

EBRSR



Chapter 19: Community Reintegration

Abstract

While the majority of stroke survivors return to live in the community, re-integration may be an enormous challenge. The ability to return to an acceptable lifestyle, participating in both social and domestic activities is important for perceived quality of life. The present review examines issues arising following discharge from hospital care or rehabilitation into the community. These include social support, impact of caregiving on informal carers, family functioning, provision of information and education, leisure activities, driving, sexuality and return to work.

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Key points

Early supported discharge may not be efficacious compared to conventional care for outpatient stroke rehabilitation.

Early supported discharge with home therapy may not be more beneficial than early supported discharge with day clinic therapy for ambulation or balance.

Education programs may not benefit patient or caregiver outcomes.

There is conflicting evidence about the effect of psychosocial and emotional support programs to improve mental health, activities of daily living, quality of life and optimism.

Discharge planning and active care management may not improve patient or caregiver outcomes.

Self management programs may be beneficial for improving self-efficacy.

Home exercise programs with picture descriptions may not be beneficial for improving activities of daily living, balance, ambulation and mobility, and self-efficacy.

Community walking programs may be beneficial for improving balance, ambulation and mobility as well as community reintegration and social support.

For caregivers, client centered support with activities of daily living may not be beneficial for improving activities of daily living, balance, ambulation and mobility, community reintegration and social support, quality of life and optimism, self-efficacy or caregiver burden.

Sexual rehabilitation programs may not be beneficial for improving activities of daily living, mental health, quality of life and optimism and sexual health.

Simulator training, useful field of view training or Dynavision training may not be beneficial for improving driving related outcomes

Occupational workplace therapy may not be beneficial for improving activities of daily living, balance, ambulation and mobility, cognition or quality of life and optimism.

Modified Sackett Scale

| Level of evidence | Study design | Description |
|-------------------|------------------------------------|--|
| Level 1a | Randomized controlled trial (RCT) | More than 1 higher quality RCT (PEDro score ≥ 6). |
| Level 1b | RCT | 1 higher quality RCT (PEDro score ≥ 6). |
| Level 2 | RCT | Lower quality RCT (PEDro score < 6). |
| | Prospective controlled trial (PCT) | PCT (not randomized). |
| | Cohort | Prospective longitudinal study using at least 2 similar groups with one exposed to a particular condition. |
| Level 3 | Case Control | A retrospective study comparing conditions, including historical cohorts. |
| Level 4 | Pre-Post | A prospective trial with a baseline measure, intervention, and a post-test using a single group of subjects. |
| | Post-test | A prospective post-test with two or more groups (intervention followed by post-test and no re-test or baseline measurement) using a single group of subjects |
| | Case Series | A retrospective study usually collecting variables from a chart review. |
| Level 5 | Observational | Study using cross-sectional analysis to interpret relations. Expert opinion without explicit critical appraisal, or based on physiology, biomechanics or "first principles". |
| | Case Report | Pre-post or case series involving one subject. |

New to the 19th edition of the Evidence-based Review of Stroke Rehabilitation

1) PICO conclusion statements

This edition of Chapter 19: community reintegration interventions synthesizes study results from only randomized controlled trials (RCTs), all levels of evidence (LoE) and conclusion statements are now presented in the Population Intervention Comparator Outcome (PICO) format.

For example:

Population: Stroke survivors

| | | Intervention | Comparator | | |
|-------------------|--|----------------|------------|------|---------------------|
| SPASTICITY | | | | | |
| LoE | Conclusion Statement | | | RCTs | References |
| 1b | Bilateral arm training may not have a difference in efficacy when compared to TENS for improving spasticity. | | | 1 | Stinear et al. 2014 |
| | | ↑ | | | |
| | | Outcome | | | |

New to these statements is also the use of colours where the levels of evidence are written.

Red statements like above, indicate that the majority of study results when grouped together show no significant differences between intervention and comparator groups.

Green statements indicate that the majority of study results when grouped together show a significant between group difference in favour of the intervention group.

For example:

Population: Stroke survivors

| | | Intervention | | | |
|-----------------------|--|----------------|-------------------|------|---|
| MOTOR FUNCTION | | | | | |
| LoE | Conclusion Statement | | | RCTs | References |
| 1a | Bilateral arm training may produce greater improvements in motor function than conventional therapy. | | | 4 | Meng et al. 2018; Lee et al. 2017; Stinear et al. 2008; Desrosiers et al. 2005 |
| | | ↑ | | | |
| | | Outcome | Comparator | | |

Yellow statements indicate that the study results when grouped together are mixed or conflicting, some studies show benefit in favour of the intervention group, while others show no difference between groups.

For example:

Population: Stroke survivors

| | Outcome | Intervention | | |
|------------|--|---------------------|-------------|--|
| | DEXTERITY | | | |
| LoE | Conclusion Statement | | RCTs | References |
| 1a | There is conflicting evidence about the effect of CIMT to improve dexterity when compared to conventional therapy or motor relearning programmes during the acute/subacute phase poststroke. | | 4 | Shah et al. 2016; Yoon et al. 2014; Boake et al. 2007; Ro et al. 2006 |

Comparator

2) Community reintegration rehabilitation outcome measures

For the studies reviewed, upper extremity rehabilitation outcome measures were classified into the following broad categories to allow for synthesis of results and formulation of PICO conclusion statements:

Activities of Daily Living: These outcome measures assessed performance and level of independence in various everyday tasks.

Balance, Ambulation and Mobility: These outcome measures assessed motor function, balance, ambulatory abilities and gait.

Caregiver Burden: These outcome measures assess the level of burden for caretakers of stroke survivors.

Cognition: These outcome measures assessed an individual's overall cognitive processing capability factoring in multiple domains.

Community Reintegration and Social Participation: These outcome measures assess an individual's ability to reintegrate into their community and social behaviours.

Mental Health: These outcome measures assess psychiatric dysfunction in a number of mental health related dimensions.

Driving: These outcome measures assess both motor related skills and cognitive/perceptual skills for driving motor vehicles.

Quality of Life and Optimism: These outcome measures assessed an individual's overall quality of life and their perception of it, generally compared to their preinjury status.

Satisfaction with care: These outcome measures assessed an individual's satisfaction with various aspects of their care.

Self-efficacy: These outcome measures assess an individual's confidence in their own knowledge and abilities, and can relate to both a patient or their caregiver.

Sexuality: These outcome measures assess sexual function and dysfunction.

Education: These outcome measures assessed an individual's knowledge of stroke, living with stroke and related information to care services.

Stroke severity: These outcome measures assessed the severity of one's stroke through a global assessment of a multitude of deficits a stroke survivor may experience.

Outcome measures that fit these categories are described in the next few pages.

Outcome measure definitions:

Activities of Daily Living

Adelaide Activities Profile: is measurement of the ability and frequency with which elderly individuals engage in activities of daily living. The measure contains 4 subscales (domestic chores, household maintenance, service to others and social activities). The measure asks elderly individuals to describe their performance of 21 different activities within a three-month period. Each activity is rated from 0-3 to indicate frequency. Larger scores indicate greater frequency. This measure has been shown to have good construct validity and has been translated into multiple languages (Kanashiro & Yassuda, 2011; Bond & Clark, 1998).

Activity Independence Score (AIS): is a composite score derived from measures meant to assess both an individual's activity level, and their independence when performing said activities. It contains 6 components (place of residence, activities of daily living, walking, use of public transit or car, employment and chopping/cooking/cleaning/laundry). Scoring depends on the component, but the total score is from 0 to 140 with higher scores indicating greater levels of activity and/or more independence in their completion. This measure was designed and created ad hoc (Christie & Weigall, 1984).

Barthel Index (BI): Is a measure of how well a stroke survivor can function independently and how well they can perform activities of daily living (ADL). The measure consists of a 10-item scale (e.g. feeding, grooming, dressing, bowel control). Possible total scores range from 0 to 100. This measure has been shown to have good reliability and validity in its full form (Gonzalez et al. 2018; Park et al. 2018).

Functional Independence Measure (FIM): Is an 18-item outcome measure composed of both cognitive (5-items) and motor (13-items) subscales. Each item assesses the level of assistance required to complete an activity of daily living on a 7-point scale. The summation of all the item scores ranges from 18 to 126, with higher scores being indicative of greater functional independence. This measure has been shown to have excellent reliability and concurrent validity in its full form (Granger et al. 1998, Linacre et al. 1994).

Frenchay Activities Index (FAI): Is a measure of activities that stroke survivors have participated in recently. The measure consists of 15 items that are in turn split up into 3 subscales (domestic chores, leisure/work and outdoor activities). These items include preparing meals, washing clothes, light/heavy housework, social outings etc. Each task is then scored on a 4-point scale with 1 being the lowest score. This measure has been shown to have good reliability and concurrent validity in its full form (Schuling et al. 1993).

Lawton Instrumental Activities of Daily Life Scale: Is a measure of functional impairment in more complex daily living skills (in comparison to basic activities of daily living). The scale examines 8 domains of function: ability to use the telephone, shopping, food preparation, housekeeping, laundry, transportation, responsibility for medications, and finances. 1 point is given if the patient is independent and capable in each domain, for a total possible score ranging from 0 (low function and dependent) to 8 points (high function and independent). The scale is a valid and accepted test of functional status and has good interrater reliability (Graf, 2008; Lawton & Brody, 1969).

London Handicap Scale: is a self-reported questionnaire intended to assess an individual's functional ability and activities of daily living. The questionnaire contains 6 domains; mobility, physical independence, occupation, social integration, social orientation and economic self-sufficiency. Each domain is rated on a 6-point Likert scale, from 'no disadvantage' to 'most severe disadvantage' on that domain. The test is scored between 0 and 1, with lower scores corresponding to a greater disadvantage (Harwood et al., 1994).

Nottingham Extended Activities of Daily Life (NEADL): Is a measure of a stroke survivor's independence with regards to their performance on various activities of daily living. The measure consists of 22 functional tasks (e.g. walking, cooking, cleaning, participation in active hobbies). These tasks are then further divided into 4 distinct subscales (mobility, kitchen, domestic, and leisure activities). In turn, each task is measured on a 5-point (0=not at all, 4=on my own with no difficulty). This measure has been shown to have good reliability and validity (das Nair et al. 2011; Sahin et al. 2008).

Stroke Impact Scale (SIS): Is a patient-reported measure of multi-dimensional stroke outcomes. The measure consists of 59 functional tasks (e.g. dynamometer, reach and grab, walking, reading out loud, rating emotional regulation, word recall, number of tasks completed, and shoe tying). These tasks are then divided into 8 distinct subscales which include: strength, hand function, mobility, communication, emotion, memory, participation and activities of daily living (ADL). Each task is measured on a 5-point scale (1=an inability to complete the task, 5=not difficult at all). The measure has been shown to have good reliability and validity (Mulder & Nijland. 2016; Richardson et al. 2016).

Observer Assessed Disability: is a measure meant to assess disability on 18 (or 13) different movements. Each one is rated by an assessor as 'performed' or 'not performed'. The movements are hierarchal in nature, and the measure is sensitive to change in stroke populations (Partridge, Johnston & Edwards, 1987).

Balance, Ambulation and Mobility

6-Minute Walk Test: Is a measure of walking endurance, in which the distance walked by participants in a straight line within 6 minutes is reported. The test is proven to be valid and reliable in stroke (Fulk et al. 2008).

Berg Balance Scale: Is a 14-item scale that measures balance ability and control while sitting and standing. Each item is ranked on a 4-point scale for a total score of 56. The measure is shown to have high interrater, intrarater, and test-retest reliability (Blum et al. 2008).

Modified Rivermead Mobility Index (MRMI): Is a patient-reported measure that helps a trained clinician assess how high a patient's level of mobility is. This measure consists of 15 questions some of which include: can you manage a flight of stairs by yourself? Can you bathe yourself? Can you go from lying down on your bed to sitting up? These questions are then evaluated by having the patient respond in a yes or no fashion. This measure has good reliability and validity (Collen et al. 1991).

Timed Up & Go Test (TUG): Is a measure of the ability of a stroke patient to perform sequential motor tasks. This measure consists of 1 functional task which involves the patient standing up from a chair, walking 3 metres, turning around and sitting back down again. This task is then evaluated on a scale from 1 to 5 (1=normal function, 5=severely abnormal function). This measure has been shown to have good reliability and validity (Steffen et al. 2002; Shumway-Cook et al. 2000).

Cognition

Mini Mental Status Examination (MMSE): Is a brief screening tool and quantitative assessment of cognitive impairment. It is one of the most commonly used instruments for this purpose. The exam consists of 11 questions/tasks in 7 cognitive domains: 1) orientation to time; 2) orientation to place; 3) registration of 3 words; 4) attention and calculation; 5) recall of 3 words; 6) language; and 7) visual construction. The test is scored out of 30 possible points, with a score of 18-24 denoting mild impairment and a score of 0-17 denoting severe impairment. The test has been found to be valid as a screening tool, and is sensitive for detecting moderate/severe impairment, but not mild impairment. It has good interrater reliability. The MMSE is appropriate for screening for post-stroke cognitive impairment (Bour et al. 2010; Tombaugh & McIntyre, 1992; Dick et al. 1984).

Montreal Cognitive Assessment (MoCA): Is one of the most commonly used tools designed to detect mild cognitive impairment. It is a brief, 30-item test that consists of various subtests evaluating: short-term memory, visuospatial abilities, executive function, attention, concentration, working memory, language, and orientation to time and space. A cut-off score ≤ 26 represents cognitive impairment. The MoCA was found to be valid and exhibits excellent sensitivity in mild cognitive impairment. It was therefore found to be superior to the MMSE in screening for mild cognitive impairment. It exhibited good sensitivity in detecting moderate and severe impairment. Specificity was also high. It is sensitive and appropriate for use in detecting post-stroke cognitive impairment (Dong et al. 2010; Nasreddine et al. 2005).

Community reintegration and social support

McMaster Family Assessment Device: is a questionnaire developed as a screening instrument to assess family functioning and identify problem areas. It contains 7 different subscales (problem solving, communication, roles, affective responsiveness, affective involvement, behavior control and general functioning) which are based off of the McMaster Model of Family Functioning. The questionnaire contains a total of 53 items that are rated on a 4 point scale from 'strongly disagree' to 'strongly agree'. It has been shown to be both reliable and valid in a number of clinically and culturally different populations (Shek, 2001; Kabacoff et al., 1990; Epstein, Baldwin & Bishop, 1983).

Reintegration to Normal Living Index (RNLI): Assesses the degree to which individuals who had experienced traumatic or incapacitating illness achieve reintegration into normal social activities. It consists of 11 items with domains of: daily functioning, recreational and social activities, family roles, personal relationships and perception of self. Each statement is rate on a visual analogue scale (1-minimal reintegration, 10-maximum reintegration). The tool has been validated for self-administration in stroke survivors (McKellar et al. 2015).

Social adjustment scale: Is a 54-item self-report scale of social adjustment to assess expressive and instrumental performance over the past two weeks in six role areas: vocational, social and leisure activities, relationships with extended family, marital partner role, parental role and role within the family. Where questions are categorized into: performance at expected tasks, amount of friction with people, finer aspects of interpersonal relations, feelings and satisfactions. Each question is scored on a five-point scale, higher scores denote greater impairment (Gameroff et al. 2012).

Social Problem Solving Inventory: is a multidimensional, self-reported assessment of social-problem solving skills. It consists of 70 items, with 2 major scales (problem orientation scale and problem-solving skills scale) and 7 subscales (cognition, emotion, behavior, problem definition, formulation, generation of alternative solutions and decision making). The measure has good psychometric properties (D'Zurilla & Nezu, 1990).

UCLA Loneliness Scale: In its revised version is a 10-item self-report scale that focuses on the psychological experience of loneliness. Items are scored on a 4-point scale (1-never, 4-often), higher scores are indicative of greater loneliness. The measure has high internal consistency (Hartke and King, 2003).

Barrera's Inventory of Socially Supportive Behaviors: is a measure designed to examine how frequently a particular individual receives different social supports. The entire inventory contains 40 items, each of which describes a particular type of support an individual might receive. Participants are instructed to rate the frequency with which each item had occurred in the last month using a five-point Likert Scale, which higher scores indicating a greater frequency. It has shown good reliability and good validity (Barrera, Sandler & Ramsay, 1981).

ESCROW profile: Measures the use of social resources through suitability of the environment, reliance on social agencies, available help in the home, financial resources, ability to make decisions and vocational status (Evans et al. 1988).

Interpersonal Support Evaluation List (ISEL): Is a patient reported measure that allows clinicians to evaluate how patients perceive the level of support they receive from their

family/caregivers. This assessment consists of 40 distinct questions that are divided into 4 subscales: tangible support, belonging support, self-esteem support and appraisal support. These questions are then evaluated on a 4-point scale (0=definitely false, 3=definitely true). This measure has been shown to have good reliability and validity (Cohen & Hoberman 1983).

Medical Outcomes Study (MOS) Social Support Survey: An 11-item survey, items are scored from: 1=none of the time, to 5=all of the time. Higher scores indicate greater support (Smith et al. 2012).

Social Support Inventory for Stroke Survivors (SSIS): This instrument measures social support through the source, quantity, quality and type of support. It has subscores for five sources of support (close, personal, family and friends, community individuals, community groups, and professionals), as well as overall quality and quantity. The measure has been found to have good construct and concurrent validity (Friedland et al. 1992).

Use of Community/Aids Received: Is a measure of the frequency with which patients post-stroke access community services/aids. There are various services/resources available in the community including but not limited to: homecare, outpatient rehabilitation, telehealth programs etc (Evans et al. 2002).

Mental Health

Beck Depression Inventory (BDI): Is a widely used instrument for the detection and assessment of the severity of depression. It can be administered by a trained interviewer or as a questionnaire. The BDI is composed of 21 multiple choice sets, each with 4 self-evaluative statements scored on a scale of 0 (least indicative of depression) to 3 (most indicative of depression). Scores are added to provide a total score from 0-63. Generally, a score >19 is associated with clinically relevant depression. The inventory is simple and easy to administer. It also assesses cognitive symptoms more than somatic, making it ideal for assessing depression in the context of stroke. The BDI is externally valid, is internally consistent and has high test-retest reliability (Aben et al. 2002; Beck, Steer & Carbin, 1988).

Center for Epidemiological Studies Depression Scale (CESD): Is a screening tool for depression. It is a 20-item questionnaire assessing how often patients experienced depressive symptoms within the past week. It has high internal consistency, test-retest reliability and validity. It is generalizable for use in stroke patients, however questions concerning somatic symptoms should be interpreted with caution in this population (Pickard, Dalal & Bushnell, 2006; Lewinsohn et al. 1997).

Depression, anxiety and stress scale (DASS-21): Is a 21-item instrument consisting of three 7-item self-report scales measuring the severity of common depression and anxiety symptoms. Items are scored on a 4-point Likert scale (0=did not apply to me at all over the last week, 3=applied to me very much over past week). The scale has good internal consistency and concurrent validity (Sansom et al. 2015).

General Health Questionnaire: has many different versions of various sizes, but the 28-item one is the most popular. The tool is meant to identify minor psychiatric disorders and mental health problems. The 28-item version consists of 4 subclasses (somatic symptoms, anxiety/insomnia, social dysfunction and severe depression) each with 7 items. It has been validated and found reliable in 38 different languages (Jackson, 2007).

Geriatric Depression Scale (GDS): Is a self-rating screening test for depression in the elderly. A long form of the scale consists of 30 yes/no questions relating to how the examinee felt over the preceding week, while the short form consists of 15 questions. One point is given for each response indicating depression symptoms. Depression severity can be categorized into mild (11-20 long form; 5-9 short form) or moderate-severe (21-30 long form; 10-15 short form). Both versions of the test have been extensively validated. They both have high internal consistency, test-retest reliability, sensitivity and specificity. The test has also been validated for use with elderly stroke patients and found to have a high predictive value (McDowel, 2006; Agrell & Dehlin, 1989; Sheikh & Yesavage, 1986).

Hospital Anxiety and Depression Scale (HADS): Is a measure of depression and anxiety symptomatology designed to detect these disorders among physically ill patients. The scale is divided into an anxiety portion (HADS-A) and a depression portion (HADS-D), each scored out of 21 points. The total test consists of 14 items (7 in each subscale), each evaluated on a 4-point scale. The HADS has been found to be sensitive, specific, have moderate-excellent internal consistency and be a valid and appropriate test for screening post-stroke depression (Aben et al. 2002; Zigmond & Snaith, 1983).

Patient Health Questionnaire (PHQ-9): is an instrument designed to assess the severity of depression. It contains 9-items assessing the frequency of depressive symptoms, and a 10th

item relating to whether these difficulties are causing problems in their life. Each item is rated on a 4-point scale, with higher scores indicating more severe depression. It has been found to be both reliable and valid (Kroenke, Spitzer & Williams, 2001).

Perceived Stress Scale: is a questionnaire designed to assess an individual's levels of stress within the last month. The measure contains 10 items posed as questions about whether or not the participant has experienced a particular feeling. Each item is then rated on a 5-point Likert scale on the frequency that the individual experiences those particular feelings. The measure has shown good psychometric properties and is widely used for assessing stress (Cohen, Kamarck & Mermelstein, 1994).

Positive affect scale: It is a 10-item scale that assesses psychological wellbeing. Total scores range from 10 to 50 with higher scores indicating more psychological wellbeing (Cameron et al. 2015).

Profile of Mood States: Is a measure of mood states and mood changes in psychiatric populations. The measure is quick and easy to administer, and can be completed in 3 to 5 minutes, however it may take longer for populations that have trouble reading due to illness or injury. The original POMS includes 65 items in total, with 58 scored items and seven unscored items designed to measure "friendliness." A shortened version of POMS was created in 1991, which removed less psychometrically sound or confusing items. This version, known as EPOMS, consists of 30-items and has been adapted in other languages as well. The psychometric properties of both scales have been investigated, and the abbreviated EPOMS scale has proven even greater reliability and validity than the full-scale POMS instrument (Bourgeois et al. 2010).

Stroke Aphasic Depression Questionnaire: is an assessment designed to measure depression in aphasic stroke patients. The questionnaire contains 21 items, and each item is scored on a 4-point scale. Higher scores indicate more severe depression. The measure has displayed good psychometric properties (Sutcliffe & Lincoln, 1998).

Symptom Checklist 90-item revised: Is a 90-item self-report symptom inventory for the assessment of psychological symptoms and distress. Items are scored on a 5-point Likert scale (Derogatis and Spitzer, 1999).

Quality of Life & Optimism

Antonovsky's Orientation to Life Questionnaire: is a measure designed to assess the sense of coherence. This is generally defined as the extent to which someone believes their environment is predictable, and things will work out as expected. It is separated into 3 subscales; comprehensibility contains 11 items, manageability contains 10 items and meaningfulness contains 8 items. A short abbreviated version with 13 items is also available. The questionnaire has been adapted into 49 different languages and has been shown to be a valid and reliable measure across numerous cultures. (Eriksson & Mittelmark, 2017).

CarerQOL: is an assessment of well-being and subjective burden of caregivers. Well being is assessed on a 10-point visual analog scale rating a participants mood at the time of test administration. Subjective burden is assessed with 7 items relating to situations or problems that may apply to the caregiver. Each of these items is rated on a 3 point scale (no, some, a lot of) that indicates the frequency or perceived relation to that particular situation or problem. It has displayed good reliability and validity in psychometric testing (Hoefman, Exel & Brouwer, 2013).

Dartmouth co-op charts: is a measure of quality of life and health status. It consists of 9 domains (physical function, emotional function, daily activities, social activities, social support, change in health, overall health, pain and quality of life). (Mant et al. 2000).

Dyadic coping instrument (DCI): Is a 37-item scale with 5-point response options (1=very rarely, 5=very often) that measures couples' dyadic coping and stress communication. Through an understanding of: each partner's own coping, each partner's perception of the other's coping, each partner's observation of how they cope as a couple. This measure has good internal consistency and construct validity (Robinson-Smith et al. 2016).

Herth Hope Scale: Is a 30-item, four-point (0 to 4) self-administered scale to assess hopefulness. The range of scores on the scale is from 0 to 90, where higher scores indicate greater hopefulness (Johnson & Pearson, 2000).

Medical Outcome Trusts' Short Form Health Survey (SF-36 or SF-12): Is a commonly used measure of health-related quality of life and overall health status. The test contains 36 items (or 12) encompassing 8 subscales: 1) physical functioning; 2) role limitations – physical; 3) bodily pain; 4) general health; 5) vitality; 6) social functioning; 7) role limitations – emotional; and 8) mental health. The result of each subscale is transformed to a score from 0-100 representing the lowest and highest possible scores, respectively. Two summary measures, physical and mental health, are generated by weighting the relevant subscales. The test has been validated in a wide range of populations, including stroke and traumatic brain injury patients. In stroke, the survey has demonstrated convergent validity and has high reliability (Guilfoyle et al. 2010; Hagen, Bugge & Alexander, 2003).

Nottingham Health Profile: is an assessment about an individual's perceived health status and quality of life. It contains 38 questions in 6 subdomains (energy, pain, emotional reaction, sleep, social isolation and physical abilities) that are all weighted so that the sum of their score is equal to 100. It also contains a second part, which assesses whether their health is causing problems in certain areas of life (eg. Work, vacations). It has shown good consistency and reliability, as well as sensitivity (Wann-Hansson et al., 2004).

Preference based stroke index: Is a health-related quality of life scale for stroke survivors. It includes 10 items (walking, climbing stairs, physical activities/sports, recreational activities,

work, driving, speech, memory, coping and self-esteem. Each item has a 3-point response scale. The scale has been shown to have adequate content and construct validity (Poissant et al. 2003).

Rosenberg Self-esteem Scale: is a measure of global self-worth, assessing both positive and negative feelings the individual has toward themselves. It has 10-items, each rated on a 4-point Likert scale. Higher scores indicate higher self-esteem. It shows excellent internal consistency and reliability, and good validity (Rosenberg, 1965).

Satisfaction with life scale: A 5-item scale that measures global cognitive judgements of one's life satisfaction. Items are scored on a 7-point scale (1=strongly disagree, 7=strongly agree) (Diener et al. 1985).

Stroke Specific Quality of Life Questionnaire (SS-QoL): Is a patient reported questionnaire that consists of 49 items which are in turn divided into 12 distinct domains. The domains are as follows: energy, family roles, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision and work/productivity. Some of the questions include: I feel tired most of the time, I feel as though I am burdening my family, I am having trouble speaking, I am having trouble walking, etc. These questions are then evaluated on a 5-point scale (1=total dependence/strongly agree; 5=total independence/strongly disagree). This assessment has been shown to have excellent test-retest reliability and excellent inter-rater reliability plus strong validity (Hilari & Byng 2001; Williams et al. 1999).

Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39): Is a measure of health-related quality of life specific to stroke patients. It is an interview-administered self-report scale developed from the items from the Stroke-Specific Quality of Life Scale (SS-QoL), modified for those with aphasia. It includes 4 additional items reflecting common difficulties in patients with aphasia: speech, decision-making, and impact of aphasia on family and social life. The test has been shortened from the 49-item SS-QoL to 39 items. Similarly, to the SS-QoL, each item is rated on a 5-point Likert scale with higher scores representing better function. The 39 items are divided into 4 domains: 1) physical; 2) psychosocial; 3) communication; and 4) energy. Subdomain and overall scores are obtained by averaging responses and obtaining an average score. The scale has been validated in both aphasia and general stroke patients. It also exhibits good internal consistency and test-retest reliability (Hilari et al. 2009; Hilari et al. 2003).

Utrecht Proactive Coping Competence Scale: is a self-rated measure of proactive coping mechanisms. It consists of 21 items, each assessed on a 4-point Likert scale. Each item is posed in the form of a question relating to aspects of coping (eg. To what extent can you make realistic plans?) and the participant rates their competence. Higher scores indicate a higher perceived level of coping competency. The measure has shown good psychometric properties in multiple languages (Tielemans et al. 2014).

Ways of coping-cardiovascular accident scale: Is a 31-item, 4-point self-administered scale used to measure various ways of coping. The range of scores is from 0 to 93, higher scores indicate a greater range of coping responses. The scale contains three subscales: Seek and Use, Social Support and Focus on the positive and distancing (Johnson et al. 2000).

WHO Quality of Life (WhoQoL): Is a measure of quality of life using a self-administered questionnaire. The scale was developed as a comprehensive and cross-cultural measure of subjective quality of life. The initially developed scale, WhoQoL-100, consists of 100 items with each rated on a 5-point Likert scale related to how the subject felt over the preceding 2 weeks. Higher scores denote greater satisfaction. The WhoQoL-Bref was created to shorten the

cumbersome 100-item questionnaire and contains questions concerning physical health, psychological health, social relationships, environment, and overall quality of life and general health. Both forms of the questionnaire have demonstrated validity and good reliability (Trompenaars et al. 2005).

World Health Organization Quality of Life Scale (WHO-QoL Scale): Is a patient-reported measure that consists of 6 broad domains (physical health, psychological health, level of independence, social relations, environment, spirituality/religion/personal beliefs). Each domain has 4 distinct questions for a total of 24 questions. This assessment is evaluated on a 5-point scale (1=not at all, 5=an extreme amount). This assessment has been shown to have good reliability and validity (Khan et al. 2003).

Self-efficacy

Chinese Self-Management behavior Questionnaire: is a translated measure that is designed to assess self-efficacy and self-management behavior post-disease. It assesses self-efficacy in illness management (6 items), cognitive symptom management (6 items) communication with physicians (3 items), medication adherence (4 items) and self-blood pressure monitoring (2 items). It has shown good reliability in previous psychometric analysis (Sit et al., 2016).

Morisky Medication Adherence Scale: is an 8 item questionnaire designed to assess medication adherence (originally for diabetics). Each item is a question pertaining to medication-taking behavior, with items assessing either adherence or non-adherence. It has been found to be a reliable, valid measure that has been translated into multiple languages since its initial inception (De Oliveira-Filho et al., 2014; Al-Qazaz et al., 2010).

Occupational Gaps Questionnaire (OGQ): Is a patient reported measure that seeks to evaluate the presence of occupational gaps. An occupational gap is the difference between what action a person wants/needs to do and what they can actually do. This assessment consists of 28 distinct questions (ex. social/leisure activities, activities of daily living, work-related activities etc. These questions are then evaluated using a two-question scale: "Do you perform this activity?" and "Do you want to perform this activity?", after which the patient either responds yes or no. This measure has been shown to have good reliability and validity (Eriksson, Tham & Kottorp 2013).

Recovery Locus of Control Scale: is an assessment of an individual's perceived locus of control. It is made up of 40-items answered with 'yes' or 'no'. The items are based on assessing either an internal locus of external locus of control. Higher scores indicate a more internal locus, whereas lower scores indicate a more external locus of control. It has satisfactory reliability and validity (Macleod, L. & Macleod, G., 1998).

Stroke self-efficacy questionnaire: Is a 13-item self-report scale measuring self-efficacy judgements and confidence in specific domains of functioning post-stroke. Individuals rate their belief in their ability to achieve each of the 13-items on a 10-point scale (0-not at all confident, 10-very confident) (Jones et al. 2008).

Caregiver self-efficacy

Caregiver Competence Scale: is a 4-item scale designed to assess the competence and confidence an individual has in their role as a caregiver. Each item is rated from 1-4, with higher numbers indicating greater levels of confidence. This scale has been shown to have good reliability and valid in multiple languages and patient groups (Henriksson et al., 2012; Pearlin et al., 1990).

Pearlin's 7-item Mastery Scale: Assesses a caregiver's sense of control over their life. Total scores range from 7 to 28, where higher scores indicate more mastery (Cameron et al. 2015).

Preparedness for caregiving scale: Is an 8-item, 5-response option scale (0 to 4). The scale assesses perception of preparedness to manage caregiving tasks and stresses. Higher scores reflect greater preparedness (King et al. 2012).

Sense of competence questionnaire: Consists of 27 items, where the caregiver has to indicate the extent of agreement for each item on a 4-point rating scale. The range of scores is from 27 to 108, the higher the score, the greater the caregiver burden. The item has both good reliability and validity (Reimer et al. 1998).

Satisfaction

Client Satisfaction Questionnaire: is a self-reported measure designed to assess and individual's satisfaction with services received by them or their family. There are a number of versions with a varying number of items, from 8 up to 31. Items in this measure cover 9 different conceptual domains of satisfaction (physical surroundings, procedures, support staff, kind/type of service, treatment staff, quality of service, amount/length/quantity of service, outcome of service, and general satisfaction). It has shown good reliability and validity in psychometric analysis (Attkisson & Greenfield, 1995).

Larson Scale – Consumer Satisfaction: is a measure originally designed to assess patient satisfaction with pharmacological care services. The measure consists of 45 items in the form of statements, which the participant rates on a 5-point Likert scale from 'very strongly disagree' to 'very strongly agree'. These items are broken down into 9 dimensions of satisfaction (explanation, consideration, technical competence, financial aspects, accessibility, availability, efficacy, drug quality and general satisfaction) (Larson & MacKeigan, 1994).

Pound satisfaction scale: Assesses patient or caregiver satisfaction with services received during inpatient rehabilitation and post-discharge. It consists of 13 items with response categories of: strongly agree, agree, disagree or strongly disagree. It has been shown to have good construct validity and internal consistency (Pound et al. 1994).

Satisfaction with stroke care questionnaire: Is a 20-item questionnaire that is comprised of 8 items measuring satisfaction with inpatient stroke care, 12 items measuring satisfaction with stroke care after discharge. Items are scored on a 4-point rating scale (0-strongly disagree, 3-strongly agree). The higher the sum score, the greater their satisfaction with inpatient care or care after discharge (Boter et al. 2003).

Education

Stroke Care Information Test: Consists of 36, four-part multiple-choice questions about physical loss, cognition, perceptual disorders, language impairment and sexuality. The range of scores is from 0 to 36. The measure has satisfactory reliability and differentiates stroke education participants from non-participants (Evans et al. 1988).

Health education impact questionnaire: A scale designed to evaluate patient education programs in chronic conditions, through scales of: positive and active engagement in life, health directed behavior, skill and technique acquisition, constructive attitudes and approaches, self-monitoring and insight, health services navigation, social integration and support, and emotional wellbeing (Osborne et al. 2007).

Stroke Knowledge and Lifestyle Modification Questionnaire: A questionnaire that assesses knowledge of risk factors, appropriate behaviors for stroke risk reduction, appropriate response to stroke symptoms, objective health indicators, alcohol use and smoking (Allen et al. 2009).

Driving

Adelaide Driving Self-efficacy Scale: is a measure designed to test an individual's confidence in performing certain driving behaviours. The measure consists of 12 different driving related behaviours, and asks the participant to rate their confidence in performing that behavior on a Likert scale from 0 to 10, with higher numbers indicating greater levels of confidence. The scale has been shown to have good internal consistency, and construct validity (George, Clark & Crotty, 2007).

Useful Field of View: Is a measure of functional visual field. It can map an individual's visual field (area that information can be acquired and processed without eye or head movement). The tool consists of a large computer screen and can evaluate visual processing speed, divided attention and selective attention through the completion of 3 computerized tasks. A percentage score is given based on the percentage reduction in useful field of view. The test has been shown to have moderate/high test-retest reliability and good criterion validity in a post-stroke population assessed for driving ability (George & Crotty, 2010).

Visual Scanning Analyzer: Is a validated instrument for the standardized assessment of the extent to which the participant scans or neglects his/her visual field and has been shown to be correlated with driving performance. The apparatus is a dome fitted with lights controlled by a portable computer that participant places their head in. Lights are presented at a fixed location in the dome. A computer records the number of correct light identifications by the participants. There is a scanning, neglect, and fixate tasks. Higher scores on lights seen, and lower scores on time taken indicate better performance (Crotty et al. 2009).

Sexual Health

Changes in Sexual Functioning Questionnaire: is a 36-item (35 for females) assessment in the form of a structured interview that is designed to examine illness and medication related changes to an individual's sexual functioning. The measure is made up of 5 different domains; sexual desire frequency (2 items), sexual desire/interest (3 items), sexual pleasure (1 item), sexual arousal (3 items) and orgasm (3 items). Additional items relate to how the functioning has changed over time. Previous work has shown the measure to have good reliability and validity (Meston & Derogatis, 2002; Clayton, McGarvey & Clavet, 1997).

Stroke Severity

Modified Rankin Scale (MRS): Is a measure of functional independence for stroke survivors. The measure contains 1 item. This item is an interview that lasts approximately 30-45 minutes and is done by a trained clinician. The clinician asks the patient questions about their overall health, their ease in carrying out ADLs (cooking, eating, dressing) and other factors about their life. At the end of the interview the patient is assessed on a 6-point scale (0=bedridden, needs assistance with basic ADLs, 5=functioning at the same level as prior to stroke). This measure has been shown to have good reliability and validity (Quinn et al. 2009; Wilson et al. 2002).

National Institutes of Health Stroke Scale (NIHSS): Is a measure of somatosensory function in stroke survivors during the acute phase of stroke. This measure contains 11 items and 2 of the 11 items are passive range of motion (PROM) assessments delivered by a clinician to the upper and lower extremity of the patient. The other 9 items are visual exams conducted by the clinician (e.g. gaze, facial palsy dysarthria, level of consciousness). Each item is then scored on a 3-point scale (0=normal, 2=minimal function/awareness). This measure has been shown to have good reliability and validity (Heldner et al. 2013; Weimar et al. 2004).

Oxford Handicap Scale: Is a clinician-evaluated assessment that measures the severity of a patient's handicap. This assessment requires specific questions being asked by said clinician about the patient's physical state. These results are then compiled and evaluated on a 6-point scale (0=none/no handicap, 5=severe handicap). This measure has been shown to have good reliability and validity (Perel et al. 2008).

Stroke-Adapted Sickness Impact Profile (SA-SIP30): Is a 30-item questionnaire that consists of 8 distinct subscales (body care and movement, social interaction, mobility, communication, emotional behavior, household management, alertness behaviour and ambulation). Each question consists of a yes or no answer by the patient with yes being given a score of 1 and no being given a score of 0. The higher the score, the more severe the patient's stroke. This measure has been shown to have good reliability and validity (Van Straten et al. 2000).

Caregiver burden

Bakas Caregiver Outcome Scale: is a 10-item (or 15) measure designed specifically to examine the changes resulting from providing care to a stroke survivor. Items are rated on a 7-point scale from -3 to 3, with larger numbers indicating a change for the better and lower numbers corresponding to a change for the worse. A zero on an item would imply no change took place since their role as caregiver began on that particular aspect of their life. This measure has extensive psychometric data and has proven to be a reliable and valid instrument (Bakas, 2014).

Caregiver Burden Scale (CBS): Is a caregiver-reported measure that can serve as a barometer for the overall health a patient's primary caregiver. This assessment consists of 28 distinct questions that help measure the caregiver's physical and mental health. These questions are evaluated on a 4-point scale (1=strongly agree, 4=strongly disagree). This assessment has been shown to have good reliability and validity (Chang et al. 2010).

Family Caregiving Consequence Inventory (Frail elder subscale): This 11-item subscale quality of care and the degree to which needs are met. Scores can range from 1 (least satisfaction) to 3 (most satisfaction). The measure has adequate reliability and validity (Shyu et al. 2010)

Family systems strengths questionnaire: An assessment of family system strengths (Malini et al. 2015).

Life Situation Among Spouses after the Stroke event: Consists of 13 questions, divided into four subscales: worries (three items), powerlessness (four items), personal adjustment (four items), and social isolation (two items). The spouse indicates the extent of agreement for each item on a five-point rating scale (1-all the time, 5-not at all). Scores range from 13 to 65 points, where higher scores are indicative of a better life situation (Larson et al. 2005).

Pressing problem index: Is a semi-structured interview where caregivers identify current problems in their caregiving. For each problem mentioned, the stressfulness of the problem is rated from 1 to 5 (1=not stressful and effective, 5=very stressful and effective). A total index is created from a composite score for each of the identified problems and dividing this by the total number of problems. Higher scores are indicative of greater stress and less effective management (Hartke and King, 2003).

Zarit Burden Interview: or sometimes called the Zarit Burden Inventory, is a 22-item scale in which caregivers are assessed on feelings of stress, guilt and resentment towards their role as caregiver. Responses to each item were rated on a 4-point Likert scale from 0-4, where higher numbers indicate a higher frequency of experiencing the particular feeling or emotion. Total scores range from 0 to 88. A higher total score indicates a greater perceived burden. There is evidence to support its reliability and validity (Yap, 2010).

Introduction

Throughout a stroke survivor's journey, they will transition through several settings along their continuum of care. To ensure a seamless transition to the home or community post-discharge from rehabilitation, timely information exchange from health care providers to the patient and their caregivers is critical and this channel of communication should be always open (Mountain et al. 2020). Importantly it is this collaboration between clinicians and the patient and their family that optimizes a successful return to the community. Not all patients will be eligible for inpatient rehabilitation, or will only receive a short length of stay, as such many patients find themselves back in the community shortly after their stroke. Populations that may be at increased risk for experiencing difficulties during the transition back to the community include: Indigenous people, those living in rural communities, transgender individuals, and those who experience systemic, cultural or language barriers (Mountain et al. 2020).

The Canadian Stroke Best Practice guidelines recommend that patients, their families and healthcare providers have talked about or set a plan for the following items, when transitioning between care settings (Mountain et al. 2020):

Box One: Transitions of Care Checklist

This checklist is provided as a guide to help ensure evidence- and consensus- based recommendations are applied to develop a collaborative action plan for each person as they transition to different settings and phases of care.

This checklist is applicable to primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. The transitions of care checklist should enable the health care team member to work with the person with stroke and their family to have meaningful dialogues regarding necessary information and services to ensure positive and successful care transitions.

Support for people with stroke, families and caregivers may include:

- Shared decision making/participation regarding transitions across stages of care.
- Accurate and up to date information about the next care setting, what can be expected, and how to prepare.
- Access to restorative care and active rehabilitation to improve and/or maintain function based on the individualized care plan.
- Advance care planning, palliative care and end-of-life care as applicable.
- Counseling, preparation and ongoing assessment for adjustment to change of: living setting; abilities; social roles and relationships; participation, leisure and vocational activities; and, home environment. Also consider impact on family (e.g., spouse or partner, children); potential resource issues (financial), and independence (e.g., driving).
- Written discharge instructions and recommendations should be included in collaborative action plans, and include goals and follow-up care.
- Access to a designated contact person in the hospital or community for continuity of care and questions.
- Access to and advice from health and social service organizations appropriate to needs and stage of transition and recovery.
- Links to and information about local community agencies such as stroke groups, peer visiting programs, meal provider agencies, and other services and agencies.
- Where possible, access to peer supports who have had a stroke and experienced transitions following the acute phase.
- All communications should be available in aphasia-friendly formats as required and appropriate to the health literacy of people with stroke, their families and caregivers.

Figure 1. Transitions of care checklist, available at: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/transition-of-care-nov2019/csbpr-transitions-box1-18nov19->

[final.ashx?rev=e7205dc183a548278bd88109c05cbe80&hash=12E78D6ED33324F51A8D688F5B4333D5](https://www.heartandstroke.ca/-/media/1-stroke-best-practices/rehabilitation-nov2019/csbpr-transitions-table2-core-education-across-the-continuumstroke13nov19.ashx?rev=a00f1a53260349e2a46a55254b363776&hash=A1D44E6C-CC062A65F2E3AF2C128EA102)

Importantly, the stroke survivor and their caregivers should have an education plan that addresses their goal setting and learning needs (Mountain et al. 2020).

Recommendations for core education plan features across a variety of stroke settings are available at: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/rehabilitation-nov2019/csbpr-transitions-table2-core-education-across-the-continuumstroke13nov19.ashx?rev=a00f1a53260349e2a46a55254b363776&hash=A1D44E6C-CC062A65F2E3AF2C128EA102>.

All members of the interdisciplinary team should share relevant information on the stroke survivor with healthcare providers at the next stage of care including medication use, recovery progress, planned appointments and patient goals in a formal, typed discharge summary.

When returning back into the community, resumption of former vocational, leisure and social activities may be difficult dependent on the stroke survivor's motor, sensory, cognitive and visual field deficits. This can include temporary restrictions on activities such as driving. Reported rates of returning to work after a stroke are highly variable amongst the literature with ranges from 7.3% to 74.5% (Mountain et al. 2020; Edwards et al. 2018). Assessing a stroke survivor's suitability for driving should include tests of sensory perceptual functioning including vision, visual fields and visual attention; a motor assessment focusing on strength, range of motion, coordination and reaction time; and a cognitive assessment focusing on problem solving, speed of decision making, judgement and reading/symbol comprehension (Mountain et al. 2020).

The following sections detail interventions that address issues in reintegrating to the community including education programs, emotional support, active care management, caregiver training, sexual functioning, return to driving, and returning to work.

Patient Education Programs



Adopted from: <https://www.bluenovius.com/healthcare-marketing/pharma-care-patient-education/>

Despite the advancements in medical treatment, prevention, and care of stroke, part of the progress depends in part on patient and caregiver education. A recent study reported the results of focus groups and interviews conducted with stroke patients and their informal carers (Hare et al., 2006). From the data collected, the following three themes were identified; prominent and ongoing psychological and emotional issues, lack of information for patients and carers and the importance of primary care in facilitating contact with services in the community. In general, participants felt that more information was needed about stroke, living with stroke and access to services in addition to a broader range of issues including networking opportunities, environmental adaptations and benefits advice. Overall, patients reported persisting needs, including need for information and support, which were not being addressed by available sources (Hare et al., 2006). For younger individuals with stroke, provision of information about stroke may be the most frequently unmet need along with financial needs, assistance with non-care activities (e.g. social activities), intellectual fulfillment, adaptations, vehicles, social life and physiotherapy (Kersten et al., 2002).

Nine RCTs were found evaluating comprehensive educational programs for stroke rehabilitation. Five RCTs compared thorough educational provisions to generic information or usual care (Ostwald et al., 2014; Green et al., 2007; Hoffmann et al., 2007; Lowe et al., 2007; Mannt et al., 1998). Three RCTs compared educational programs with specific reinforcement strategies or follow up sessions to usual care (Eams et al., 2011; Johnston et al., 2007; Lorenc et al., 1992). One RCT compared group education sessions to conventional care (Rodgers et al., 1999).

The methodological details and results of all nine RCTs evaluating patient education programs for community rehabilitation are presented in Table 1.

Table 1. RCTs evaluating education-oriented interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size_{start} Sample Size_{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|--|---|---|
| Educational programs vs conventional care/generic information | | |
| <u>Ostwald et al.</u> (2014) RCT (5) N _{Start} =159 N _{End} =134 TPS=Acute, Subacute, Chronic | E: Mailed resource information + informational home visits C: Mailed resource information (12mo) Duration: 6mo | <u>Patient</u> <ul style="list-style-type: none"> • Geriatric Depression Scale (-) • Stroke Impact Scale – social participation (-) • Short Form 36 (+exp) • Perceived Stress Scale (-) • Functional Independence Measure – Cognitive (+exp) <u>Caregiver</u> <ul style="list-style-type: none"> • Geriatric Depression Scale (-) • Short Form 35 (+exp) • Perceived Stress Scale (-) • Zarit Burden Inventory (-) |
| <u>Green et al.</u> (2007) RCT (8) N _{Start} =200 N _{End} =164 TPS=NR | E: one-on-one educational-counselling interview + an appointment at a “lifestyle class” C: Conventional care + access to pamphlets Duration: 1 interview, 1 class, within 1-2 months of study admission | <ul style="list-style-type: none"> • Stroke knowledge (+exp) • Actively changing <ul style="list-style-type: none"> • Smoking (-) • Diet (-) • Physical activity (-) • Weight loss (-) |
| <u>Hoffmann et al.</u> (2007) RCT (8) N _{Start} =138 N _{End} =133 TPS=Acute | E: Computer-generated tailored written information C: Generic written information Duration: 3mo | <ul style="list-style-type: none"> • Knowledge of Stroke (-) • Self-efficacy (-) • HADS – depression (-) • HADS – Anxiety (+con) • perceived health status (-) • Satisfaction of content (+exp) |
| <u>Lowe et al.</u> (2007) RCT (6) N _{Start} =100 N _{End} =84 TPS=NR | E: Conventional care + “Carefile” book C: Conventional care Duration: 3mo follow up | <ul style="list-style-type: none"> • Stroke Knowledge Questionnaire (+exp) • Satisfaction with information received (-) |
| <u>Mant et al.</u> (1998) RCT (8) N _{Start} =93 N _{End} =71 TPS=Subacute | E: Information packages about stroke, its effects, and local contact names and support groups (at discharge) C: No information package Duration: 6mo | <u>Patients</u> <ul style="list-style-type: none"> • Knowledge of stroke (-) • access to community services (-) • Dartmouth COOP charts (health status) (-) • quality of life (-) • HADS – A (-) • HADS – D (-) • London Handicap Scale (-) <u>Caregivers</u> <ul style="list-style-type: none"> • Knowledge of stroke (-) • Caregiver strain index (-) • Short form 36 (-) |
| Educational Programs with reinforcement/follow up vs conventional care | | |
| <u>Fames et al.</u> (2011) RCT (7) N _{Start} =138 N _{End} =119 TPS=Subacute | E: Education and support package, which included an information booklet + telephone contact with a trained professional C: Conventional care Duration: 3mo | <ul style="list-style-type: none"> • Knowledge of Stroke Questionnaire (-) • Self-efficacy to Perform Self-Management Behaviour (-) • Hospital Anxiety and Depression Scale – Anxiety (-) • Hospital Anxiety and Depression Scale – Depression (-) • Stroke and Aphasia Quality of Life Scale (-) • Satisfaction with information (+exp) • Caregiver Strain Index (-) |

| | | |
|--|--|---|
| <p>Johnston et al. (2007) RCT (7) N_{Start}=203 N_{End}=158 TPS=Subacute</p> | <p>E: Information and exercises + regular home visits and telephone calls C: Conventional care Duration: 6wks intervention (6mo follow up)</p> | <ul style="list-style-type: none"> • Barthel Index (-) • Observer Assessed Disability (+exp) • Hospital Anxiety and Depression Scale – Anxiety (-) • Hospital Anxiety and Depression Scale – Depression (-) • Satisfaction with treatment (-) • Recovery Locus of Control (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> • Short Form 36 – physical functioning (-) • Hospital Anxiety and Depression Scale – Anxiety (-) • Hospital Anxiety and Depression Scale – Depression (-) • Recovery Locus of Control (-) • Satisfaction with treatment (-) |
| <p>Lorenc et al. (1992) RCT (3) N_{Start}=30 N_{End}=30 TPS=NR</p> | <p>E1: Information package about stroke E2: Information package + asked to question themselves on the material C: Conventional care Duration: NR</p> | <p><u>E1 vs E2 vs C</u></p> <ul style="list-style-type: none"> • Knowledge (+exp2) • Larson Scale - Consumer satisfaction (-) |
| Group Educational Sessions vs conventional care | | |
| <p>Rodgers et al. (1999) RCT (8) N_{Start}=204 N_{End}=154 TPS=Acute</p> | <p>E: Attend the Stroke Education Program C: Conventional care + access to pamphlets Duration: 6mo</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> • Short Form 36 <ul style="list-style-type: none"> • Energy (-) • Mental health (-) • Pain (-) • Physical function (-) • Role limitation (emotional) (-) • Role limitation (physical) (-) • Social function (-) • General health perception (-) • Stroke knowledge (+exp) • HADS – A (-) • HADS – D (-) • Nottingham Extended ADLs (-) • Oxford Handicap Scale (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> • Short Form 36 <ul style="list-style-type: none"> • Energy (-) • Mental health (-) • Pain (-) • Physical function (-) • Role limitation (emotional) (-) • Role limitation (physical) (-) • Social function (+con) • General health perception (-) • General Health Questionnaire 30 (-) • Knowledge of Stroke (+exp) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.

+exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group

+exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group

+con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group

- indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about early patient education programs

| SATISFACTION | | | |
|--------------|---|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Educational programs may not have a difference in efficacy compared to conventional care for improving satisfaction. | 3 | Hoffmann et al., 2007; Lowe et al., 2007; Lorenc et al., 1992 |
| 1a | Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving satisfaction. | 3 | Eams et al., 2011; Johnston et al., 2007; Lorenc et al., 1992 |
| 1b | <u>For caregivers:</u> Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving satisfaction. | 1 | Johnston et al., 2007 |

| COGNITION | | | |
|-----------|---|------|----------------------|
| LoE | Conclusion Statement | RCTs | References |
| 2 | Educational programs may produce greater improvements in self-efficacy than conventional care . | 1 | Ostwald et al., 2014 |

| MENTAL HEALTH | | | |
|---------------|--|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Educational programs may not have a difference in efficacy compared to conventional care for improving mental health. | 3 | Ostwald et al., 2014; Hoffmann et al., 2007; Mannt et al., 1998 |
| 2 | <u>For caregivers:</u> Educational programs may not have a difference in efficacy compared to conventional care for improving mental health. | 1 | Ostwald et al., 2014 |
| 1a | Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving mental health. | 2 | Eams et al., 2011; Johnston et al., 2007 |
| 1b | <u>For caregivers:</u> Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving mental health. | 1 | Johnston et al., 2007 |
| 1b | Group educational programs may not have a difference in efficacy compared to conventional care for improving mental health. | 1 | Rodgers et al., 1999 |
| 1b | <u>For caregivers:</u> Group educational programs may not have a difference in efficacy compared to conventional care for improving mental health. | 1 | Rodgers et al., 1999 |

SELF-EFFICACY

| LoE | Conclusion Statement | RCTs | References |
|-----|---|------|---|
| 1b | Educational programs may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 1 | Hoffmann et al., 2007 |
| 1a | Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 2 | Eams et al., 2011; Johnston et al., 2007 |
| 1b | <u>For caregivers:</u> Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 1 | Johnston et al., 2007 |

ACTIVITIES OF DAILY LIVING

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|-----------------------|
| 1b | Educational programs may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 1 | Mannt et al., 1998 |
| 1b | There is conflicting evidence about the effect of educational programs with reinforcement to improve activities of daily living when compared to conventional care . | 1 | Johnston et al., 2007 |
| 1b | Group educational programs may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 1 | Rodgers et al., 1999 |

QUALITY OF LIFE & OPTIMISM

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|---|
| 1a | Educational programs may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 3 | Ostwald et al., 2014; Hoffmann et al., 2007; Mannt et al., 1998 |
| 1b | <u>For caregivers:</u> There is conflicting evidence about the effect of educational programs to improve quality of life and optimism when compared to conventional care . | 1 | Ostwald et al., 2014; Mannt et al., 1998 |
| 1b | Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 1 | Eams et al., 2011 |
| 1b | <u>For caregivers:</u> Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 1 | Johnston et al., 2007 |
| 1b | Group educational programs may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 1 | Rodgers et al., 1999 |

| | | | |
|-----------|--|---|----------------------|
| 1b | For caregivers: Group educational programs may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 1 | Rodgers et al., 1999 |
|-----------|--|---|----------------------|

STROKE SEVERITY

| LoE | Conclusion Statement | RCTs | References |
|-----------|---|------|----------------------|
| 1b | Group educational programs may not have a difference in efficacy compared to conventional care for improving stroke severity. | 1 | Rodgers et al., 1999 |

COMMUNITY REINTEGRATION & SOCIAL SUPPORT

| LoE | Conclusion Statement | RCTs | References |
|-----------|--|------|---|
| 1b | Educational programs may not have a difference in efficacy compared to conventional care for community reintegration and social support. | 1 | Ostwald et al., 2014; Mannt et al., 1998 |

EDUCATION

| LoE | Conclusion Statement | RCTs | References |
|-----------|---|------|---|
| 1a | Educational programs may not have a difference in efficacy compared to conventional care for improving education. | 5 | Green et al., 2007; Hoffmann et al., 2007; Lowe et al., 2007; Mannt et al., 1998; Lorenc et al., 1992 |
| 1b | For caregivers: Educational programs may not have a difference in efficacy compared to conventional care for improving education. | 1 | Mannt et al., 1998 |
| 1b | There is conflicting evidence about the effect of educational programs with reinforcement to improve education when compared to conventional care . | 2 | Eams et al., 2011; Lorenc et al., 1992 |
| 1b | Group educational programs may produce greater improvements in education than conventional care . | 1 | Rodgers et al., 1999 |
| 1b | For caregivers: Group educational programs may produce greater improvements in education than conventional care . | 1 | Rodgers et al., 1999 |

CAREGIVER BURDEN

| LoE | Conclusion Statement | RCTs | References |
|-----------|---|------|---|
| 1a | Educational programs with reinforcement may not have a difference in efficacy compared to conventional care for improving caregiver burden. | 3 | Ostwald et al., 2014; Eams et al., 2011; Mannt et al., 1998 |

Key Points

Education programs may not benefit patient or caregiver outcomes.

Psychosocial and Emotional Support



Adopted from: http://www.emcdda.europa.eu/topics/pods/psychosocial-interventions_en

When the stroke experience is viewed in terms of a psychosocial transition, the role of social support in stroke rehabilitation becomes important. Unfortunately, social support may be underestimated during physical rehabilitation because social support appears to have only limited effect during the acute rehabilitation stage. However, as noted by Glass and Maddox (1992), the effects of social support do not appear until after the first month post-stroke, when patients are often discharged and attempting to re-integrate into the community. Hence discharge outcome measures may not necessarily be predictive of the final outcome at the time of discharge. Overall, higher levels of support appear to be associated with improved functional gain (Colantonio et al., 1993; Glass & Maddox, 1992; Glass et al., 1993; Tsouna-Hadjis et al., 2000) as well as lower levels of depression and improved mood and social involvement (Tsouna-Hadjis et al., 2000).

Five RCTs were found that evaluated psychosocial support interventions in stroke survivors. Four RCTs compared individual, often home-based psychosocial support and counselling to conventional care (Robinson-Smith et al., 2016; Glass et al., 2004; Clark et al., 2003; Friedland & McMoll, 1992). One RCTs compared group psychosocial therapy sessions to conventional care (Wang et al., 2013).

The methodological details and results of all five RCTs evaluating psychosocial and emotional support for community rehabilitation are presented in Table 2.

Table 2. RCTs evaluating psychosocial support-oriented interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size_{start} Sample Size_{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|--|--|--|
| Individual psychosocial support therapy vs conventional care | | |
| <u>Robinson-Smith et al. (2016)</u> RCT (4) N _{start} =10 N _{end} =8 TPS = Acute | E: Psychoeducational therapy for 6 home sessions C: Usual care Duration: 4-5months | Patients <ul style="list-style-type: none"> • Dyadic coping Scale (-) • Centre for epidemiologic studies-depression (+exp) • Quality of life (+exp) • Self-care efficacy (-) Caregivers <ul style="list-style-type: none"> • Centre for Epidemiologic Studies – Depression (-) • Dyadic coping Scale (-) |
| <u>Glass et al. (2004)</u> RCT (7) N _{start} =291 N _{end} =265 TPS=Subacute | E: Psychosocial intervention that included home sessions with a mental health worker C: Conventional care. Duration: 45min/d, 1d/wk for 12wk | <ul style="list-style-type: none"> • Barthel Index (-) • Center for epidemiologic studies - depression (-) • Mini mental state exam (-) • Barrera’s Inventory of Socially Supportive Behaviours (-) • Self-efficacy (-) |
| <u>Clark et al. (2003)</u> RCT (6) N _{start} =68 N _{end} =62 TPS=Acute | E: Stroke information package + counselling visits C: Conventional care Duration: 3 visits (1hr each) over 5mo | <ul style="list-style-type: none"> • Adelaide Activities Profile (+exp) • Barthel Index (+exp) • Short Form Heal Survey 36 (+exp) • McMaster Family Assessment Device (+exp) • Geriatric Depression Scale (-) • Hospital Anxiety and Depression Scale – Anxiety (+exp) • Mastery Scale (-) |
| <u>Friedland & McColl (1992)</u> RCT (5) N _{start} =107 N _{end} =78 TPS=Chronic | E: Social support intervention C: Conventional care Duration: 6-12 sessions over 3mo | <ul style="list-style-type: none"> • Social Support Inventory for Stroke Survivors (-) • Interpersonal Support Evaluation List (-) • General Health Questionnaire-28 (-) • Stroke-Adapted Sickness Impact Profile (-) |
| Group psychosocial therapy sessions vs conventional care | | |
| <u>Wang et al. (2013)</u> RCT (4) N _{start} =170 N _{end} =127 TPS=NR | E: Community based stroke nursing education and support group programme C: General stroke education programme Duration: 2hrs, 3x/wk, 8wks, 6mo follow up | <ul style="list-style-type: none"> • Self-efficacy (-) • warning signs and treatment (-) • risk factors for stroke (+exp) • diet (-) • social participation (-) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.

+exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group

+exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group

+con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group

- indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about early supported discharge

| COGNITION | | | |
|-----------|--|------|--------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Individual psychosocial support may not have a difference in efficacy compared to conventional care for improving cognition. | 1 | Glass et al., 2004 |

| MENTAL HEALTH | | | |
|---------------|---|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | There is conflicting evidence about the effect of individual psychosocial support to improve mental health when compared to conventional care . | 4 | Robinson-Smith et al., 2016; Glass et al., 2004; Clark et al., 2003; Friedland & McMoll, 1992 |
| 2 | <u>For caregivers:</u> There is conflicting evidence about the effect of individual psychosocial support to improve mental health when compared to conventional care . | 1 | Robinson-Smith et al., 2016 |
| 2 | Group psychosocial support may not have a difference in efficacy compared to conventional care for improving mental health. | 1 | Wang et al., 2013 |

| SELF-EFFICACY | | | |
|---------------|--|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Individual psychosocial support may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 3 | Robinson-Smith et al., 2016; Glass et al., 2004; Clark et al., 2003 |
| 2 | Group psychosocial support may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 1 | Wang et al., 2013 |

| ACTIVITIES OF DAILY LIVING | | | |
|----------------------------|--|------|--|
| LoE | Conclusion Statement | RCTs | References |
| 1a | There is conflicting evidence about the effect of individual psychosocial support to improve activities of daily living when compared to conventional care . | 2 | Glass et al., 2004; Clark et al., 2003 |

| QUALITY OF LIFE & OPTIMISM | | | |
|----------------------------|--|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | There is conflicting evidence about the effect of individual psychosocial support to improve quality of life and optimism when compared to conventional care . | 4 | Robinson-Smith et al., 2016; Glass et al., 2004; Clark et al., 2003; Friedland & McMoll, 1992 |
| 2 | <u>For caregivers:</u> There is conflicting evidence about the effect of individual psychosocial support to improve quality of life and optimism when compared to conventional care . | 1 | Robinson-Smith et al., 2016 |

STROKE SEVERITY

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|--------------------------|
| 2 | Individual psychosocial support may not have a difference in efficacy compared to conventional care for improving stroke severity. | 1 | Friedland & McMoll, 1992 |

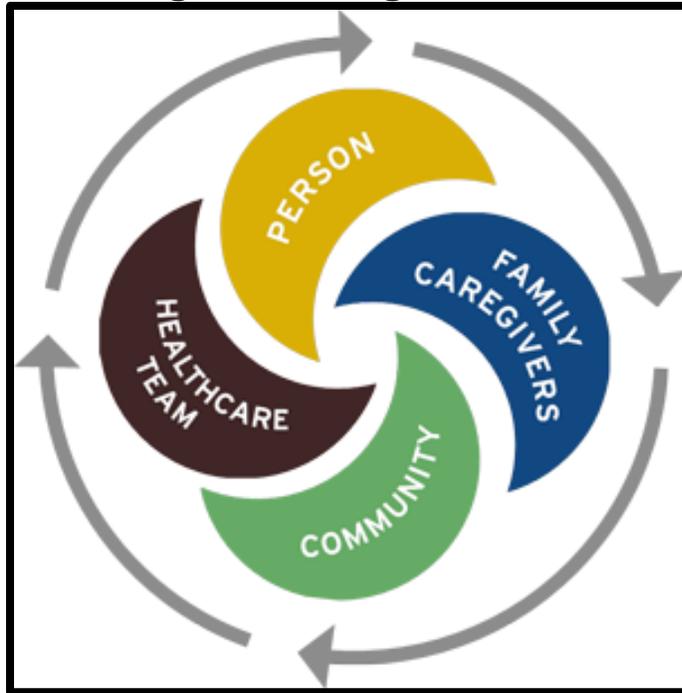
COMMUNITY REINTEGRATION & SOCIAL SUPPORT

| LoE | Conclusion Statement | RCTs | References |
|-----|---|------|--|
| 1a | Individual psychosocial support may not have a difference in efficacy compared to conventional care for improving community reintegration and social support. | 3 | Glass et al., 2004; Clark et al., 2003; Friedland & McMoll, 1992 |

Key Points

There is conflicting evidence about the effect of psychosocial and emotional support programs to improve mental health, activities of daily living, quality of life and optimism.

Discharge Planning and Active Care Management



Adopted from: https://health.ucdavis.edu/nursing/Research/research_distinctions/ca_mobile.html

Given the need for ongoing support, patients and their carers should be included in making decisions and setting goals at the time of discharge home from inpatient care. Although patients and their families may be provided with a great deal of information at the time of discharge, patients may experience dissatisfaction around their relative lack of involvement in the process of decision-making in discharge planning (Almborg et al., 2009). Stroke rehabilitation is not the single responsibility of any one individual, but a collaborative effort between all members in a patient's circle of care. How that care is provided is a coordinated and targeted effort that requires planning, organisation and communication both between the patient and their circle of care, and among the caregivers themselves. How that care is delivered can take on any number of forms (education, home visits, weekly phone calls). By employing a strategy whereby patients are actively monitored post-discharge, clinicians can ensure they address their issues and concerns in a timely manner. Studies in the following section often include education and psychosocial support that has been addressed above, Importantly however, the individual(s) administering the intervention is in contact with the other members in a patient's circle of care and will communicate patient needs or concerns to them.

16 RCTs were found that evaluated some form of enhanced discharge planning and/or active follow up. 14 RCTs compared active care management to conventional care (Saal et al., 2015; Mayo et al., 2008; Burton & Gibbon, 2005; Tilling et al., 2005; Boter et al., 2004; Smith et al., 2004; Lincoln et al., 2003; Mant et al., 2000; Dennis et al., 1997; Foster & Young, 1996; Towle et al., 1989; Christie & Weigall, 1984). One RCT compared a pre-discharge home visit to a home interview in the clinic (Drummond et al., 2013). One RCT compared a six-month patient re-assessment to conventional care (Forster et al., 2009).

The methodological details and results of all 16 RCTs evaluating discharge planning and active care management for community rehabilitation are presented in Table 3.

Table 3. RCTs evaluating active care management and follow-up interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size_{start} Sample Size_{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|--|---|---|
| Active Care Management vs conventional care/information only | | |
| Saal et al. (2015) RCT (8) N _{start} =265 N _{end} =230 TPS=Subacute | E: Post-discharge stroke outreach support C: Usual care Duration: 12mo | <ul style="list-style-type: none"> • Stroke Impact Scale (-) • World Health Organization Quality of Life (-) • Geriatric Depression Scale (-) • Symptom Checklist (-) |
| Allen et al. (2009) RCT (9) N _{start} =380 N _{end} =319 TPS=Chronic | E: Post discharge management + enhanced discharge planning C: Usual Care Duration: 6mo | <ul style="list-style-type: none"> • National Institutes of health Stroke Scale (-) • Length of Stay/ Reduction of Mortality (-) • Stroke Specific Quality of Life (-) • Stroke Knowledge and Lifestyle Modification (+exp) |
| Mayo et al. (2008) RCT (8) N _{start} = 190 N _{end} =157 TPS= Acute | E: Home visits + telephone contacts C: Conventional care Duration: 6wks | <ul style="list-style-type: none"> • Physical Component Summary (SF36) score of the SF36 (-) • Mental Component Summary (-) • EQ5D (-) • Preference-based Stroke Index (-) • Reintegration to Normal Living Index (-) • Barthel Index (-) • Geriatric Depression Scale (-) |
| Claiborne (2006) RCT (5) N _{start} =28 N _{end} =28 TPS=Acute | E: Care coordination C: Usual Care Duration: 3mo | <ul style="list-style-type: none"> • Geriatric Depression Scale (+exp) • SF-36 – mental component scale (+exp) |
| Burton & Gibbon (2005) RCT (7) N _{start} =176 N _{end} =128 TPS= Acute | E: Home visits from stroke nurse C: No follow-up Duration: Variable, 0-12 months (3mo outcomes) | <ul style="list-style-type: none"> • Beck Depression Inventory (-) • Barthel Index (+exp) • Nottingham Health Profile (-) • Caregiver Strain Index (+exp) |
| Tilling et al. (2005) RCT (7) N _{start} =340 N _{end} =188 TPS= Subacute | E: Support from the Family Support Organizer C: Conventional care Duration: 12mo | <p><u>Patients</u></p> <ul style="list-style-type: none"> • Reintegration to Normal Living Index (+exp) • Pound Satisfaction Scale – Patient (-) • Home adaptations & equipment (-) • Hospital anxiety and depression scale – Anxiety (-) • Hospital anxiety and depression scale – Depression (-) • Barthel Index (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> • Hospital anxiety and depression scale – Anxiety (-) • Hospital anxiety and depression scale – Depression (-) • Pound Satisfaction Scale – Caregiver (-) • Caregiver Strain Index (-) |
| Boter et al. (2004) RCT (6) N _{start} = 536 N _{end} = 486 TPS=Acute | E: Home visit+ telephone calls by a nurse following discharge C: Conventional care Duration: 3 calls, 1 home visit in 5mo | <p><u>Patients</u></p> <ul style="list-style-type: none"> • Satisfaction with Stroke Care Questionnaire – 19 (-) • Short Form 36 (-) • Hospital Anxiety and Depression Scale – Anxiety (+exp) • Hospital Anxiety and Depression Scale – Depression (-) • Barthel Index (-) |

| | | |
|---|--|--|
| | | <ul style="list-style-type: none"> Modified Rankin Scale (-) Use of health services (+con) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> Caregiver Strain Index (-) Sense of Competence Questionnaire (-) Social Support List – Discrepancies (-) |
| <p>Smith et al. (2004) RCT (8) N_{Start}=170 N_{End}=133 TPS=Subacute</p> | <p>E: Stroke Recovery Programme Manual + bi-weekly meetings with the multi-disciplinary care team C: Conventional care Duration: 1x/2wks in hospital (3mo follow up)</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> Stoke knowledge (-) Hospital Anxiety and Depression Scale – Anxiety (+exp) Hospital Anxiety and Depression Scale – Depression (-) Barthel Index (-) Frenchay Activities Index (-) London Handicap Scale (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> Stoke knowledge (-) General Health Questionnaire 28 (-) |
| <p>Lincoln et al. (2003) RCT (5) N_{Start}= 250 N_{End}= 187 TPS=NR</p> | <p>E: The Stroke Family Support Organiser (FSO) service C: Conventional care Duration: 9mo</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> General Health Questionnaire – 28 (-) Barthel Index (-) Extended Activities of Daily Living (-) Knowledge of Stroke (+exp) Knowledge of community services (+exp) Knowledge of emotional support (+exp) Satisfaction with information on stroke (-) Satisfaction with information on community services (+exp) Satisfaction with information on emotional support (+exp) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> General Health Questionnaire – 28 (-) Caregiver Strain Index (-) Extended Activities of Daily Living (-) Knowledge of Stroke (+exp) Knowledge of community services (-) Knowledge of emotional support (+exp) Satisfaction with information on stroke (-) Satisfaction with information on community services (-) Satisfaction with information on emotional support (+exp) |
| <p>Mant et al. (2000) RCT (8) N_{Start}=520 N_{End}=323 TPS=Subacute</p> | <p>E: Family support care + information package C: Conventional care Duration: 6mo, contact frequency variable</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> Knowledge of Stroke (-) Frenchay activity index (-) Barthel Index (-) London Handicap Scale (-) HADS -A (-) HADS – D (-) Dartmouth co-op chart <ul style="list-style-type: none"> Physical fitness (-) Feelings (-) Daily activities (-) Social activities (-) Pain (-) Change in health (-) Overall health (-) Social support (-) Quality of life (-) |

| | | |
|--|--|--|
| | | <p><u>Caregivers</u></p> <ul style="list-style-type: none"> • Knowledge of Stroke (-) • Frenchay activity index (+exp) • General Health Questionnaire 28 (-) • Caregiver Strain Index (-) • Short Form 36 <ul style="list-style-type: none"> • Change (-) • Energy (+exp) • Mental health (+exp) • Pain (+exp) • Physical function (+exp) • Role limitation (emotional) (-) • Role limitation (physical) (-) • Social function (-) • General health perception (+exp) • Dartmouth co-op chart <ul style="list-style-type: none"> • Physical fitness (-) • Feelings (-) • Daily activities (-) • Social activities (-) • Pain (-) • Change in health (-) • Overall health (-) • Social support (-) • Quality of life (+exp) |
| <p><u>Dennis et al. (1997)</u> RCT (8) N_{start}= 417 N_{end}=327 TPS=Acute</p> | <p>E: Post-stroke visits from a stroke family care worker C: Conventional care Duration: 6mo</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> • Oxford Handicap Scale (-) • Barthel Index (-) • Frenchay Activities Inventory (-) • General health questionnaire – 30 (-) • social adjustment scale (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> • Caregiver hassle (-) • Frenchay Activities Index (-) • General health questionnaire – 30 (+exp) • Social adjustment scale (-) |
| <p><u>Forster & Young (1996)</u> RCT (6) N_{start}= 240 N_{end}= 191 TPS=Subacute</p> | <p>E: Specialized nurse visits (7x) C: Conventional care Duration: 12mo</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> • Frenchay Activities of daily Living (-) • Nottingham Health Profile (-) • Barthel Index (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> • General Health Questionnaire – 28 (-) |
| <p><u>Towle et al. (1989)</u> RCT (7) N_{start}=44 N_{end}=44 TPS=Chronic Note: depressed stroke patients</p> | <p>E: Information booklets+ follow up from social worker C: Information booklets Duration: 4mo</p> | <ul style="list-style-type: none"> • Extended activities of daily living questionnaire (-) • Frenchay activities index (-) • Use of community/ aids received (-) |
| <p><u>Christie and Weigall, (1984)</u> RCT (5) N_{start}=213 N_{end}=213 TPS=Chronic</p> | <p>E: Client-centred social work + home visits C: Conventional care Duration: 7 sessions over 12mo</p> | <ul style="list-style-type: none"> • Activity Independence Score (-) • Reduction of Mortality (-) • Use of community/acute health care resources (-) |
| Home visit pre-discharge vs home assessment interview (not in home) | | |
| <p><u>Drummond et al. (2013)</u> RCT (6) N_{start}=93 N_{end}=85 TPS=Acute/Subacute</p> | <p>E: Home visit by an occupational therapist C: home assessment interview (in hospital) Duration: 1 visit/interview</p> | <ul style="list-style-type: none"> • Nottingham Extended Activities of Daily Living Scale (-) • Barthel Index (-) • Rivermead Mobility Index (-) • Stroke Aphasic Depression Questionnaire (-) |

| | | |
|---|--|--|
| | | <ul style="list-style-type: none"> • General Health Questionnaire-28 (-) • Caregiver strain index (-) • European Quality of Life – 5D (-) |
| Six month patient re-assessment vs conventional care | | |
| <u>Forster et al.</u> (2009) RCT (8) N _{start} = 265 N _{end} =242 TPS=Chronic | E: 6mo post-stroke structured patient/carer re-assessment C: Conventional care Duration: 2 assessments | <u>Patient outcomes</u> <ul style="list-style-type: none"> • Frenchay Activities Inventory (-) • Barthel Index (-) • Hospital anxiety and depression scales (-) <u>Caregiver outcomes</u> <ul style="list-style-type: none"> • Caregiver strain index (-) • General Health Questionnaire-28 (-) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.

+exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group

+exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group

+con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group

- indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about discharge planning and active care management

| ACTIVITIES OF DAILY LIVING | | | |
|----------------------------|--|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 12 | Saal et al., 2015; Mayo et al., 2008; Burton & Gibbon, 2005; Tilling et al., 2005; Boter et al., 2004; Smith et al., 2004; Lincoln et al., 2003; Mant et al., 2000; Dennis et al., 1997; Foster & Young, 1996; Towle et al., 1989; Christie & Weigall, 1984 |
| 1a | <u>For caregivers:</u> Active care management may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 3 | Lincoln et al., 2003; Mant et al., 2000; Dennis et al., 1997 |
| 1b | Pre-discharge home visits may not have a difference in efficacy compared to in clinic home assessment interview for improving activities of daily living. | 1 | Drummond et al., 2013 |
| 1b | Six-month reassessment may not have a difference in efficacy compared to no reassessment for improving activities of daily living. | 1 | Forster et al., 2009 |

| BALANCE, AMBULATION & MOBILITY | | | |
|--------------------------------|---|------|-----------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Pre-discharge home visits may not have a difference in efficacy compared to in clinic home assessment interview for improving balance, ambulation and mobility. | 1 | Drummond et al., 2013 |

| SATISFACTION | | | |
|--------------|--|------|--|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving satisfaction. | 3 | Tilling et al., 2005; Boter et al., 2004; Lincoln et al., 2003 |
| 1b | <u>For caregivers:</u> Active care management may not have a difference in efficacy compared to conventional care for improving satisfaction. | 2 | Tiling et al., 2005; Lincoln et al., 2003 |

MENTAL HEALTH

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|---|
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving mental health. | 10 | Saal et al., 2015; Mayo et al., 2008; Claireborne 2006; Burton & Gibbon, 2005; Tilling et al., 2005; Boter et al., 2004; Smith et al., 2004; Lincoln et al., 2003; Mant et al., 2000; Dennis et al., 1997 |
| 1a | <u>For caregivers:</u> Active care management may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 6 | Tiling et al., 2005; Smith et al., 2004; Lincoln et al., 2003; Mant et al., 2000; Dennis et al., 1997; Forster & Young, 1996 |
| 1b | Pre-discharge home visits may not have a difference in efficacy compared to in clinic home assessment interview for improving mental health. | 1 | Drummond et al., 2013 |
| 1b | Six-month reassessment may not have a difference in efficacy compared to no reassessment for improving mental health. | 1 | Forster et al., 2009 |
| 1b | <u>For caregivers:</u> Six-month reassessment may not have a difference in efficacy compared to no reassessment for improving mental health. | 1 | Forster et al., 2009 |

SELF-EFFICACY

| LoE | Conclusion Statement | RCTs | References |
|-----|---|------|--------------------|
| 1b | <u>For caregivers:</u> Active care management may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 1 | Boter et al., 2004 |

QUALITY OF LIFE & OPTIMISM

| LoE | Conclusion Statement | RCTs | References |
|-----|---|------|--|
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 8 | Saal et al., 2015; Allen et al., 2009; Mayo et al., 2008; Claireborne, 2006; Burton & Gibbon, 2005; Boter et al., 2004; Mant et al., 2000; Forster & Young, 1996 |
| 1b | <u>For caregivers:</u> There is conflicting evidence about the effect of active care management to improve activities of daily living when compared to conventional care . | 1 | Mant et al., 2000 |
| 1b | Pre-discharge home visits may not have a difference in efficacy compared to in clinic home assessment interview for improving quality of life and optimism. | 1 | Drummond et al., 2013 |

STROKE SEVERITY

| LoE | Conclusion Statement | RCTs | References |
|-----|---|------|---|
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving stroke severity. | 3 | Allen et al., 2009; Boter et al., 2004; Dennis et al., 1997 |

COMMUNITY REINTEGRATION & SOCIAL SUPPORT

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|---|
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving community reintegration and social support. | 6 | Mayo et al., 2008; Tiling et al., 2005; Boter et al., 2004; Dennis et al., 1997; Towle et al., 1989; Christie & Weigall, 1984 |
| 1a | <u>For caregivers:</u> Active care management may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 3 | Smith et al., 2004; Lincoln et al., 2003; Mant et al., 2000 |

EDUCATION

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|---|
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving education. | 4 | Allen et al., 2009; Smith et al., 2004; Lincoln et al., 2003; Mant et al., 2000 |
| 1a | <u>For caregivers:</u> Active care management may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 3 | Boter et al., 2004; Dennis et al., 1997 |

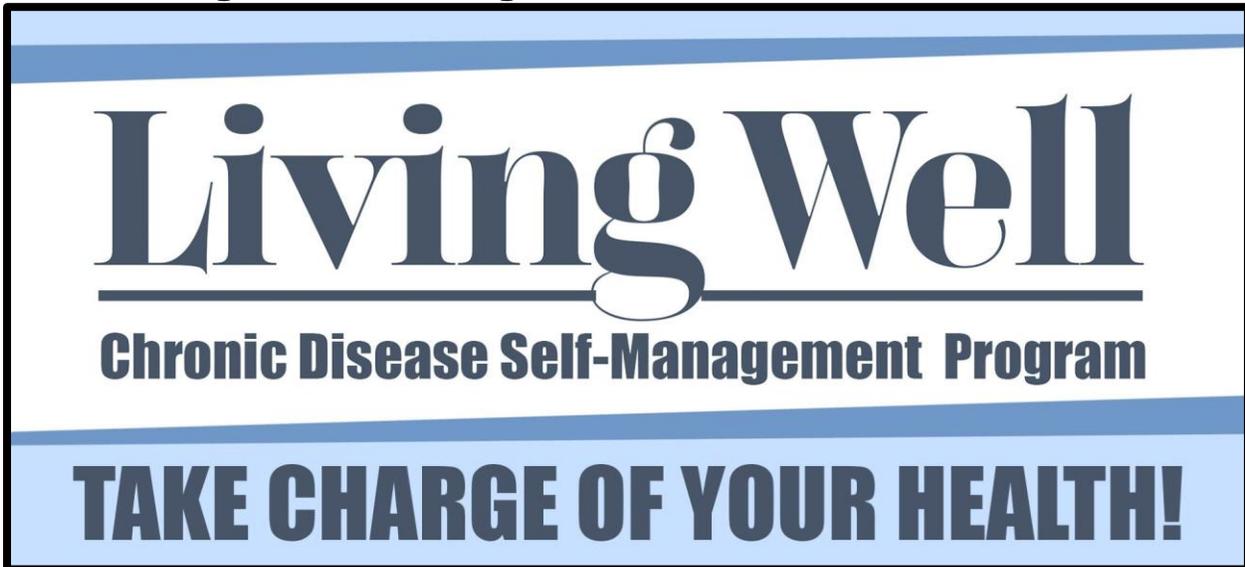
CAREGIVER BURDEN

| LoE | Conclusion Statement | RCTs | References |
|-----|---|------|--|
| 1a | Active care management may not have a difference in efficacy compared to conventional care for improving caregiver burden. | 6 | Tiling et al., 2005; Burton & Gibbon, 2005; Boter et al., 2004; Lincoln et al., 2003; Mant et al., 2000; Dennis et al., 1997 |
| 1b | Pre-discharge home visits may not have a difference in efficacy compared to in clinic home assessment interview for improving caregiver burden. | 1 | Drummond et al., 2013 |
| 1b | Six-month reassessment may not have a difference in efficacy compared to no reassessment for improving caregiver burden. | 1 | Forster et al., 2009 |

Key Points

Discharge planning and active care management may not improve patient or caregiver outcomes.

Self-Management Strategies



Adopted from: <https://www.princegeorgescountymd.gov/3199/Chronic-Disease-Self-Management-Program>

The concept of self-management has existed since its introduction by Bandura in 1977 as part of the Social Learning Theory. It has been defined as “people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives” (Jones & Riazi, 2011). Essentially, self-management functions to influence how people behave, motivate themselves, feel, and think which ultimately facilitates ones’ well-being. For patients affected by chronic conditions like stroke, adopting self-management concepts during rehabilitation facilitates recovery and maintenance of the progress made. Programs that promote self-management thinking help stroke patients to modify their behavior and lifestyle such that when challenges are encountered and difficult to overcome, the individuals can still maintain a sense of resilience despite any negative outcomes that may occur (Dixon et al., 2007; Jones & Riazi, 2011). These types of programs have previously been offered in various forms, whether through family support programs, self-help groups, or community services. It is important to note that self-management programs differ from educational programs (i.e. programs that involve knowledge learning or skills training) since they are designed to encourage patients to actively participate in the management of their own condition (Foster et al., 2007).

Six RCTs were found that evaluated self-management strategies. Five RCTs compared self management programs to conventional care (McKellar et al., 2015; Sit et al., 2016; Jones et al., 2016a; Cadhilac et al., 2011; Johnson & Pearson, 2000). One RCT compared a weekly medication text reminder to usual care (Kamal et al., 2015).

The methodological details and results of all five RCTs evaluating self-management strategies for community rehabilitation are presented in Table 4.

Table 4. RCTs evaluating self management interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size_{start} Sample Size_{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|--|--|---|
| Self-management programs vs conventional care | | |
| McKellar et al. (2015) RCT (5) N _{Start} =77 N _{End} =57 TPS=Subacute | E: Heart and Stroke Foundation booklet, tip sheet, and Cue to Action Trigger Tool (CRCATT) +visits from a research coordinator C: Heart and Stroke Foundation booklet | <ul style="list-style-type: none"> • Reintegration to Normal Living Index (-) |
| Sit et al. (2016) RCT (8) N _{Start} =210 N _{End} =175 TPS=NR | E: Health Empowerment Intervention for Stroke Self-Management C: Usual care Duration: 13wks | Chinese Self-management behaviour questionnaire <ul style="list-style-type: none"> • Illness management self-efficacy (+exp) • Cognitive self-management (+exp) • Physician communication (+exp) • Medication adherence (-) • Self blood-pressure monitoring (+exp) • Barthel Index (+exp) • Chinese Lawton instrumental activities of daily living (+exp) |
| Jones et al. (2016a) RCT (7) N _{Start} =78 N _{End} =66 TPS=Subacute | E: Bridges self-management program C: Usual care Duration: 12wks | <ul style="list-style-type: none"> • Stroke Self-Efficacy Questionnaire (-) • Hospital Anxiety and Depression Scale – Anxiety (-) • Hospital Anxiety and Depression Scale – Depression (-) • Medical Outcomes Trust's Short Form (-) • Nottingham Extended Activities of Daily Living (-) • Stroke and Aphasia Quality of Life (-) |
| Cadhilac et al. (2011) RCT (7) N _{Start} =143 N _{End} =122 TPS=Chronic | E1: Attend a stroke specific self-management program (8wks) E2: Attend a generic self-management program (6wks) C: No management program Duration: 2.5hrs/wk, 6mo (follow up) | <ul style="list-style-type: none"> • Irritability, Depression and Anxiety Scale (-) • Health Education Impact Questionnaire – positive/active life engagement (-) • Assessment of Quality of Life (-) • Adherence (+exp) |
| Johnson & Pearson (2000) RCT (5) N _{Start} =41 N _{End} =41 TPS=Chronic | E: StrokeWise educational course C: Conventional care Duration: 2hrs, 2x/wk, 4wks | <ul style="list-style-type: none"> • Beck Depression Inventory (+exp) • Herth Hope Scale (+exp) • Ways of Coping-Cardiovascular Accident (-) |
| Weekly text reminders vs conventional care | | |
| Kamal et al. (2015) RCT (7) N _{Start} =200 N _{End} =162 TPS=Subacute | E: Automated weekly SMS reminders customized to patient condition. C: Usual Care Duration: 2mo | <ul style="list-style-type: none"> • Morisky Medication Adherence (+exp) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.
 +exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group
 +exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group
 +con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group
 - indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about self-management strategies

| ACTIVITIES OF DAILY LIVING | | | |
|----------------------------|---|------|---------------------------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1a | There is conflicting evidence about the effect of self-management programs to improve activities of daily living when compared to conventional care . | 2 | Sit et al., 2016; Jones et al., 2016a |

| COMMUNITY REINTEGRATION & SOCIAL SUPPORT | | | |
|--|--|------|-----------------------|
| LoE | Conclusion Statement | RCTs | References |
| 2 | Self-management programs may not have a difference in efficacy compared to conventional care for improving community reintegration and social support. | 1 | McKellar et al., 2015 |

| MENTAL HEALTH | | | |
|---------------|---|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Self-management programs may not have a difference in efficacy compared to conventional care for improving mental health. | 3 | Jones et al., 2016a; Cadhilac et al., 2011 Johnson & Pearson, 2000 |

| QUALITY OF LIFE & OPTIMISM | | | |
|----------------------------|--|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Self-management programs may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 3 | Jones et al., 2016a; Cadhilac et al., 2011 Johnson & Pearson, 2000 |

| SELF-EFFICACY | | | |
|---------------|---|------|--|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Self-management programs may produce greater improvements in self-efficacy than conventional care . | 3 | Jones et al., 2016a; Sit et al., 2016; Cadhilac et al., 2011 |
| 1b | Weekly text reminders may produce greater improvements in self-efficacy than conventional care . | 1 | Kamal et al., 2015 |

| EDUCATION | | | |
|-----------|---|------|-----------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Self-management programs may not have a difference in efficacy compared to conventional care for improving education. | 1 | Cadhilac et al., 2011 |

Key Points

Self management programs may be beneficial for improving self-efficacy.

Caregiver Training and Support Programs



Adopted from: <https://www.mcmasteroptimalaging.org/blog/detail/blog/2019/07/16/supporting-caregivers-of-frail-older-adults>

In their 1998 review of interventions with families post stroke, Korner-Bitensky et al. (1998) concluded that helping caregivers to maintain social and leisure activity may result in improved caregiver wellbeing. Roughly 52.1% of caregivers spend more than 8 hours a day providing caregiving support to the stroke survivor (Yu et al., 2013). In an observational study, Yu et al. (2013) found that 72.7% of caregivers were women and many suffered from hypertension (70.4%), heart disease (33.3%), bone and joint disease (16%), and diabetes (12.3%). Many caregivers indicated having adopted several coping strategies such as acceptance, active coping, planning, and positive reframing, to manage their role as a caregiver and to cope with the caregiving stress. Caregivers may find themselves in the position of having to provide skilled nursing assistance to the stroke survivor while having little or no experience in delivering appropriate care and support. They often receive no training or instruction and, therefore, have no choice but to learn what is required of them in their new role by trial and error (Silverstone & Horowitz, 1987). The role of caregiver may be perceived simply as an accepted obligation (Hare et al., 2006; Sit et al., 2004). The demands associated with learning how to appropriately care for and support the stroke survivor may be perceived as overwhelming by the carer (Grant et al., 2004a). Studies in this section will focus on interventions designed around the caregiver, as opposed to the patient

19 RCTs were found that evaluated caregiver training and support programs. Eight RCTs compared caregiver training programs to conventional care (Van den Berg et al., 2016; Bakas et al., 2015; Wang et al., 2015; Forster et al., 2013; King et al., 2012; Bakas et al., 2009a; Kalra et al., 2004; Grant et al., 1999). Ten RCTs compared caregiver education and/or counselling to conventional care (Cameron et al., 2015; Malini et al., 2015; Smith et al., 2012; Perrin et al., 2010; Pierce et al., 2009; Franzen-Dahlin et al., 2008; Stiener et al., 2008; Larson et al., 2005b; Hartke & King, 2003; Van den Heuvel et al., 2002). One RCT compared caregiver education to caregiver counselling to conventional care (Evans et al., 1988).

The methodological details and results of all 19 RCTs evaluating caregiver training and support programs for community rehabilitation are presented in Table 5.

Table 5. RCTs evaluating caregiver-oriented interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size _{start} Sample Size _{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|---|--|--|
| Caregiver training programs vs conventional care | | |
| Van den Berg et al. (2016) RCT (8) N _{Start} =63 N _{End} =63 TPS=Acute | E: caregiver-mediated training program with an exercise support app and Fitbit Zip C: Usual interdisciplinary rehabilitation care Duration: 8wks | <p><u>Patient</u></p> <ul style="list-style-type: none"> Stroke Impact Scale <ul style="list-style-type: none"> mobility (-) memory (-) strength (-) ADLs (-) Social participation (-) Recovery (-) Patient Timed up and Go (-) Berg Balance Scale (-) Barthel Index (-) Nottingham Extended ADL (-) Length of Stay (-) Self-efficacy (+exp) HADS (-) <p><u>Caregiver</u></p> <ul style="list-style-type: none"> HADS (-) careerQOL (-) Caregivers Strain Index (-) Self-efficacy (-) |
| Bakas et al. (2015) RCT (8) N _{Start} =254 N _{End} =176 TPS=Chronic | E: Telephone Assessment and Skill-Building Kit resource guide. C: Telephone Information and Support only Duration: 8wks | <p><u>Caregivers</u></p> <ul style="list-style-type: none"> Patient health questionnaire-9 (-) Bakas caregiving outcomes scale (-) Unhealthy days (+exp) |
| Wang et al. (2015) RCT (6) N _{Start} =51 N _{End} =51 TPS = Chronic | E: Weekly personalized caregiver home based (CHI) training C: Usual Care Duration: 90min/d, 5d/wk for 12wks | <p><u>Patients</u></p> <ul style="list-style-type: none"> Stroke Impact Scale <ul style="list-style-type: none"> Physical (+exp) Memory (-) Communication (+exp) Emotion (-) Social participation (+exp) General recovery (+exp) Walking speed (-) 6 Minute Walking Test (+exp) Berg Balance Scale (+exp) Barthel Index (BI) (+exp) <p><u>Caregiver</u></p> <ul style="list-style-type: none"> Caregiver Burden Scale (-) |
| Forster et al. (2013) RCT (5) N _{Start} =930 N _{End} =690 TPS=Subacute | E: London Stroke Carers Training Course (LSCTC) C: Conventional care Duration: all training done before patient discharge | <p><u>Patients</u></p> <ul style="list-style-type: none"> Nottingham Extended Activities of Daily Living (-) Barthel Index (-) EQ-5D (-) HADS-Anxiety (-) HADS Depression (-) SIS (-) |

| | | |
|---|--|---|
| | | <u>Caregivers</u> <ul style="list-style-type: none"> • Caregiver Burden Scale (-) • HADS Anxiety (-) • HADS Depression (-) • EQ-5D (-) • Frenchay Activities Index (-) |
| <u>King et al. (2012)</u> RCT (7) N _{Start} =225 N _{End} =145 TPS=NR | E: Caregiver problem solving intervention + sessions with a clinical psychology student C: wait-list control Duration: 10 sessions, | <u>Patients</u> <ul style="list-style-type: none"> • Functional Independence Measure (-) <u>Caregivers</u> <ul style="list-style-type: none"> • Centre for Epidemiological Studies – Depression (-) • Bakas Caregiving Outcome Scale (-) • Preparedness for Caregiving Scale (-) • Profile of Mood Scale - Tension-Anxiety (-) • McMaster Family Assessment Device – General Functioning (-) • Perceived health (+exp) • Social problem Solving Index (-) |
| <u>Bakas et al. (2009a)</u> RCT (6) N _{Start} =40 N _{End} =40 TPS=NR | E: Telephone Assessment and Skill-Building Kit resource notebooks + weekly calls from a nurse offering advice C: Brochure on family caregiving + weekly calls from a nurse who did not offer advice Duration: 8wks | <u>Caregivers</u> <ul style="list-style-type: none"> • Usefulness of intervention (+exp) • Ease of Use of intervention (+exp) • Acceptability of intervention (+exp) • Satisfaction of intervention (+exp) |
| <u>Kalra et al. (2004)</u> RCT (7) N _{Start} =300 N _{End} =268 TPS=NR | E: Training in basic nursing + techniques for personal care (3-5 sessions, 30-45min) C: Conventional care Duration: 3mo follow up | <u>Patients</u> <ul style="list-style-type: none"> • Patient mortality (-) • Health care / social care cost (+exp) • Barthel Index (+exp) • Hospital anxiety and depression scale – anxiety (+exp) • Hospital anxiety and depression scale – depression (+exp) • EuroQOL (+exp) <u>Caregivers</u> <ul style="list-style-type: none"> • Frenchay Activities Index (-) • Hospital anxiety and depression scale – anxiety (+exp) • Hospital anxiety and depression scale – depression (+exp) • EuroQOL (+exp) • Caregiver burden scale (+exp) |
| <u>Grant (1999)</u> RCT (4) N _{Start} =30 N _{End} =30 TPS=Subacute Note: subjects are caregivers | E1: Social problem solving telephone partnerships E2: Sham telephone intervention C: Conventional care Duration: 13wks (a 3hr home visit at discharge + phone calls 1 st month weekly, 2 nd + 3 rd month biweekly) | <u>Caregivers</u> <ul style="list-style-type: none"> • Short Form 36 <ul style="list-style-type: none"> • physical functioning (-) • general health (-) • Problem Solving Inventory (-) • Client Satisfaction Questionnaire (-) • Center for Epidemiological Studies – depression (-) • Preparedness for Caregiving (-) • Caregiving Burden Scale (-) |
| Caregiver education and/or counselling vs conventional care | | |

| | | |
|---|--|--|
| <p>Cameron et al. (2015) RCT (6) N_{Start}=31 N_{End}=19 TPS=Acute</p> | <p>E1: Timing it Right Stroke Family Support Program (caregiver-directed) (info only) E2: Timing it Right Stroke Family Support Program (stroke support person-directed) (telephone follow up calls) C: Usual care Duration: 1 in person session, 6 calls/mo, 6mo</p> | <p><u>Caregivers</u> <u>E1 vs E2</u></p> <ul style="list-style-type: none"> Positive affect scale (-) Centre for epidemiological studies depression scale (-) Medical outcomes study social support scale (-) Pearlin's mastery scale (-) <p><u>E1/E2 vs C</u></p> <ul style="list-style-type: none"> Positive affect scale (-) Centre for epidemiological studies depression scale (-) Medical outcomes study social support scale (+exp2) Pearlin's mastery scale (+exp1) |
| <p>Malini (2015) RCT (4) N_{Start}=240 N_{End}=238 TPS=Chronic</p> | <p>E: Social support groups with fellow villagers C: Usual care Duration: 2x/mo, 3mo</p> | <ul style="list-style-type: none"> Family strength questionnaire (+exp) |
| <p>Smith et al. (2012) RCT (6) N_{Start}=38 N_{End}=32 TPS=NR</p> | <p>E: Web-based Educational videos, online chat sessions, e-mail and message boards, a resource room + professional guide for caregivers C: online information only Duration: 11wks, 1 topic /wk</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> Mastery Scale (-) Centre for epidemiological studies depression scale (-) Self-esteem (10-Item Self-Esteem Scale) (-) Social support (MOS Social support survey) (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> Mastery Scale (-) Centre for epidemiological studies depression scale (+exp) Self-esteem (10-Item Self-Esteem Scale) (-) Social support (MOS Social support survey) (-) |
| <p>Perrin et al. (2010) RCT (3) N_{Start}=89 N_{End}=61 TPS=NR</p> | <p>E: Transition Assistance Program including interview with clinical interventionalist + videophone contacts C: Conventional care Duration: 3mo</p> | <p><u>Patients</u></p> <ul style="list-style-type: none"> Functional independence measure (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> Caregiver Strain Index (+exp) Center for Epidemiological Studies – depression (-) |
| <p>Pierce et al. (2009) RCT (5) N_{Start}=103 N_{End}=78 TPS=NR</p> | <p>E: Use of "Caring Web" C: Did not use "Caring Web" Duration: 12mo</p> | <p><u>Caregivers</u></p> <ul style="list-style-type: none"> Centre for epidemiological studies depression scale (+exp) Satisfaction with Life Scale (-) Healthcare service use (+exp) Hospital re-admissions (+exp) |
| <p>Franzen-Dahlin et al. (2008) RCT (6) N_{Start}=100 N_{End}=91 TPS=NR</p> | <p>E: Specialist stroke nurse lead group meetings C: Conventional resources Duration: 1x/mo, 6mo</p> | <p><u>Patient</u></p> <ul style="list-style-type: none"> Barthel Index (-) Perceived health status VAS (-) <p><u>Caregivers</u></p> <ul style="list-style-type: none"> Comprehensive Psychopathological Rating Scale-Self-Affective (-) Availability of social integration (-) Availability of attachment (-) |

| | | |
|--|--|---|
| | | <ul style="list-style-type: none"> Abbreviated Antonovsky's Orientation to Life Questionnaire (-) Stroke Knowledge Questionnaire (-) Perceived economic situation (-) |
| Steiner et al. (2008) RCT (4) N _{Start} =103 N _{End} =73 TPS=NR | E: Use of "Caring Web" C: Did not use caring web Duration: 12mo | <u>Caregivers</u> <ul style="list-style-type: none"> Emotional support (-) Physical help (-) Caregiver health (-) |
| Larson et al. (2005b) RCT (5) N _{Start} =100 N _{End} =94 TPS=Subacute | E: Group education and support program (1/mo) C: Single session with a stroke specialist Duration: 6mo | <u>Caregivers</u> <ul style="list-style-type: none"> Present Quality of Life (-) General Well-being (-) Energy (-) Life situation (-) Worries (-) Powerlessness (-) Personal adjustment (-) Social isolation (-) Health state (-) |
| Hartke and King (2003) RCT (5) N _{Start} =124 N _{End} =88 TPS=Chronic | E: Weekly conference call education sessions + an information manual for caregivers C: Conventional care + information manual Duration: 8wks | <u>Caregivers</u> <ul style="list-style-type: none"> Centre for Epidemiological Studies – Depression (-) UCLA Loneliness Scale (-) Caregiver Competence Scale (+exp) The Burden Interview (+exp) Pressing Problem Index (-) |
| Van den Heuvel et al. (2002) Schure et al. (2006) RCT (5) N _{Start} =257 N _{End} =190 TPS=Chronic | E1: Group based support program E2: Home based support program C: Conventional care Duration: 14wks | <u>E1 v E2</u> <u>Caregivers</u> <ul style="list-style-type: none"> Satisfaction <ul style="list-style-type: none"> Informational support (+exp1) Emotional support (+exp1) Advisory support (-) self-knowledge (-) burden (-) Knowledge of patient care (-) Self-efficacy of patient care (-) Utrecht Coping List - Seeking social support (-) Amount of social support (-) Short Form 36 – mental well-being (-) Caregiver Strain Index (-) <u>E1/E2 vs C</u> <ul style="list-style-type: none"> Knowledge of patient care (+exp1) Knowledge of self-care (-) Utrecht Coping List - Seeking social support (+exp1) Amount of social support (+exp1) Short Form 36 – mental well-being (-) Caregiver Strain Index (-) |
| Caregiver education program vs caregiver counselling program vs conventional care | | |
| Evans et al. (1988) RCT (5) N _{Start} =213 N _{End} =188 TPS=Subacute | E1: Educational classes (2 sessions, 1hr) E2: Counselling sessions (2hrs education + 7 biweekly counselling sessions, 1hr) C: Conventional care Duration: 3mo post discharge (data @ 6mo follow up) | <u>E1/E2 vs C</u> <ul style="list-style-type: none"> Stroke Care Information Test (+exp2) Family Assessment Device (+exp1, +exp2) ESCROW (-) Personal Adjustment and Rolls Skills (+exp2) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.

+exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group
 +exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group
 +con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group
 - indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about caregiver training and support programs

| ACTIVITIES OF DAILY LIVING | | | |
|----------------------------|---|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Caregiver training programs may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 5 | Van den Berg et al., 2016; Wang et al., 2015; Forster et al., 2013; King et al., 2012; Kalra et al., 2004 |
| 1b | <u>For caregivers:</u> Caregiver training programs may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 2 | Forster et al., 2013; Kalra et al., 2004 |
| 1b | Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 2 | Perrin et al., 2010; Franzen-Dahlin et al., 2008 |

| BALANCE, AMBULATION & MOBILITY | | | |
|--------------------------------|--|------|--|
| LoE | Conclusion Statement | RCTs | References |
| 1a | There is conflicting evidence about the effect of caregiver training programs to improve balance, ambulation and mobility when compared to conventional care . | 2 | Van den Berg et al., 2016; Wang et al., 2015 |

| SATISFACTION | | | |
|--------------|--|------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1b | <u>For caregivers:</u> There is conflicting evidence about the effect of caregiver training programs to improve satisfaction when compared to conventional care . | 2 | Bakas et al., 2009a; Grant et al., 1999 |
| 2 | <u>For caregivers:</u> Group based support program may produce greater improvements in satisfaction than home based support program | 1 | Van den Heuvel et al., 2002 |

| COMMUNITY REINTEGRATION & SOCIAL SUPPORT | | | |
|--|--|------|--|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving community reintegration and social support. | 1 | Smith et al., 2012 |
| 1b | <u>For caregivers:</u> Caregiver training programs may not have a difference in efficacy compared to conventional care for improving community reintegration and social support. | 2 | King et al., 2012; Grant et al., 1999 |
| 1a | <u>For caregivers:</u> Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving community reintegration and social support. | 8 | Cameron et al., 2015; Malini et al., 2015; Smith et al., 2012; Pierce et al., 2009; Franzen-Dahlin et al., 2008; Stiener et al., 2008; Hartke & King, 2003; Van den Heuvel et al., 2002; |
| 2 | Caregiver counselling programs may produce greater improvements in community reintegration and social support than caregiver education programs . | 1 | Evans et al., 1988 |
| 1b | <u>For caregivers:</u> Caregiver education programs may not have a difference in efficacy compared to family support program for improving community reintegration and social support. | 1 | Cameron et al., 2015 |
| 2 | <u>For caregivers:</u> Group-based support programs may not have a difference in efficacy compared to home-based support programs for improving community reintegration and social support. | 1 | Van den Heuvel et al., 2002 |

| MENTAL HEALTH | | | |
|---------------|---|------|--|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Caregiver training programs may not have a difference in efficacy compared to conventional care for improving mental health. | 3 | Van den Berg et al., 2016; Forster et al., 2013; Kalra et al., 2004 |
| 1a | <u>For caregivers:</u> Caregiver training programs may not have a difference in efficacy compared to conventional care for improving mental health. | 6 | Van den Berg et al., 2016; Bakas et al., 2015; Forster et al., 2013; King et al., 2012; Kalra et al., 2004; Grant et al., 1999 |
| 1b | Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving mental health. | 1 | Smith et al., 2012 |
| 1a | <u>For caregivers:</u> Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving mental health. | 6 | Cameron et al., 2015; Smith et al., 2012; Franzen-Dahlin et al., 2008; Perrin et al., 2009; Pierce et al., |

| | | | |
|----|--|---|--------------------------|
| | | | 2009 Hartke & King, 2003 |
| 1b | <u>For caregivers:</u> Caregiver education programs may not have a difference in efficacy compared to family support program for improving mental health. | 1 | Cameron et al., 2015 |

QUALITY OF LIFE & OPTIMISM

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|---|
| 1b | There is conflicting evidence about the effect of caregiver training programs to improve quality of life and optimism when compared to conventional care . | 2 | Forster et al., 2013; Kalra et al., 2013 |
| 1a | <u>For caregivers:</u> Caregiver training programs may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 5 | Van den Berg et al., 2016; Forster et al., 2013; King et al., 2012; Kalra et al., 2004; Grant et al., 1999 |
| 1b | Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 2 | Smith et al., 2012; Franzen-Dahlin et al., 2008 |
| 1a | <u>For caregivers:</u> Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 5 | Smith et al., 2012; Pierce et al., 2009; Franzen-Dahlin et al., 2008; Larson et al., 2005b; Van den Heuvel et al., 2002 |
| 2 | <u>For caregivers:</u> Group-based support programs may not have a difference in efficacy compared to home-based support programs for improving quality of life and optimism. | 1 | Van den Heuvel et al., 2002 |

SELF-EFFICACY

| LoE | Conclusion Statement | RCTs | References |
|-----|--|------|--|
| 1b | Caregiver training programs may produce greater improvements in self-efficacy than conventional care . | 1 | Van den Berg et al., 2016 |
| 1a | <u>For caregivers:</u> Caregiver training programs may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 3 | Van den Berg et al., 2016; King et al., 2012; Grant et al., 1999 |
| 1b | Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 1 | Smith et al., 2012; |
| 1a | <u>For caregivers:</u> | 3 | Cameron et al., 2015; Smith et al., 2012; Hartke & King, 2003 |

| | | | |
|-----------|---|---|-----------------------------|
| | Caregiver education and/or counselling may not have a difference in efficacy compared to conventional care for improving self-efficacy. | | |
| 1b | For caregivers: Caregiver education programs may not have a difference in efficacy compared to family support program for improving self-efficacy. | 1 | Cameron et al., 2015 |
| 2 | For caregivers: Group-based support programs may not have a difference in efficacy compared to home-based support programs for improving self-efficacy. | 1 | Van den Heuvel et al., 2002 |

| EDUCATION | | | |
|------------------|--|-------------|--|
| LoE | Conclusion Statement | RCTs | References |
| 1b | For caregivers: There is conflicting evidence about the effect of caregiver education and/or counselling to improve education when compared to conventional care . | 2 | Franzen-Dahlin et al., 2008; Van den Heuvel et al., 2002 |
| 2 | Caregiver counselling programs may produce greater improvements in education than caregiver education programs . | 1 | Evans et al., 1988 |
| 2 | For caregivers: Group-based support programs may not have a difference in efficacy compared to home-based support programs for improving education. | 1 | Van den Heuvel et al., 2002 |

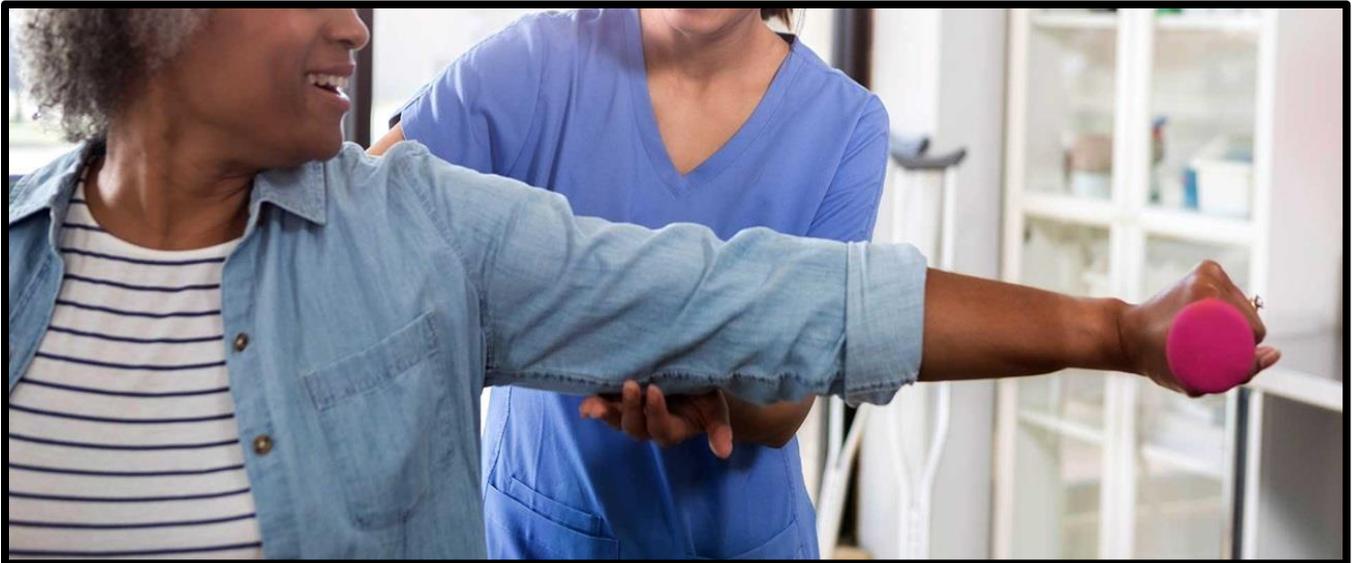
| CAREGIVER BURDEN | | | |
|-------------------------|--|-------------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Caregiver training programs may not have a difference in efficacy compared to conventional care for improving caregiver burden. | 7 | Van den Berg et al., 2016; Bakas et al., 2015; Wang et al., 2015; Forster et al., 2013; King et al., 2012; Kalra et al., 2004; Grant et al., 1999 |
| 1b | There is conflicting evidence about the effect of caregiver education and/or counselling to improve caregiver burden when compared to conventional care . | 4 | Perrin et al., 2010; Hartke & King, 2003; Van den Heuvel et al., 2002 |
| 2 | For caregivers: Group-based support programs may not have a difference in efficacy compared to home-based support programs for improving caregiver burden. | 1 | Van den Heuvel et al., 2002 |

Key Points

Caregiver training may not have specific benefits to carers.

Exercise and Physiotherapy Interventions

Adopted from: <https://www.hopkinsmedicine.org/health/conditions-and-diseases/stroke/arm-care-after-a-stroke>



A 2003 analysis of the effect of comprehensive occupational therapy (OT) interventions identified a small but significant favourable effect of OT intervention on ADL, extended ADL and social participation (Steultjens et al., 2003). Community-based, group exercise has also been examined for its possible social benefit. While effective in improving physical function as well as satisfaction with physical performance, evidence regarding the impact of group exercise on participation outcomes is less clear. On the other hand, factors such as perceived recovery, the amount of retained activities, and community reintegration have been found to predict perceived participation (Eriksson et al., 2013). The following section focuses on community or home-based exercise rehabilitation regimes.

Three RCTs were found that evaluated exercise and physiotherapy programs. One RCT compared a client centered home exercise program to conventional care (Bertilsson et al., 2016). One RCT compared a home exercise program with accompanying photo descriptions to a standard home exercise program (Kara et al., 2015). One RCT compared a community walking program to conventional care (Kim et al., 2014).

The methodological details and results of all three RCTs evaluating exercise and physiotherapy for community rehabilitation are presented in Table 6.

Table 6. RCTs evaluating exercise and physiotherapy interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size_{start} Sample Size_{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|--|---|---|
| Client centered home exercise program vs conventional care | | |
| <u>Bertilsson et al. (2016)</u> RCT (4) N _{start} =183 N _{end} =145 TPS=Subacute Note: subjects are caregivers | E: Client-centered support with activities of daily living C: Usual activities of daily living care Duration: 12mo | Caregivers <ul style="list-style-type: none"> • Caregiver burden scale (-) • Provision of Informal care (-) • Occupational Gaps questionnaire (-) • Life satisfaction (-) |
| Home exercise program with picture descriptions vs home exercises alone | | |
| <u>Kara et al. (2015)</u> RCT (8) N _{start} =42 N _{end} =36 TPS=Subacute | E: Standard home exercise programme and pictorial representations of the home exercises C: Standard home exercise programme alone Duration 4wks | <ul style="list-style-type: none"> • Adherence rate (-) • Modified Rivermead Mobility Index (-) • Barthel Index (-) |
| Community walking training vs standard rehabilitation | | |
| <u>Kim et al. (2014)</u> RCT (8) N _{start} =26 N _{end} =22 TPS=Chronic | E: Community walking training program (CWTP) + Standard rehabilitation C: Standard rehabilitation Duration: 30min/d, 5d/wk, 4wks | <ul style="list-style-type: none"> • Community Walking Course Assessment (timed) (+exp) • Stroke Impact Scale – social participation (+exp) • 10 Meter Walk Test (+exp) • 6 Minute Walking Test (+exp). |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.

+exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group

+exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group

+con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group

- indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about exercise and physiotherapy interventions

| ACTIVITIES OF DAILY LIVING | | | |
|----------------------------|--|------|-------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Home exercise program with picture description may not have a difference in efficacy compared to conventional home exercise for improving activities of daily living. | 1 | Kara et al., 2015 |

| BALANCE, AMBULATION & MOBILITY | | | |
|--------------------------------|--|------|-------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Home exercise program with picture description may not have a difference in efficacy compared to conventional home exercise for improving balance, ambulation and mobility. | 1 | Kara et al., 2015 |
| 1b | Community walking program may produce greater improvements in balance, ambulation and mobility than conventional care . | 1 | Kim et al., 2014 |

| COMMUNITY REINTEGRATION & SOCIAL SUPPORT | | | |
|--|---|------|------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Community walking program may produce greater improvements in community reintegration and social support than conventional care . | 1 | Kim et al., 2014 |

| QUALITY OF LIFE & OPTIMISM | | | |
|----------------------------|---|------|-------------------------|
| LoE | Conclusion Statement | RCTs | References |
| 2 | <u>For caregivers:</u> Client centered support with activities of daily living may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 1 | Bertilsson et al., 2016 |

| SELF-EFFICACY | | | |
|---------------|--|------|-------------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Home exercise program with picture description may not have a difference in efficacy compared to conventional home exercise for improving self-efficacy | 1 | Kara et al., 2015 |
| 2 | <u>For caregivers:</u> Client centered support with activities of daily living may not have a difference in efficacy compared to conventional care for improving self-efficacy. | 1 | Bertilsson et al., 2016 |

| CAREGIVER BURDEN | | | |
|------------------|---|------|-------------------------|
| LoE | Conclusion Statement | RCTs | References |
| 2 | Client centered support with activities of daily living may not have a difference in efficacy compared to conventional care for improving caregiver burden. | 1 | Bertilsson et al., 2016 |

Key Points

Home exercise programs with picture descriptions may not be beneficial for improving activities of daily living, balance, ambulation and mobility, and self-efficacy.

Community walking programs may be beneficial for improving balance, ambulation and mobility as well as community reintegration and social support.

For caregivers, client centered support with activities of daily living may not be beneficial for improving activities of daily living, balance, ambulation and mobility, community reintegration and social support, quality of life and optimism, self-efficacy or caregiver burden.

Sexual Functioning Rehabilitation



Adopted from: <https://www.nia.nih.gov/health/sexuality-later-life>

In a UK survey of 315 stroke survivors aged 18 to 65 years (Kersten et al., 2002), 233 responded to a question regarding changes in their sex life following the stroke event. Of those 233 respondents, 64% reported difficulties. The stroke event may have a negative impact on existing intimate relationships and make new ones seem unobtainable (Murray & Harrison, 2004). In interviews with stroke survivors (aged 38 to 81, mean age = 48.8 years) 2 years post stroke, Murray and Harrison (2004) discovered that the stroke survivors tended to have a negative self-image and did not believe others could find them attractive. Romance and sexuality are issues that have been identified as important to stroke survivors and their significant others (Buzzelli et al., 1997; Murray & Harrison, 2004); however, little research has been conducted concerning the sexual relationships of stroke survivors and even less has addressed the means by which sexual function, relationships and intimacy following stroke may be improved.

One RCT was found that evaluated sexual functioning rehabilitation. One RCT compared a structured sexual rehabilitation program to conventional care (Sansom et al., 2015).

The methodological details and results of the single RCT evaluating sexual rehabilitation for community rehabilitation is presented in Table 7.

Table 7. RCTs evaluating sexual functioning interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size ^{start} Sample Size ^{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|---|--|---|
| Sansom et al. (2015) RCT (6) NStart=10 NEnd=10 TPS=NR | E: Structured sexual rehabilitation program C: Usual care Duration: single 30min session (6wk follow up) | <ul style="list-style-type: none"> Changes in Sexual Functioning Questionnaire – short form (-) Depression, Anxiety and Stress Scale (-) Functional Independence Measure (-) Stroke and Aphasia Quality of Life Scale (-) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.

+exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group

+exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group

+con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group

- indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about sexual rehabilitation programs

| ACTIVITIES OF DAILY LIVING | | | |
|----------------------------|--|------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Sexual rehabilitation program may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 1 | Sansom et al., 2015 |

| MENTAL HEALTH | | | |
|---------------|---|------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Sexual rehabilitation program may not have a difference in efficacy compared to conventional care for improving mental health. | 1 | Sansom et al., 2015 |

| QUALITY OF LIFE & OPTIMISM | | | |
|----------------------------|--|------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Sexual rehabilitation program may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 1 | Sansom et al., 2015 |

| SEXUAL HEALTH | | | |
|---------------|---|------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Sexual rehabilitation program may not have a difference in efficacy compared to conventional care for improving sexual health. | 1 | Sansom et al., 2015 |

Key Points

Sexual rehabilitation programs may not be beneficial for improving activities of daily living, mental health, quality of life and optimism and sexual health.

Return to Driving



Adopted from: <https://www.herrmanandherrman.com/blog/elderly-drivers-diminished-driving-skills/>

The ability to drive is a significant marker of independence. As noted by Churchill (1998), *“resumption of driving often represents the final step toward independence and reintegration into the community.”* Inability to drive may be associated with disruption in lifestyle, an inability to participate in the community, resume pre-stroke roles or maintain independence and autonomy (White et al., 2012). Resumption of driving, although perceived as a relief, may be accompanied by a lack of confidence (White et al., 2012). Stroke patients who do not resume driving report that this decision negatively impacted social activities and wellbeing (Mackenzie & Paton, 2003). Similarly, Finestone et al. (2010) reported that driving is significantly associated with community reintegration one year following stroke ($p < 0.001$, adjusted for health status). However, the ability to drive is dependent on good vision and reflex response, quick decision-making and keen attentiveness, which may be compromised by perceptual, cognitive and physical disorders that often accompany stroke (Fisk et al., 2002; Smith-Arena et al., 2006; Tan et al., 2011).

Four RCTs were found that evaluated interventions for returning to driving. Two RCTs compared simulator training to driving related cognitive tasks (Akinwuntan et al., 2010; Akinwuntan et al., 2005b). One RCT was found comparing useful field of view training to visuo-perceptual training (Mazer et al., 2003). One RCT compared Dynavision training to no training (Crotty et al., 2009).

The methodological details and results of the four RCTs evaluating return to driving for community rehabilitation are presented in Table 8.

Table 8. RCTs evaluating return to driving interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size_{start} Sample Size_{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|--|---|--|
| Simulator training vs cognitive training | | |
| Akinwuntan et al. (2010) RCT (8) N _{Start} =83 N _{End} =69 TPS=Subacute | E: Simulator based training C: Driving related cognitive tasks Duration: 1hr, 3x/wk, 5wks | <ul style="list-style-type: none"> • Useful Field of View (-) |
| Akinwuntan et al. (2005b) Devos et al. (2009) RCT (8) N _{Start} =83 N _{End} =73 TPS=Subacute | E: Simulator based training C: Driving related cognitive tasks Duration: Duration: 1hr, 3x/wk, 5wks (driving assessment @ 6-8mo post-stroke) | <ul style="list-style-type: none"> • Stroke Drivers' Screening Assessment <ul style="list-style-type: none"> • Dot cancellation (-) • Square Matrix – Orientation/direction (-) • Road sign recognition (+exp) • Binocular Acuity (-) • Kinetic Vision (-) • Useful Field of View (-) • Deemed 'fit to drive' (+exp) • On-road Test Ride for Investigating Practical fitness to drive performance (+exp) |
| Useful field of view training vs computer visuoperceptual training | | |
| Mazer et al. (2003) RCT (7) N _{Start} =97 N _{End} =84 TPS=Subacute | E: Useful Field of View visual information processing training C: Visuoperceptual retraining with commercially available computer software Duration: 30-60min, 2-4x/wk, 20 sessions total | <ul style="list-style-type: none"> • Useful Field of View (+exp) • On-road driving test (-) • Test of Everyday Attention (-) • Visuoperception battery (-) • Everyday attention (-) |
| Dynavision training vs no training | | |
| Crotty et al. (2009) RCT (6) N _{Start} =97 N _{End} =84 TPS=Subacute | E: Dynavision training intervention C: No training Duration: | <ul style="list-style-type: none"> • On-road assessment (-) • Abilities in Response Time Measures (-) • Visual Scanning Analyzer (-) • Adelaide Driving Self-Efficacy Scale (-) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.
 +exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group
 +exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group
 +con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group
 - indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about return to driving therapies

| DRIVING | | | |
|----------------|---|-------------|---|
| LoE | Conclusion Statement | RCTs | References |
| 1a | Simulator training may not have a difference in efficacy compared to driving related cognitive training for improving driving. | 2 | Akinwuntan et al., 2010; Akinwuntan et al., 2005b |
| 1b | Useful field of view training may not have a difference in efficacy compared to visuoperceptual training for improving driving. | 1 | Mazer et al., 2003 |
| 1b | Dynavision training may not have a difference in efficacy compared to no training for improving driving. | 1 | Crotty et al., 2009 |

Key Points

Simulator training, useful field of view training or Dynavision training may not be beneficial for improving driving related outcomes

Return to Work



Adopted from: <https://www.wsi.com/articles/a-brief-history-of-the-dreaded-office-cubicle-1399681972>

After a stroke, returning to work is no easy task. For many younger, previously working stroke survivors, returning to work is of significant importance for quality of life, and life satisfaction (Vestling, Tufvesson & Iwarsson, 2003). Standard rehabilitation usually consists of occupational therapy in some capacity, for those patients who would benefit from it. Much of the therapy consists within a hospital, care center or patient's home. Alternatively, occupational therapy occurring at the workplace, provides an environment where training can be directly transferred to the workplace. This type of intervention could help improve stroke survivors' ability to return to their job.

One RCT was found that evaluated return to work interventions. One RCT compared a occupation workplace intervention to conventional care (Ntsiea et al., 2015).

The methodological details and results of the single RCT evaluating return to work for community rehabilitation is presented in Table 9.

Table 9. RCTs evaluating return to work interventions for community reintegration

| Authors (Year) Study Design (PEDro Score) Sample Size _{start} Sample Size _{end} Time post stroke category | Interventions Duration: Session length, frequency per week for total number of weeks | Outcome Measures Result (direction of effect) |
|---|---|---|
| Ntsiea et al. (2015) RCT (6) N _{start} =80 N _{end} =72 TPS=Acute | E: Occupational workplace intervention C: Standard care Duration: tailored to patient | <ul style="list-style-type: none"> • Return to Work (+exp) • Barthel Index (-) • Montreal Cognitive Assessment (-) • Stroke Specific Quality of Life Scale (-) • Modified Rivermead Mobility Index (-) |

Abbreviations and table notes: C=control group; D=days; E=experimental group; H=hours; Min=minutes; RCT=randomized controlled trial; TPS=time post stroke category (Acute: less than 30 days, Subacute: more than 1 month but less than 6 months, Chronic: over 6 months); Wk=weeks.

+exp indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the experimental group

+exp₂ indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the second experimental group

+con indicates a statistically significant between groups difference at $\alpha=0.05$ in favour of the control group

- indicates no statistically significant between groups differences at $\alpha=0.05$

Conclusions about return to work therapies

| ACTIVITIES OF DAILY LIVING | | | |
|-----------------------------------|--|-------------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Occupational workplace therapy may not have a difference in efficacy compared to conventional care for improving activities of daily living. | 1 | Ntsiea et al., 2016 |

| BALANCE, AMBULATION & MOBILITY | | | |
|---|---|-------------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Early supported discharge may not have a difference in efficacy compared to conventional care for improving balance, ambulation and mobility. | 1 | Ntsiea et al., 2016 |

| COGNITION | | | |
|------------------|---|-------------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Occupational workplace therapy may not have a difference in efficacy compared to conventional care for improving cognition. | 1 | Ntsiea et al., 2016 |

| QUALITY OF LIFE & OPTIMISM | | | |
|---------------------------------------|--|-------------|---------------------|
| LoE | Conclusion Statement | RCTs | References |
| 1b | Occupation workplace therapy may not have a difference in efficacy compared to conventional care for improving quality of life and optimism. | 1 | Ntsiea et al., 2016 |

Key Points

Occupational workplace therapy may not be beneficial for improving activities of daily living, balance, ambulant and mobility, cognition or quality of life and optimism.

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