 9 months.	The mean number of contacts/patient was 6.44, which were made in-person, or by telephone. Patient outcomes: At 4 and 6 months, there were no significant differences in median GHQ-12, BI or EADL scores of stroke survivors between groups, but the FSO group had better knowledge of stroke and were more satisfied with the service they received than the control group. The pattern of results was similar for the caregiver.
Grant et. al. 2002 **RCT** **USA**	CA: ☒ Blinding: Patient ☒ Assessor ☑ ITT: ☒	74 primary, informal caregivers of individuals who had experienced an ischemic stroke, had moderate disability (FIM score 36-96), and had been discharged home. 91% of the caregivers were women. The mean age of the caregivers, was 57 years. 47% of stroke survivors were men. The mean age of male stroke patients was 73 years and 75 years for women.	Participants were randomized to either Social Problem Solving Telephone Partnership (SPTP) intervention, sham intervention, or a control group, shortly following discharge from hospital. STPT intervention involved the training of social problem solving skills to manage caregiver problems and cope with stress. This included a 3 hour session with a trained nurse in the home, followed by weekly (weeks 2-4), and bi weekly (weeks 6-12) telephone contacts to maintain skills. Sham intervention group received the same telephone contacts to identify the health services the stroke survivor had received since the last contact. The control group received discharge	**Outcomes:** general health (SF-36), problem solving skills (Social Problem-Solving Inventory), satisfaction with health care (Client Satisfaction Questionnaire), depression (Centre for Epidemiological Studies Depression Scale), caregiver preparedness (Preparedness for Caregiving Scale), caregiver burden (Caregiver Burden Scale) Assessments were conducted at baseline, week 5 of intervention, 9 and 13 weeks post discharge	The intervention group demonstrated a significant improvement over time in social functioning (p=0.0176). The intervention group also demonstrated significant improvements in general health (vitality, p=0.013; role limitations related to emotional problems, p=0.007; mental health, p=0.001), problem solving (negative problem orientation, p<0.001; rational problem solving, p=0.025; impulsivity/ carelessness style, p=0.007), caregiver preparedness (p<0.001), and caregiver depression (p<0.001)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			planning services only.		
Evans et al. 1998 **USA** **RCT**	CA: ☒ Blinding: Patient ☒ Assessor ☒ ITT: ☒	188 primary caregivers of all patients who had sustained a stroke at a single Veteran's hospital. >90% of the stroke survivors were male. The mean age was 62 years. >90% of the caregivers were female. The mean age was 49 years.	Participants were randomized to a control group (n=63), an education group (n=64) or a counseling group (n=61). Participants in the control group may have received social services but contacts were limited. Participants in the education group attended 2x one-hour classes, while those in the counseling group received 2 hours of education (same as education group) + an additional 7 individual 1 hour counselling sessions.	**Outcomes**: Stroke Care Information Test (SCIT), Family Assessment Device, ESCROW profile, Personal Adjustment and Role Skills Scale (PARS) Assessments were conducted at baseline (by 3rd week of hospitalization), 6 months and one year following stroke	Mean SCIT scores and FAD scores (problem solving, communication and global family function sub scores) for participants in both treatment groups were significantly better, compared with control at both 6 months and one year. At one year, the mean affective involvement sub score of the FAD was significantly lower (better) for participants in both treatment groups compared with control. There were no significant differences among groups in the mean role assignment or affective responsiveness sub scores of the FAD, at either 6 months or one year. There were no significant differences in mean ESCROW scores among groups at 6 months or one year. The mean PARS scores for participants in the counseling group were significantly higher at 6 months and one year, compared with the other 2 groups.
Dennis et al. 1997 **UK** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☑ ITT: ☑	417 patients with a confirmed stroke within the previous 30 days	Patients were randomized to receive either post stroke visits by a stroke family care worker (n=210) who identified unmet needs and aimed at fulfilling them or usual care (no family care worker, n=207) for 6 months.	**Primary outcome:** Frenchay Activities Index (FAI), Oxford Handicap Scale, Barthel Index, General Health Questionnaire, Social Adjustment Scale, Caregiving Hassles Scale **Secondary outcomes:** Hospital Anxiety & Depression Scale (HADS), mental Adjustment to Stroke Scale, Caregiver Satisfaction Questionnaire Assessments were conducted at 6 months following randomization	There were no significant differences between groups on any of the primary outcomes. Among the 246, there were no significant differences between groups on any of the outcomes of interest, except for lower median GHQ scores (4 vs. 7.5) and lower median caregiver hassle score (4 vs. 8) and lower HADS score (anxiety sub score: 7 vs. 7.5). Both patients and caregivers in the intervention group were more satisfied with certain aspects of care (more attentive care during hospitalization, satisfaction with outpatient services, provision of information, feeling supported)

Reference List

Cameron JI, Gignac MA. "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Educ Couns* 2008;70:305-14.

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;42:302-06.

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. *Disabil Rehabil* 2013;35:315-24.

Cameron JI, Stewart DE, Streiner DL, et al. What makes family caregivers happy during the first 2 years post stroke? *Stroke* 2014;45:1084-89.

Cameron JI, Bastawrous M, Marsella A, et al. Stroke survivors', caregivers', and health care professionals' perspectives on the weekend pass to facilitate transition home. *J Rehabil Med* 2014;46:858-63.

Cecil R, Thompson K, Parahoo K, et al. Towards an understanding of the lives of families affected by stroke: a qualitative study of home carers. *J Adv Nurs* 2013;69:1761-70.

Creasy KR, Lutz BJ, Young ME, et al. The impact of interactions with providers on stroke caregivers' needs. *Rehabil Nurs* 2013;38:88-98.

Dennis M, O'Rourke S, Slattery J, et al. Evaluation of a stroke family care worker: results of a randomised controlled trial. *BMJ* 1997;314:1071-76.

Denno MS, Gillard PJ, Graham GD, et al. Anxiety and depression associated with caregiver burden in caregivers of stroke survivors with spasticity. *Arch Phys Med Rehabil* 2013;94:1731-36.

Evans RL, Matlock AL, Bishop DS, et al. Family intervention after stroke: does counseling or education help? *Stroke* 1988;19:1243-49.

Gallacher K, Morrison D, Jani B, et al. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS Med* 2013;10:e1001473.

Godwin KM, Ostwald SK, Cron SG, et al. Long-term health-related quality of life of stroke survivors and their spousal caregivers. *J Neurosci Nurs* 2013;45:147-54.

Grant JS, Elliott TR, Weaver M, et al. Telephone intervention with family caregivers of stroke survivors after rehabilitation. *Stroke* 2002;33:2060-65.

Hayes J, Chapman P, Young LJ, et al. The prevalence of injury for stroke caregivers and associated risk factors. *Top Stroke Rehabil* 2009;16:300-07.

Ko JY, Aycock DM, Clark PC. A comparison of working versus nonworking family caregivers of stroke survivors. *J Neurosci Nurs* 2007;39:217-25.

Lincoln NB, Francis VM, Lilley SA, et al. Evaluation of a stroke family support organiser: a randomized controlled trial. *Stroke* 2003;34:116-21.

Mackenzie A, Perry L, Lockhart E, et al. Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disabil Rehabil* 2007;29:111-21.

McPherson CJ, Wilson KG, Chyurlia L, et al. The caregiving relationship and quality of life among partners of stroke survivors: a cross-sectional study. *Health Qual Life Outcomes* 2011;9:29.

Perkins M, Howard VJ, Wadley VG, et al. Caregiving strain and all-cause mortality: evidence from the REGARDS study. *J Gerontol B Psychol Sci Soc Sci* 2013;68:504-12.

Rochette A, Desrosiers J, Bravo G, et al. Changes in participation level after spouse's first stroke and relationship to burden and depressive symptoms. *Cerebrovasc Dis* 2007;24:255-60.

Smith LN, Lawrence M, Kerr SM, et al. Informal carers' experience of caring for stroke survivors. *J Adv Nurs* 2004;46:235-44.

Steiner V, Pierce L, Drahuschak S, et al. Emotional support, physical help, and health of caregivers of stroke survivors. *J Neurosci Nurs* 2008;40:48-54.

Tilling K, Coshall C, McKevitt C, et al. A family support organiser for stroke patients and their carers: a randomised controlled trial. *Cerebrovasc Dis* 2005;20:85-91.