

CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Transitions of Care Following Stroke Evidence Tables Patient and Family Education Following Stroke

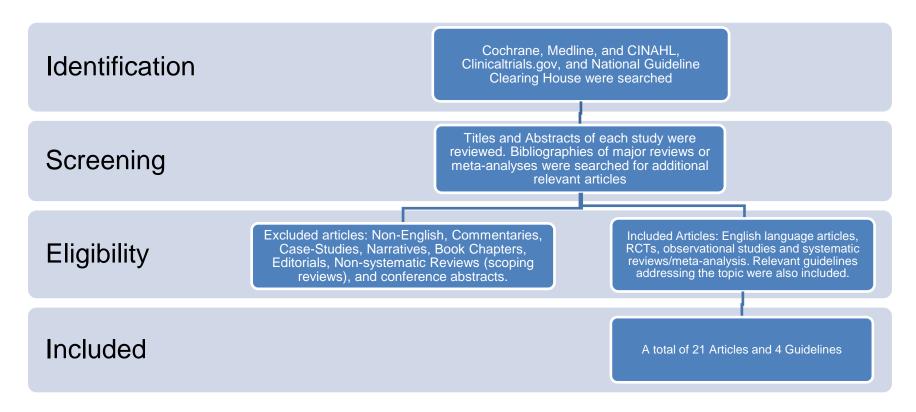
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on Behalf of the Canadian Stroke Best Practice Recommendations
Transitions of Care Following Stroke Writing Group

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Search Strategy



Cochrane, Medline, and CINAHL, Clinicaltrials.gov, and National Guideline Clearing House were 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 21 articles and 4 guidelines were included and were separated into separate categories designed to answer specific questions.

Published Guidelines

Guideline	Pacammandations
Intercollegiate Stroke Working Party. National clinical guideline for stroke, 4th edition. National Institute for Health and Clinical Excellence London: Royal College of Physicians, 2012. Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with stroke:	Recommendations A Patients and their carers should have their individual practical and emotional support needs identified: • before they leave hospital • when rehabilitation ends or at their 6-month review • annually thereafter. B Health and social services personnel should ensure that: • any identified support needs are met • support services appropriate to the needs of the patient and carers are provided • patients are informed about organisations able to provide other relevant services, and how to contact them • patients and carers receive all the financial and practical support to which they are entitled. C Patients should be provided with information tailored to their own specific needs regularly during the acute, rehabilitation and longer-term care phases of the illness. Information Needs of Patients and Carers • Stroke patients and their carers should be offered information about stroke and Rehabilitation [Evidence Level D].
rehabilitation, prevention and management of complications, and discharge planning. A national clinical guideline. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network (SIGN); 2010 June.	 Information should be available to patients and carers routinely and offered using active information strategies, which include a mixture of education and counseling techniques [Evidence Level A]. Information should be tailored to the information needs of individual patients and carers, followed up to check understanding and ensure clarity, and repeated as appropriate [Evidence Level A]. Information should be tailored to the communication needs and visual needs of individual patients and carers. Patients with aphasia should be provided with accessible and easy to read material, be given sufficient time for assimilation and be followed up by health professionals to ensure understanding [Evidence Level D]. Information needs should be monitored and information should be provided at appropriate time [Evidence Level A] Carer Support Where a carer is suspected of being clinically depressed or anxious, they should be encouraged to seek help by contacting the appropriate member of the general practice team [Good Practice Point]. Stroke Liaison Workers NHS Board areas should consider developing specialist stroke nurse led support services that include education, information provision and liaison, in the community for people who have had a stroke and their carers [Good Practice Point].
Management of Stroke Rehabilitation Working Group. VA/DoD clinical practice guideline for the management of stroke rehabilitation. Washington (DC): Veterans Health Administration, Department of Defense; 2010. p.p.70-72	 Patient, Family Support, and Community Resources Recommend all stroke patients and family caregivers receive a thorough psychosocial assessment with psychosocial intervention and referrals as needed. The psychosocial assessment of both the patient with stroke and the primary family caregiver should include the following areas: History of pre-stroke functioning of both the patient and the primary family caregiver (e.g., demographic information, past physical conditions and response to treatment, substance use and abuse, psychiatric, emotional and mental status and history, education and employment, military, legal, and coping strategies) Capabilities and care giving experiences of the person identified as the primary caregiver

Guideline	Recommendations
	 c. Caregiver understanding of the patient's needs for assistance and caregiver's ability to meet those needs d. Family dynamics and relationships e. Availability, proximity, and anticipated involvement of other family members f. Resources (e.g., income and benefits, housing, and social network) g. Spiritual and cultural activities h. Leisure time and preferred activities i. Patient/family/caregiver understanding of the condition, treatment, and prognosis, as well as hopes and expectations for recovery j. Patient/family/caregiver expectations of stroke-related outcomes and preferences for follow-up care 3. Families and caregivers should be educated in the care of patients who have experienced a severe stroke, who are maximally dependent in ADL, or have a poor prognosis for functional recovery; as these patients are not candidates for rehabilitation intervention. 4. Families should receive counseling on the benefits of nursing home placement for long-term care.
	Discharge from Rehabilitation Recommend patient and family are educated regarding pertinent risk factors for stroke. Recommend that the family and caregivers receive all necessary equipment and training prior to discharge from rehabilitation services. [I] Family counseling focusing on psychosocial and emotional issues and role adjustment should be encouraged and made available to patients and their family members upon discharge.
	 Long-Term Management Recommend post-discharge telephone follow-up with patients and caregivers be initiated and include problem solving and educational information. If available, asynchronous and real-time tele-health, video, and web-based technologies, (e.g., web-based support groups, tele-rehabilitation), should be considered for patients who are unable to travel into the facility for care and services. Patient and family should be educated regarding pertinent risk factors for stroke. Provide patient information about, and access to community based resources.
	 Family/Community Support Patients and caregivers should be educated throughout the rehabilitation process to address patient's rehabilitation needs, expected outcomes, procedures and treatment as well as appropriate follow-up in the home/ community. [B] Patient and caregiver education should be provided in both interactive and written formats. [B] Caregivers should be provided in a variety of methods of training based on their specific needs, cognitive capability, and local resources; Training may be provided in individual or group format, and in community-based programs. [B]
Clinical Guidelines for Stroke Management 2010. Melbourne (Australia): National Stroke Foundation; 2010 Sep. p. 81-82; 97-98.	 Safe transfer of care from hospital to community A documented post-discharge care plan is developed in collaboration with the patient and family and a copy provided to them. This may include relevant community services, self-management strategies (e.g. information on medication and compliance advice, goals and therapy to continue at home), stroke support services, any further rehabilitation or outpatient appointments, and an appropriate contact number for any queries [Grade GPP]
	 Carer Training Relevant member of the multidisciplinary team should provide specific and tailored training for carers/family before the stroke survivor is discharged home. This should include training, as necessary, in personal care techniques,

Guideline	Recommendations			
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	communication strategies, physical handling techniques, ongoing prevention and other specific stroke-related problems, sage swallowing and appropriate dietary modifications, and management of behaviours and psychosocial			
	issues [Grade B]			
	Community rehabilitation and follow-up services			
	 Contact with and education by trained staff should be offered to all stroke survivors and families/carers after 			
	discharge [Grade C].			
	Stroke survivors can be managed using a case management model after discharge. If used, case manages should be about to recognize and managed depression and help to coordinate appropriate interventions via a medical.			
	be about to recognize and manage depression and help to coordinate appropriate interventions via a medical practitioner [Grade C].			
	 Stroke survivors and their carers/families should be provided with contact information for the specialist stroke service 			
	and a contact person (in the hospital or community) for any post-discharge queries for at least the first year following			
	discharge [Grade GPP].			
	O-16 Management			
	Self-Management			
	 Stroke survivors who are cognitively able should be made aware of the availability of generic self-management programs before discharge from hospital and be supported to access such programs once they have returned to the 			
	community [Grade C].			
	Stroke-specific programs for self-management should be provided for those who require more specialized programs			
	[Grade GGP].			
	A collaboratively developed self-management care plan can be used to harness and optimize self-management skills 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 real activities (Create CRR).			
	with goal setting, therapy sessions, discharge planning, and long-term activities [Grade GPP]. • Carers should be provided with information about the availability and potential benefits of local stroke support groups			
	and services, at or before the person's return to the community [Grade C].			
	 Carers should be offered support services after the person's return to the community. Such services can use a 			
	problem-solving or educational-counselling approach [Grade C].			
	Assistance should be provided for families/carers to manage stroke survivors who have behavioural problems [Grade]			
B BW 7 1/2 5 5 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	GPP].			
Duncan PW, Zorowitz R, Bates B, Choi JY,	Patient and Family/Caregiver Education 1. Recommend that patient and family/caregiver education be provided in an interactive and written format.			
Glasberg JJ, Graham GD, Katz RC, Lamberty	 Recommend that clinicians consider identifying a specific team member to be responsible for providing information to 			
K, Reker D. Management of adult stroke	the patient and family/caregiver about the nature of the stroke, stroke management rehabilitation and outcome			

the patient and family/caregiver about the nature of the stroke, stroke management rehabilitation and outcome

Guideline	Recommendations
rehabilitation care: a clinical practice guideline. Stroke, 2005;36:e117 -125	expectations, and their roles in the rehabilitation process. 3. Recognize that the family conference is a useful means of information dissemination. 4. Recommend that patient and family education be documented in the patient's medical record to prevent the occurrence of duplicate or conflicting information from different disciplines.
	Educate Patient/Family, Reach Shared Decision About Rehabilitation Program, and Determine Treatment Plan: 4. Recommend that patient and caregiver education be provided in an interactive and written format. Provide the patient and family with an information packet that may include printed material on subjects such as the resumption of driving, patient rights/responsibilities, support group information, and audiovisual programs on stroke.
	Is Patient Ready for Community Living? 1. Recommend that the patient, family, and caregivers be fully informed about, prepared for, and involved in all aspects of healthcare and safety needs. 2. Recommend that the family and caregivers receive all necessary equipment and training in moving and handling, in order to position and transfer the patient safely in the home environment. 3. Recommend that the patient have appropriate vocational and income support opportunities. Stroke patients who worked before their strokes should be encouraged to be evaluated for the potential to return to work, if their condition permits. Vocational counseling should be offered when appropriate. 4. Recommend that leisure activities be identified and encouraged and that the patient be enabled to participate in these activities. 5. Recommend that case management be put in place for complex patient and family situations. 6. Recommend that acute care hospitals and rehabilitation facilities maintain up-to-date inventories of community resources, provide this information to stroke patients and their families and caregivers, and offer assistance in obtaining needed services. Patients should be given information about, and offered contact with, appropriate local statutory and voluntary agencies.

Evidence Tables

Self-Management

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Foster et al. 2007 UK Cochrane Review	NA	18 studies (17 different samples) were included. 7442 participants with multiple chronic conditions (e.g. arthritis, chronic pain, stroke, hypertension, heart failure etc.). Persons undergoing cancer therapies were excluded. Samples sizes ranged from 71 to 1140. Mean age ranged from 44-79 years	All studies that assessed interventions for patients with chronic diseases were included if the programs focused on: educational formats of delivery; self-management principles; and were delivered by non-professionals, or "lay people" There were three main types of interventions identified in the review: an arthritis self-management program, the chronic disease self-management program (CDSMP) and its equivalent (The Expert Patient Programme EPP), and other disease-specific interventions. Stroke was identified as a chronic condition under the studies that assessed the effects of the CDSMP.	Primary outcomes: health status, health behavior, health care use and self-efficacy Secondary outcomes: knowledge of chronic condition, social, attendance level, communication with health care providers, costs, caregiver outcomes, adverse events. Assessments were conducted at 6 months (n=15) and 12 months (n=2)	Health Status: There were small but statistically significant improvements in pain (SMD -0.10; 95% CI -0.17 to -0.04), disability (SMD -0.15; 95% CI -0.25 to -0.05) and fatigue (SMD -0.16; 95% CI -0.23 to -0.09), depression (SMD -0.16; 95% CI -0.24 to -0.07) and anxiety (SMD -0.14; 95% CI -0.25 to -0.04) associated with the intervention group. Significant improvements were also reported found for health distress (SMD -0.25; 95% CI -0.34 to -0.15) in the intervention group. No significant differences in fatigue, shortness of breath, psychological well-being, clinical measures or health related quality of life were found between the groups. Health Behaviour: There were small but statistically significant increases in levels of exercise (SMD -0.20; 95% CI -0.27 to -0.12) and in the frequency of practice of cognitive strategies for symptom management (WMD -0.55; 95% CI -0.85 to -0.26) in the intervention group compared to control group. Heath care use: No statistically significant differences were found between groups for health care provider visits or time spent in hospital.
Lennon et al. 2013 Australia Systematic Review	NA	15 studies (9 RCTs, 6 non-RCTs) including 1,233 patients >18 years, diagnosed with stroke, and who were focused on self-management interventions, at any	Studies that specified that patients were participating specifically in a "self-management" intervention.	Outcomes: None stated a priori	9 different self-management programs were identified. Mean time from stroke onset to initiation of program ranged from 24 days to >4 years. In 9 cases, the programme being delivered had

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		point post stroke. Mean age of participants across all included studies was 67 years.			been informed by Social Cognitive Theory. The programs were group-based (n=8) and delivered one-on-one (n=7). Components of the programs included workbooks, DVDs, problemsolving quizzes and exercise sessions. In all studies there were elements of information provision, problem solving, and goal-setting. In 6/9 RCTS, there were significant improvements associated with the intervention group in: disability and confidence in recovery, the stroke-specific quality of life sub-scales of family roles (p<0.01), fine motor tasks, (p<0.05), stroke knowledge, and mRS scores. In the non-randomized studies, significant improvements were reported in at least one of the studies for: depression, mobility (6-minute walk test), balance, the Stroke Self-Efficacy Questionnaire and Recovery Locus of Control Measure.
Harwood et al. 2011 New Zealand RCT	CA: ☑ Blinding: Patient ☑ Assessor☑ ITT: ☑	172 patients > 15 years, 6-12 weeks post stroke living outside of institutional care and identified as Maori or Pacific ethnicity. Most patients were identified for potential inclusion during their acute hospital stay. 48% of participants were male. Mean age: 61.4 years	Patients were randomized to either intervention a (n=48), b (n=46), both a and b (n=32) or control (n=31). Intervention a (DVD): involved watching an 80 minute DVD. The patient was subsequently able to take the DVD with them. The DVD was culturally specific, involved stories from stroke survivors and was focused on information provision. Intervention b (TCS – Take Charge Session): involved an 80-minute session with a research assistant. Patients were	Primary outcome: SF-36 (physical and mental component summary scores), Frenchay Activities Index (FAI), Caregiver Strain Index (CSI), blood pressure, assessed at 12 months. Secondary outcomes: Barthel index (BI), dependency (modified Rankin score >2) and rehabilitation service use, assessed at 6 and 12 months.	There were no statistically significant differences in any outcomes at 6 months. Outcomes assessed at 12 months: At 6 months, mean physical component score of the SF-36 was significantly higher among participants in the TCS group (p=0.004) and mean CSI scores among caregivers were lower (p=0.03), compared with the other treatment and control groups. At 12 months, significantly fewer participants in the TCS group were dependent (OR= 0.42, 95% CI 0.2 to 0.89, p = 0.023) and a lower mean CSI score (– 1.5 points, 95% CI –2.8 to –0.1, P = 0.034). There were no other significant differences between groups.

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Cadilhac et al. 2011 Australia RCT		143 patients > 18 years, more than 3 months post stroke. 78% of participants experienced the index stroke >12 months previously. 59% of participants were female. Mean age: 69.4 years	guided in a patient-centered goal setting process for recovery. The control group received a 30-minute session with a research assistant. Patients were given written educational material. Participants were randomized to one of three groups: Stroke-Specific Self-Management Program (SSMP)(n=48), the Stanford Chronic Disease Self-Management Program, referred to as the generic group (n=47) or standard care (n=48). Patients in the SSMP participated in an 8 week (1x per week – 2.5 hours) co-facilitated program, delivered by health professionals and trained peer leaders. The information provided was stroke-specific and reinforced at each visit,	Primary outcome: Feasibility, assessed by the numbers of patients who expressed interest, attended and completed the program. Secondary outcomes: Health Education Impact Questionnaire, Assessment of Quality of Life tool, and mood (Irritability, depression, and anxiety scales). Assessments were conducted at baseline, post-intervention and 6 months.	There was no difference in the number of patients who completed the generic vs. the SSMP intervention (38% vs. 52%; P=0.18). There was no difference in the number of adverse events (n=36) between the generic, SSMP or control groups (p=0.47). Patients in all groups demonstrated improvement over time. There were no significant differences in outcomes between the generic and SSMP groups for any of the secondary outcomes.
			as required. The generic group participated in a 6-week program (2.5 hours per night, one night per week), covering a wide range of topics, which was co-facilitated and led by trained leaders.		

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Kendall et al. 2007 Australia	CA: ☑ Blinding: Patient 函 Assessor函	100 patients less than a few months since first-ever stroke no history of dementia or psychiatric disorder, living	The standard care group received the typical information and care provided by the hospital team upon discharge from hospital. Participants were randomized to either intervention (n=58) or control groups (n=42).	Outcomes: Stroke Specific Quality of Life Scale (SSQOL). Assessments were	Self-efficacy was found to be significant predictor of all outcome variables on the SSQOL (p<0.01). Self-efficacy was therefore included as a covariate in the final models.
RCT	ITT: ⊠	independently in the presence of a family or friend (i.e. an "enabler"). Mean age: 66 years.	Intervention was the Stanford University's Chronic Disease Self-Management (CDSM) + one stroke-specific information session. Duration of the course was 7 weeks (2 hours per night). Courses were delivered in community settings and facilitated by two trained health professionals using the highly structured course protocol. Participants in the control group received usual care.	conducted every 3 months after stroke up to 1 year (4 time points).	Physical domain: Over time, participants in the intervention group demonstrated greater improvement in 1/5 SSQoL domains (fine motor task). Psychological domain: Over time, participants in the intervention group demonstrated greater improvement in 3/7 SSQoL domains (family roles, self-care, and work productivity.
Johnston et al. 2007 UK	CA: 国 Blinding: Patient 国	203 patients with a confirmed diagnosis of stroke admitted to an acute hospital and 172	Patients were admitted either during their hospital stay or after discharge. They were	Primary outcome: Observer Assessed Disability (OAD), Barthel Index (BI)	Patients receiving the workbook had statistically significantly greater recovery from disability (OAD), compared to the control group (p=0.019).
RCT	Assessor⊠ ITT: ☑	carers. 61% of patients were male. Mean age: 69 years. 61% of carers were female. Mean age was 61 years.	randomized to either the control (n=100) or intervention (n=103) group. Intervention involved the use of a workbook for the patient and their caregiver. A "workbook implementer" facilitated	Secondary outcomes: Hospital anxiety & Depression Scale (HADS), SF-36 (caregiver), satisfaction (0-10 scale), perceived control (Recovery Locus of Control Scale (RLOC)), confidence (0-10 scale).	There were no statistically significant differences between groups in in mean BI, HADS or satisfaction with care over time. Significantly more patients in the intervention group were lost to follow-up (28% vs. 16%, p<0.05).

Study/Type Qual	Sample Description	Method	Outcomes	Key Findings and Recommendations
		the use of the workbook over a five week period with a home visit during the first, second and last week and phone calls during the third and fourth week. The workbook included stroke related information and strategies and tools for coping. The workbook's focus was to encourage and facilitate patient self-management.	Assessments were conducted at baseline (<2 weeks after discharge), 8 weeks and at 6 months.	

Patient and Caregiver Education and Skills Training

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Patients & Caregi	vers				
Forster et al. 2012 UK	NA	21 RCTs (n=2289 patients, n=1290 carers) with stroke or TIA. Trials in which information	The effectiveness of an information intervention vs. standard care was examined.	Primary Outcomes: Patient and/or carer stroke and stroke services knowledge, patient and carer	Patient outcomes Knowledge: SMD=0.29, 95% CI 0.12 to 0.46, p<0.001. Results from 6 trials (n=536) included. Subgroup analyses did not identify significant
Cochrane Review		provision was provided as part of a more complex intervention	In 14 trials, the intervention was focused	mood (e.g., depression and anxiety).	differences in effect between passive and active interventions (p>0.05).
		were excluded. In 19 of the trials, the majority of patients were	on either the patient or carer exclusively. The timing of the	Secondary Outcomes: Activities of daily living, participation, social activities, perceived health status,	Depression: MD=-0.52, 95% CI -0.93 to -0.10, p<0.05. Results from 7 trials (n=720) included. Subgroup analysis demonstrated a significant difference between passive and active
		>60 years.	intervention was implemented prior to discharge (n=9), at varying times within 12	quality of life, satisfaction with information, hospital readmission and service contact, compliance with	interventions in favor of active information (p<0.05). Anxiety: MD=-0.34, 95% CI -1.17 to 0.50, p>0.05.
			months of stroke (n=7)	treatment, and death and/or	Results from 7 trials (n=720) included.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			and was >12 months (n=4)	institutionalization.	Death: OR=0.86, 95% CI 0.59 to 1.25, p>0.05. Results from 9 trials (n=1553) included.
					Satisfaction with stroke information: OR=2.07, 95% CI 1.33 to 3.23, p<0.001. Results from 5 trials (n=541) included.
					Satisfaction with service information: OR=1.18, 95% CI 0.76 to 1.83, p>0.05. Results from 4 trials (n=452) included.
					Caregiver outcomes Knowledge: SMD=0.74, 95% CI 0.06 to 1.43, p<0.05. Results from 4 trials (n=336) included.
					Psychological Distress: OR=1.13, 95% CI 0.65 to 1.97, p>0.05. Results from 4 trials (n=498) included.
					Satisfaction with stroke information: OR=1.78, 95% CI 0.88 to 3.60, p>0.05. Results from 2 trials (n=165) included.
					Satisfaction with service information: OR=1.30, 95% CI 0.71 to 2.37, p>0.05. Results from 3 trials (n=214) included.
Chau et al. 2014 China	CA: ☑ Blinding: Patient ☑	188 patients who had been discharged from acute inpatient rehabilitation and had	Patients were randomized to a short-term, user-pay, post-discharge stroke	Patient outcomes: Chinese version of modified Barthel Index (BI),Mini Mental State Examination	At one year, 38 patients in the intervention group and 33 caregivers completed the study and 89 patients in the control group and 78 caregivers in the control group.
RCT	Assessor ☑ ITT: 図	been residing in the community prior to stroke and their caregivers (n=140).	rehabilitation program for approximately 4 months, with the aim of discharge home (n=60), or usual care (post-discharge,	(MMSE), Geriatric Depression Scale (GDS), State Self-Esteem Scale (SSES), institutionalization rate	There were no significant differences between groups at either 4 or 12 months on any of the following outcomes: BI, MMSE, GDS, SSES and ZBI.
		56% of patients were male. Mean age was 72 years.	rehabilitation in a geriatric day hospital)(n=128). Although the total therapy time was similar between	Caregiver outcome: Zarit Burden Interview (ZBI)	Mean gain in BI scores from baseline to 12-months for intervention and control groups were: 23.2 vs. 17.4.
		74% of caregivers were female. Mean age was 55 years. 45% of caregivers were	groups (12 hours/week), therapies were provided 6 days/week vs. 2 days/week.	Assessments were conducted at baseline, 4 and 12 months.	The odds of institutionalization at 12 months were higher among patients in the control group (OR=4.96, 95% CI 1.13-21.75), after controlling for

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		spouses.			age, sex, household income, stroke type, baseline BI score, and cognitive impairment.
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 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 in 16 visits (70 minutes each)(n=79)	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 Study (MOS (caregiver only), F-COPES (caregiver only) Assessments were conducted at baseline, 6 and 12 months.	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 caregiver's 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. 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.
Eames et al. 2013 Australia RCT	CA: ☑ Blinding: Patient ☑ Therapist☑ Assessor☑ ITT: ☑	138 stroke/TIA patients and their carers; only 55.5% of participating patients were paired with participating carers. Patients who were admitted from residential care and/or were expected to be discharged to residential care were excluded. 28% and 60% of patients and carers, respectively, assessed for eligibility	Patients and their carers were randomized to receive an education and support package (n=71) or usual care (n=67) for 3 months. The intervention consisted of an individually tailored information package and verbal reinforcement. Usual care included unstructured, informal education provided by stroke unit team members.	Primary Outcome: Knowledge of Stroke Questionnaire Secondary Outcomes: Self-efficacy (9 domains), Hospital Anxiety & Depression (HAD) Scale, feeling of being informed, satisfaction with information, Caregiver Strain Index (caregivers only), and Stroke & Aphasia QoL-39 Generic (patients only)	No significant between group differences were found with respect to stroke knowledge at 3-month follow-up. Patients in the intervention group reported significantly greater self-efficacy (access to stroke information domain, p<0.04), feeling of being informed (p<0.01), and satisfaction with medical (p<0.001), practical (p<0.01), service/benefit (p<0.05), and secondary prevention (p<0.001) information received. No other significant between group differences were reported.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		were enrolled in the trial.		Assessments were conducted prior to hospital discharge and at 3 month follow-up.	
Forster et al. 2013 UK Cluster RCT	CA: ☑ Blinding: Patient 図 Therapist図 Assessor☑ ITT: ☑	928 patients with acute ischemic or hemorrhagic stroke admitted to a stroke unit, expected to return home, and their caregivers. 56% of patients were male. Mean age was 71 years. 69% of caregivers were female. Mean age was 61 years.	36 clusters (stroke units with high percentages of patients expected to be discharged home) were randomized to an intervention (n=18) or control group (n=18). 450 patient/caregiver dyads in the intervention group participated in the London Stroke Carers Training course (LSCTC) (same protocol as Kalra et al. 2004). The protocol emphasized skills essential for daily management of ADL and was hospital-based. 478 patient/caregiver dyads received usual care.	Primary patient outcome: Nottingham EADL at 6 months Secondary patient outcomes: Hospital Anxiety & Depression (HAD) Scale, cost effectiveness at 6 months Primary caregiver outcome: Caregiver's Burden Scale (CBS) at 6 months Secondary caregiver outcomes: Frenchay Activities Index (FAI), HADS, EQ-5D Assessments were conducted at 6 and 12 months.	146 and 145 patients lost to follow up in the intervention and control groups, respectively. At 6 months there was no significant difference in the mean patient NEADL scores between groups (27.4 vs. 27.6, p=0.866) or caregiver's CBS scores (45.5 vs. 45.0, p=0.660). There were no significant differences between groups for either the patient or the caregiver at 6 and 12 months for any of the secondary outcomes. Based on both the social and social + health perspectives, the probabilities that the intervention would be considered cost-effective for either the patient or the caregiver, were low.
Kalra et al. 2004 UK RCT	CA: ☑ Blinding: Patient ☑ Therapist☑ Assessor☑	300 patient admitted to a stroke rehabilitation unit who were previously independent in ADLs prior to stroke and their caregiver. 80% of patients were male. Median age was 76 years.	Patient/caregiver dyads were randomized to receive the London Stroke Carers Training course (LSCTC) (n=151) or conventional caregiver instruction (n=149). Caregivers in the intervention group received instruction about caring for a stroke patient and "hands-on" training in basic nursing techniques, whereas conventional instruction consisted of information and advice.	Patient Outcomes: Mortality, institutionalization, modified Rankin Scale (mRS), Barthel Index (BI), Frenchay Activities Index (FAI), Hospital Anxiety and Depression (HAD) Scale, EuroQol VAS, a satisfaction questionnaire, and cost of care. Caregiver Outcomes: FAI, HAD, Caregiver Burden Scale (CBS), EuroQol VAS, and a satisfaction questionnaire.	Patients outcomes: There were no significant differences between groups at either 3 or 12 months post stroke in mortality, the need for institutionalization, combined mortality, need for institutionalization, or the number of patients who were independent (mRS scores 0-2). At 3 months, (but not 12 months), a significantly higher number of patients had achieved a BI score >18 (77% vs. 52%, p=0.007). Patients in the intervention group had significantly lower median HAD scores and higher EuroQol scores at both 3 and 12 months. Caregiver outcomes: Caregivers who received

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			3-5, 30-45 minute sessions were provided, depending on need, prior to discharge from inpatient rehabilitation.	Assessments were conducted at baseline and at 3 and 12 months post-stroke onset.	structured training reported significantly less caregiver burden (p<0.001 at both 3 and 12 months) and anxiety and depression (both at p<0.001 at 12 months) and improved quality of life (p<0.001 at both 3 and 12 months).
Smith et al. 2004 UK	CA: ☑ Blinding: Patient 坚 Assessor☑	170 patients admitted to a stroke rehabilitation unit and their carers (n=97).	Patient/caregiver dyads were randomized to receive either usual care (n=86) or an education intervention consisting of	Primary outcome: Knowledge of Stroke questionnaire (developed specifically for the study), completed by both patient	There were no significant differences in stroke knowledge between treatment groups at 3 & 6-month assessment, nor were there significant changes in knowledge scores between or within groups from baseline to 6 months (carers and
RCT	ITT: ☑	Median age of patients was 74.5 years. 50% of patients were male. Median age of carers was 66 years. 61% were female.	a Stroke Recovery Programme Manual and hospital-based 20 minute bi-weekly meetings with the multi-disciplinary care team to receive information, discuss progress and develop goals (n=84).	Secondary outcomes: Barthel Index (BI), Frenchay activities Index (FAI), London Handicap Scale (LHS), Hospital Anxiety & Depression Scale (HAD), GHQ-28 (carer), and patient and carer satisfaction.	patients). At 3 and 6 months, participants in the education program had significantly greater reductions in HAD scores (anxiety component). There were no other significant differences reported between treatment groups, although patients and carers in the intervention group reported higher levels of satisfaction with the amount of information they had received and with the amount of contact post discharge.
Clark et al. 2003 Australia RCT	CA: ☑ Blinding: Patient ☑ Therapist☑ Assessor☑	68 patients with ischemic or hemorrhagic stroke and their spouses. 58% of patients were male. Mean ag was 72 years. Mean age of spouses was 72 years.	Patient/caregiver dyads were randomized at discharge to either the intervention group, receiving a stroke information package and 3, one-hour counselling visits from a social worker (n=35) or the control group, receiving no information or counselling (n=33)	Patient outcomes: Family Assessment Device (FAD), Barthel Index (BI), Adelaide Activities Profile (AAP), SF-36, Geriatric Depression Scale (GDS), Hospital Anxiety & Depression scale (HAD), Mastery Scale Carer outcomes: FAD, SF-36 Assessments were conducted at admission, discharge from inpatient rehabilitation and 6 months after discharge.	Over time, the mean FAD scores for patients and carers improved significantly, while the scores for those in the control group declined. Mean FAD and BI scores had improved significantly more among patients in the intervention group at 6 months. There were no significant differences between groups on SF-36, HAD, GDS, or Mastery at 6 months.
Rodgers et al. 1999	CA: ☑ Blinding: Patient 坚	204 stroke patients and their informal caregivers (n=176).	Patient/caregiver dyads were randomized to receive either an	Primary outcome (patient): SF-36	Participation in the SEP program was low with 51 patients and 20 carers attending ≥3 sessions.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
UK RCT	Therapist⊠ Assessor☑ ITT: ☑	52% of the patients were female. Mean age was 75 years. 69% of caregivers were female. Mean age was 59 years.	invitation to attend the Stroke Education Program (SEP) or conventional stroke unit care (control). The SEP involved one 1-hour small group education sessions for inpatients and their carers, followed by six 1-hour educational sessions after discharge. The control group had access to information leaflets about stroke.	Secondary outcomes (patient): Stroke knowledge, satisfaction with services, Hospital Anxiety & Depression Scale (HAD), Nottingham Extended ADL, Oxford Handicap Scale (OHS) Caregiver outcomes: Presence of a possible psychiatric disorder, stroke knowledge Assessments were conducted at 6 months in the patient/caregiver's home	There were no significant differences between groups in 6-month median SF-36 scores (including combined scores from both patients and caregivers). Median social functioning score of caregivers in the SEP group was significantly lower (62.5 vs. 100, p=0.04). The only significant difference between groups on any of the patient secondary outcomes was higher stroke knowledge among patients in the SEP group (p=0.02). Caregiver stroke knowledge was also significantly better among those in the SEP group (p=0.01).
Mant et al. 1998 UK RCT	CA: ☑ Blinding: Patient ☑ Therapist☑ Assessor☑	71 patients admitted to hospital following acute stroke and their informal caregivers (n=49) 65% of the patients were male. Mean age was 73 years.	Patient/caregiver dyads were randomly assigned to an intervention group that received information packages, delivered to their homes one week after randomization, related to stroke, its effects, and local contact names and support groups (n=48) or a control group that received no information package (n=45).	Patient outcomes: Stroke knowledge (study specific questionnaire), satisfaction with information received, London Handicap Scale (LHS), Hospital Anxiety & Depression Scale (HAD) Dartmouth Coop Chart Caregiver outcomes: Stroke knowledge (study specific questionnaire), satisfaction with information received, SF-36, Carer Strain Index (CSI) Assessments were conducted at 6 months post stroke.	The odds of a correct response were significantly higher for patients in the intervention group for 1/11 knowledge questions. The odds of a correct response were not significantly higher for any of the questions for caregivers in the intervention group. The odds of being satisfied with the information received were not higher for patients or caregivers in the intervention group. There were no significant differences between groups for any of the other outcomes except for significantly higher median SF-36 score (mental health) among caregivers in the control group (84 vs. 72, p=0.04).
Patients Only					
Hoffman et al. 2007 Australia	CA: ☑ Blinding: Patient ⊠	138 patients who had been admitted to the stroke unit of a single hospital following stroke	Participants were randomly assigned to receive either computer-generated tailored written	Primary outcome: Knowledge of Stroke Questionnaire (developed specifically for the study)	There were no significant differences between groups in mean change scores for stroke knowledge or self-efficacy or HAD (depression). The mean HAD anxiety scores had improved

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
RCT	Assessor ☑ ITT: ☑	or TIA. 55% of patients were male (there was a significantly higher number of males in the intervention group). Mean age was 68 years.	information (n=69) or generic written information (n=69). The intervention material was customized for each patient based on collaboration between the nurse and the patient. Patients selected from 34 available topics and determined their optimal format for layout and presentation. Pre-printed fact sheets related to stroke were provided to patients in the control group.	Secondary outcomes: Hospital Anxiety & Depression Scale (HADS), COOP charts, satisfaction with provided information. Assessments were conducted at baseline and 3 months	significantly more among patients in the control group. Patients receiving the intervention were significantly more satisfied with the content (p=0.003) and presentation (p<0.001) of the written information they received. Significantly more patients in the control group expressed a desire for additional information (p<0.001).
Lowe et al. 2007 UK RCT	CA: ☑ Blinding: Patient ☑ Therapist☑ Assessor☑ ITT: ☑	100 consecutive stroke patients admitted to an acute stroke unit. The median age was 73 years. 60% of patients were male.	Patients were randomized at the point of stroke diagnosis to receive either usual care (stroke information handouts)(n=50) or usual care + the "CareFile" (n=50). The CareFile consisted of a book containing general information, community contacts/local support agencies, and patient-specific information. Any information not pertinent for the individual patient was removed. The contents of the file were reviewed with the patient at a bedside discharge meeting – patients were advised to take the file with them to future appointments.	Primary outcome: Stroke Knowledge Questionnaire (SKQ) Secondary outcomes: Satisfaction with Information Given, utilization of CareFile, blood pressure, mood (Yale single item) Assessments were conducted at baseline, 3 and 6 months	At 3 and 6 months following stroke, patients in the CareFile group demonstrated significantly greater stroke knowledge (p<0.05 and p<0.005, respectively). At six months, 98% patients in the intervention group reported that the CareFile provided useful information and 53% said that they used it as reference material regarding their stroke. While 98% of all patients reported that they would recommend its use to other stroke patients, at 3 & 6 months <30% of patients in both groups reported receiving sufficient information about stroke causes and prevention. There were no significant between group differences regarding satisfaction with information received. There were no significant differences between groups at any of the assessment points in blood pressure or mood.
Caregiver Only					
Legg et al. 2011	NA	8 RCTs (n=1007	RCTs examining non-	Primary Outcome:	Primary outcomes

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
UK Cochrane Review		participants) including informal caregivers of stroke survivors.	pharmacological interventions designed to positively impact on caregivers' knowledge, beliefs, attitude or behaviour vs. no care or routine care. Interventions included: providing information and support (n=4), psychoeducation (n=3), and teaching procedural knowledge (n=1).	Caregiver stress, strain, and well-being at end of follow up Secondary Outcomes: Levels of stress, distress, anxiety, depression, health related quality of life, and satisfaction	Teaching procedural knowledge: The single study (Kalra et al 2004) demonstrated reduced caregiver stress and strain (MD= -8.67, 95% CI: -11.3 to -6.04, p<0.001). Support and information: There was no significant reduction in caregiver strain associated with the intervention (SMD= -0.29; 95% CI -0.86 to 0.27, p = 0.11). Data from 2 trials were included. Psych-education: There was no significant reduction in caregiver strain associated with the intervention (SMD= -0.01; 95% CI -0.34 to 0.36, p= 0.94). Data from 2 trials were included. No studies collected data on caregiver well-being. Secondary outcomes: The only significant improvements reported for any of the secondary outcomes were associated with the Teaching Procedural Knowledge' intervention. Depression (MD= -0.61, 95% CI: -0.85 to -0.37, p<0.001), and health related quality of life (MD=-11.97, 95% CI: -15.59 to -8.35, p<0.001).
King et al. 2012 USA RCT	CA: ☑ Blinding: Patient ☑ Assessor ☑ ITT: ☑	255 caregivers who were identified during acute rehabilitation of a stroke survivor, to be discharged back home. 78% of caregivers were female (62% were spouses). Mean age was 54.5 years. 40% of patients were male. Mean age was 61 years.	Caregivers were randomized to either the intervention (n=136) or control (n=119) group. The intervention was a caregiver problem solving intervention (CPSI) that involved 10 sessions with a clinical psychology student (advanced) and focused on skills for problem solving and coping with the stressors of caregiving. The control group was a wait-list group that received usual care.	Caregiver outcomes: Centre for Epidemiological Studies-Depression Scale (CES-D), Bakas Caregiving Outcome Scale (BCOS), Preparedness for Caregiving Scale), Profile of Moods Scale (5-item Tension-Anxiety subscale), And General Functioning scale of the McMaster Family Assessment Device (FAD). Moderator/mediator variables: Caregiver perceived health, Appraisal of Caregiving Scale, social Problem- Solving SPSI-R short form	There were no significant differences in outcomes between the intervention and control group over time. The mediator variable, caregiving appraisal (threat appraisal domain), was significantly associated with greater depression and anxiety, less preparedness and more negative perceived life change. (p<0.0001) over the study period. At 3-4 months after discharge (time 2), caregivers in the intervention group experienced significant lower levels of depression and improved health and perceived caregiver outcomes compared to wait-list controls. These differences were not maintained at 6 or 12 months.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Bakas et. al. 2009 RCT USA	CA: Blinding: Patient Assessor ITT: ITT:	50 caregivers of stroke survivors with ongoing needs. 73% of caregivers were female. The mean age 57 years. 64% of stroke survivors were male (significantly more males in the control group). Mean age was 65 years.	Participants were randomized to receive either Telephone Assessment & Skills-Building Kit (TASK) intervention (n=21) or a control group (n=19). TASK intervention consisted of participants being mailed a notebook containing 38 written tip sheets addressing 5 areas of skill building needs, a stress management workbook, and a brochure on family caregiving. The intervention groups also received weekly calls (for 8 weeks) by a nurse to provide individualized interventions in priority skill areas identified by the caregiver. Individuals in the control group received a brochure on family caregiving, as well as weekly calls from a nurse who did not provide any advice or information.	Outcomes were assessed at baseline, 3-4, 6 and 12 months after discharge. Optimism: Revised Life Orientation Test (LOT-R), task difficulty: Oberst Caregiving Burden Scale Difficulty Subscale (OCBS), threat appraisal: Appraisal of Caregiving Threat subscale (ACS), depressive symptom assessment: Patient Health Questionnaire Depression Scale (PHQ-9), life changes: Bakas Caregiving Outcomes Scale (BCOS), and general health perception: SF-36 Assessments were conducted at baseline, 4, 8, and 12 weeks	There were significant increases in caregiver optimism at all 3 follow up time points in the TASK group compared with the control group (4 week, p=0.02; 8 weeks, p=0.02; 12 weeks p=0.02), but significant decreases in task difficulty only reported at 4 weeks (p=0.03). Threat appraisal skills were significantly improved in the TASK group at both 8 (p=0.02) and 12 week (p=0.01).
Draper et. al. 2007 RCT Australia	CA: ☑ Blinding: Patient ☑ Assessor ☑ ITT: ☑	39 caregivers of aphasic stroke patients living at home with a persistent language deficit <12 months post stroke, who were recruited from rehabilitation hospitals. Mean caregiver age: intervention, 64 years; control, 60 years.	Caregivers were randomized to receive either immediate (n=19) or delayed (n=20) treatment after a 3 months waiting period. The intervention consisted of group sessions addressing education, skills training, support, and stress	Primary outcomes: General Health Questionnaire- 28 item version (GHQ-28), Relatives' Stress Scale (RSS), a communications questionnaire Assessments were conducted at baseline, post treatment, and 3 months	The mean total GHQ-28 scores of caregivers in the immediate group were significantly reduced post treatment (6.26 to 3.21, p=0.006), but were not significantly different from baseline at 3-month follow-up (4.26). The same pattern of results was noted for caregivers in the wait-listed group. There were no significant improvements in RRS scores or communication skills from baseline to end of treatment between treatment groups (immediate and delayed groups).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			management (coping skills for depression and anxiety). Sessions occurred weekly for 4 weeks (2 hours sessions)	post treatment	

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