Canadian Stroke Best Practices

CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Rehabilitation, Recovery and Community Participation Following Stroke

Part One: Stroke Rehabilitation Planning for Optimal Care Delivery Evidence Tables

Support for Patients, Families and Caregivers

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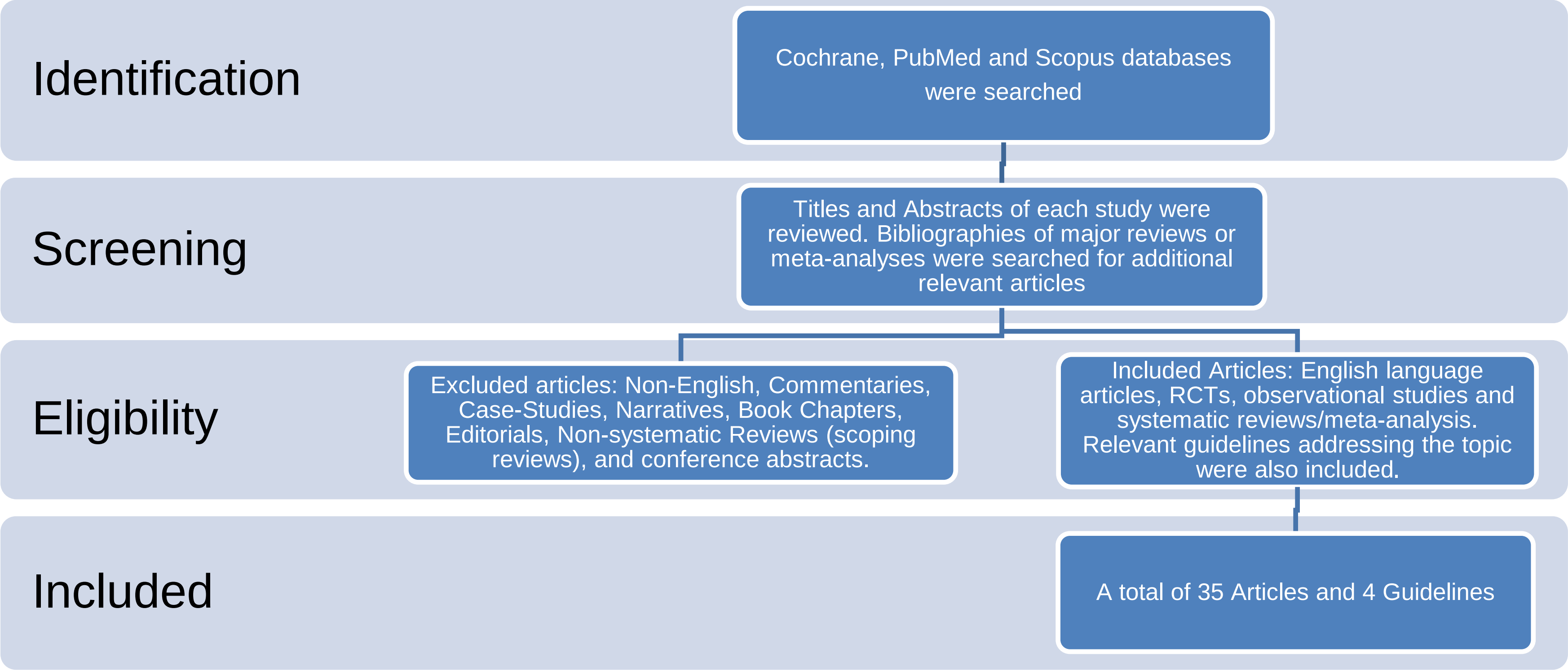
Search Strategy



Identification

Cochrane, PubMed and Scopus databases were searched

Screening

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

Eligibility

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.

Included

A total of 35 Articles and 4 Guidelines

Cochrane, PubMed and Scopus databases were searched using terms such as Stroke AND education AND caregiver OR support. 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 35 articles and 4 guidelines were included and were separated into separate categories designed to answer specific questions.

Published Guidelines

Guideline	Recommendations
National Clinical Guideline for Stroke for the UK and Ireland. London: Intercollegiate Stroke Working Party; 2023 May 4. **Available at: www.strokeguideline.org.**	Stroke rehabilitation should be needs-led and not time-limited, and available to those people with stroke for whom: – ongoing needs have been identified by the person with stroke, their carer(s) or the multidisciplinary team across all areas of stroke recovery, e.g. functional abilities, mental health, cognitive function, psychological well-being, education regarding stroke, social participation, management of complications and care needs; – and their needs remain related to the stroke and/or are best met by the skills of the stroke team (p. 63) People with stroke should be provided with information and education regarding fatigue being a common post-stroke problem, and with reassurance and support as early as possible, including how to prevent and manage it, and signposting to peer support and voluntary sector organisations. Information should be provided in appropriate and accessible formats (p. 106). Healthcare professionals should be aware of the psychological needs of people with stroke and their family/carers, and routinely provide education, advice, and emotional support for them. (p. 124)
Clinical Guidelines for Stroke Management 2017. Melbourne (Australia): National Stroke Foundation. **Chapter 8. Community participation and long-term care**	Practice Statement Consensus-based recommendation Carers should receive psychosocial support throughout the stroke recovery continuum to ensure carer wellbeing and the sustainability of the care arrangement. Carers should be supported to explore and develop problem solving strategies, coping strategies and stress management techniques. The care arrangement has a significant impact on the relationship between caregiver and stroke survivor so psychosocial support should also be targeted towards protecting relationships within the stroke survivors support network.
Winstein CJ, Stein J, Arena R, Bates B, Cherney LR, Cramer SC, Deruyter et al; on behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Quality of Care and Outcomes Research. **Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American Heart Association/American Stroke Association.** ***Stroke* 2016;47:e98–e169**	It may be useful for the family/caregiver to be an integral component of stroke rehabilitation. Class IIb; LOE A It may be reasonable that family/caregiver support include some or all of the following on a regular basis: Class IIb, LOE A • Education • Training • Counseling • Development of a support structure • Financial assistance It may be useful to have the family/caregiver involved in decision making and treatment planning as early as possible and throughout the duration of the rehabilitation process. Class IIb, LOE B

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: 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

Evidence Tables

Impact of Stroke on Patients, Family & Informal Caregivers

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Skajaa et al. 2024 **Denmark** **Retrospective study**	NA	1,923,732 individuals included in a national registry of whom 70,917 were partners of stroke survivors, 70,664 were partners of MI survivors and 354,570 were partners of individuals from the general population. Mean ages of partners were 68 years (stroke), 65 (MI and 45 (general population). The majority of partner were women (65% to 73%). Also included were adult children of: stroke survivors (207,386), MI survivors (183, 309) and 1,036,886 adult children of individuals from the general population. Mean ages ranged from 42 to 45 years, 48% from all groups were women.	The risks of the primary outcomes were estimated, comparing the stroke and MI cohorts (partners and adult children) with the general population cohorts, using propensity score matching and controlling for age and sex of both study participants and their respective partners or parents, year of index date, household income, highest achieved education, comorbidities (32 distinct conditions), co-medications, and health care utilization.	**Primary outcomes:** Depression, substance use disorders, anxiety disorders, and self-harm or suicide	*Partner cohort* The 3-year absolute risks of depression, substance abuse disorders, anxiety disorders and self harm or suicide were 1.03%, 0.73%, 0.29% and 0.04%, respectively. Compared with the general population cohort, the risks of depression and substance abuse disorders were increased significantly (adj RR=1.31, 95% CI 1.19 to 1.41 and adj RR=1.42, 95% CI 1.29 to 1.55) in the stroke partner cohort. The risk of depression increased with increasing stroke severity. Compared with the MI cohort, the risks of the primary outcome components were not increased significantly in the stroke partner cohort. *Adult children cohort* The 3-year absolute risks of depression, substance abuse disorders, anxiety disorders and self-harm or suicide were 0.55%, 0.65%, 0.21% and 0.05%, respectively. Compared with the general population cohort, the risks of substance abuse disorders and self-harm, or suicide were increased significantly (adj RR=1.11, 95% CI 1.05 to 1.19 and adj RR=1.42, 95% CI 1.11 to 1.84) in the stroke adult child cohort. Compared with the MI cohort, the risks of the primary outcome components were not increased significantly in the stroke adult child cohort.
Sennfält & Ullberg 2020 **Sweden** **Survey**	NA	5,063 community dwelling dyads from the Riksstroke database. Mean age of stroke survivors was ~73 years, 62% were men.	Surveys were sent to both patients and carers, 3-5 years post stroke. Surveys sent to the stroke survivor were designed to assess if the person was dependent	**Primary outcome:** A model to predict poor psychological well-being of the caregiver (defined as a score of <61 on SF-36)	Among the stroke survivors, 56.5% were independent, 33.4% were partially dependent, and 10.1% were completely dependent. Poor psychological well-being was reported in 51.4% of caregivers providing care to stroke survivors who were

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		Mean age of caregivers was ~65 years, 32% were men. Caregivers were predominantly spouses but 19.2% of adult children had taken on that role.	(mRS ≥3). Surveys sent to caregivers focused on the amount of care provided, caregiver support and caregiver well-being		completely dependent. The corresponding values for caregivers providing care for persons who were partially dependent and completely dependent were 34.7% and 19.3%, respectively. The odds of poor psychological well-being were significantly higher among caregivers of stroke survivors who were dependent (OR=2.87, 95% CI 2.17–3.8). Women caregivers as well as those expressing an unmet need of support were more likely to report poor psychological well-being (OR=1.73, 95% CI 1.48–2.02 and OR=2.25, 95% CI 1.69–2.99, respectively), while caregiving children were less likely to report poor well-being (OR=0.78, 95% CI 0.66–0.93).
Loh et al. 2017 **Singapore** **Systematic review &meta-analysis**	NA	12 cross-sectional studies (n=1756) including caregivers of stroke survivors.	The estimates of psychiatric morbidity (eg, anxiety, depression) of caregivers measured after stroke onset, were pooled. The methods used to assess psychiatric morbidity were based on standardized instruments or clinical interview	**Primary outcome:** Pooled prevalences of depression and anxiety	The pooled prevalence of depressive symptoms among caregivers was 40.2% (95% CI 30.1%-51.1%). Results from 11 studies were included. The pooled prevalence of anxiety symptoms among caregivers was 21.4% (95% CI 11.6%-35.9%). Results from 3 studies were included.
Atteih et al. 2015 **UK** **Prospective study**	NA	162 next-of-kin primary caregivers of 256 patients included in ASPIRE-S. Mean age was 59.4 years, 75.3% were women.	Home interviews were conducted with stroke survivors at 6 months. One week prior to the in-home assessment, caregivers were sent a postal questionnaire to complete and given the opportunity to clarify during the home visit. The questionnaire included 4 sections: demographics, satisfaction with care,	**Primary carer outcomes:** Satisfaction with care (100-point scale: 0–24: very satisfied, 25–49: moderately satisfied, 50–74: moderately dissatisfied, and 75–100: very dissatisfied), Hospital Anxiety and Depression Scale (HADS), and vulnerability (Vulnerable Elders	Mean satisfaction score was 44.2. 8·6% of caregivers were very satisfied, 53·5% were moderately satisfied and 37·9% were moderately dissatisfied. Approximately 1/4 of caregivers indicated that they were dissatisfied/very dissatisfied with both the information received from the hospital (33%) and the help and support received since coming home (24·2%). 23·9% of caregivers were dissatisfied with the information received from the community. Mean HADS-A and HADS-D scores were 5.9 and 3.6. 31.3% of caregivers were anxious (HADS-A ≥8), and 18.3% were depressed (HADS-D ≥8).

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				Scale [VES], 0-13 points)	Mean VES score was 1.1. 11.5% of caregivers indicated they felt vulnerable (VES ≥3) Factors related to caregiver anxiety included stroke survivor anxiety (OR = 3·47, p= 0·010), stroke survivor depression (OR = 5·17, p = 0·002), stroke survivor cognitive impairment (OR = 2·35, p= 0·049), and caregiver vulnerability (OR = 4·03, p= 0·023). Factors related to caregiver depression included caregiver vulnerability (OR = 10·62, p= 0·001), stroke survivor anxiety (OR = 4·41, p= 0·006), and stroke survivor depressive symptoms (OR = 6·91, p= 0·001).
Olai et al. 2015 **Sweden** **Prospective study**	NA	338 stroke patients, ≥65 years, and their 260 informal caregivers. Mean patient age was 78 years, 57% were women. Mean age of caregivers was 63 years, 45% were spouses, 40% were children of the patients, 48% were living in the same household or the same building as the patient, another 40% in the same municipality,	One week after discharge from hospital, patients had a structured and standardized face-to-face interview in their homes or in nursing homes, which was repeated at 3 and 12 by one of two registered nurses. During the interviews information on education, marital status, cohabitation, type of housing, functional ability, and self-rated health was collected. At the first interview, patients were asked to name their most important informal caregiver. This person received a postal questionnaire at the time of each interview, including items related to the nature and amount of assistance provided	**Primary outcomes:** Determinants of caregivers' support and caregiver burden	3 months after discharge, 309 patients and 210 caregivers remained for follow-up. At one, 314 patients and 190 caregivers remained for follow-up. At the time of discharge, 50.6% of patients were independent in their functional ability, 26.3% were partly dependent, and 23.2% were dependent. Prior to stroke admission caregivers spent an average of 5.0 hours per week providing care. Their mean support score (range of possible scores 0-60) was 9.8 (women caregivers) and 7.9 (men caregivers). One week after discharge, caregivers spent an average of 10.5 hours per week providing care. Their mean support score was 14.7 (women caregivers) and 13.0 (men caregivers). Three months after discharge, caregivers spent an average of 12.7 (women) and 7.9 (men) hours per week providing care. Their mean support score was 14.6 (women caregivers) and 10.8 (men caregivers). Twelve months after discharge, caregivers spent an average of 8.8 (women) and 9.6 (men) hours per week providing care. Their mean support score was 14.3 (women caregivers) and 10.7 (men caregivers).

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					Significant determinants of the amount of care provided were low functional ability of patient, low level of municipal social service support, close relationship to the patient (spouse), low patient MMSE score, short distance to patient's home, and male sex. Significant determinants of caregiver burden were increasing amount of informal caregiver support provided, small amount of municipal social service support, close relationship to the patient, decreasing patient MMSE, and decreasing patient age. Significant associations between informal caregiver and patient responses (dyad responses) were found for Hospital Anxiety and Depression (anxiety), total Nottingham Health Profile, and Gothenburg Quality of Life Instrument activity scale. Associations were stable over time.
Cameron et al. 2014 **Canada** **Prospective study**	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:**	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
				Stroke Impact Scale, MMSE and Charlson index	
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) 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 ≥18 years, and providing care for a stroke survivor with spasticity for at least 6 months. 70.6% of caregivers were	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)	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%)

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		women. Mean age was 52 years. 78% of caregivers were either the survivor's spouse or adult children.		**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	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) and 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) and higher PHQ-9 category (OR=4.55, 95% CI 2.94-7.14, p<0.001).
Goodwin et al. 2013 **USA** **Prospective 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). Mean age was 71 years, 80% of stroke survivors were males. 80% of caregivers were women. Mean age was 65 years.	Data were 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	NA	Population-based, longitudinal study of 30,239 African	Data were obtained using telephone surveys and in-home examination. Data	**Primary outcome:** Effect of care-giver status on all-cause	12.3% of participants were family caregivers.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
USA ***RAasons for Geographical and Racial Differences in Stroke (REGARDS)***		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)	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, hypertension, history of stroke or heart disease) were also obtained. Following enrolment data on all-cause mortality was collected every 6 months.	mortality (proportional hazards model)	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.
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	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
				Scale, Caregiver mastery (Pearlin), Centre for Epidemiological Studies Depression Scale **Survivor assessments:** Stroke Impact Scale, MMSE and Charlson index	
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 **USA** **Cross-sectional study**	NA	275 veterans who had sustained a first-ever 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.	Telephone surveys of survivors and their caregivers were conducted on a single occasion. The association between caregiver characteristics and the development of injuries was explored.	Items from the National Alliance for Caregiving (NAC) Survey, the Behavioural Risk Factors Surveillance Survey and the Centre for Epidemiological Studies Depression Scale (CES-D), were used.	66 (12.6%) of caregivers were injured. Caregivers who reported a 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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
				The 5-level classification system of the NAS was used to assess burden (1=low, 5=high)	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. 76% of spouses were female. Their mean age was 69 years.	Data were collected at 2 weeks and 6 months following stroke by interview in the participant's home. Pre-stroke data were also collected during these interviews. Changes in participation-level outcomes (LIFE-H, perceived burden and presence of symptoms of depression) were examined over time.	**Primary 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 most 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 ≥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 & Family

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Huang et al. 2024 **Canada** **Qualitative study**	NA	19 stroke survivors (11 men and 8 women) aged 18–55 years, whose stroke had occurred >6 months previously.	Seni-structured interviews were conducted remotely (Zoom) by 2 female residents to explore their experiences during stroke recovery and to assess current gaps in support and resources. Interviews were 60-90 minutes in length.	**Primary outcome:** NA	4 key themes emerged (1) the need for longitudinal medical follow-up and information provision. (2) the need for psychological/psychiatric care. (3) the need to adapt community supports and resources to young survivors. (4) the need to centralize and integrate community stroke services and resources
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.	**Primary outcome:** 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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
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.	**Primary outcome:** 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 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 caregiver's 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.	**Primary outcome:** 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,	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	**Primary outcome:** 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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		occupational and physical therapists, speech-language pathologists and case workers). 70.8% of caregivers were female. Mean age was 65.5 years.	identification of needs that they perceived to be unmet. The data were analyzed using the “Timing it Right” framework (described below).		
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	**Primary outcome:** 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. 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

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					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 women. Their mean age was 70 years. Median BI score at discharge was 14.	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) **Stroke Survivor assessment:** Barthel Index (BI)	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%) 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**	NA	Caregivers of 90 patients who had experienced a stroke 3-11 months previously and who were living in the community.	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	**Primary outcome:** 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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Cross-sectional study		62% of the patients were male. The mean age was 68 years. 72% of the carers were female. The mean age was 58 years.	themes and issues were identified qualitatively.		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. Carers reported lack of timely access to comprehensive information on all aspects of stroke

Interventions to Support Patients and Family Caregivers

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Bakas et al. 2022 **USA** **Systematic review**	NA	18 studies published from 2016-2021 that included caregivers of patients recovering from stroke (n=10) or patient/caregiver dyads (n=8). Sample sizes ranged from a total of 7 to 349 caregivers or dyads. Participants were recruited from acute hospitalization and from the community. Most	The interventions included elements of skills building, psychoeducation and support and were provided mainly face-to-face (group or individual) with some telephone and web-based elements. Total number of sessions offered ranged from 1-24.	**Primary outcome:** Survivor and caregiver outcomes, not stated a priori	*Family Caregiver outcomes* i) Survivor: In 3 trials, statistical tests of significance were performed. In one trial, significantly greater improvements in measures of cognition, depression, and anxiety were reported among participants in the intervention group. In another trial, improvements in QoL were significantly greater in the intervention group. ii) Caregiver outcomes: A wide range of outcomes were assessed, the most common of which assessed burden, depression/anxiety and QoL. In 7 trials, there was significantly greater improvement in the intervention group. *Patient/caregiver dyad outcomes*

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		caregivers were spouses.			i) Survivor: In 3 trials, statistical tests of significance were performed. In all 3 trials, participants in the intervention group had significantly greater improvements in one or more outcomes, including life satisfaction. ii) Caregiver outcomes: In 4 trials, participants in the intervention group had significantly greater improvements on one or more outcomes, on at least one occasion.
Lutz et al. 2021 **Cluster RCT** ***COMPASS Transitional Care (COMPASS-TC)***	CA: ☑ Blinding: Patient☒ Assessor☑ ITT: ☑	2,777 caregivers of patients included in the trial. 68% were women. Mean age was 64 years. Most caregivers were a spouse or child.	Participants were randomized to receive a comprehensive post-acute stroke transitional care (TC) management program or usual care. The intervention included telephone follow-up within 2 business days of hospital discharge and a clinic visit 7 to 14 days post-discharge. During the clinic visit, eligible patients discharged from intervention hospitals and their caregivers received a 10-item caregiver assessment evaluating the patient's need for caregiving as well as caregiver availability, assistance provided, general health, and stress and strain.	**Primary outcome:** Caregiver Questionnaire, developed specifically for the study	Of the 4,208 caregivers identified at enrollment, 29% completed the follow-up Caregiver Questionnaire. The average caregiver strain for both groups was 29.0 (range 0-100). Caregiver strain was associated with increasing stroke severity and increasing co-morbidities. Women reported higher caregiver strain. Caregivers reported extended periods of caregiving, with 79% providing care for ≥9 weeks. 33% provided care for ≥30 hours. On average, caregivers reported assisting with 1.0 ADL and 6.3 Instrumental ADLs per week post stroke. >70% of caregivers assisting with ADLs post-stroke had not assisted with ADLs pre-stroke.
Pucciarelli et al. 2021 **Italy**	Among the RCTs quality score (/100) ranged from 61.5 to 100. Among the	16 trials (13 RCTs, 3 quasi RCTs) including stroke survivor–caregiver dyads discharged home from rehabilitation hospitals.	In 7 trials, the intervention was composed of a written guide for stroke survivors, and/or video training, group discussions and face-to-face consultations, which	**Primary outcome:** i) survivor: generic and specific QoL, physical functioning, ADL, anxiety and depression, assessed	*Survivor outcomes* The intervention was not associated with significant improvement in depression (SMD=-0.16, 95% CI -0.33 to 0.02; results from 5 trials).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Systematic review & meta-analysis	quasi RCTs, quality scores were 88.8 (n=1) and 100 (n=2)	Among 2,997 survivors, mean age was 69.2 years, 58% were men. Among 2,187 caregivers, mean age was 58 years, 25% were men.	were implemented in a hospital setting. Interventions used in 3 trials were educational + telephone support after discharge. Four trials offered an educational intervention and support with home visits following discharge; and two trials used an educational intervention and telephone support with home visits after discharge.	at 3-6 months post stroke ii) caregiver: QoL, burden, depression and anxiety	The intervention was associated with significantly higher measures of physical function (SMD=0.17, 95% CI 0.0 to 0.35; results from 5 trials), QoL (SMD=0.17, 95% CI 0.03 to 0.31; 5trials) and memory (mean SIS score=4.07, 95% CI 1.14 to 7.01; results from 4 trials). There were no significant differences between groups in the SIS composite physical, emotional or communication dimensions, or measures of ADL. *Caregiver outcomes* The intervention was associated with significantly lower depression scores (SMD= –0.19, 95% CI –0.40 to 0.00; results from 6 trials). There was no significant effect from the intervention of caregiver QoL or caregiver burden.
Walker et al. 2020 **UK** **RCT (feasibility)** ***Biopsychosocial intervention for stroke carers (BISC)***	CA: ☑ Blinding: Patient ☒ Assessor☑ ITT: ☑	35 stroke and caregiver dyads, recruited within one year of stroke. Mean age of stroke survivors was 70 years, 57% were men. Mean age of caregivers was 62 years, 26% were men.	Participants were randomized to an intervention or usual care group. The intervention consisted of 6 weekly, 2-hour structured sessions delivered by a research psychologist. Topics covered in the sessions included an introduction to stroke and caring, adjustment and mood, emotions and thoughts, dealing with problems, stress and coping, and a wellbeing action plan.	**Primary caregiver outcomes:** HADS, EQ5D-5L and caregiver burden scale, assessed at 6 months post randomization **Primary stroke survivor outcomes:** mRS, Barthel Index (BI), HADS, and EQ5D-5L	At 6 months, there were 17 caregivers remaining and 14 stroke survivors. In the control group, there were 13 caregivers and 14 stroke survivors. *Caregiver outcomes (intervention vs. control at baseline/6 months)* Mean EQ-5D: 0.77 vs. 0.73/0.88 vs. 0.91 Mean HADS total score: 13.2 vs.15.1/8.9 vs. 8.2 Mean Caregiver Burden Scale: 28.6 vs. 29.2/18.7 vs. 16.8 *Stroke survivor outcomes (intervention vs. control at baseline/6 months)* Mean EQ-5D: 0.56 vs. 0.44/0.65 vs. 0.73 Mean HADS total score: 12.8 vs.19.0/10.9 vs. 9.5 Mean mRS: 3.72 vs. 3.06/2.07 vs. 2.33 Mean BI: 11.8 vs. 10.8/15.6 vs. 15.8 No statistical tests of significance were performed.
Bakas et al. 2015 **USA**	CA: ☑ Blinding: Patient ☒	254 family caregivers, aged ≥21 years, recruited from 2 rehabilitation and 6	Participants were randomized to the Telephone Assessment and Skill-Building Kit	**Primary outcomes:** Depressive symptoms (PHQ-9 ≥5), life changes, (Bakas	At baseline, 47.2% of caregivers in the TASK II group and 50.4% in the ISR group had PHQ-9 ≥5 (p=0.61).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
RCT	Assessor☑ ITT: ☑	acute care hospitals who had access to a phone, and planned to be providing care for ≥1 year. Mean age was 54.3 years, 78.3% were women. The mean length of time from discharge from hospital to recruitment was 38 days.	(TASK II) group (n=123) or to the information, support, and referral (ISR) group (n=131). Patients in both groups received a pamphlet and a series of 8 weekly phone calls from study nurse + an additional call at 12 weeks. The focus of the calls in the TASK-II group was on training caregivers how to identify and prioritize their needs and concerns, and to address them using innovative skill-building strategies. The focus of calls in the ISR group was on providing support through active listening strategies.	Caregiving Outcomes Scale [BCOS]), unhealth days (summing 2 items asking caregivers to estimate the number of days in the past 30 days that their own physical or mental health had not been good). Assessments were conducted at baseline, 8, 12 24 and 52 weeks	There was no significant difference between groups in the mean change in PHQ-9 or BCOS scores from baseline at any of the assessment points. There were significantly fewer mean unhealthy days compared with baseline among persons in the TASK-II group at 8 weeks (-1.1 vs. 1.8, p=0.025), but not at any other time point. In the subgroup of persons with PHQ-9 scores ≥5 at baseline (i.e. some form of depression), the mean decline in PHQ-9 scores was significantly greater in the TASK II group at 8 weeks (-3.6 vs. -0.9, p=0.013), 24 weeks (-3.5 vs.-1.6, p=0.041) and 52 weeks (-4.0 vs. -1.1, p=0.008). At 52 weeks, 20 caregivers were lost to follow up in the TASK-II group, and 38 were lost in the ISR group.
Ostwald et al. 2014 **USA** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☑ ITT: ☑	159 stroke survivors who had sustained a stroke in the previous 12 months and who had been discharged home and their spousal caregivers. Potential participants were identified using acute care admission hospital charts. 75% of caregivers were female. Mean age was 62 years.	Dyads were randomized to receive monthly mailed information packages related to signs & symptoms of stroke, prevention, stress reduction strategies with links to support groups, advocacy organizations and National Stroke Association periodical (n=80) or information packages + home-based visits for 6 months by advance care practice nurses, occupational and physical therapists. On average, over the 6-month study period, dyads participated	**Primary outcome:** SF-36 (self-rated health status), Geriatric Depression Scale (GDS), Perceived Stress Scale (PSS), Stroke Impact Scale (patient only), Zarit Burden Scale (caregiver only) **Secondary outcomes:** FIM (patient only) mutuality Scale, Caregiver Preparedness Scale (caregiver only), Medical Outcomes	Caregivers in the intervention group had significantly improved self-rated health scores at 6 months. There were no significant differences between groups at either 6 or 12 months for the outcomes related to depression, stress and burden. By 12 months there was significant improvement in 2 domains of the F-COPES (mobilizing family support and acquiring social support) among caregivers in the intervention group, with significant declines among participants in the control group. Stroke survivors in the intervention group demonstrated greater improvement in self-rated health status at 6 months. There were no other significant differences on any of the other primary outcomes.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			in 16 visits (70 minutes each)(n=79)	Study (MOS (caregiver only), F-COPES (caregiver only) Assessments were conducted at baseline, 6 and 12 months.	Stroke survivors in the intervention group had increased their FIM (cognitive) scores significantly more than those in the control group. There were no other significant differences on any of the other secondary outcomes.
Steiner et al. 2008 **USA** **RCT**	CA: ☒ Blinding: Patient ☒ 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).	**Primary outcome:** 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 times 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 ☒ 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	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

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
				Caregiver outcomes: Caregiver Strain Index, HADS Assessments were conducted at 3 months and 1 year after randomization	they received regarding applying for benefit and social services.
Lincoln et al. 2003 **UK** **RCT**	CA: ☑ Blinding: Patient ☒ 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 9 months, there were no significant differences in median GHQ-12, BI or EADL scores between groups, but the FSO group had better knowledge of stroke, stroke prevention, community services, and emotional support. There were no differences between groups in overall satisfaction with information on services received. The pattern of results was similar for the caregiver, although the median scores for satisfaction with information on practical help and emotional support were higher among caregivers in the FSO group at both 4 and 9 months.
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	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-	**Primary 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	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
		age of male stroke patients was 73 years and 75 years for women.	hour session with a trained nurse in the home, followed by weekly (weeks 2-4), and biweekly (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 planning services only.	Caregiving Scale), caregiver burden (Caregiver Burden Scale) Assessments were conducted at baseline, week 5 of intervention, 9 and 13 weeks post discharge	
Mant et al. 2000, 2005 (one-year outcomes) **UK** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☑ ITT: ☑	520 patients ≥18 years admitted to hospital following acute stroke, who were recruited within 6 weeks of the event, along with their closest carer. Mean age of patients was 74 years, mean age of carers was 65 years.	Patients and carers were randomized to a family-support group (n=258) or a usual care group (n=262; control). Participants in the FS group were referred to a family support organizer, who provided services at their discretion	**Patient and Carer outcomes:** Frenchay Activities Index (FAI), Dartmouth co-op charts, stroke knowledge **Patient outcomes:** Barthel Index (BI), Rivermead Mobility Index (RMI), London Handicap Scale (LHS), Hospital Anxiety & Depression Scale (HADS) **Carer outcomes:** General Health Questionnaire-28 (GHQ-28), Caregiver Strain Index (CSI), SF-36	323 patients and 267 carers completed the 6 months follow up. The family support organizer contacted all but one of the 156 followed up patients in the intervention group, with an average of one hospital visit, one home visit, and three telephone calls, and liaised with one other service per family in the first 6 months. For some families, contacts were more extensive, with up to five hospital visits, four home visits, seven telephone calls, and liaison with five different services. There was no significant difference between groups with respect to the use of services, with one exception. A greater proportion of patients in the control group received PT services. At 6 months, the median FAI scorer of carers in the FS group was significantly higher (33 vs. 31.5, p=0.03). 5 of the SF-36 sub scores for carers and one part of the Dartmouth co-op charts were significantly higher in the FS group. There were no significant differences between groups for any of the outcomes for patients.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					One-year outcomes 294 patients and 212 carers completed one-year follow-up. The average number of contacts of any sort between six and 12 months was 3. There was no significant difference between groups in median FAI scores. One domain of the SF-36 (energy and vitality) was significantly higher in the FS group. There were no significant differences between groups for any of the outcomes for patients.
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.	**Primary 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.

Abbreviations

ADL: Activities of daily living	CA: Concealed allocation
CI: Confidence interval	EQ5D: EuroQOL five dimensions questionnaire
HADS: Hospital Anxiety & Depression Scale	ITT: Intention-to-treat

MD: Mean difference	MMSE: Mini Mental State Examination
mRS: Modified Rankin Scale	NA: Not assessed
OR: Odds ratio	QoL: Quality of life
RR: Relative risk	SIS: Stroke Impact Scale
SMD: Standardized mean difference	

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