



CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Transitions and Community Participation Following Stroke Evidence Tables

Support for People with Stroke, Their Families and Caregivers through Transitions

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Transitions and Community Participation Following Stroke Writing Group
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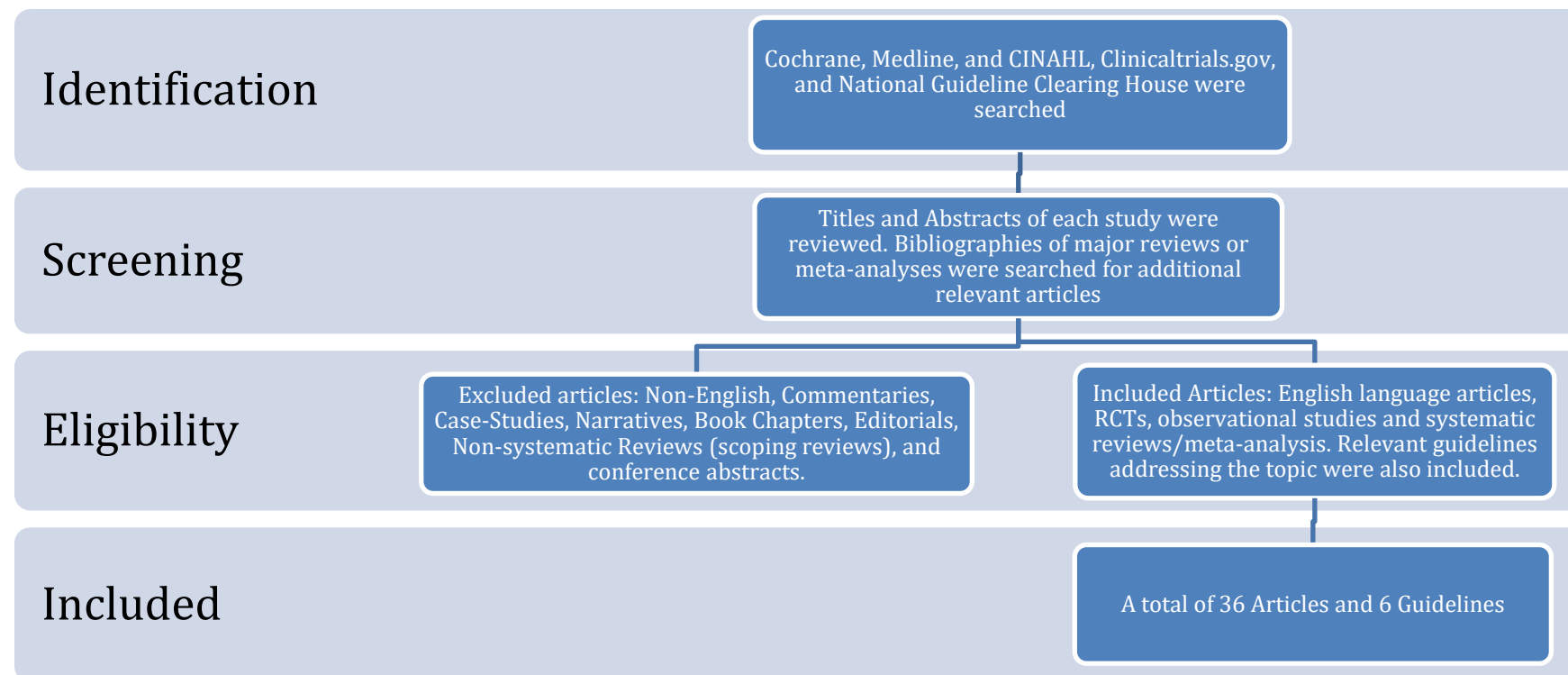
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Search Strategy



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 36 articles and 6 guidelines were included and were separated into separate categories designed to answer specific questions.

Published Guidelines

Guideline	Recommendations
Clinical Guidelines for Stroke Management 2017. Melbourne (Australia): National Stroke Foundation.	Practice Statement Consensus-based recommendation Hospital services should ensure that stroke survivors and their families/carers have the opportunity to identify and discuss their postdischarge needs (including physical, emotional, social, recreational, financial and community support) with relevant members of the interdisciplinary team.
National Clinical guidelines for stroke” 5th Edition 2016; Intercollegiate Stroke Working Party. Royal College of Physicians	2.16.1 (F) After a person with stroke has returned to the home or care home setting, their carer should: – have their need for information and support reassessed whenever there is a significant change in circumstances (e.g. if the health of the carer or the person with stroke changes); – be reminded and assisted in how to seek further help and support. 6.5.1 Recommendations (Commissioning long-term services) Commissioners should ensure that, between health and social services and other agencies, people with stroke can: – receive the practical (e.g. housing, employment) and emotional support they need to live with long-term disability; – access suitable social and leisure activities outside their homes; – receive maintenance interventions (e.g. provision of exercise programmes and peer support) to enhance and maintain health and well-being. Commissioners in health and social care should ensure that the carers of people with stroke: – are aware that their needs can be assessed separately; – are able to access the advice, support and help they need; – are provided with information, equipment and appropriate training (e.g. manual handling) to enable them to care for a person with stroke; – have their need for information and support reassessed whenever there is a significant change in circumstances (e.g. if the health of the carer or the person with stroke changes).
Winstein CJ, Stein J, Arena R, Bates B, Cherney LR, Cramer SC, Deruyter F, Eng JJ, Fisher B, Harvey RL, Lang CE, MacKay-Lyons M, Ottenbacher KJ, Pugh S, Reeves MJ, Richards LG, Stiers W, Zorowitz RD; 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.	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

Guideline	Recommendations
Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. <i>Stroke</i> 2016;47:e98–e169	
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. <i>Stroke</i> 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
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].
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]

Guideline	Recommendations
	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, safe 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 managers should be able 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]. 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 GPP]. - 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].

Guideline	Recommendations
	Assistance should be provided for families/carers to manage stroke survivors who have behavioural problems [Grade GPP].

Evidence Tables

Impact of Stroke on Patients, Family & Informal Caregivers

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
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 Scale, 0-13 points)	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). 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

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					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). 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.

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					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	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	NA	69 qualitative studies, published from 2000 onwards that explored the adult patient experience of stroke	Data were analyzed using framework synthesis, informed by Normalization Process	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

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Systematic review		management in any setting and provided information on patient burden.	Theory and organized into themes.		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 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	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,	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)

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		the survivor's spouse or adult children		based on physician diagnosis	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) 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	NA	Population-based, longitudinal study of 30,239 African	Data was obtained using telephone surveys and in-home	Primary outcome: Effect of care-giver status on all-cause	12.3% of participants were family caregivers.

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USA Reasons 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)	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, 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	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	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.

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			disability and behavioural/psychological symptoms and caregiver's emotional distress.	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	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 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%	Telephone surveys of survivors and their caregivers were conducted on a single occasion. The association between caregiver characteristics and the	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.

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		of caregiver's were the survivor's spouse.	development of injuries was explored.	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 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 interviews. Changes in participation-level outcomes (LIFE-H, perceived burden and presence of symptoms	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).

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			of depression) were examined over time.		These changes were associated with increased caregiver strain, but not with depression.

Support Needs for the Caregiver & Family

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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	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 and knowledge received and

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		survivors ranged in age from 37-95 years.			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.	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).	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		70.8% of caregivers were female. Mean age was 65.5 years.			
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. 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	NA	42 family carers of patients who had been admitted to an acute stroke unit and	Surveys were conducted before discharge and 4-6 weeks after, to examine carer's needs,	Carer assessments: Carer Assessment Scale (CAS), + 1 open-ended question enquiring about	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Cross-sectional study		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.	knowledge, satisfaction and competence in caring for stroke survivors. Surveys were completed over a 14-month period	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)	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 Cross-sectional study	NA	Caregivers of 90 patients who had experienced a stroke 3-11 months previously and who were living in the community. 62% of the patients were male. The mean age was 68 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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		72% of the carers were female. The mean age was 58 years.			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
Ellis et al. 2010 UK Cochrane review	NA	16 RCTs (n=4,759) including survivors of acute stroke or their closest informal carer or both	Trials compared referrals to a stroke liaison worker with usual care. Typically, a stroke liaison worker provides a multifaceted service including education and information provision, social support and liaison with other services. The intervention was usually provided from the point of patient discharge from hospital. Interventions were classified as proactive and structure (patients identified prior to discharge and a fixed number of visits provided on a broad range of topics), reactive and flexible (designed to meet	Primary outcomes (patient): Subjective health status, extended ADL (EADL) Secondary outcomes (patient): Death, place of residence, ADL, dependency, depression, knowledge about stroke, use of services, satisfaction with services, participation. Primary outcome (carer): Subjective health status Secondary outcomes (carer): Extended ADL, mental health, knowledge about stroke, satisfaction with services.	Patient outcomes: Intervention by a stroke liaison worker was not associated with an improvement in subjective health status (SMD -0.03, 95% CI -0.11 to 0.04, p=0.34) or performance in EADL (SMD= 0.05, 95% CI -0.02 to 0.12, p=0.16), or any of the secondary outcomes. There were no interactions based on the classification of the intervention. In subgroup analysis, the odds of dependency and death or dependency were significantly reduced in the stroke liaison group for patients with Barthel index scores of 15-19 (OR=0.62, 95% CI 0.44-0.87 and OR=0.55, 95% CI 0.38- 0.81). Carer outcomes: Intervention by a stroke liaison worker was not associated with significant improvements in the primary outcome or any of the secondary outcomes. Patients and carers reported improved satisfaction with some aspects of service provision. Patients and carers in the liaison groups reported they were significantly more satisfied that 'someone has really listened'. Carers felt they had not been neglected and

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			needs as they arise) and proactive and focused (fixed duration but may focus on a specific issue)		had received enough information related to the nature of stroke and recovery and rehabilitation.
Managing Aftercare for Stroke (MAS): MAS-II - A Longitudinal Complex-interventional Study in Post-rehabilitation Stroke Patients (NCT03097146)		100 patients ≥18 years, recovering from an ischemic stroke which had occurred within the previous 6 months. Patients to be recruited from a single centre.	Single group intervention study of comprehensive multidisciplinary stroke care, provided in both an outpatient setting (e.g., secondary prevention) or in the community, close to the patients' home, based on a case management system ("Ambulanzpartner").	Primary outcome: EuroQoL-5D, assessed at 12 months Secondary outcomes: Post Stroke Checklist (PSC), mRS, BI, modified Ashworth Scale (MAS), Pain Detect, Freiburg questionnaire for coping (FKV), Montreal Cognitive Assessment (MoCA), Token Test, Hamilton Rating Test for Depression, all assessed at 12 months	TBA
Bakas et al. 2015 USA RCT	CA: ☒ Blinding: Patient ☒ Therapist ☒ Assessor ☒ ITT: ☒	254 family caregivers, aged ≥21 years, recruited from 2 rehabilitation and 6 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.	Participants were randomized to the Telephone Assessment and Skill-Building Kit (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	Primary outcomes: Depressive symptoms (PHQ-9 ≥5), life changes, (Bakas Caregiving Outcomes Scale [BCOS]), unhealthy 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	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). 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 sub group 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).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			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.		At 52 weeks, 20 caregivers were lost to follow up in the TASK-II group, and 38 were lost in the ISR group.
Fens et al. 2014 The Netherlands Controlled trial	NA	171 consecutive patients who were being discharged home following admission for stroke from 2 hospitals in different regions, aged ≥50 years who were living in the catchment area of the regional home care organization. Mean age of patients was 72 years, 54% were men. Mean age of carers was 64 years, 25% were men.	The authors developed a long-term care model for stroke patients and caregivers living at home after hospitalization or inpatient rehabilitation. The model included a coordinating stroke care professional who collaborated with a multidisciplinary team, provided a structured assessment and included 5 regular home visits over a period of 18 months, which leading to further follow-up care (such as advice, healthcare facilities and physical aids) or referral to other healthcare professionals (such as a physiotherapist or an occupational therapist). 77 patients and 60 carers were assigned to the intervention group and 67 patients and 40 carers to a	Primary outcome (patients): Quality of Life, assessed using the Stroke Adapted Sickness Impact Profile-30 (SASIP-30) Secondary outcomes: BI, the Frenchay Activities Index (FAI), Hospital Anxiety Depression Scale (HADS) Primary outcome (carer): QoL, assessed using the Life Satisfaction questionnaire-9 (LiSAT-9) Secondary outcomes: HADS and the Caregivers Strain Index (CSI) Outcomes were assessed at baseline (2-4 weeks following discharge) and 6, 12 and 18 months later	Patient outcome: There were no significant differences between groups at any time points in median SASIP-30, BI or HADS scores, nor were there any significant differences in the median change scores between groups at any time point (0-6 months, 0-12 months or 0-18 months) for the outcomes of SASIP-30, BI or HADS-A. At baseline, patients in the intervention group had significantly lower median FAI scores (17.5 vs. 27.0), but at no other time points were scores significantly different. The median changes in FAI scores from baseline for patients in the intervention group were significantly greater (and in a positive direction) at all time points (0-6 months, 6- vs. -3, $p>0.001$; 0-12 months 3 vs. -1.0, $p=0.006$ and or 0-18 months 3.5 vs. -4, $p<0.001$). The median change in HADS-D was significantly greater for patients in the intervention group from baseline to 12 months (0 vs. 0, $p=0.048$). Caregiver outcomes: Carers in the control group had significant higher median LiSAT-9 scores at baseline and 18 months (5.1 vs. 4.9 and 5.0 vs. 4.7), while carers in the intervention group had significantly higher median HADS-A and HADS-D scores at baseline. There were no other significant differences in median scores between groups for any of the other outcomes at any time points.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			usual care control group		There were no significant differences between groups in median change scores for any outcome, at any time point with a single exception. From baseline to 6 months, there was a decline in median HADS-D scores for carers in the intervention group (median change -1 vs. 1, $p=0.028$).
Rochette et al. 2013 Canada RCT	CA: ☒ Blinding: Patient ☒ Therapist ☒ Assessor ☒ ITT: ☒	186 patients discharged home within 3 weeks of admission to hospital following a first-ever mild stroke (CNS score >8.5, or mRS 0-2 at baseline), without moderate or severe cognitive impairment. Mean age was 62.5 years, 42.5% were female	Patients were contacted during the first month of their return home and those who consented were randomized to a YOU CALL group (n=94) or a WE CALL group (n=92). Patients in the YOU CALL group were provided with the name and phone number of a trained healthcare professional whom the patient could call with questions. Patients in the WE CALL group received scheduled telephone, internet and paper documentation support, initiated by the trained professional over a 6-month period.	Primary outcomes: Unplanned use of health services for an adverse event, Quality of Life Index, EQ-5D Secondary outcomes: Planned use of healthcare services, Beck Depression Inventory II, LIFE-H 3.1 Assessments were conducted at baseline, 6 months and 1 year	During the study period, only 6 patients in the YOU CALL group phoned. Most of the questions patients asked during these calls were related to secondary prevention. 78.3% of patients in the WE CALL group were contacted at each of the scheduled times. There were no significant differences between groups on any of the primary or secondary outcomes between baseline and 6 months. Patients in both groups made modest gains on most of the outcomes assessed. At 6-months, over half the patients in both groups reported having difficulty with mobility, family relationships, work and recreation. Many patients in both groups still faced the same challenges at 1 year. Patients in the WE CALL group perceived the intervention positively. At one year, 47 patients could not be reached for final assessment.
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	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	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		female. Caregivers included spouses (69%), adult children (19%), and friends (19%). Mean age was 55 years.	(email), "Tip of the Month" and educational links or a control (non-Web user) group (n=37).		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). At 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 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.	Participants were randomized to receive either the Stroke Family Support Organizer (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	Stroke Survivor & caregiver outcomes: General Health Questionnaire-12 (GHQ-12), Barthel index (BI), Nottingham Extended ADL (EADL), stroke knowledge, satisfaction with information, overall satisfaction.	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

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		No demographic details were reported for the caregivers.	patients within 4 weeks of stroke	Assessments were conducted at 4 and 9 months.	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 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 planning services only.	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
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 outcome for patients. 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 outcome for patients.
Evans et al. 1998	CA: ☒	188 primary caregivers of all	Participants were randomized to a control	Primary Outcomes: Stroke Care Information	Mean SCIT scores and FAD scores (problem solving, communication and global family function sub scores)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
USA RCT	Blinding: Patient ☒ Assessor ☒ ITT: ☒	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.	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.	Test (SCIT), Family Assessment Device, ESCROW profile, Personal Adjustment and Role Skills Scale (PARS) Assessments were conducted at baseline (by 3 rd week of hospitalization), 6 months and one year following stroke	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	There were no significant differences between groups on any of the primary outcomes. Among the 246 carers, 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)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
				Assessments were conducted at 6 months following randomization	

Telemedicine for Stroke Rehabilitation

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Chen et al. 2016 China Systematic review & meta-analysis	NA	7 RCTs that included patients ≥ 18 years who had sustained a stroke and received rehab therapies through telemedicine systems for a minimum of 4 weeks in duration. Mean ages of patients ranged from 53-75 years.	In 6 trials, virtual reality-based training was used to provide rehab therapies, while therapies or support were provided by either the phone or the internet in 2 trials. The control group in most trials was usual or standard care.	Primary outcome: Measures of disability or ADL assessment Secondary outcomes: Motor function, cognitive assessments, health-related QoL	Using the results from 4 trials, there was no difference in mean Barthel Index scores between groups (SMD=-0.05, 95% CI -0.24-0.13, p=0.57). Using the results from 2 trials, there was no difference in mean Berg Balance Scale scores between groups (SMD=-0.17, 95% CI -0.70-0.37, p=0.54). Using the results from 2 trials, there was no difference in mean Fugl-Meyer (Upper Extremity) scores between groups (SMD=0.05, 95% CI -0.09-1.09, p=0.10).
Laver et al. 2013 Australia Cochrane review	NA	10 RCTs (n=860) including patients with all stroke types, including SAH at all levels of severity and at all stages stroke recovery. 2 trials recruited patients in the acute stage of stroke while the remainder recruited patients in the subacute and chronic stage.	Trials comparing telerehabilitation (services delivered using information and communication technologies) programs composed of ≥ 1 session, compared with in-person or no rehabilitation and trials comparing 2 different types of telerehabilitation. All interventions were delivered in patient's homes. 4 trials used customised computer-based training programmes and 4 delivered an exercise	Primary outcome: Independence in ADL Secondary outcome: Upper-limb function, mobility, participant satisfaction, HR QoL, cognitive function, functional communication	There was no significant difference in the ability to perform ADLs between groups (SMD=0.0, 95% CI -0.15-0.15, p=0.990). The results from 2 trials included. There was no significant difference in upper-extremity performance between groups (MD Fugl Meyer Assessment=3.65, 95% CI -0.26-7.57, p=0.067). The results from 2 trials included. Pooled analyses for other outcomes were not possible.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			programme using technologies to enable communication between the participant and the teletherapist. Most interventions included at least 3 contacts with follow-up periods of at least 1 month		
Chumbler et al. 2012, 2015 USA Stroke Telerehabilitation (STeleR) RCT	CA: ☒ Blinding patient: ☒ assessor: ☒ ITT: ☒	52 veterans who had suffered a stroke within the previous 2 years, aged 45-90 years, living in the community, without cognitive impairment, and a discharge FIM score of 18-88 were included.	Patients were randomized to a STeleR group (n=25) or to a usual care group (n=23) The STeleR intervention focused on improvement of functional mobility. The program lasted 3 months, and included 3 components: 3x 1 hour televisits to the participant's home, 5 telephone calls and an in-home messaging device system to instruct patients on functional exercises and adaptive strategies. Patients in the usual care group could receive any services provided by VA or non-VA, at their discretion	Primary outcome (2012): Telephone Version of FIM (FONEFIM), overall function domain of the Late-Life Function and Disability Instrument (LLFDI) Secondary outcome (2012): Additional domains of the LLFDI Primary outcomes (2015): Falls Efficacy Scale (FES), Stroke-specific Patient Satisfaction with Care Scale (SSPSC)-9 items for hospital care, 4 items for home care Outcomes were assessed a baseline, 3 and 6 months	48 patients completed baseline assessments. 2012 Mean±sd scores for STeleR and usual care groups at baseline and 6 months were: FONEFIM (motor domain): 83.5±9.5 to 83.7±9.9 vs. 81.5±12.1 to 80.9±12.0, p=0.306 LLFDI (overall function total): 49.5±10.1 to 54.6±12.0 vs. 51.7±12.8 to 50.6±11.7, p=0.248 LLFDI (disability components): Personal role frequency: 47.6±10.8 to 49.6±18.1 vs. 49.2±14.8 to 47.2±11.9, p=0.025 Difficulty dimension total: 53.9±21.5 to 68.0±16.6 vs. 62.2±15.3 to 59.5±17.7, p=0.025 Instrumental role difficulty: 52.5±21.5 to 68.1±13.2 vs. 61.2±15.9 to 58.0±18.7, p=0.031. There were no significant differences between groups on any of the other LLFDI function domains (upper, lower or advance lower extremity scores), or the remaining disability components (frequency dimension total and social role frequency) 2015 There were no significant differences in mean baseline FES scores between groups or 6-month follow-up. The scores in both groups increased over time (2.2 vs. 2.3 points)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					There was a significant increase in the mean SSPSC score (hospital care) at 6 months between groups favouring the STeleR group (+4.5 vs. -3.2, p=0.029). There was no significant difference in mean SSPSC score (home care) at 6 months between groups (+1.7 vs. -0.4, p=0.077). Dropouts and losses to follow-up: n=5

Abbreviations

CA: Concealed allocation
CI: Confidence Interval
ITT: Intention-to-treat
MD: mean difference
NA: Not assessed
OR: Odds ratio
SMD: standardized mean difference

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