



CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Rehabilitation, Recovery and Community Participation Following Stroke

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

Patient, Family & Caregiver Education

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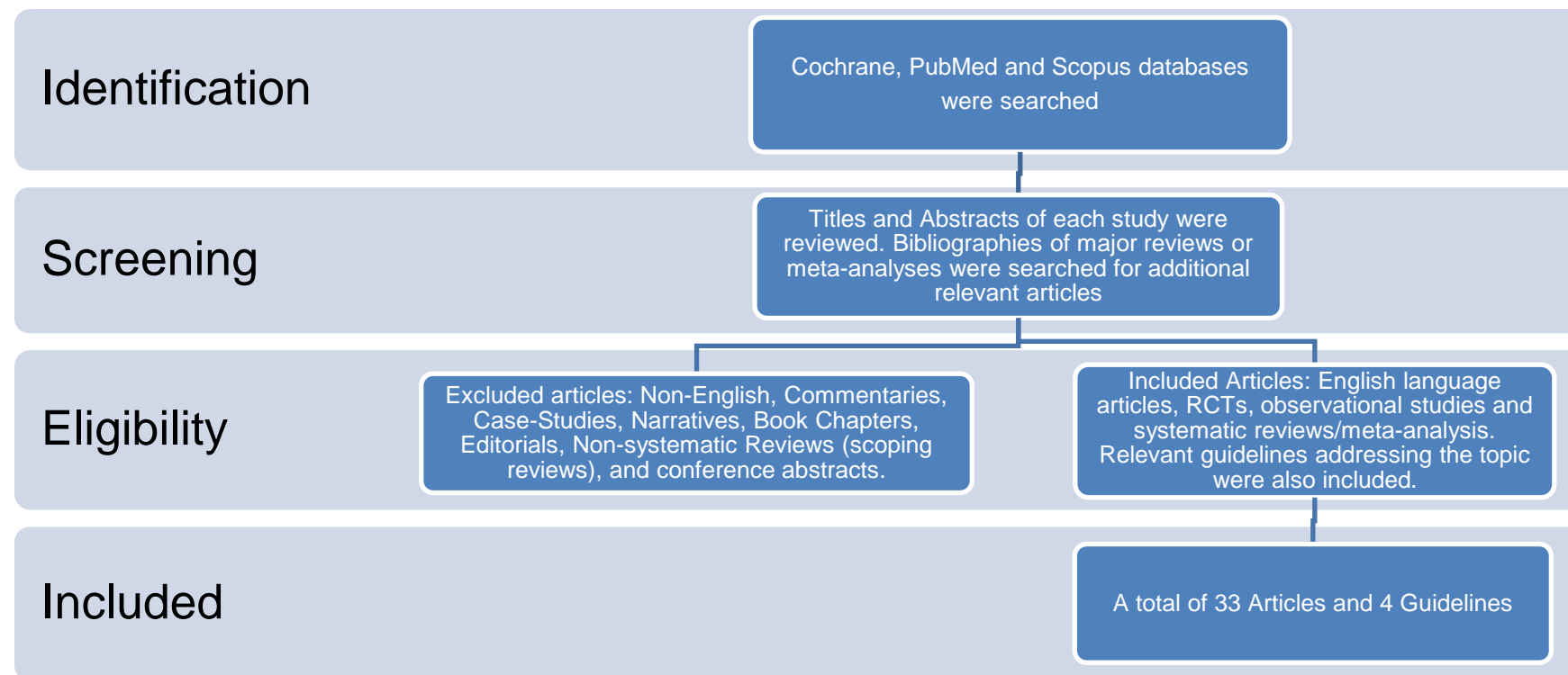
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Search Strategy



Cochrane, PubMed and Scopus databases were searched using terms such as Stroke AND education AND caregiver OR support. Titles and abstract of each article were reviewed for relevance. Bibliographies were reviewed to find additional relevant articles. Articles were excluded if they were: non-English, commentaries, case-studies, narrative, book chapters, editorials, non-systematic review, or conference abstracts. Additional searches for relevant best practice guidelines were completed and included in a separate section of the review. A total of 33 articles and 4 guidelines were included and were separated into separate categories designed to answer specific questions.

Published Guidelines

Guideline	Recommendations
<p>National Clinical Guideline for Stroke for the UK and Ireland. London: Intercollegiate Stroke Working Party; 2023 May 4.</p> <p>Available at: www.strokeguideline.org.</p>	<p>Stroke rehabilitation should be needs-led and not time-limited, and available to those people with stroke for whom: – ongoing needs have been identified by the person with stroke, their carer(s) or the multidisciplinary team across all areas of stroke recovery, e.g. functional abilities, mental health, cognitive function, psychological well-being, education regarding stroke, social participation, management of complications and care needs; – and their needs remain related to the stroke and/or are best met by the skills of the stroke team (p. 63)</p> <p>People with stroke should be provided with information and education regarding fatigue being a common post-stroke problem, and with reassurance and support as early as possible, including how to prevent and manage it, and signposting to peer support and voluntary sector organisations. Information should be provided in appropriate and accessible formats (p. 106).</p> <p>Healthcare professionals should be aware of the psychological needs of people with stroke and their family/carers, and routinely provide education, advice, and emotional support for them. (p. 124)</p>
<p>Clinical Guidelines for Stroke Management 2017. Melbourne (Australia): National Stroke Foundation.</p> <p>Chapter 8. Community participation and long-term care</p>	<p>Practice Statement Consensus-based recommendation</p> <p>Carers should receive psychosocial support throughout the stroke recovery continuum to ensure carer wellbeing and the sustainability of the care arrangement. Carers should be supported to explore and develop problem solving strategies, coping strategies and stress management techniques. The care arrangement has a significant impact on the relationship between caregiver and stroke survivor so psychosocial support should also be targeted towards protecting relationships within the stroke survivors support network.</p>
<p>Winstein CJ, Stein J, Arena R, Bates B, Cherney LR, Cramer SC, Deruyter et al; on behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Quality of Care and Outcomes Research.</p> <p>Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American Heart Association/American Stroke Association.</p> <p>Stroke 2016;47:e98–e169</p>	<p>It may be useful for the family/caregiver to be an integral component of stroke rehabilitation. Class IIb; LOE A</p> <p>It may be reasonable that family/caregiver support include some or all of the following on a regular basis: Class IIb, LOE A</p> <ul style="list-style-type: none"> • Education • Training • Counseling • Development of a support structure • Financial assistance <p>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</p>

Guideline	Recommendations
<p>Bakas T, Clark PC, Kelly-Hayes M, King RB, Lutz BJ, Miller EL. American Heart Association Council on Cardiovascular and Stroke Nursing and the Stroke Council.</p> <p>Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American heart association and American stroke association.</p> <p><i>Stroke</i> 2014;45:2836-52</p>	<p>Recommendations for caregiver vs dyad interventions:</p> <p>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</p> <p>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</p> <p>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</p>

Evidence Tables

Self-Management

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Chen et al. 2018 China RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	144 patients with first-ever stroke admitted to hospital with slight to moderate neurological deficits (NIHSS <15 at admission) and a MMSE score >20. Mean age was 65 years, 74% were men.	Patients were randomized 1:1 to a nurse-led patient-centered self-management empowerment intervention (PCSMEI) group or routine care. The PCSMEI program was composed of 5 daily sessions during the first week of the program during hospital stay, one small group session during the second week, one discharge instruction at patient bedside with caregiver, and 4 weekly telephone follow-ups.	Primary outcomes: The Stroke Self-Efficacy Questionnaire (SSEQ), Barthel Index (BI), rehospitalization Outcomes were assessed at 4 times: at baseline (T0), at discharge (T1), 1-month post discharge (T2), and at 3 months post discharge (T3).	There was significantly greater improvement in SSEQ scores among patients in the PCSMEI group at T1, T2 and T3. At T3, there was significantly greater improvement in BI scores in the PCSMEI group, but not at T1 or T2. At T3, there were no significant differences in rehospitalization between groups.
Lo et al. 2018 China RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	128 participants discharged home following one admission to one of 3 acute stroke units. Mean age was 67.5 years, 59% were men. Mean time since stroke was 45 days.	Participants were randomized to a 4-week nurse-led stroke self-management program (SESSMP), consisting of one home visit (week 1), two 2-hour community group sessions (week 2–3), and 3 follow-up phone calls (week 4) or usual care.	Primary outcomes: Stroke Self Efficacy Questionnaire (SSEQ), Stroke Self-Management Outcome Expectation Scale (SSMOES), and Stroke Self-Management Behaviors Performance Scale (SSMBPS) Outcomes were assessed at baseline and 8 weeks.	There was significantly greater improvement in all 3 outcomes in the SESSMP group at 8 weeks. <i>B</i> co-efficient and 95% CIs were 7.50, 2.55–12.45 (SSEQ); 9.74, 5.47–14.01 (SSMOES) and 8.63, 3.38–13.87 (SSMBPS)

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Fryer et al. 2016 Australia Cochrane review	The overall risk of bias was assessed as low.	14 trials with 1,863 adult participants, living in the community recovering from stroke.	<p>Trials compared interventions composed of ≥1 component of self management or targeted more than a single domain of change, or both, with a control intervention (either an inactive control such as waiting list or usual care or an active control such as education only).</p> <p>Interventions were provided on a one-to-one basis (n=9 studies) or group (n=5 studies) and all were delivered face-to-face except one. Programme providers were predominantly trained stroke-allied health professionals (n=13 studies). Duration of the programmes varied from 4 weeks to 6 months.</p>	<p>Primary outcome: Quality of life (QoL)</p> <p>Secondary outcomes: Self efficacy, activity limitations, impairments</p>	<p>Self-management programs were associated with a significant improvement in QoL (SMD=0.20, 95% CI 0.00 to 0.41; 6 trials. Low quality of evidence) and self-efficacy (SMD=0.33, 95% CI 0.04 to 0.61; 6 trials). Low quality of evidence.</p> <p>Self- management programs were not associated with significant improvements in activity limitations (SMD=0.22, 95% CI -0.03 to 0.46: 4 trials. Moderate quality of evidence) or impairment (MD=-0.56, 95% CI -1.27 to 0.15; 6 trials). Low quality of evidence.</p>
Lennon et al. 2013 Australia Systematic Review	NA	<p>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.</p> <p>Mean age of participants across all</p>	Studies that specified that patients were participating specifically in a “self-management” intervention.	<p>Outcomes: None stated a priori</p>	<p>9 different self-management programs were identified.</p> <p>Mean time from stroke onset to initiation of program ranged from 24 days to >4 years.</p> <p>In 9 cases, the programme being delivered had been informed by Social Cognitive Theory.</p> <p>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</p>

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		included studies was 67 years.			<p>sessions. In all studies there were elements of information provision, problem solving, and goal setting.</p> <p>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.</p> <p>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.</p>
Harwood et al. 2011 New Zealand RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	172 patients > 15 years, 6-12 weeks post stroke living outside of institutional care and identified as Māori or Pacific ethnicity. Most patients were identified for potential inclusion during their acute hospital stay. Mean age was 61.4 years, 48% were men.	Patients were randomized to either intervention a (n=48), b (n=46), both a and b (n=32) or control (n=31). <i>Intervention a (DVD):</i> 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. <i>Intervention b (TCS – Take Charge Session):</i> involved an 80-minute session with a research assistant. Patients were guided in a patient-	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.	<p>There were no statistically significant differences in any outcomes at 6 months.</p> <p>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.</p> <p>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, $P = 0.034$).</p> <p>There were no other significant differences between groups.</p>

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			<p>centered goal setting process for recovery.</p> <p>The <i>control</i> group received a 30-minute session with a research assistant. Patients were given written educational material.</p>		
<p>Cadilhac et al. 2011</p> <p>Australia</p> <p>RCT</p>	<p>CA: <input checked="" type="checkbox"/></p> <p>Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/></p> <p>ITT: <input checked="" type="checkbox"/></p>	<p>143 patients > 18 years, more than 3 months post stroke. 78% of participants experienced the index stroke >12 months previously. Mean age was 69.4 years, 59% were women.</p>	<p>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).</p> <p>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.</p> <p>The generic group participated in a 6-week program (2.5 hours per night, one night per week), covering a wide</p>	<p>Primary outcome: Feasibility, assessed by the numbers of patients who expressed interest, attended and completed the program.</p> <p>Secondary outcomes: Health Education Impact Questionnaire, Assessment of Quality-of-Life tool, and mood (Irritability, depression, and anxiety scales).</p> <p>Assessments were conducted at baseline, post-intervention and 6 months.</p>	<p>There was no difference in the number of patients who completed the generic vs. the SSMP intervention (38% vs. 52%; p=0.18).</p> <p>There was no difference in the number of adverse events (n=36) between the generic, SSMP or control groups (p=0.47).</p> <p>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.</p>

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			<p>range of topics, which was co-facilitated and led by trained leaders.</p> <p>The standard care group received the typical information and care provided by the hospital team upon discharge from hospital.</p>		
<p>Huijbregts et al. 2008</p> <p>Canada</p> <p>Prospective study MOST (Moving on after stroke) And LWS (Living with stroke)</p>	NA	<p>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).</p>	<p>Participants were recruited by brochures, referrals, presentations etc. and were allowed to choose which of the two programs they wanted to attend.</p> <p>Participants in the first program (MOST) 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</p>	<p>Outcomes:</p> <p>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 Assessment (CMSA) (activity inventory component)</p> <p>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).</p>	<p>MOST vs. LWS groups:</p> <p>There were no statistically significant differences in outcomes between the two groups.</p> <p>Within MOST group:</p> <p>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).</p> <p>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).</p> <p>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).</p> <p>GDS: No statistically significant improvements in GDS scores in the MOST group.</p> <p>There were no significant improvements in CMSA scores in the MOST group.</p> <p>Within LWS group:</p> <p>Patients in the LWS group only experienced statistically significant gains in FIM scores (F=4.73; P<0.09)</p> <p>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</p>

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			<p>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.</p> <p>Participants in the second program, LWS, received 6 group sessions (1 time per 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).</p>		<p>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%; $P<0.001$)</p>
Kendall et al. 2007 Australia RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/>	100 patients less than a few months since first-ever stroke no history of dementia or psychiatric disorder, living independently in the	Participants were randomized to either intervention (n=58) or control groups (n=42).	Outcomes: Stroke Specific Quality of Life Scale (SSQOL). Assessments were conducted every 3	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
	ITT: <input checked="" type="checkbox"/>	presence of a family or friend (i.e. an “enabler”). Mean age was 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.	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 RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	203 patients with a confirmed diagnosis of stroke admitted to an acute hospital and 172 carers. Mean age was 69 years, 61% of patients were men. 61% of carers were female. Mean age was 61 years.	Patients were admitted either during their hospital stay or after 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	Primary outcome: Observer Assessed 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	Patients receiving the workbook had statistically significantly greater recovery from disability (OAD), compared to the control group (p=0.019). There were no statistically significant differences between groups 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).

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			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.	discharge), 8 weeks and at 6 months.	

Patient & Caregiver Education and Skills Training

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
<i>Patients & Caregivers</i>					
Crocker et al. 2021 UK Cochrane review	Most trials were at high risk of bias (lack of blinding)	33 RCTs, including 5,255 stroke-survivor and 3,134 carers.	The effectiveness of an information intervention vs. standard care was examined. Interventions were classified as active (e.g. lecture) or passive (booklets, leaflets).	Primary outcome: Knowledge of stroke and stroke services, mood Secondary outcomes: Depression, quality of life, psychological distress, satisfaction with information, and burden	<i>Active information provision vs. control (stroke survivors)</i> Active information provision was associated with significantly increased stroke knowledge (SMD=0.41, 95% CI 0.17-0.65, 3 trials). GRADE: low quality Active information was not associated with a significant reduction in the number of cases of persons with anxiety (RR=0.85, 95% CI 0.68-1.06; 5 trials). GRADE: low quality; however, the symptoms of anxiety were reduced significantly (MD=-0.73, 95% CI -1.1 to -0.36; 6 trials). GRADE: low quality. Active information did not significantly decrease the number of cases of persons with depression (RR=0.83, 95% CI 0.68-1.01; 5 trials). GRADE: low quality; however, the symptoms of depression were reduced significantly (MD=-0.80, 95% CI -1.27 to -0.34; 8 trials). Moderate quality of evidence.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					<p>Quality of life was assessed in a single trial, using the WHOQOL-BREF. Active information was associated with improvement in 4 domains (physical, psychological, social and environment).</p> <p><i>Active information provision vs. control (carers)</i> Including the results of 3-4 trials, active information strategies were not associated with significant improvements in any of the outcomes of interest.</p> <p><i>Passive information provision vs. control (stroke survivors)</i> Including the results of 3 trials, passive information strategies were not associated with significant improvements in any of the outcomes of interest.</p> <p><i>Passive information provision vs. control (carers)</i> Passive information strategies were examined in a single RCT. They were not associated with significant improvements in any of the outcomes of interest, or the outcomes of interest were not assessed.</p> <p>No subgroup analyses (e.g., sex) were performed.</p>
Eames et al. 2013 Australia RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	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	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)	<p>No significant between group differences were found with respect to stroke knowledge at 3-month follow-up.</p> <p>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.</p> <p>No other significant between group differences were reported.</p>

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		for eligibility were enrolled in the trial.		Assessments were conducted prior to hospital discharge and at 3-month follow-up.	
Forster et al. 2013 UK Training Caregivers After Stroke (TRACS) Cluster RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	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: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	300 patients admitted to a stroke rehabilitation unit who were previously independent in ADLs prior to stroke and their caregiver.	Patient/caregiver dyads were randomized to receive the London Stroke Carers Training course (LSCTC) (n=151) or conventional caregiver instruction (n=149). Caregivers in	Patient Outcomes: Mortality, institutionalization, modified Rankin Scale (mRS), Barthel Index (BI), Frenchay Activities Index (FAI), Hospital Anxiety and Depression	Patient 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).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		80% of patients were men. Median age was 76 years.	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.	(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.	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 RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	170 patients admitted to a stroke rehabilitation unit and their carers (n=97). Median age of patients was 74.5 years. 50% of patients were men. Median age of carers was 66 years. 61% were female.	Patient/caregiver dyads were randomized to receive either usual care (n=86) or an 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).	Primary outcome: Knowledge of Stroke questionnaire (developed specifically for the study), 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.	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). 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: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/>	68 patients with ischemic or hemorrhagic stroke and their spouses.	Patient/caregiver dyads were randomized at discharge to either the intervention group, receiving a stroke information package	Patient outcomes: Family Assessment Device (FAD), Barthel Index (BI), Adelaide Activities Profile (AAP), SF-36, Geriatric	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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
	ITT: <input checked="" type="checkbox"/>	58% of patients were male. Mean age was 72 years. Mean age of spouses was 72 years.	and 3, one-hour counselling visits from a social worker (n=35) or the control group, receiving no information or counselling (n=33)	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.	There were no significant differences between groups on SF-36, HAD, GDS, or Mastery at 6 months.
Rodgers et al. 1999 UK RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	204 stroke patients and their informal caregivers (n=176). 52% of the patients were women. Mean age was 75 years. 69% of caregivers were women. Mean age was 59 years.	Patient/caregiver dyads were randomized to receive either an 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.	Primary outcome (patient): SF-36 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	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). 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	CA: <input checked="" type="checkbox"/>	71 patients admitted to hospital following acute	Patient/caregiver dyads were randomly	Patient outcomes:	The odds of a correct response were significantly higher for patients in the intervention group for 1/11 knowledge

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
UK RCT	Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	stroke and their informal caregivers (n=49). 65% of the patients were male. Mean age was 73 years.	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).	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.	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).
<i>Patients Only</i>					
Hoffman et al. 2007 Australia RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	138 patients who had been admitted to the stroke unit of 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.	Participants were randomly assigned to receive either 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	Primary outcome: Knowledge of Stroke Questionnaire (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	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 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).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			determined their optimal format for layout and presentation. Pre-printed fact sheets related to stroke were provided to patients in the control group.		
Lowe et al. 2007 UK RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	100 consecutive stroke patients admitted to an acute stroke unit. The median age was 73 years. 60% of patients were men.	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 6 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.
<i>Caregiver Only</i>					
Elsheikh et al. 2022 Egypt RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/>	110 adult family caregivers of stroke survivors with onset <6 months who needed daily assistance. Median age was 35	Participants were randomized 1:1 to an intervention or usual care group. The intervention group received a tailored multidimensional	Primary outcome: Zarit Burden Interview (ZBI) Secondary outcomes: WHO Quality of Life-BREF	There was no significant difference between groups at any time point in mean ZBI scores. There was significantly greater improvement in the psychological (p< 0.001) and social relationship (p= 0.036) domains of the Life-BREF over 6 months.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
	ITT: <input checked="" type="checkbox"/>	years, 74.5% were women.	interventions provided by specially-trained nurses over 6 months, which included 3 home visits, 6 home based telephone calls and one peer-support session	Assessments were conducted at baseline, 6 and 12 months.	
Patchwood et al. 2021 UK Cluster RCT Organising Support for Carers of Stroke Survivors (OSCARSS)	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	35 clusters representing 414 carers of adult stroke survivors. Mean age was 62 years, 77% were women. 75% of carers were spouses. Mean time since stroke was 6 months (median 2.3 months).	Carers within clusters were randomized to an intervention group or usual care group. The intervention, the <i>Carer Support Needs Assessment Tool for Stroke</i> was a staff-facilitated, carer-led approach to help identify, prioritise and address the specific support needs of carers, requiring at least one face-to-face support contact dedicated to carers, typically provided in the home, with reviews as required.	Primary outcome: 3-month caregiver strain (Family Appraisal of Caregiving Questionnaire, FACQ) Secondary outcomes: FACQ subscales of caregiver distress and positive appraisals of caregiving, mood (Hospital Anxiety and Depression Scale) and satisfaction with stroke services	Primary outcome data were available for 84% of carers. The mean difference in scores between groups (adjusted for SES variables) was -0.04 (95% CI -0.20 to 0.13, p=n/s). There were no significant differences between groups for any of the secondary outcomes. The authors noted the intervention was not fully delivered as intended. In a cost-effectiveness analysis, the cost of the intervention was slightly higher with a very modest gain in quality-adjusted life years (i.e., not cost-effective).
King et al. 2012 USA RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	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.	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	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),	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

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		40% of patients were male. Mean age was 61 years.	the stressors of caregiving. The control group was a wait-list group that received usual care.	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.	outcomes compared to wait-list controls. These differences were not maintained at 6 or 12 months.
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), psychoeducation (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

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					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).
Bakas et. al. 2009 RCT USA	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	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.	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 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 weeks (p=0.01).
Draper et. al. 2007	CA: <input checked="" type="checkbox"/> Blinding:	39 caregivers of aphasic stroke patients living at home with a	Caregivers were randomized to receive either immediate (n=19)	Primary outcomes: General Health	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

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
RCT Australia	Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	persistent language deficit <12 months post stroke, who were recruited from rehabilitation hospitals. Mean caregiver age: intervention, 64 years; control, 60 years.	or delayed (n=20) treatment after a 3-month waiting period. The intervention consisted of group sessions addressing education, skills training, support, and stress management (coping skills for depression and anxiety). Sessions occurred weekly for 4 weeks (2 hours sessions)	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	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).

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: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	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 vs. 82.6, p=0.74 Mean Nottingham EADL: 31.0 vs. 31.2, 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.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					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).
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 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 to 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 study; very low-quality evidence]). Secondary outcomes: CME significantly improved standing balance (SMD=0.53, 95% CI 0.19 to 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])

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					<p>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]).</p> <p>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).</p>
Barzel et al. 2015 Germany Cluster RCT HOMECIMT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	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 (CIMT, $n=85$ 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	<p>At the end of treatment, patients in both groups had significantly improved MAL (Quality of movement [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 to 0.46, $p=0.0156$).</p> <p>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, $p=0.815$).</p> <p>At 6 months follow-up, the mean difference from baseline in MAL (QOM and amount of use [AOU] sub scores) was significantly greater for CIMT patients.</p> <p>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).</p> <p>At 6 months follow-up there were no significant differences between groups in mean change from baseline for any of the other secondary outcomes.</p> <p>9 patients were lost to follow-up (5 CIMT, 4 standard therapy)</p>

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
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	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
Galvin et al. 2011 Ireland RCT	CA: ☒ Blinding: Patient ☒ Assessor ☒	40 patients, ≥18 years, admitted to hospital with first-ever unilateral stroke, who were participating in a physiotherapy program,	Within 2 weeks of stroke onset, patients were randomly assigned 1:1 to either a control group who received routine therapy	Primary outcome: Lower limb section of the Fugl-Meyer Assessment modified by Lindmark (LL-FMA)	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

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
	ITT: <input checked="" type="checkbox"/>	and had a family member willing to participate in the program. The mean age was 65 years, 50% were men.	as inpatients or outpatients, with no formal input from their family member, or the family-mediated exercise (FAME) group who received routine rehabilitation + 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.	<p>Secondary outcomes: Motor Assessment Scale (MAS), 6-Minute Walk Test (6MWT), BI, Reintegration to Normal Living Index (RNLI), Nottingham Extended Activities of Daily Living Index (N-EADL), Caregiver Strain Index (CSI)</p> <p>Assessments were conducted at baseline, post intervention and 3 months follow-up</p>	<p>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), $p < 0.001$ BI: 16.3 (14.2) vs. 32.3 (24), $p 0.04$</p> <p>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): 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), $p=0.02$</p> <p>There were no significant differences between groups in mean change scores for LL-FMA, MAS, BBS or BI at 3 months.</p> <p>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), $p < 0.001$).</p> <p>There were 5 dropouts or losses to follow-up (3 in the control group, 2 in the FAME group)</p>
Harris et al. 2010 Canada RCT	CA: <input checked="" type="checkbox"/> Blinding: Patient <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	50 participants with subacute stroke, recruited from the experimental arm of the GRASP study. Mean age was 68.7 years, 56% were men.	<p>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.</p> <p>Outcomes of participants who had caregiver support</p>	<p>Primary outcomes: Fugl-Meyer Upper-Limb Motor Impairment Scale (FM-UL), Chedoke Arm and Hand Activity Inventory (CAHAI), Motor Activity Log (MAL)</p>	<p>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, $p = 0.024$</p> <p>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.</p>

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			(n=29) and those without support (n=21), were compared. Caregiver support consisted of verbal encouragement, actively participating in activities with the participant, and helping to organize the equipment and exercise booklet.		

Teach-back Method

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Mashhadi et al. 2021 Pakistan Systematic review	Using the QualSyst tool, the summary average quality score (SQS), was 81% (range 57% to 95%).	17 studies (9 RCTs) including participants >20 years with any non-communicable health condition. Patient conditions included multiple chronic conditions, heart failure, COPD, hip and knee arthroplasties and diabetes. No details of patient characteristics were provided.	In 6 studies (3 RCTs), including 1,782 participants, the teach-back communication was examined, with a focus on retaining information related to hospital discharge. No details of the interventions were provided. In 11 studies, mHealth interventions were assessed. No details of the interventions were provided.	Primary outcome: Hospital readmission	Of the studies of teach-back communication, 5/6 reported a significant reduction in hospital readmission. Among a group of 100 patients with heart failure, greater time spent in teach-back communication was associated with significantly greater reduction in hospital readmissions compared with the control group (44 vs. 21). The risk of readmission among heart failure patients who received teach back communication was reduced significantly compared with the control group (adjusted incidence rate ratio=0.53, 95% CI 0.32- 0.89). In a cross-sectional study of 1,033 persons with heart failure, the odds of hospitalization were significantly greater for patients who received usual care vs. teach back (OR=1.5, 95% CI 1.2–1.9).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					<p>Among a group of 88 patients with heart failure, the odds of hospital readmission were significantly lower compared with the control group (adjusted OR= 0.56, 95% CI 0.32- 0.96).</p> <p>Among 385 patients with multiple chronic conditions, those with combined low and intermediate adherence using teach back communication had significantly higher readmission compared with those with high adherence (9.3% vs. 2.0%, p<0.05).</p> <p>Among 276 patients with heart failure, there was no significant difference between groups (teach back vs. usual care) in the percentage of patients who could answer teach-back questions correctly or in the reduction of 30-day hospital readmission.</p> <p>Among the studies utilizing mHealth, 7 reported a significant reduction in hospital readmissions while 4 did not.</p>
Oh et al. 2021 South Korea Systematic review & meta-analysis	Using the Risk of Bias Assessment tool for Nonrandomized Studies tool, the domains with high risk of bias were selection of patients (2/5), adjusting for confounding variables (3/5) and blinding of outcome	5 studies including 1,078 patients with heart failure (n=3), total joint replacement (n=1), and coronary artery bypass graft (n=1), who were recently discharged from hospital. No details of patient characteristics were provided.	<p>Active interventions, which included STate Action on Avoidable Rehospitalizations (STAAR), revised TJR education packet + teach-back method, 3-day questions with a teach-back process, Integrated Plan of Care with AHA “Get with the guideline” toolkit and a teach-back tool and teach-back education with handouts, were compared with usual care.</p> <p>Interventions were initiated within 3 days of hospital admission.</p>	Primary outcome: 30-day unplanned readmission	Pooling data from 3 studies, the odds of 30-day readmission to hospital were significantly reduced (OR=0.55, 95% CI 0.31-0.91).

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
	assessor (2/5).				
Talevsk et al. 2020 Australia Systematic review	Using the Effective Public Health Practice Project (EPHPP) quality assessment tool, 4 studies were rated as high quality, 9 as moderate quality and 7 as weak quality.	<p>20 studies (9 RCTs) including participants of all ages who were patients with any health condition, or clients or consumers.</p> <p>Patient conditions included breast cancer, neurological conditions, asthma, post menopausal women, diabetes, post-partum depression, heart failure, COPD, "older people", Emergency Department patients, kidney transplant patients and post-caesarean surgery.</p> <p>Mean ages of participants ranged from 9 to 79 years. The percentage of women ranged from 33% to 100%, but sex distribution was not reported in several studies.</p>	<p>The most common intervention was providing training and education to staff who were employing teach-back (n=8). Two studies reported the use of evaluative and iterative strategies (audit, weekly emails). In 2 studies, interactive or technical assistance was provided by tracking teach-back encounters via patient EMR. In 2 studies, the focus of the intervention was developing stakeholder relationships using teach-back champions (nurses), or through team meetings. In 6 studies, interventions to support clinicians were described (e.g., clinical reminders for teach-back). In one study, feedback from patients was solicited through interview on the teach-back process. In 3 studies, teach-back was integrated into the EMR. In one study, prizes were awarded to patients in a monthly knowledge contest.</p> <p>Studies were conducted across multiple sites including hospitals (n=8), emergency departments (ED; n = 3), outpatient clinics (n=4), primary care practices (n=2), community health centers (n=1) and nursing homes (n=1).</p>	<p>Primary outcomes: Outcomes were grouped into 3 categories; 1) Knowledge, skills and attitudes (disease knowledge, comprehension and retention, patient satisfaction); 2) behavior change (selfcare practices, medication adherence); and 3) objective health-related outcomes (hospital readmissions, quality of life)</p> <p>Most outcomes were measured immediately post-intervention (n=11). In studies with follow-up, duration ranged from 2 weeks to 1 year.</p>	<p>There were significant improvements in outcomes reported in 19/20 studies.</p> <p>Examples include: A significant increase in the Oxford Happiness Inventory score in the TB group compared to the control group immediately post intervention (62.9 vs 29.8; p<0.001) in a trial including breast cancer patients.</p> <p>A significant increase in patient satisfaction from 29.7% to 77.3% following TB implementation among neurological patients.</p> <p>In a group of patients with low health literacy, discharged from the ED, comprehension of post ED medications, self-care and follow-up instructions were all improved significantly, compared with standard care. There were no significant differences between groups in comprehension or patient satisfaction.</p> <p>Among nursing home residents, there was a significantly greater improvement in health literacy scores in those in the TB intervention group compared with the control group immediately post intervention (110.1 vs. 74.9).</p> <p>Among kidney transplant patients, self-management scores in the TB group were significantly higher compared with the control group at 2-month follow-up (82.5 vs 74.4).</p>

Abbreviations

CA: Concealed allocation	CI: Confidence Interval
ITT: Intention-to-treat	MD: mean difference
NA: Not assessed	OR: Odds ratio
RCT: randomized controlled trial	RR: relative risk
QualSyst: Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields	SMD: standardized mean difference

References

- The Attend Collaborative Group. Family-led rehabilitation after stroke in India (ATTEND): A randomized control trial. *Lancet* 2017; 390(10094): 588-599.
- Bakas T, Farran CJ, Austin JK, Given BA, Johnson EA, Williams LS. Stroke caregiver outcomes from the Telephone Assessment and Skill-Building Kit (TASK). *Top Stroke Rehabil* 2009;16:105-21.
- Barzel A, Ketels G, Stark A, Tetzlaff B, Daubmann A, Wegscheider K, et al. Home-based constraint-induced movement therapy for patients with upper limb dysfunction after stroke (HOMECIMT): a cluster-randomised, controlled trial. *Lancet Neurol* 2015;14(9):893-902.
- Cadilhac DA, Hoffmann S, Kilkenny M, Lindley R, Lalor E, Osborne RH, Batterby M. A phase II multicentered, single-blind, randomized, controlled trial of the stroke self-management program. *Stroke* 2011;42:1673-79.
- Chen L, Chen Y, Chen X, Shen X, Wang Q, Sun C. Longitudinal study of effectiveness of a patient-centered self-management empowerment intervention during pre-discharge planning on stroke survivors. *Worldviews Evid Based Nurs*. 2018;15:197–205
- Clark MS, Rubenach S, Winsor A. A randomized controlled trial of an education and counselling intervention for families after stroke. *Clin Rehabil* 2003;17:703-12.
- Crocker TF, Brown L, Lam N, Wray F, Knapp P, Forster A. Information provision for stroke survivors and their carers. *Cochrane Database of Systematic Reviews* 2021, Issue 11. Art. No.: CD001919
- Draper B, Bowring G, Thompson C, Van Heyst J, Conroy P, Thompson J. Stress in caregivers of aphasic stroke patients: a randomized controlled trial. *Clin Rehabil* 2007;21:122-30.
- Eames S, Hoffmann T, Worrall L, Read S, Wong A. Randomised controlled trial of an education and support package for stroke patients and their carers. *BMJ Open* 2013;3:e002538.
- Forster A, Dickerson J, Young J, Patel A, Kalra L, Nixon J et al. A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis. *Lancet* 2013;382:2069-76.
- Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. *Cochrane Database of Syst Rev* 2016, Issue 8. Art. No.: CD010442
- Galvin R, Cusack T, O'Grady E, Murphy TB, Stokes E. Family-mediated exercise intervention (FAME). Evaluation of a novel form of exercise delivery after stroke. *Stroke* 2011; 42: 681-686.
- Harris JE, Eng J, Miller WE, Dawson AS. The role of caregiver involvement in upper-limb treatment in individuals with subacute stroke. *Physical Therapy* 2010; 90(9): 1302-1310.
- Harwood M, Weatherall M, Talemaitoga A, Barber PA, Gommans J, Taylor W et al. Taking charge after stroke: promoting self-directed rehabilitation to improve quality of life--a randomized controlled trial. *Clin Rehabil* 2012;26:493-501.
- Hoffmann T, McKenna K, Worrall L, Read SJ. Randomised trial of a computer-generated tailored written education package for patients following stroke. *Age Ageing* 2007;36:280-86.

- Huijbregts MP, Myers AM, Streiner D, Teasell R. Implementation, process, and preliminary outcome evaluation of two community programs for persons with stroke and their care partners. *Top Stroke Rehabil* 2008;15:503-520.
- Johnston M, Bonetti D, Joice S, Pollard B, Morrison V, Francis JJ, Macwalter R. Recovery from disability after stroke as a target for a behavioural intervention: Results of a randomized controlled trial. *Disabil Rehabil* 2007;29:1117-27.
- Kalra L, Evans A, Perez I, Melbourn A, Patel A, Knapp M, Donaldson N. Training carers of stroke patients: Randomised controlled trial. *BMJ* 2004;328:1099-1104.
- Kendall E, Catalano T, Kuipers P, Posner N, Buys N, Charker J. Recovery following stroke: The role of self-management education. *Soc Sci Med* 2007;64:735-46.
- King RB, Hartke RJ, Houle T, Lee J, Herring G, Alexander-Peterson BS, Raad J. A problem-solving early intervention for stroke caregivers: one-year follow-up. *Rehabil Nurs* 2012;37:231-43.
- Legg LA, Quinn TJ, Mahmood F, Weir CJ, Tierney J, Stott DJ, Smith LN, Langhorne P. Non-pharmacological interventions for caregivers of stroke survivors. *Cochrane Database of Systematic Reviews* 2011, Issue 10. Art. No.: CD008179.
- Lennon S, McKenna S, Jones F. Self-management programmes for people post stroke: A systematic review. *Clin Rehabil* 2013;27:867-78.
- Lo SHS, Chang AM, Chau JPC. Stroke Self-management support improves survivors' self-efficacy and outcome expectation of self-management behaviors. *Stroke*. 2018 Mar;49(3):758-760.
- Lowe DB, Sharma AK, Leathley MJ. The CareFile Project: A feasibility study to examine the effects of an individualised information booklet on patients after stroke. *Age Ageing* 2007;36:83-89.
- Mant J, Carter J, Wade DT, Winner S. The impact of an information pack on patients with stroke and their carers: A randomized controlled trial. *Clin Rehabil* 1998;12:465-76.
- Mashhadi SF, Hisam A, Sikander S, Rathore MA, Rifaq F, Khan SA, Hafeez A. Post Discharge mHealth and Teach-Back Communication Effectiveness on Hospital Readmissions: A Systematic Review. *Int J Environ Res Public Health*. 2021 Oct 4;18(19):10442.
- Oh S, Choi H, Oh EG, Lee JY. Effectiveness of discharge education using teach-back method on readmission among heart failure patients: A systematic review and meta-analysis. *Patient Educ Couns*. 2023 Feb;107:107559.
- Patchwood E, Woodward-Nutt K, Rhodes SA, Batistatou E, Camacho E, Knowles S et al. Organising Support for Carers of Stroke Survivors (OSCARSS): A cluster randomised controlled trial with economic evaluation. *BMJ Open*. 2021 Jan 12;11(1):e038777.
- Rodgers H, Atkinson C, Bond S, Suddes M, Dobson R, Curless R. Randomized controlled trial of a comprehensive stroke education program for patients and caregivers. *Stroke* 1999;30:2585-91.
- Smith J, Forster A, Young J. A randomized trial to evaluate an education programme for patients and carers after stroke. *Clin Rehabil* 2004;18:726-36.
- Talevski J, Wong Shee A, Rasmussen B, Kemp G, Beauchamp A. Teach-back: A systematic review of implementation and impacts. *PLoS One*. 2020 Apr 14;15(4):e0231350.

Vloothuis JD, Mulder M, Veerbeek JM, Konijnenbelt M, Visser-Meily JM, Ket JC, et al. Caregiver-mediated exercises for improving outcomes after stroke. The *Cochrane Database Syst Rev* 2016;12:CD011058.

Wang TC, Tsai AC, Wang JY, Lin YT, Lin KL, Chen JJ, Lin BY, Lin TC. Caregiver-mediated intervention can improve physical functional recovery of patients with chronic stroke: A randomized controlled trial. *Neurorehabil Neural Repair* 2015; 29(1): 3:12.