Canadian Stroke
Best Practices

CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Transitions and Community Participation Following Stroke Evidence Tables

Education for People with Stroke, Their Families and Caregivers Following Stroke

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Transitions and Community Participation Following Stroke Writing Group

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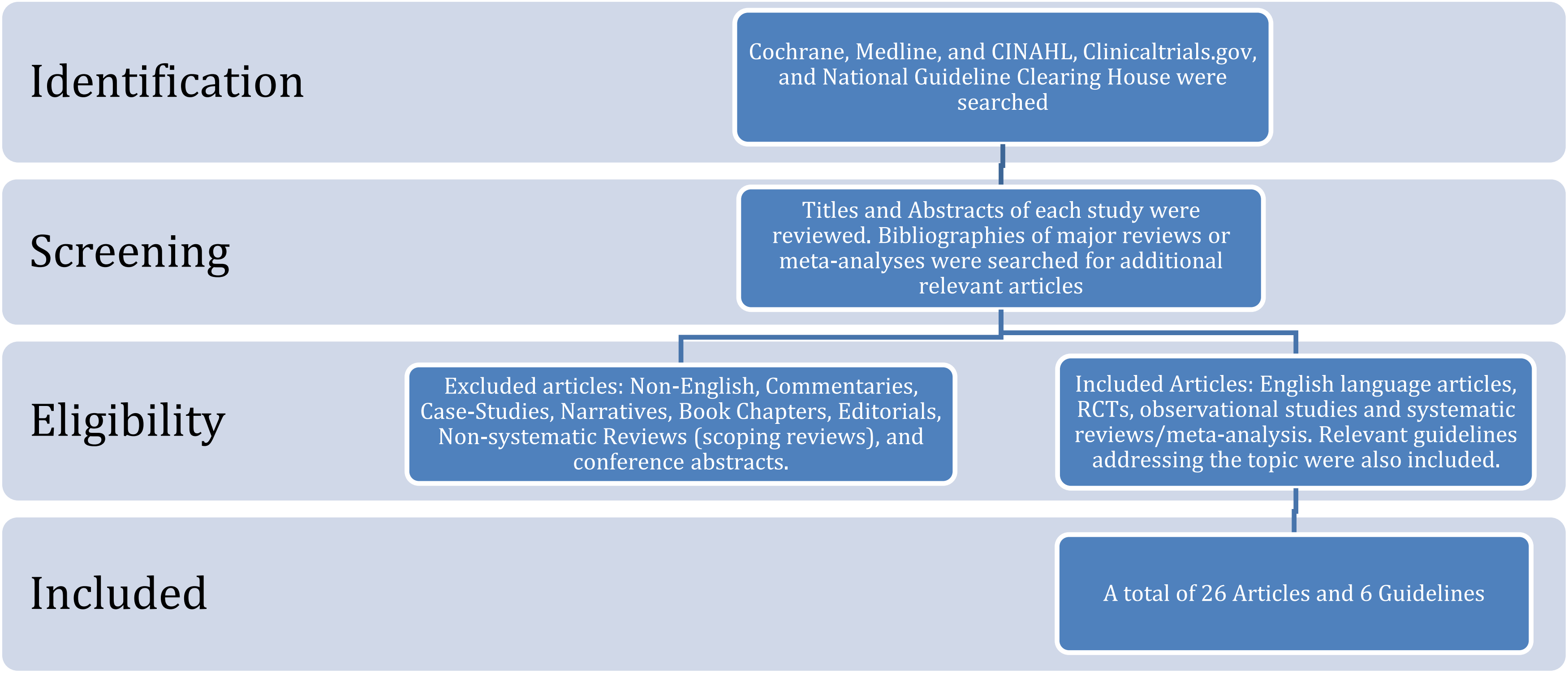
Search Strategy



Identification

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

Screening

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

Eligibility

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

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

Included

A total of 26 Articles and 6 Guidelines

Cochrane, Medline, and CINAHL, Clinicaltrials.gov, and National Guideline Clearing House were search using medical subject. Titles and abstract of each article were reviewed for relevance. Bibliographies were reviewed to find additional relevant articles. Articles were excluded if they were: non-English, commentaries, case-studies, narrative, book chapters, editorials, non-systematic review, or conference abstracts. Additional searches for relevant best practice guidelines were completed and included in a separate section of the review. A total of 26 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.	**Strong Recommendation** • All stroke survivors and their families/carers should be offered information tailored to meet their individual needs using relevant language and communication formats. • Information should be provided at different stages in the recovery process. • An approach of active engagement with stroke survivors and their families/carers should be used allowing for the provision of material, opportunities for follow-up, clarification, and reinforcement. **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 Recommendations (Carers)** A The views of the person with stroke should be sought, to establish the extent to which they wish carers and others to be involved in the planning and delivery of their care. B If the person with stroke agrees, family/carers should be involved in significant decisions as an additional source of information about the person both clinically and socially. C The primary carer(s) of a person with stroke should be offered an educational programme which: – explains the nature, consequences and prognosis of stroke and what to do in the event of a further stroke or other problems e.g. post-stroke epilepsy; – teaches them how to provide care and support; – gives them opportunities to practise giving care; – provides advice on secondary prevention, including lifestyle changes. D When care is transferred out of hospital to the home or care home setting, the carer of a person with stroke should be offered: – an assessment of their own needs, separate to those of the person with stroke; – the practical or emotional support identified as necessary; – guidance on how to seek help if problems develop. E The primary carer(s) of a person with stroke should be provided with the contact details of a named healthcare professional (e.g. a stroke co-ordinator) who can provide further information and advice. 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.
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,	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

Guideline	Recommendations
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. **Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American Heart Association/American Stroke Association.** ***Stroke* 2016;47:e98–e169**	• Training • Counseling • Development of a support structure • Financial assistance It may be useful to have the family/caregiver involved in decision making and treatment planning as early as possible and throughout the duration of the rehabilitation process. Class IIb, LOE B
Bakas T, Clark PC, Kelly-Hayes M, et al. Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American heart association and American stroke association. *Stroke* 2014;45:2836-52	Recommendations for caregiver vs dyad interventions: Stroke caregiver interventions are probably recommended in preference to dyadic interventions when stroke caregiver outcomes are most desired. Class IIa; Level of Evidence A Stroke dyad interventions are probably recommended in preference to stroke: Caregiver interventions when survivor outcomes are most desired. Class IIa; Level of Evidence A Recommendations for types of interventions: Interventions that combine skill building (eg, problem solving, stress management, goal setting) with psycho-educational strategies should be chosen over interventions that only use psycho-educational strategies. Class I; Level of Evidence A Interventions that involve only psycho-education are not recommended and have the potential to jeopardize social functioning in some survivors and caregivers. Class III; Level of Evidence B Interventions that consist of support only or a combination of support and psycho-education are not well established and do not have sufficiently strong evidence. Class IIb; Level of Evidence B Recommendations for tailoring vs one-size-fits-all interventions: Interventions that are tailored or individualized on the basis of the needs of stroke caregivers should be chosen over nontailored one-size-fits-all interventions. Class I;Level of Evidence A Postdischarge assessments with tailored interventions based on changing needs should be performed to improve caregiver outcomes. Class I;Level of Evidence C Individual approaches are probably recommended over group interventions. Class IIa; Level of Evidence B

Guideline	Recommendations
	Recommendations for mode of delivery for interventions: Interventions that are delivered face to face and/or by telephone are recommended. Class I; Level of Evidence A Interventions delivered completely by telephone can be useful, particularly when face-to-face access is not feasible. Class IIa; Level of Evidence B Interventions delivered by the Web might be considered for those with computer access. Class IIb; Level of Evidence B Recommendations for number of sessions for interventions: Interventions consisting of 5 to 9 sessions are recommended. Class I;Level of Evidence A Interventions with a wide range of sessions (eg, 0–60) delivered by a family support organizer are not as useful and may jeopardize social functioning in some survivors and caregivers. Class III; Level of Evidence B
Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning. A national clinical guideline. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network (SIGN); 2010 June.	**Information Needs of Patients and Carers** • Stroke patients and their carers should be offered information about stroke and Rehabilitation [Evidence Level D]. • Information should be available to patients and carers routinely and offered using active information strategies, which include a mixture of education and counseling techniques [Evidence Level A]. • Information should be tailored to the information needs of individual patients and carers, followed up to check understanding and ensure clarity, and repeated as appropriate [Evidence Level A]. • Information should be tailored to the communication needs and visual needs of individual patients and carers. Patients with aphasia should be provided with accessible and easy to read material, be given sufficient time for assimilation and be followed up by health professionals to ensure understanding [Evidence Level D]. • Information needs should be monitored and information should be provided at appropriate time [Evidence Level A] **Carer Support** • Where a carer is suspected of being clinically depressed or anxious, they should be encouraged to seek help by contacting the appropriate member of the general practice team [Good Practice Point]. **Stroke Liaison Workers** • NHS Board areas should consider developing specialist stroke nurse led support services that include education, information provision and liaison, in the community for people who have had a stroke and their carers [Good Practice Point].
Management of Stroke Rehabilitation Working Group. VA/DoD clinical practice guideline for the management of stroke rehabilitation. Washington (DC): Veterans Health Administration, Department of Defense; 2010. p.p.70-72	**Patient, Family Support, and Community Resources** 1. Recommend all stroke patients and family caregivers receive a thorough psychosocial assessment with psychosocial intervention and referrals as needed. 2. The psychosocial assessment of both the patient with stroke and the primary family caregiver should include the following areas: a. History of pre-stroke functioning of both the patient and the primary family caregiver (e.g., demographic information, past physical conditions and response to treatment, substance use and abuse, psychiatric, emotional and mental status and history, education and employment, military, legal, and coping strategies) b. Capabilities and care giving experiences of the person identified as the primary caregiver

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** 1. Recommend patient and family are educated regarding pertinent risk factors for stroke. 2. Recommend that the family and caregivers receive all necessary equipment and training prior to discharge from rehabilitation services. [I] 3. Family counseling focusing on psychosocial and emotional issues and role adjustment should be encouraged and made available to patients and their family members upon discharge. **Long-Term Management** 1. Recommend post-discharge telephone follow-up with patients and caregivers be initiated and include problem solving and educational information. 2. If available, asynchronous and real-time tele-health, video, and web-based technologies, (e.g., web-based support groups, tele-rehabilitation), should be considered for patients who are unable to travel into the facility for care and services. 3. Patient and family should be educated regarding pertinent risk factors for stroke. 4. Provide patient information about, and access to community-based resources. **Family/Community Support** 1. Patients and caregivers should be educated throughout the rehabilitation process to address patient's rehabilitation needs, expected outcomes, procedures and treatment as well as appropriate follow-up in the home/ community. [B] 2. Patient and caregiver education should be provided in both interactive and written formats. [B] 3. Caregivers should be provided in a variety of methods of training based on their specific needs, cognitive capability, and local resources; Training may be provided in individual or group format, and in community-based programs. [B]

Associations Between Income & Participation

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Sauvé-Schenk et al. 2019 **Canada** **Qualitative study**	NA	8 low-income francophone persons living in eastern Ontario, who had sustained a stroke ≥ 6 months and had an annual income below the low-Income cut-off for their region (approximately $17,700 USD per year for a single person). There were 4 women and 4 men. Ages ranged from late 20's to early 70s. Time post stroke ranged from 10 months to 5 years.	Data acquisition for each case included: 3 semi-structured interviews with the stroke survivor, one semi-structured interview with a care partner, observations of the stroke survivor in their environment, a review of their medical charts, and completion of three assessment measures. During the interviews, participants were asked to describe their pre-stroke life situations and personal projects. They were then asked to identify their post-stroke personal projects and to describe their experience of attempting to return to these projects	**Primary outcome:** Return to participation in personally valued activities after a stroke	Monthly income ranged from 465USD to 1,300 USD per month. The stroke survivors spoke of the direct impact of living with a limited income on their ability to attain their personal projects. Low income influenced three main precursors to participation: goods, services and housing. Limited income restricted the participant's ability to purchase goods such as mobility aids, equipment, or healthy foods. Participants were limited in their ability to afford services such as transportation, personal support workers, housekeeping, and private therapy service. Limited income negatively impacted their ability to afford and maintain housing. Securing income support was identified as a personal project for 6/8 participants.
Chen et al. 2015 **UK** **Retrospective study**	NA	2,104 persons included in the South London Stroke Register cohort of 1995 to 2011 who had sustained a first-ever stroke and were alive at 3 months	Socioeconomic deprivation (SED) was measured using the Index of Multiple Deprivation covering 7 dimensions of deprivation including income, employment, health and disability, education, skills, and training, barriers to housing and services,	**Primary outcome:** Functional impairment	Three months after stroke, 25.9% in the most affluent cohort (Q1) were functional impaired. Values for persons in Q2, Q3 and Q4 were 30.3%, 31.0% and 35.1%, respectively. Compared with those in Q1 (reference category), the odds of functional impairment were: Q2: 1.29, 95% CI 0.94–1.76 Q3: 1.33, 95% CI 0.97–1.82 Q4: 1.78, 95% CI 1.31–2.43 Overall p<0.004

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			crime, and living environment. The association between SED (grouped by quartile) and functional impairment (Barthel Index score <15) was examined at 3 months and 3 years post stroke. Analysis was adjusted for demographic characteristics, comorbidities and prognostic factors		Three years after stroke, 22.1% in the most affluent cohort (Q1) were functional impaired. Values for persons in Q2, Q3 and Q4 were 23.2%, 28.3% and 31.9%, respectively. Compared with those in Q1 (reference category), the odds of functional impairment were: Q2: 1.09, 95% CI 0.70–1.69 Q3: 1.34, 95% CI 0.87–2.07 Q4: 1.77, 95% CI 1.15–2.72 Overall $p<0.046$ In subgroup analysis, the associations were significant in persons≥65 years, women, those with no baseline comorbidities and for ischemic stroke.
Egan et al. 2015 **Canada** **Retrospective study**	NA	67 individuals who were treated in acute care or rehabilitation following a first ever stroke, who were discharged to the community with FIM scores of ≥ 3 for comprehension, memory and problem solving	The average Reintegration to Normal Living Index (RNLI) score at 6, 9, 12, 18 and 24-months post stroke was compared among persons living in very low-income neighborhoods (≤$20,0000 vs. those living in neighborhoods with incomes >$20,000.	**Primary outcome:** Reintegration to Normal Living Index	Six (9.0 %) of the participants lived in very low-income neighbourhoods. Living in a very low-income neighbourhood was an independent predictor of lower RNLI scores at 6 months (β= -15.7, $p=0.028$) and 12 months (β= −14.45, $p=0.04$), but not at 9, 18 or 24 months. Overall, those in very low-income neighborhoods had significantly lower RNLI scores (β= −12.98, $p=0.003$). Independent predictors of higher RNLI scores included female sex, higher perceived health, better performance of 2-minute walk test, and better emotional well being.

Education Needs of Patients and Caregivers

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Yonaty & Kitchie 2012 **USA**	NA	A convenience sample of 71 patients ≥18 years, with a first-ever hemorrhagic or	A questionnaire, entitled "*What I want to learn about stroke*", was administered 3 times	**Primary outcome:** The importance of each topic, rated on a 5-point	32 patients completed the survey at all 3 time points.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Survey		ischemic stroke occurring within the previous week, with a plan for discharge to either home or a rehabilitation facility. Mean age of patients was 57 years, 53% were men. 67.6% of patients were discharged home.	(24-72 hours post stroke, at discharge and at 2 weeks post discharge). The questionnaire consisted of 8 stroke-related domains (medical knowledge of stroke, control of risk factors, treatment of stroke with medications, surgery and herbal or alternative medicine, rehabilitation, dietary habits after stroke and other topics.	Likert scale, and change across time.	Medical knowledge and medication treatment were rated the most important to learn. The results were stable across assessment points. Mean scores for medical knowledge were 4.29, 4.31 and 4.38. Mean scores for importance of medication knowledge were 4.24, 4.28 and 4.30. The lowest scores for importance of knowledge were related to herbal or alternative treatments and dietary habits. Patients also indicated they were not satisfied with the level of education they received for any of the 8 domains. Mean Likert scale scores were all <4.
Hafsteinsdottir et al. 2011 **The Netherlands** **Systematic review**	NA	21 studies including patients with stroke (n=1,029) or their caregivers (n=749) in the acute, rehabilitation or chronic phase	The research question was ‘‘What are the educational needs of stroke patients and their caregivers during the different phases following the stroke?’’	**Primary outcomes:** Educational needs of patients (self-defined)	5 studies focused on the needs of patients, 9 studies identified the needs of caregivers and 7 focused on the needs of both patients and caregivers. Among patients, educational needs identified included: possibility of cure with medical treatment, stress management, general medical knowledge and post stroke diet management, medications and side effects, specific medical information about their type of stroke and specific symptoms like dizziness, pain and loss of taste Unanswered questions patients had most often were related to communication difficulties, the nature of the stroke, fear of recurrent stroke, recovery, stroke prevention, memory problems, driving, return to work and tiredness. Education needs identified by caregivers included: information, communication, support and accessibility to the patient and the health care professional, dealing with psychological, emotional and behavioral problems and local service information, falls prevention maintaining adequate nutrition, staying active, managing stress, and dealing with emotional and mood

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					changes, coping with feeding problems, preventing a patient's cognitive and physical deterioration and handling a patient's changing moods Education needs identified by patients and caregivers included: diagnosis, prognosis, predicted recovery and results of studies, risk of stroke recurrence, how to prevent further stroke, driving and understanding medical jargon and abbreviations, practical caring tasks, social activities and resources available in the community. The need for information that was personally tailored was also identified.

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	**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

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			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.		-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 point post stroke. Mean age of participants across all included studies was 67 years.	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 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, problem-solving 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**	CA: ☑ Blinding: Patient ☒ Assessor☑	172 patients > 15 years, 6-12 weeks post stroke living outside of institutional care and identified as Maori or	Patients were randomized to either intervention a (n=48), b (n=46), both a and b	**Primary outcome:** SF-36 (physical and mental component summary scores), Frenchay Activities	There were no statistically significant differences in any outcomes at 6 months. **Outcomes assessed at 12 months:**

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RCT	ITT: ☑	Pacific ethnicity. Most patients were identified for potential inclusion during their acute hospital stay. 48% of participants were male. Mean age: 61.4 years	(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 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.	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.	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.
Cadilhac et al. 2011 **Australia** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor☑ ITT: ☑	143 patients > 18 years, more than 3 months post stroke. 78% of participants experienced the index stroke >12 months previously.	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	**Primary outcome:** Feasibility, assessed by the numbers of patients who expressed interest, attended and completed the program. **Secondary outcomes:** Health Education Impact Questionnaire,	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

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		59% of participants were female. Mean age: 69.4 years	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, 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. The standard care group received the typical information and care provided by the hospital team upon discharge from hospital.	Assessment of Quality of Life tool, and mood (Irritability, depression, and anxiety scales). Assessments were conducted at baseline, post-intervention and 6 months.	between the generic and SSMP groups for any of the secondary outcomes.
Huijbregts et al. 2008 **MOST (Moving on after stroke) And LWS (Living with stroke)** **Canada**	NA	23 participants (14 in MOST and 9 in LWS) an average of 24 months post stroke, with an average age of 71 years (MOST group) and 63 years (LWS group).	Participants were recruited by brochures, referrals, presentations etc. and were allowed to choose which of the two programs they wanted to attend. Participants in the first program (MOST)	**Outcomes:** Mini-Mental State Exam (MMSE) at baseline, Reintegration to Normal living index (RNLI), Activity-specific balance scale (ABC), FIM, geriatric depression scale (GDS), Chedoke McMaster Stroke	**MOST vs. LWS groups:** There were no statistically significant differences in outcomes between the two groups. **Within MOST group:** RNLI: Patients in the MOST group experienced statistically significant improvements in the RNLI score from baseline to 12 weeks after the program (F=3.43; P<0.05).

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Prospective study			received 16 group sessions (2 times per week for 2 hours) and one final “booster session” after a 6-week gap. The 17 session topics include (Listed in Table 1 of Huijbregts et al 2008): why is self-management and exercise important, goal setting, how stroke affects you and prevention, relaxation, daily activities and responsibilities, recreation and having fun, how stroke affects how you think and feel, caregivers, community resources communication, interaction with health providers, alternative treatments, loving and caring, your doctor and your medications, nutrition sleep and pain, community living). One hour is devoted to one of the topics listed and some time to work on goal setting and strategies for problem solving. The second hour is exercise. Participants in the second program, LWS, received 6 group sessions (1 time per	Assessment (CMSA) (activity inventory component) Assessments were conducted at baseline, at the end of the program and at 12 weeks after the program (all other assessments except MMSE were administered at the last two time points).	ABC: Patients in the MOST group experienced statistically significant improvements in ABC scores from baseline to right after the program and from baseline to 12 weeks after the program (F=8.94; P<0.005). FIM: Patients in the MOST group experienced statistically significant improvements in FIM scores from baseline to right after the program (F=3.97; P<0.05). GDS: No statistically significant improvements in GDS scores in the MOST group. CMSA: No statistically significant improvements in CMSA scores in the MOST group. **Within LWS group:** Patients in the LWS group only experienced statistically significant gains in FIM scores (F=4.73; P<0.09) Overall the outcomes for the MOST and LWS groups did not differ significantly. However, the MOST group of patients experienced significant improvements in multiple outcome areas, while participants in the LWS group only experienced functional gains. For participants in the MOST program, a greater percentage of people attended the first hour of the session compared to the second hour (89% vs. 77%; P<0.001)

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			week for 90 minutes). Session topics include 6 of the 8 listed in Table 1 of Huijbregts et al 2008: how a stroke happens, physical effects of stroke, communication, therapies and lifestyle changes, psychosocial effects, stroke and the younger person, issues in care giving, community).		
Kendall et al. 2007 **Australia** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor☒ ITT: ☒	100 patients less than a few months since first-ever stroke no history of dementia or psychiatric disorder, living independently in the presence of a family or friend (i.e. an “enabler”). Mean age: 66 years.	Participants were randomized to either intervention (n=58) or control groups (n=42). 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.	**Outcomes**: Stroke Specific Quality of Life Scale (SSQOL). Assessments were conducted every 3 months after stroke up to 1 year (4 time points).	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. **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	CA: ☒	203 patients with a confirmed diagnosis of stroke admitted to an	Patients were admitted either during their hospital stay or after	**Primary outcome:** Observer Assessed	Patients receiving the workbook had statistically significantly greater recovery from disability (OAD), compared to the control group ($p=0.019$).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
UK **RCT**	Blinding: Patient ☒ Assessor☑ ITT: ☑	acute hospital and 172 carers. 61% of patients were male. Mean age: 69 years. 61% of carers were female. Mean age was 61 years.	discharge. They were 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 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.	Disability (OAD), Barthel Index (BI) **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). Assessments were conducted at baseline (<2 weeks after discharge), 8 weeks and at 6 months.	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).

Patient & Caregiver Education and Skills Training

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Patients & Caregivers					
Forster et al. 2012 **UK**	NA	21 RCTs (n=2289 patients, n=1290 carers) with stroke or TIA. Trials in which information provision was	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 mood	**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 differences in effect between passive and active interventions (p>0.05).

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Cochrane Review		provided as part of a more complex intervention were excluded. In 19 of the trials, the majority of patients were >60 years.	In 14 trials, the intervention was focused on either the patient or carer exclusively. The timing of the intervention was implemented prior to discharge (n=9), at varying times within 12 months of stroke (n=7) and was >12 months (n=4)	(e.g., depression and anxiety). **Secondary Outcomes:** Activities of daily living, participation, social activities, perceived health status, quality of life, satisfaction with information, hospital readmission and service contact, compliance with treatment, and death and/or institutionalization.	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 interventions in favor of active information (p<0.05). Information interventions were not associated with significant reductions in anxiety: MD=-0.34, 95% CI -1.17 to 0.50, p>0.05. Results from 7 trials (n=720) included, or reduced odds of 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. Information intervention were not associated with significant reductions in psychological distress (OR=1.13, 95% CI 0.65 to 1.97, p>0.05. Results from 4 trials (n=498) included) or increased satisfaction with stroke information (OR=1.78, 95% CI 0.88 to 3.60, p>0.05. Results from 2 trials (n=165) included), or 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** **RCT**	CA: ☒ Blinding: Patient ☒ Assessor ☑ ITT: ☒	188 patients who had been discharged from acute inpatient rehabilitation and had been residing in the community prior to stroke and their caregivers (n=140).	Patients were randomized to a short-term, user-pay, post-discharge stroke rehabilitation program for approximately 4 months, with the aim of discharge home (n=60), or usual care (post-discharge, rehabilitation in a	**Patient outcomes:** Chinese version of modified Barthel Index (BI), Mini Mental State Examination (MMSE), Geriatric Depression Scale (GDS), State Self-Esteem Scale (SSES), institutionalization rate **Caregiver outcome:**	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. 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. Mean gain in BI scores from baseline to 12-months for intervention and control groups were: 23.2 vs. 17.4.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		56% of patients were male. Mean age was 72 years. 74% of caregivers were female. Mean age was 55 years. 45% of caregivers were spouses.	geriatric day hospital)(n=128). Although the total therapy time was similar between groups (12 hours/week), therapies were provided 6 days/week vs. 2 days/week.	Zarit Burden Interview (ZBI) 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 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 to receive monthly mailed information packages related to signs & symptoms of stroke, prevention, stress reduction strategies with links to support groups, advocacy organizations and National Stroke Association periodical (n=80) or information packages + home based visits for 6 months by advance care practice nurses, occupational and physical therapists. On average, over the 6-month study period, dyads participated 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	CA: ☑	138 stroke/TIA patients and their	Patients and their carers were	**Primary Outcome:**	No significant between group differences were found with respect to stroke knowledge at 3-month follow-up.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Australia **RCT**	Blinding: Patient ☒ Therapist☒ Assessor☑ ITT: ☒	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 were enrolled in the trial.	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.	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) Assessments were conducted prior to hospital discharge and 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.
Forster et al. 2013 **UK** ***Training Caregivers After Stroke (TRACS)*** **Cluster RCT**	CA: ☑ Blinding: Patient ☒ Therapist☒ 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	**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	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			emphasized skills essential for daily management of ADL and was hospital-based. 478 patient/caregiver dyads received usual care.	Assessments were conducted at 6 and 12 months.	
Kalra et al. 2004 **UK** **RCT**	CA: ☑ Blinding: Patient ☒ Therapist☒ Assessor☑ ITT: ☑	300 patients 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. 3-5, 30-45 minute sessions were provided, depending on need, prior to discharge from inpatient rehabilitation.	**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. Assessments were conducted at baseline and at 3 and 12 months post-stroke onset.	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 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 ☒ 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	**Primary outcome:** Knowledge of Stroke questionnaire (developed specifically for the study),	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 patients).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
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.	education intervention consisting of 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).	completed by both patient and carer **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.	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☑ ITT: ☒	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 **UK** **RCT**	CA: ☑ Blinding: Patient ☒ Therapist☒ Assessor☑	204 stroke patients and their informal caregivers (n=176). 52% of the patients were female. Mean age was 75 years.	Patient/caregiver dyads were randomized to receive either an invitation to attend the Stroke Education Program (SEP) or conventional stroke	**Primary outcome** (patient): SF-36 **Secondary outcomes** (patient): Stroke knowledge, satisfaction with services,	Participation in the SEP program was low with 51 patients and 20 carers attending ≥3 sessions. 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).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
	ITT: ☑	69% of caregivers were female. Mean age was 59 years.	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.	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	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☑ ITT: ☑	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	CA: ☑ Blinding:	138 patients who had been admitted to the stroke unit of	Participants were randomly assigned to receive either	**Primary outcome:** Knowledge of Stroke Questionnaire	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

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Australia **RCT**	Patient ☒ Assessor ☑ ITT: ☑	a single hospital following stroke or TIA. 55% of patients were male (there was a significantly higher number of males in the intervention group). Mean age was 68 years.	computer-generated tailored written 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.	(developed specifically for the study) **Secondary outcomes:** Hospital Anxiety & Depression Scale (HADS), COOP charts, satisfaction with provided information. Assessments were conducted at baseline and 3 months	improved 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,	**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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			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.		There were no significant differences between groups at any of the assessment points in blood pressure or mood.
Caregiver Only					
Legg et al. 2011 **UK** **Cochrane Review**	NA	8 RCTs (n=1007 participants) including informal caregivers of stroke survivors.	RCTs examining non-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), psycho-education (n=3), and teaching procedural knowledge (n=1).	**Primary Outcome:** 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	**Primary outcomes** 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).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
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 Outcomes were assessed at baseline, 3-4, 6 and 12 months after discharge.	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.
Bakas et. al. 2009 **RCT** **USA**	CA: ☑ Blinding: Patient ☒ Assessor ☒ 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	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	**Primary outcomes:** 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	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 weeks (p=0.01).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		group). Mean age was 65 years.	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.	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	
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.	Caregivers were randomized to receive either immediate (n=19) or delayed (n=20) treatment after a 3-month waiting period. The intervention consisted of group sessions addressing education, skills	**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 post treatment	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
		Mean caregiver age: intervention, 64 years; control, 60 years.	training, support, and stress management (coping skills for depression and anxiety). Sessions occurred weekly for 4 weeks (2 hours sessions)		

Caregiver Involvement in Rehabilitation

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Lindley et al. 2017 ***The Attend Collaborative Group (ATTEND)*** **India & Australia** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☑ ITT: ☑	1,250 patients recruited from 18 hospitals in India between January 2014 and February 2016, who were ≥18 years who had a stroke and who had an informal family-nominated caregiver. Mean age was 57.7 years, 67% were men. 91% of patients were married, 41% of caregivers were spouse.	Patients were randomized to receive the intervention (n=623) or usual care (n=627). Family members of those assigned to the intervention group received additional structured rehabilitation training, including information provision, join goal setting, carer training and task-specific training that was started in hospital and continued at home for 2 months.	**Primary outcome** Death or dependency (mRS score 3-6) at 6 months **Secondary outcomes:** LOS, place of residence, BI, Nottingham EADL scale, Quality of life (WHOQOL0BREF and the EuroQol Group 5-Dimension Self-Report Questionnaire), patient and caregiver anxiety and depression (HADS) and the Caregiver Burden Scale	At 6 months, the proportion of patients who were dead or disabled was the same in both groups 285 (47%) intervention vs: 287(47%). Unadjusted OR= 0.98; 95% CI: 0.78 to 1.23, p = 0.87 Adjusted for study site, stroke severity, age, sex, income, and education OR=1.02; 95% CI: 0.80 to 1.31, p = 0.87 There were no significant differences between groups for any of the secondary outcomes including: Rehospitalization: 14% vs. 13%, p 0.56 Mean BI score: 82.1 (23.09) vs. 82.6 (23.19), p = 0.74 Mean Nottingham EADL: 31.0 (17.67) vs. 31.2 (17.52), p = 0.86 Mean caregiver burden score: 17.7 vs. 17.6, p=0.52 There were no significant differences in HADS scores (patient or caregiver), or any of the domains of the WHOQOL0BREF or EQ-5D between groups In subgroup analysis, men had reduced odds of death or dependency at 6 months compared to women (Men: OR= 0.83; 95% CI: 0.63 to 1.10 vs. Female: OR=1.39; 95% CI: 0.93 to 2.05, p for interaction = 0.0374).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Vloothuis et al. 2016 **Netherlands** **Cochrane Review**	NA	6 RCTs including 333 patient-caregiver couple – recovering from stroke. The mean age in all studies was approximately 60 years. Mean time since onset ranged from 15 days to 10 years (3 additional trials were identified but not included in the pooled analyses)	Trials compared the effectiveness of caregiver-mediated exercises (CME) vs. usual care, no intervention, or other non- caregiver-mediated interventions. Two trials were aimed at the lower body, 5 at the upper body and 2 at both upper and lower body. The tasks of the caregiver included supervision, guidance, encouragement and/or physical help. The frequency of the intervention ranged from daily to twice a week and was provided for 30 minutes to 3 hours/day. Program length ranged from 14 days to 6 months.	**Primary Outcomes:** Patient: basic ADL measures (e.g. BI, FIM, mRS), Extended ADL measures (e.g. NEADL, FAI) Caregiver: Burden (e.g. CSI) **Secondary Outcomes:** Patient: motor impairment, gait and gait-related measures, measures of upper limb activities or function, measures of mood and QoL for patient, measures of fatigue, Caregiver: measures of mood and QoL	**Primary outcomes** There was no significant effect of CME on basic ADL at post-intervention (SMD=0.21; 95% CI: -0.02 to 0.44, p = 0.07 [4 studies; moderate-quality evidence]) or follow-up at 3-6 months (MD= 2.69; 95% CI: -8.15 to 13.55, p = 0.63 [2 studies; low-quality evidence]). In a sensitivity analysis restricted to trials that examined only CME interventions (CME-core) the intervention was associated with improvement in ADL performance, using the Barthel Index (MD= 9.45, 95% CI 2.11 to 16.78; p = 0.01; [2 studies; moderate-quality evidence]). There was no significant effect of CME on extended ADL at at post-intervention (SMD=0.07; 95% CI -0.21 to 0.35, p = 0.64 [2 studies; low-quality evidence]), or follow-up at 3-6 months (SMD= 0.11; 95% CI: -0.17 to 0.39, p = 0.45 [2 studies; low-quality evidence]) There was no significant effect of CME on caregiver burden at the end of intervention (SMD= -0.04; 95% CI: -0.45- 0.37, p = 0.86 [2 studies; moderate-quality evidence]) or follow-up (MD= 0.60; 95% CI: -0.71 to 1.91, p = 0.37 [1 studies; very low-quality evidence]). **Secondary outcomes:** CME significantly improved standing balance (SMD=0.53, 95% CI 0.19- 0.87; p = 0.002 [3 studies; low-quality evidence]), QoL (1 study; very low-quality evidence), physical functioning (MD=12.40, 95% CI 1.67 to 23.13; p = 0.02). mobility (MD= 18.20, 95% CI 7.54 to 28.86; p = 0.0008), general recovery (MD 15.10, 95% CI 8.44 to 21.76; p < 0.00001) and performance on the 6-Minute Walking Test (MD= 109.50 m, 95% CI 17.12 to 201.88; p = 0.02 [1 study; very low-quality evidence]) Patients in the control group did significantly better on performance time for the Wolf Motor Function test (MD= -1.72, 95% CI -2.23 to -1.21; p < 0.00001[2 studies; low-quality evidence]).

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					There were no significant effects for the other secondary outcomes (i.e. patient: motor impairment, upper limb function, mood, fatigue, length of stay and adverse events; caregiver: mood and quality of life).
Barzel et al. 2015 **Germany** **Cluster RCT** ***HOMECIMT***	CA: ☑ Blinding: Patient ☒ Assessor ☑ ITT: ☑	156 patients ≥18 years, cognitively intact with mild to moderate impairment of arm function, associated with a stroke sustained at least 6 months earlier, who had a caregiver prepared to be a non-professional coach. Mean age was 63 years, 40% were women.	71 practices were stratified by region and randomized 1:1 to either home constraint-induced movement therapy (CMIT, n=85 patients) or standard therapy (n=71 patients) for 4 weeks. In the home CIMT group, therapists conducted 5 home visits to instruct the patient and the coach in the principles of home CIMT, set goals and work through exercises, focusing on everyday practice. Patients were instructed to train in their home environment for 2 h each day, accompanied by a coach and to wear a mitten to immobilize their non-affected hand during the exercises. Patients in the standard therapy groups received 5 hours of routine therapy provided by a therapist.	**Primary outcomes:** Motor Activity Log (MAL), Wolf Motor Function Test (WMFT), assessed after the intervention **Secondary outcomes:** Motor Activity Log (MAL), Wolf Motor Function Test (WMFT), assessed at 6 months, 9-Hole Peg Test, ADL, IADL	At the end of treatment, patients in both groups had significantly improved MAL (QOM) scores, but the change in scores from baseline was significantly greater for patients in the CIMT group (adjusted mean change from baseline (0.56 vs. 0.31, MD= 0.26, 95% CI 0·05–0·46, p=0·0156). Both groups improved on the WMFT (performance time) from baseline to 4 weeks, although the difference between groups was not significant (-25.6% vs. -27.5%, MD=2·65% (–17·94 to –28·40, p=0·815). At 6 months follow-up, the mean difference from baseline in MAL (QOM and AOU sub scores) was significantly greater for CIMT patients. At 6 months follow-up there were no significant differences between groups in mean change from baseline for WMFT (performance time) or WMFT (functional ability). At 6 months follow-up there were no significant differences between groups in mean change from baseline for any of the other secondary outcomes. 9 patients were lost to follow-up (5 CIMT, 4 standard therapy)

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Wang et al. 2015 **Taiwan** **RCT**	CA: ☒ Blinding: Patient ☒ Assessor ☑ ITT: ☒	51 participants with chronic stroke and mild to moderate disability (> 6 months; Brunnstrom recovery stages III-V), living at home, had family members, friends, or paid workers as caregivers and still required assistance to accomplish everyday activities. Mean age was 63 years, 58% were men.	Patients and their caregivers were randomized to an (n=25) or control arm (n=26). In the intervention arm, patients and their caregivers participated in a 3-phase, 12-week weekly personalized caregiver-mediated, home-based intervention (CHI) program. A physical therapist visited the patient once a week for approximately 90 minutes to teach patients personalized rehabilitation skills and to teach the caregiver the skills necessary to assist the patient in performed the planned tasks. Those in the control group received visits from the therapist to talk about their rehabilitation progress, daily activities and general health condition, but no intervention.	**Patient outcomes:** Berg Balance Scale BBS), 10-Meter Walk Test, 6-Minute Walk Test, Barthel Index (BI), Stroke Impact Scale (SIS) **Caregiver outcomes:** Caregiver Burden Scale (CBS) Outcomes were assessed at baseline and after the intervention	**CHI significantly improved scores on the:** Patients in the CHI group improved significantly more on several domains of the SIS including Composite physical scores, Strength, Mobility and General recovery. Patients in the CHI group improved significantly more than those in the control group on the other primary outcomes 6-minute walk distance: -10.5 vs. 15.8m, p = 0.003 BBS score: -0.8 vs. 4.5, p 0.006 BI: 0.6 vs. 7.2, p = 0.008 There were no significant differences between group in mean change scores on total burden, or any of the domains of the CBS at endpoint
Dai et al. 2013 **China**	CA: ☒ Blinding: Patient ☒	48 patients with unilateral neglect associated with right hemispheric stroke,	Patients were randomized 1:1 to either an experimental- or a	**Primary outcomes:** Conventional subtests of the Rivermead	There was significant improvement in both groups over time on the mean BIT-C, FIM and PASS, but no significant differences between groups at baseline, day 12 or day 28.

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RCT	Assessor ☑ ITT: ☒	with duration of onset <6 months, and 48 primary caregivers. Mean age of patients was 61 years, 58% were men. Mean duration since stroke onset was 65 days.	control group. The experimental group received vestibular rehabilitation (VR) with the participation of their primary caregiver. During weeks 1 and 2 a registered nurse trained the experimental group in VR. Training was provided once per day for 30 minutes, for a total of 10 sessions over 2 weeks. During weeks 3 and 4, the patients were supervised and guided in VR by the primary caregivers. Both the control and experimental group received conventional rehabilitation (2 hours/day, 5 days/week).	Behavioral Inattention Test (BIT-C), FIM, Postural Assessment Scale for Stroke patients (PASS), self-reported falls There were no caregiver outcomes assessed	The degree of improvement in the VR group was significantly greater. There was no significant difference between groups in the number of falls at baseline, day 12 or day 28.
Galvin et al. 2011 **Ireland** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☑ ITT: ☑	40 patients, ≥18 years, admitted to hospital with first-ever unilateral stroke, who were participating in a physiotherapy program, and had a family member willing to participate in the program. The mean age was 65 years, 50% were men.	Within 2 weeks of stroke onset, patients were randomly assigned 1:1 to either a control group who received routine therapy as inpatients or outpatients, with no formal input from their family member, or the family-mediated exercise (FAME) group who received routine rehabilitation +	**Primary outcome:** Lower limb section of the Fugl-Meyer Assessment modified by Lindmark (LL-FMA) **Secondary outcomes:** Motor Assessment Scale (MAS), 6-Minute Walk Test (6MWT), BI, Reintegration to Normal Living Index (RNLI), Nottingham Extended Activities of Daily Living	There were significant differences in mean change scores on all outcome measures of impairment and function from baseline between the 2 groups in favour of the FAME group (control vs. FAME; mean change (SD) score) at the end of the intervention LL-FMA: 1.75 (6.3) vs. 9.5 (9.9), p = 0.01 MAS: 4.75 (6.2) vs. 11.9 (7.8), p < 0.00 BBS: 9 (9) vs. 22.8 (18.1), p = 0.02 6MWT, meters: 47.2 (50.6) vs. 164.1 (128.7), p < 0.00 BI: 16.3 (14.2) vs. 32.3 (24), p= 0.04 At follow-up, there were significant differences in mean change scores between groups in favour of the FAME group (control vs. FAME; mean change (SD) score):

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			additional lower limb FAME therapy (35 minutes/day for 8 weeks). The emphasis of the program was on achieving stability and improving gait velocity and lower limb strength.	Index (N-EADL), Caregiver Strain Index (CSI) Assessments wee conducted at baseline, post intervention and 3 months follow-up	6MWT, meters: -3.5 (32.7) vs. 39.8 (55.4), p = 0.01 RNLI: 0.4 (2.9) vs. 4.7 (4.3), p< 0.00 N-EADL: 3.6 (7.8) vs. 7.6 (8.3), p= 0.02 There were no significant differences between groups in mean change scores for LL-FMA, MAS, BBS or BI at 3 months. The mean change in CSI scores from baseline at 3 months was significantly greater for caregivers in the FAME group (0.2 (1.1) vs. -1.3 (1), p <0.001). There were 5 drop-outs or losses to follow-up (3 in the control group, 2 in the FAME group)
Harris et al. 2010 **Canada** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☑ ITT: ☑	50 participants with subacute stroke who were recruited from the experimental arm of the GRASP study. Mean age was 68.7 years, 56% were men.	The GRASP protocol consisted of the use of an exercise booklet and kit tailored according to motor impairment. The protocol was self-administered, homework-based program supervised by a study coordinator. Exercises and activities were completed for 60 minutes a day, 6 days per week for 4 weeks. Outcomes of participants who had caregiver support (n=29) and those without support (n=21), were compared. Caregiver support consisted of verbal encouragement,	**Primary outcomes:** Fugl-Meyer Upper-Limb Motor Impairment Scale (FM-UL), Chedoke Arm and Hand Activity Inventory (CAHAI), Motor Activity Log (MAL)	The mean changes from baseline were significantly greater for patients with caregiver support Grip strength (kg): 5.8 vs. 3.4, p=0.034 Exercise intensity (minutes): 896 vs. 606, p=0.003 CAHAI: 20.5 vs. 15.0, p= 0.021 MAL (amount of use): 2.1 vs. 1.0, p = 0.024 Caregiver support was an independent predictor of change in models predicting CAHAI and MAL improvement, accounting for 8.6% and 5.3% of the variance for each model, respectively.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			actively participating in activities with the participant, and helping to organize the equipment and exercise booklet.		

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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