

7. Depression and Community Reintegration Post Stroke

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7.1 Screening and Assessment of Depression and Communication Reintegration Post Stroke





7.1.1 Summary of the Measures

Outcome Measures in Post Stroke Depression and Community Reintegration

Category	Rationale	Individual Assessment Tools
Activities of daily living 	These outcome measures assessed performance and level of independence in various everyday tasks.	<ul style="list-style-type: none"> • Activities of Daily Living Scale • Adelaide Activities Profile • Assessment of Life Habits • Barthel Index (BI) • Chinese Activities of Daily Living • Frenchay Activities Index (FAI) • Functional Independence Measure (FIM) • Johns Hopkins Functioning Inventory • Karnofsky Performance Status • Lawton Instrumental Activities of Daily Life Scale • London Handicap Scale • Nottingham Extended Activities of Daily Living • Nottingham Leisure Questionnaire • Observer Assessed Disability • Stroke Impact Scale (activities of daily living) • World Health Organization Disability Assessment Schedule II
Anxiety 	These measures assessed the presence and severity of anxiety disorder, and its individual symptoms.	<ul style="list-style-type: none"> • State-trait Anxiety Inventory • Hospital Anxiety and Depression Scale (HADS)
Balance, Ambulation, Mobility 	These outcome measures assessed motor function, balance, ambulatory abilities and gait.	<ul style="list-style-type: none"> • 6-Minute Walk Test • Berg Balance Scale • Modified Rivermead Mobility Index (MRMI) • Timed Up & Go Test (TUG)
Caregiver Burden 	These outcome measures assess the level of burden for caretakers of stroke survivors.	<ul style="list-style-type: none"> • Bakas Caregiver Outcome Scale • Caregiver Burden Scale (CBS) • Family Caregiving Consequence Inventory (Frail elder subscale) • Family Systems strengths questionnaire • Life Situation Among Spouses after the Stroke event • Pressing problem index • Zarit Burden Interview
Cognition	These outcome measures assessed an individual's overall cognitive	<ul style="list-style-type: none"> • Mini Mental Status Examination (MMSE) • Montreal Cognitive Assessment (MoCA)

	processing capability factoring in multiple domains.	
Community Reintegration Social Participation 	These outcome measures assess an individual's ability to reintegrate into their community and social behaviours.	<ul style="list-style-type: none"> • McMaster Family Assessment Device • Reintegration to Normal Living Index (RNLI) • Social adjustment scale • Social Problem-Solving Inventory • UCLA Loneliness Scale • Barrera's Inventory of Socially Supportive Behaviors • ESCROW profile • Interpersonal Support Evaluation List (ISEL) • Medical Outcomes Study (MOS) Social Support Survey • Social Support Inventory for Stroke Survivors (SSIS) • Use of Community/Aids Received
Depression 	These measures assessed the severity and presence of major and/or minor depressive disorder and its individual symptoms.	<ul style="list-style-type: none"> • Bech-Rafaelsen Melancholia Scale • Beck Depression Inventory (BDI) • Beyer Six-face Rating Scale • Center for Epidemiological Studies Depression Scale (CESD) • Clinical Global Impression Scale (CGI) • Geriatric Depression Scale (GDS) • Hamilton Rating Scale for Depression (HAM-D) • Hospital Anxiety and Depression Scale (HADS) • Montgomery-Asberg Depression Rating Scale • Multiple Affective Adjective Check List (depression scale) • Patient Health Questionnaire (PHQ-9) • Post-Stroke Depression Rating Scale • Present State Examination • Profile of Mood States • Stroke Aphasic Depression Questionnaire • Stroke Inpatient Depression Inventory • Wakefield Depression Inventory • Yale Self-Reported Depression Screen • Zung Self-Rating Depression Scale
Driving 	These outcome measures assess both motor related skills and cognitive/perceptual skills for driving motor vehicles.	<ul style="list-style-type: none"> • Adelaide Driving Self-efficacy Scale • Useful Field of View • Visual Scanning Analyzer
Education 	These outcome measures assessed an individual's knowledge of stroke, living with stroke and related information to care services.	<ul style="list-style-type: none"> • Stroke Care Information Test • Health education impact questionnaire • Stroke Knowledge and Lifestyle Modification Questionnaire
Emotional	These outcome measures	<ul style="list-style-type: none"> • Emotional Distress Scale

Lability 	assessed the severity and frequency of emotional volatility and inappropriate emotional responses.	<ul style="list-style-type: none"> Emotional Incontinence – Kim’s Criteria Emotional Lability Questionnaire Lawson Mcleod Rating Scale of Emotionalism Pathological Laughing and Crying Scale Stroke Impact Scale (emotion)
Mental Health and Mood CoFactors 	These outcome measures assess psychiatric dysfunction in a number of mental health related dimensions and assessments examining aspects of behavior or personality which relate to, but are not directly equivalent with, mood related outcomes.	<ul style="list-style-type: none"> Apathy Scale Coping Inventory for Stressful Situations Depression, anxiety and stress scale (DASS-21) General Health Questionnaire Hospital Anxiety and Depression Scale (HADS) Life Orientation Test Patient Health Questionnaire (PHQ-9) Perceived Stress Scale Positive affect scale Profile of Mood States Recovery Locus of Control Scale Rosenberg Self-esteem Scale State-Trait Anger Expression Inventory Symptom Checklist 90-item revised Utrecht Proactive Coping Competence Scale
Quality of Life 	These outcome measures assessed an individual’s overall quality of life and their perception of it, generally compared to their preinjury status.	<ul style="list-style-type: none"> Antonovsky’s Orientation to Life Questionnaire Assessment of Quality of Life Instrument CarerQOL Dartmouth co-op charts Dyadic coping instrument (DCI) EuroQol Quality of Life (EQ-5D) Herth Hope Scale McGill Quality of Life Questionnaire Medical Outcome Trusts’ Short Form Health Survey (SF-36 or SF-12) Nottingham Health Profile Pictorial Thai Quality of Life Preference based stroke index Rosenberg Self-esteem Scale Satisfaction with Life Scale Sickness Impact Profile Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) Stroke-Specific Quality of Life Scale (SS-QoL-12) Utrecht Proactive Coping Competence Scale Ways of coping-cardiovascular accident scale WHO Quality of Life (WhoQoL) World Health Organization Quality of Life Scale (WHO-QoL Scale)
Satisfaction with Care	These outcome measures assessed an individual’s satisfaction with various	<ul style="list-style-type: none"> Client Satisfaction Questionnaire Larson Scale – Consumer Satisfaction Pound satisfaction scale

	aspects of their care.	<ul style="list-style-type: none"> Satisfaction with stroke care questionnaire
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.	<ul style="list-style-type: none"> Chinese Self-Management behavior Questionnaire Morisky Medication Adherence Scale Occupational Gaps Questionnaire (OGQ) Stroke self-efficacy questionnaire Caregiver Self-Efficacy <ul style="list-style-type: none"> Caregiver Competence Scale Pearlin's 7-item Mastery Scale Preparedness for caregiving scale
Sexuality 	These outcome measures assess sexual function and dysfunction.	<ul style="list-style-type: none"> Changes in Sexual Functioning Questionnaire
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.	<ul style="list-style-type: none"> Modified Rankin Scale (MRS) National Institutes of Health Stroke Scale (NIHSS) Oxford Handicap Scale Stroke-Adapted Sickness Impact Profile (SA-SIP30)

7.1.2 Measurements of Activities of Daily Living

These outcome measures assessed performance and level of independence in various everyday tasks.

Barthel Index (BI)

The Barthel Index is a measure of one's ability to perform activities of daily living. The scale consists of 10 items: personal hygiene, bathing, feeding, toilet use, stair climbing, dressing, bowel control, bladder control, ambulation or wheelchair mobility and chair/bed transfers. Each item has a five-stage scoring system and a maximum score of 100 points, where higher scores indicate better performance. The scale is suitable for monitoring on the phone and is shown to have a high inter-rater reliability (Park 2018).

Frenchay Activities Index (FAI)

The 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).

Functional Independence Measure (FIM)

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 (Stineman et al. 1996).

Stroke Impact Scale (activities of daily living)

SIS (ADL) 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).

7.1.3 Measurements of Anxiety**State-trait Anxiety Inventory (STAI)**

The State-trait Anxiety Inventory (STAI) is a self-report measure that aims to assess anxiety as an emotional state (state anxiety) and individual differences in anxiety proneness (trait anxiety). It is a 20-item scale with a 4-point scale from 1) Not at all; 2) Somewhat; 3) Moderately so; and 4) Very much so. Items were selected for the STAI based on highly significant correlations with widely used measures of anxiety at the time of conception (Spielberger 1983).

7.1.4 Caregiver Burden**Bakas Caregiver Outcome Scale**

The 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)

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).

Zarit Burden Interview

The 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).

7.1.5 Community Reintegration and Social Participation

Reintegration to Normal Living Index (RNLI)

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).

7.1.6 Depression

These measures assessed the severity and presence of major and/or minor depressive disorder and its individual symptoms.

Beck Depression Inventory (BDI)

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 et al. 1988).

Center for Epidemiological Studies Depression Scale (CESD)

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 (Lewinsohn et al. 1997, Pickard et al. 2006).

Geriatric Depression Scale (GDS)

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 (Agrell & Dehlin 1989, McDowell 2006, Sheikh & Yesavage 1986).

Hamilton Rating Scale for Depression (HAM-D)

HAM-D is a commonly used instrument for evaluating the severity of depression and other mood disorders that was created in 1960. The scale consists of 21 items with only 17 included in scoring. Mood, guilt, suicidal ideation, agitation and somatic symptoms are assessed in either a structured interview or written self-report format. Test items are scored on a scale of 0-4, although some items are scored only as high as 2 or 3. There is no concrete cut-off score for depression, however a score of 7 is

often the consensus. Internal reliability ranges from poor-excellent, and interrater and test-retest reliability is good-excellent. The scale's validity for evaluating post-stroke depression has been established and its sensitivity and specificity found to be within acceptable ranges (Aben et al. 2002, Bagby et al. 2004, Shahid et al. 2011).

Hospital Anxiety and Depression Scale (HADS)

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).

Montgomery-Asberg Depression Rating Scale

The Montgomery-Asberg Depression Rating Scale is a 10-item questionnaire meant to assess depressive symptoms. Each item is rated on a 6-point Likert scale. Higher scores are indicative of greater levels of depression. The scale has shown good psychometric properties in multiple patient groups and in multiple languages (Kang et al. 2013).

Patient Health Questionnaire

The 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 et al. 2001).

Stroke Aphasic Depression Questionnaire

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).

7.1.7 Driving

Screen for the Identification of cognitively impaired Medically At-Risk Drivers (SIMARD)

The SIMARD is a paper and pencil screening tool used in the primary care setting for identifying individuals who are at risk of driving competence decline due to cognitive impairment. It was created by identifying best predictors of passing and failing the On-Road evaluation. The SIMARD takes less than 7 minutes to administer and can be scored in less than 2 minutes. It consists of an immediate recall task, converting numbers to words, word retrieval, and a delayed recall task (Dobbs & Schopflocher 2010).

Trail Making Test (TMT A & B)

The TMT consists of two parts (A and B). TMT-A involves a participant drawing lines sequentially to connect 25 circled numbers. The TMT-B introduces an added element of letters. The participant must alternate from number to letter (1, A, 2, B, 3, C) and they are scored based on time to complete the task (Tombaugh 2004). Interpreting the TMT requires normative data of similar individuals. This test is a

popular subtest in many neuropsychological batteries and is sensitive to various neurological impairments (Tombaugh 2004).

7.1.8 Emotional Lability

Stroke Impact Scale (emotion)

The SIS (emotion) 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).

7.1.9 Mental Health and Mood CoFactors

Coping Inventory for Stressful Situations

The Coping Inventory for Stressful Situations is a 48-item measure that covers 3 subscales (Task-, Emotion- and Avoidance-oriented coping), each containing 16 of the items. The measure asks a participating individual how frequently they would engage in different coping strategies. Each item is rated on 5-point Likert scale, where higher scores indicate they use this strategy more frequently. It has been shown to have good internal consistency, validity, and adequate test-retest reliability (McWilliams et al. 2003).

Depression, Anxiety and Stress Scale (DASS-21)

DASS 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

The 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).

Symptom Checklist 90-item revised

SC 90r 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 & Savitz 1999).

7.1.10 Quality of Life

EuroQol Quality of Life (EQ-5D)

EQ-5D is a widely used measure of quality of life. It is a brief, self-reported scale covering 5 dimensions: 1) mobility; 2) self-care; 3) usual activities; 4) pain/discomfort; and 5) anxiety/depression. There are two different versions of the scale, one with 3 levels (EQ-5D-3L) and one with 5 levels (EQ-5D-5L) in which subjects rate each dimension from 1 to 3 or 1 to 5, respectively. A “health state” is generated from the score on each dimension, generating a state of 11111 to 33333 in the EQ-5D-3L or 11111 to 55555 in the EQ-5D-5L, with lower numbers representing better health-related quality of life. A summary value can be calculated from each health state to generate a value from 0 to 1. In the second part of the test, subjects rate their current state of health from 0 (worst imaginable) to 100 (best possible) on a visual analogue scale (EQ VAS). The EuroQol scale has been extensively validated in many populations, including stroke survivors. The scale has also been shown to have good reliability (Golicki et al. 2015, Janssen et al. 2013).

Nottingham Health Profile

The 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).

Sickness Impact Profile

The Sickness Impact Profile is an assessment of quality of life. It is divided into 12 subdomains, covering 3 major domains (physical, psychological, and social). There are 136 items total, each one a ‘yes’ or ‘no’ question. The measure has shown good psychometric properties (Stummer et al. 2015).

7.1.11 Self-Efficacy

Stroke Self-efficacy Questionnaire

SSEQ 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 Competence Scale

CCS 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).

7.2 Depression Post Stroke

7.2.1 Overview of Post-Stroke Depression

Depression is a common complication of stroke. Prevalence of depression (major and minor) has been reported to affect 23-40% of stroke patients. White (2002) reported that major depression was present

in 9-37% of stroke survivors in the first in the 6 months, 5-16% next year and 19-21% thereafter in 1725 patients studied. Most cases of PSD is evident within the first two years and episodes last on average months or more with some persisting for years. Depression is often observed in severe physical illnesses. In post stroke depression there is less emphasis on feelings of low self-esteem, guilt and self-blame and more emphasis on hypochondriac concerns, lethargy and behavioural disturbances; one of the challenges is that diminished energy, weight loss, insomnia, poor concentration and psychomotor alterations all of which can be associated with the stroke itself. Patients may be unable to communicate their feelings due to aphasia which makes diagnosis more challenging.

DSM V. Criteria for Depression

DEPRESSIVE DISORDER DUE TO ANOTHER MEDICAL CONDITION (DSM V: page 180-183)

Diagnostic Criteria

1. A prominent and persistent period of depressed mood or markedly diminished interest of pleasure in all or almost all, activities that predominates in the clinical picture.
2. There is evidence from history, physical examination, or laboratory findings that the disturbance is the direct pathophysiological consequence of another medical condition.
3. The disturbance is not better explained by another mental disorder (e.g., adjustment disorder, with depressed mood, in which the stressor is a serious medical condition).
4. The disturbance does not occur exclusively during the course of a delirium.
5. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

7.2.2 Risk Factors for Depression

The most commonly identified risk factors for post stroke depression include:

- Female sex (especially those with severe depression)
- Previous history of depression
- Stroke severity, functional limitations or need for assistance with activities of daily living
- Cognitive impairment
- Social factors (living alone, divorced or living in a nursing home)

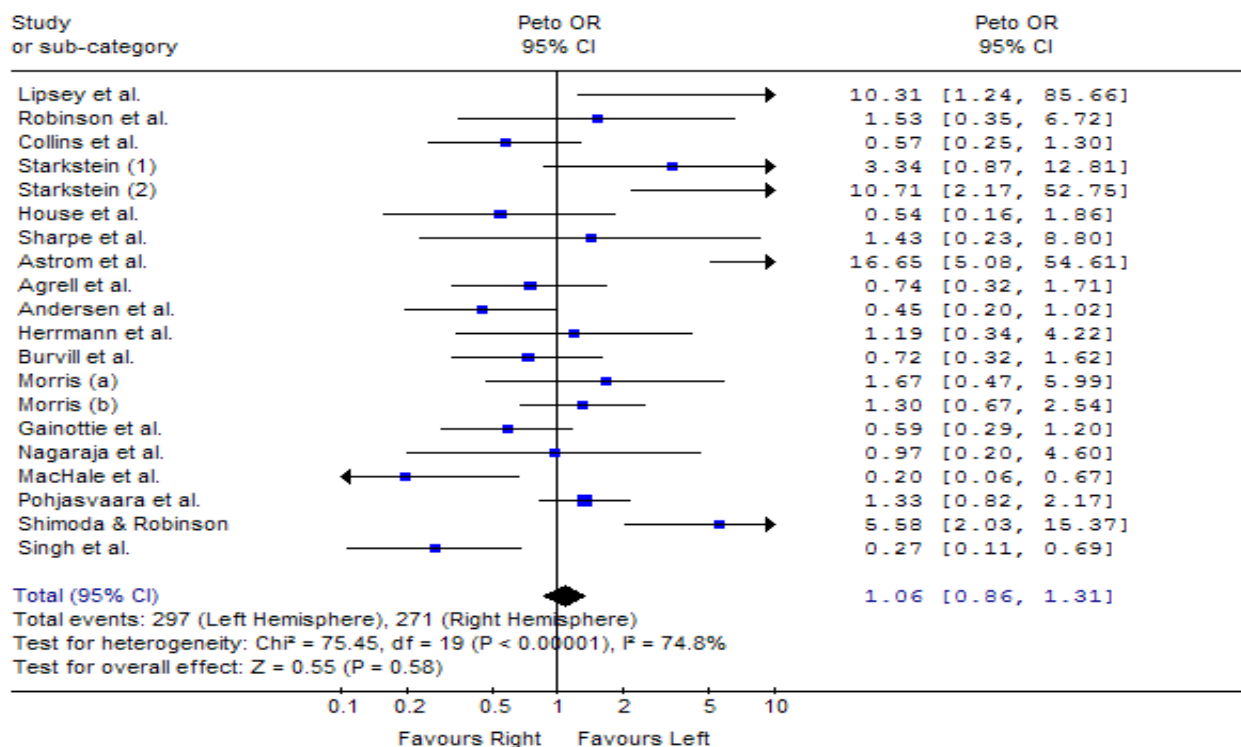
Possible Reasons for the High Incidence of Depression Post Stroke

1. Stroke risk factors coincide with high depression risk.
2. Disability causes a reactive depression.
3. Stroke induces neurotransmitter changes which lead to depression.
4. In acute onset depression there is increased risk associated with left frontal strokes and least risk with right frontal lesions.
5. In sub-acute or delayed stroke (2-6 months post stroke) there is no association with frontal regions and weak association with laterality of lesion location with greater risk in right hemispheric lesions.

7.2.3 Stroke Location and Depression

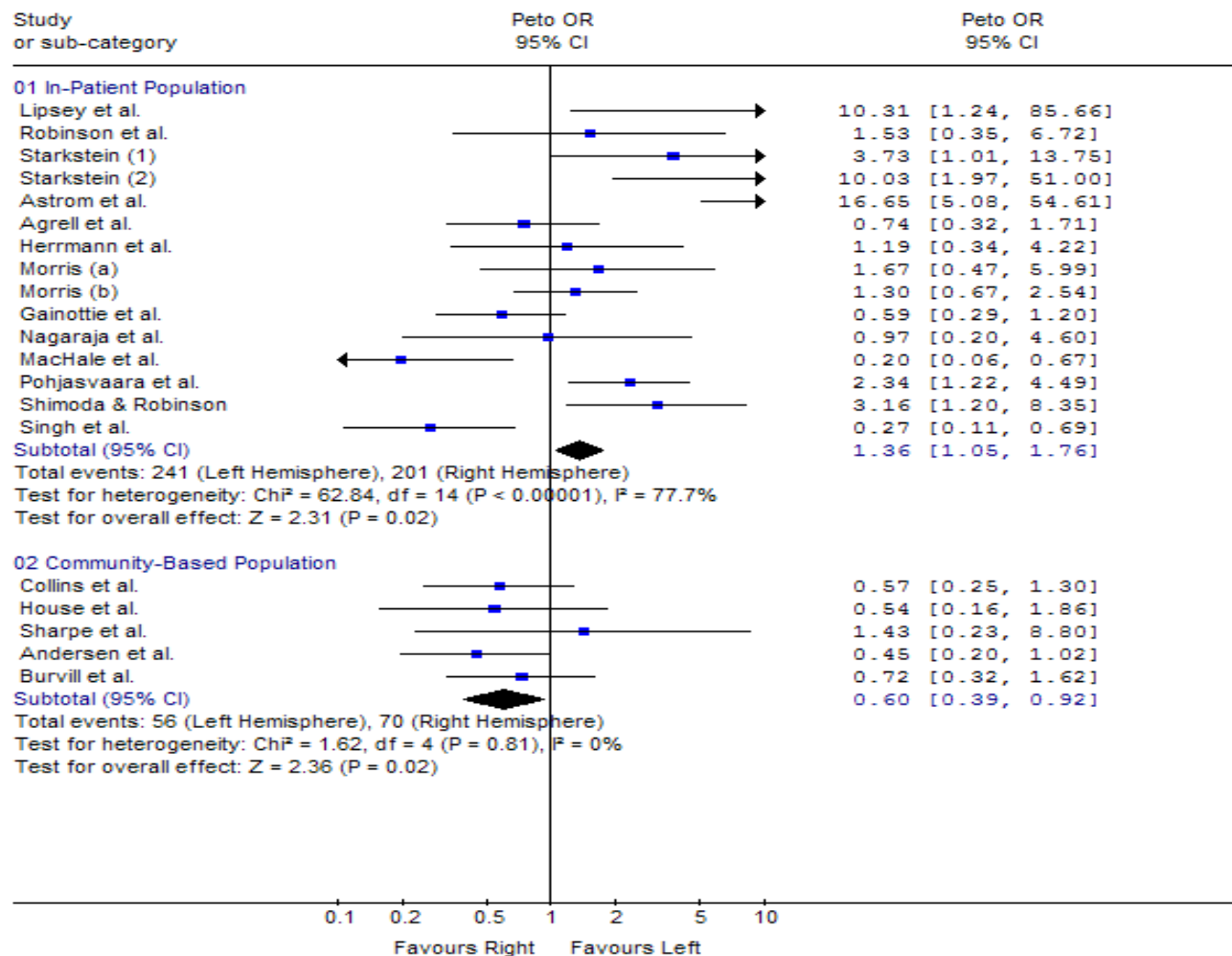
Robinson et al. (1984) found left frontal strokes appeared to be at higher risk of depression and questioned whether this was not associated with specific neurotransmitter changes in the brain with disruption of certain neural pathways. Other investigators not been able to consistently duplicate findings. More recent meta-analyses failed to establish a definitive relationship between site of stroke and depression. At present not known if stroke location influences developing depression. Our own meta-analysis of research data (Bhogal et al. 2004) (see below) shows:

Figure 1. Odds Ratio of Post-Stroke Depression After Left Hemisphere Stroke, n=20*



1. Left hemispheric strokes are more likely to be depressed in hospital (earlier on).
2. Right hemispheric strokes are more likely to be depressed in the community (later on).

Despite a wealth of research, it has not been established whether stroke location influences likelihood of depression.

Figure 2. Odds of Developing Post-Stroke Depression Following Left Hemispheric Stroke According to Patient Source, n = 19*

7.2.4 Impact of Depression Post Stroke

Functional Impairment and Depression

Depression has a powerful negative impact post-stroke. It has been estimated that the impact of depression on physical and functional outcomes accounts for 5-48% of the variance which is a potentially huge impact. Depressed patients post stroke are more likely to suffer deterioration in their physical functioning on discharge from rehab. Function and depression seem to interact - decreased function leads to depression while depression leads to decreased function. Depression post stroke has a powerful negative impact on physical and functional recovery.

Depression and Social Activities Post Stroke

Stroke impacts on how patients perceive themselves (self-image). This is in turn associated with depression and social withdrawal which in turn worsens depression. Social withdrawal is common post

stroke and it is recommended that social withdrawal be dealt with early to limit its negative impact. Depression impacts upon social activity and vice-versa post-stroke.

Cognitive Impairment and Depression Post Stroke

It is well known that depression is associated with cognitive impairment although its impact on cognitive function has not been well studied in stroke patients.

Mortality and Depression Post Stroke

Depression has been linked to higher mortality among elderly patients with physical illness. Three studies have demonstrated a link between depression and increased mortality (refs). Depression post stroke is associated with greater mortality.

Why is Depression Post Stroke Important?

Depression post stroke is important because it is associated with:

- Increased physical impairment and decreased physical recovery.
- Increased cognitive impairment.
- Decrease social participation and quality of life.
- Increased risk for mortality.
- Increased risk of depression for informal caregivers.
- Increase healthcare utilization for both.

7.2.5 Screening and Assessment of Depression

Canadian Best Practice Recommendations (2015)

1. All patients with stroke should be screened for depressive symptoms, given the high prevalence of depression post-stroke, the need for screening to detect depression, and the stroke evidence for treating symptomatic depression post-stroke.
2. Screening should be undertaken using a validated tool to maximize detection for depression.
3. Stroke patient assessments should include evaluation of risk factors for depression, particularly a history of depression.
4. For patients who experience some degree of communication challenge or deficits following stroke, appropriate strategies for screening of possible PSD should be implemented to ensure adequate assessment and access to appropriate treatment.

Why Screen for Depression? (Mitchell & Kakkadasam 2011, Mitchell et al. 2010, Mitchell et al. 2011)

Screening for depression is important to ensure an accurate diagnosis post stroke. It has been shown that the accuracy of informal identification and diagnosis of depression is poor, reported to be approximately 33-48% (doctors) and 43% (nurses in an inpatient setting). There is a tendency toward false positives (exceed true positives by 3:1). Accuracy is particularly reduced in cases of: 1) Late life depression; 2) Minor vs. Major depression; 3) Populations with known risk of depression. Lowe et al. (2004) compared the sensitivity of formal screening with clinical observation by a physician (versus formal diagnosis); it was 40% with the physician but increased to 88% with HADS and 98% with PHQ-9.

Which Screening Tools are Typically Used?

- Geriatric Depression Scale (GDS)
- Hospital Anxiety and Depression Scale (HADS)

- Patient Health Questionnaire (PHQ-9)
- Stroke Aphasic Depression Questionnaire (SAD-Q)
- Aphasic Depression Rating Scale (ADRS)

Summary of Screening Tools for Depression

Tool	# of Items	Response Format	Total Score	Identification of Depression	Time to Administer	Training Req'd
GDS	30	Yes/No	0-30	Normal = 0-10; ≥ 11 indicate presence of depression; 11-20 = mild depression; 21-30 = moderate to severe depression.	6-10 mins	No
HADS	14(7)	Multiple choice response options 4 point scale	0-42 (21)	Scale authors recommended either 8/9 (high sensitivity) or 10/11 (high specificity) be used to identify the presence of depression using the depression subscale of the HADS. A recent report suggested scores of ≥ 8 represent the presence of minor PSD.	2-6 mins	No
PHQ-9	9	Multiple choice response options 4 point scale	0-27	Scores ≥ 10 (sensitivity = 80%; specificity = 73%) for identification of PSD 6-8 weeks post stroke.	2-5 mins	No
SAD-Q	10	Observer rating of observed behavior 4 point scale	0-30	Scores ≥ 15 represent the presence of depression.	3-4 mins	No
ADRS	9	Observer rating based on interview and observation Rating scale varies per item	0-32	Scores of ≥ 9 are used to indicate the presence of depression.	N/A	Yes

Post Screening Assessment

Patients identified as at risk (screening) should be referred to a psychiatrist or psychologist or an appropriate clinician with an interest in depression management for further assessment and diagnosis.

7.3 Management of Depression Post Stroke

Drug Therapy for Post-Stroke Depression

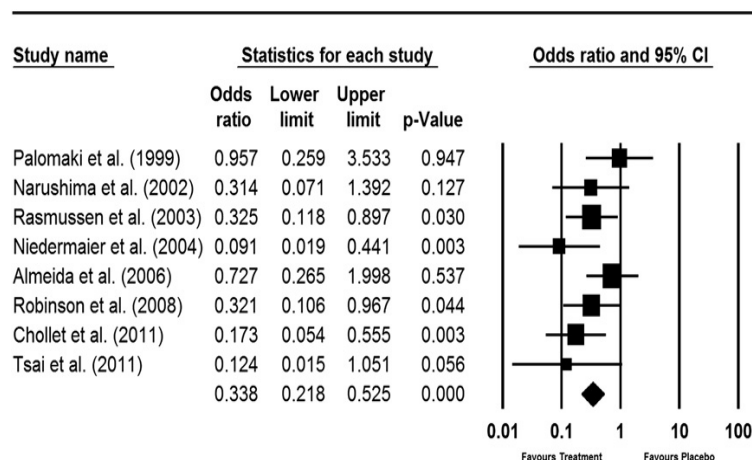
Drug therapy is based on imbalance or underactivity of brain noradrenergic or serotonergic systems and involves three classes of drugs:

- Heterocyclic antidepressants (Nortriptyline)
- Selective Serotonin Reuptake Inhibitor (SSRI) antidepressants (citalopram, paroxetine)
- Amphetamines (methylphenidate)

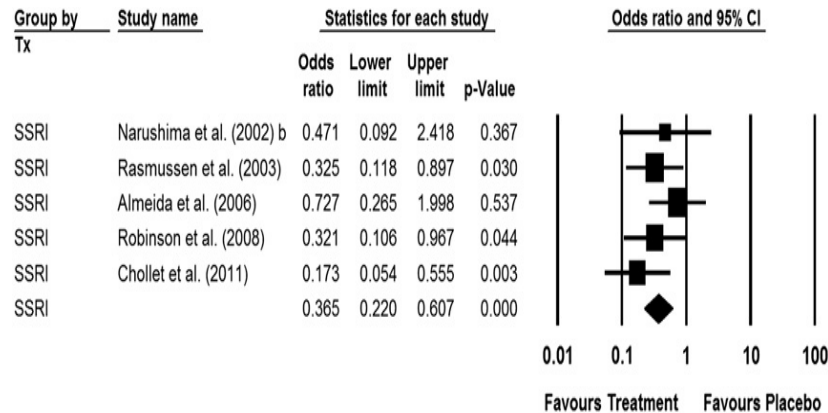
7.3.1 Prevention and Prophylactic Use of Antidepressants

There are a number of trials suggesting routine use of antidepressants can prevent development of depression. Early initiation of antidepressant therapy, in non-depressed stroke patients, may reduce the odds of development of a stroke. Only 10% of stroke patients treated with sertraline or mirtazapine developed depression compared to 30-40% in placebo group (Niedermaier et al. 2004, Rasmussen et al. 2003). The impact of prophylactic antidepressants has been questionable in systematic reviews (Hackett & Anderson 2005). Optimum timing and duration of treatment and identification of the most appropriate recipients for a program of indicated prevention requires additional research.

Salter et al. (2013) did a pooled analysis of 8 RCTs which demonstrated reduced odds for the development of PSD associated with: 1) Pharmacological treatment (OR 0.34; 95% CI 0.20-0.53; $P < .001$); 2) Treatment duration of 1 year (OR 0.31; 95% CI 0.18-0.56; $P < .001$); 3) Use of a selective serotonin reuptake inhibitor (OR 0.37; 95% CI 0.22-0.61; $P < .001$).



*active treatment conditions (Narushima et al. 2002) combined for purposes of overall analysis



*data from Narushima et al. (2002) for fluoxetine vs. placebo conditions only.

Highlighted Study

Chollet et al. (2011) (FLAME study)

RCT (9) N _{Start} =118 N _{End} =113 TPS=Acute	E: Fluoxetine (20mg/d) C: Placebo Duration: 3mo	Montgomery-Asberg Depression Rating Scale (+exp)
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118 patients free from clinical depression and not taking any antidepressant medication with Fugl-Meyer (FM) scores of <55 were randomly assigned to receive either 20 mg/day fluoxetine or matching placebo within 5-10 days of stroke onset for 90 days. All patients received usual rehabilitation care delivered by organised stroke teams. Frequency of depression was significantly greater in the placebo group when compared to the treatment group (29% vs. 7%, $p=0.002$). There was a significant between group difference reported in mean change in symptoms of depression over 90 days ($p=0.032$). Mean FM total and lower limb subscores were significantly higher in the fluoxetine group compared with control (54 vs 35, $p<0.01$ and 24 vs. 19, $p=0.001$); change in FM scores was also higher in the fluoxetine group.

Treatment of Established Depression

7.3.2 Heterocyclic Antidepressants

Heterocyclic antidepressants block reuptake of serotonin and norepinephrine within the brain, increasing levels within the brain. RCTs (nortriptyline and imipramine) were beneficial, reducing PSD. Side effects, especially in elderly patients, were quite high. There is strong evidence that heterocyclic anti-depressants improve post-stroke depression.

Highlighted Study

Robinson et al. (2000)

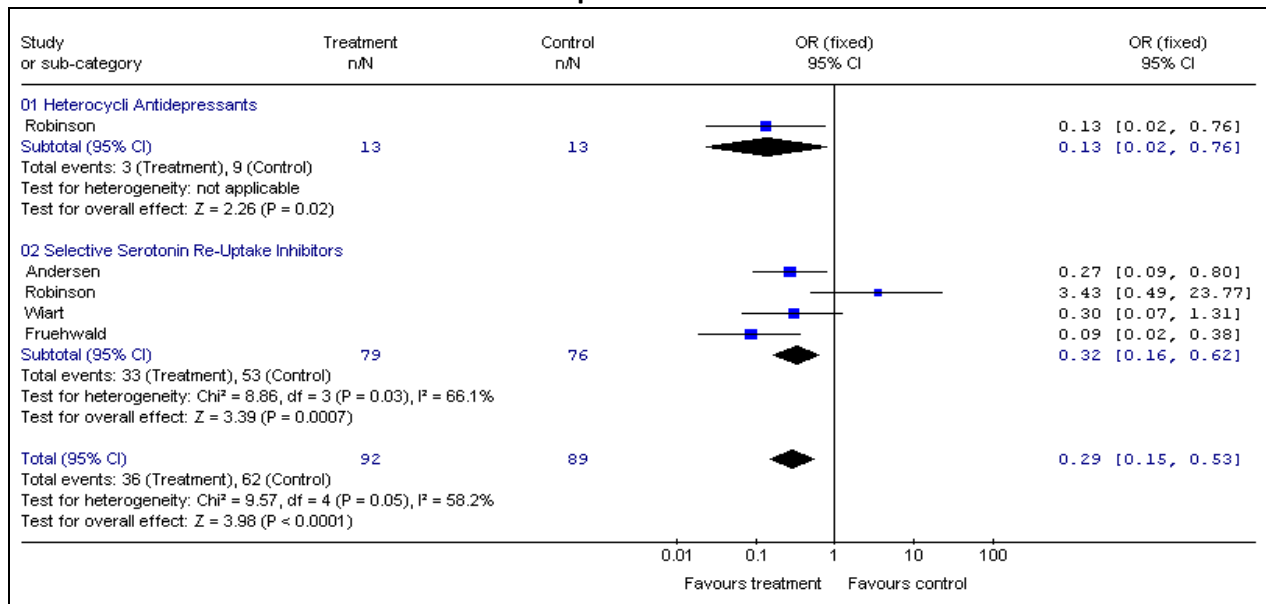
RCT (8) N _{Start} =56 N _{End} =40	E1: Nortriptyline (25-100mg/d) E2: Fluoxetine (10-40mg/d) C: Placebo	E1 vs C • Hamilton Depression Rating Scale (+exp1) • Hamilton Anxiety rating Scale (-)
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TPS=Subacute	Duration: 12wks	<ul style="list-style-type: none"> Functional Independence Measure (+exp1) Johns Hopkins Functioning Inventory (-)
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Summary of Heterocyclic Antidepressants in Post Stroke Depression

Authors/Year	PEDro Score	N	Drug	Result
Robinson et al. 2000	8	56	Nortriptyline	+
Lauritzen et al. 1994	8	58	Imipramine and Mianserin	+
Lipsey et al. 1984	8	39	Nortriptyline	+

Odds Ratio and 95% Confidence Interval of Response to Treatment in Placebo Controlled Studies



Conclusions

Nortriptyline may be beneficial for improving post-stroke depression.

The literature is mixed concerning heterocyclic antidepressants ability to improve activities of daily living

7.3.3 Selective Serotonin Reuptake Inhibitors (SSRIs)

SSRIs selectively block serotonin reuptake thereby increasing levels of serotonin in the brain. Six RCTs (Fluoxetine, Citalopram, Sertraline) of which 3 were positive, two were negative and one while negative regarding depression management showed positive impact on QoL. Meta-analysis (Mead et al. 2013) of 52 using SSRIs for any indication during the initial year post stroke. Patients who received SSRIs were less likely to be dependent (MRS > 3), disabled or neurologically impaired and less likely to be anxious and depressed. Interestingly, a subgroup analysis of patients who were not depressed at study onset

also showed a benefit from SSRI treatment. There is strong evidence that SSRI antidepressants are effective in the treatment of post-stroke depression.

Highlighted Study

Escitalopram/Citalopram vs placebo		
Kim et al. (2017)		
RCT (8) N _{start} =478 N _{end} =405 TPS=Acute	E: Escitalopram (10mg/d) C: Placebo Duration: 12wks	Montgomery-Asberg Depression Scale (-) Emotional Incontinence – Kim's Criteria (+exp) Spielberger Trait Anger Scale (+exp) Barthel Index (-) Stroke Specific Quality of Life Scale (-)

Highlighted Study

Robinson et al. (2008)		
RCT (7) N _{Start} =176 N _{End} =134 TPS=Subacute	E1: Escitalopram (5-10mg/d) E2: Problem-solving therapy C: Placebo Duration: 1yr	E1, E2 vs C Incidence of Depression (+exp1) Functional Independence Measure (-)

Highlighted Study

Andersen et al. (1994)		
RCT (8) N _{Start} =66 N _{End} =59 TPS=Subacute	E: Citalopram (10-20mg/d, 6wk) C: Placebo Duration: 6wks	Hamilton Depression Rating Scale (+exp) Bech-Rafaelsen Melancholia Scale (+exp)

Highlighted Study

Choi-Kwon et al. (2006)		
RCT (8) N _{Start} =152 N _{End} =125 TPS=Chronic	E: Fluoxetine (20mg/d, 3mo) C: Placebo Duration: 3mo	Beck Depression Inventory (-) Visual Analog Scale – Excessive Inappropriate Laughing (-) Visual Analog Scale – Excessive Inappropriate Crying (+exp) Visual Analog Scale – Post-stroke Anger Proneness (+exp)

Highlighted Study

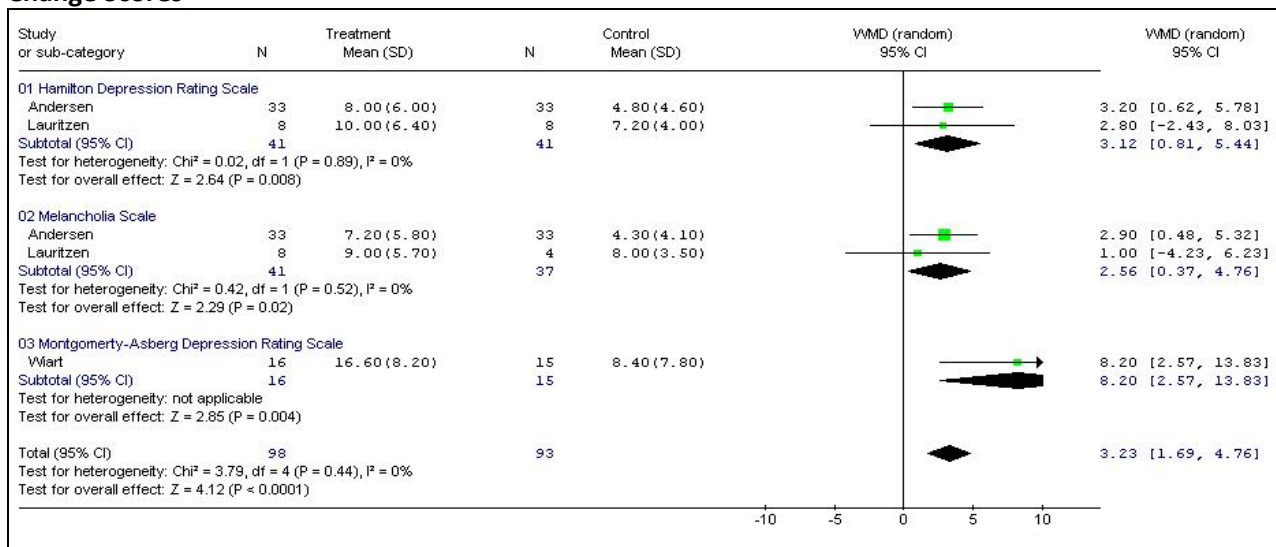
Chollet et al. (2011) (FLAME study)		
RCT (9) N _{Start} =118 N _{End} =113 TPS=Acute	E: Fluoxetine (20mg/d) C: Placebo Duration: 3mo	Montgomery-Asberg Depression Rating Scale (+exp)

118 patients free from clinical depression and not taking any antidepressant medication with Fugl-Meyer (FM) scores of <55 were randomly assigned to receive either 20 mg/day fluoxetine or matching placebo within 5-10 days of stroke onset for 90 days. All patients received usual rehabilitation care delivered by organised stroke teams. Frequency of depression was significantly greater in the placebo group when compared to the treatment group (29% vs. 7%, $p=0.002$). There was a significant between group difference reported in mean change in symptoms of depression over 90 days ($p=0.032$). Mean FM total and lower limb subscores were significantly higher in the fluoxetine group compared with control (54 vs 35, $p<0.01$ and 24 vs. 19, $p=0.001$); change in FM scores was also higher in the fluoxetine group.

Summary of SSRI Antidepressants in PSD

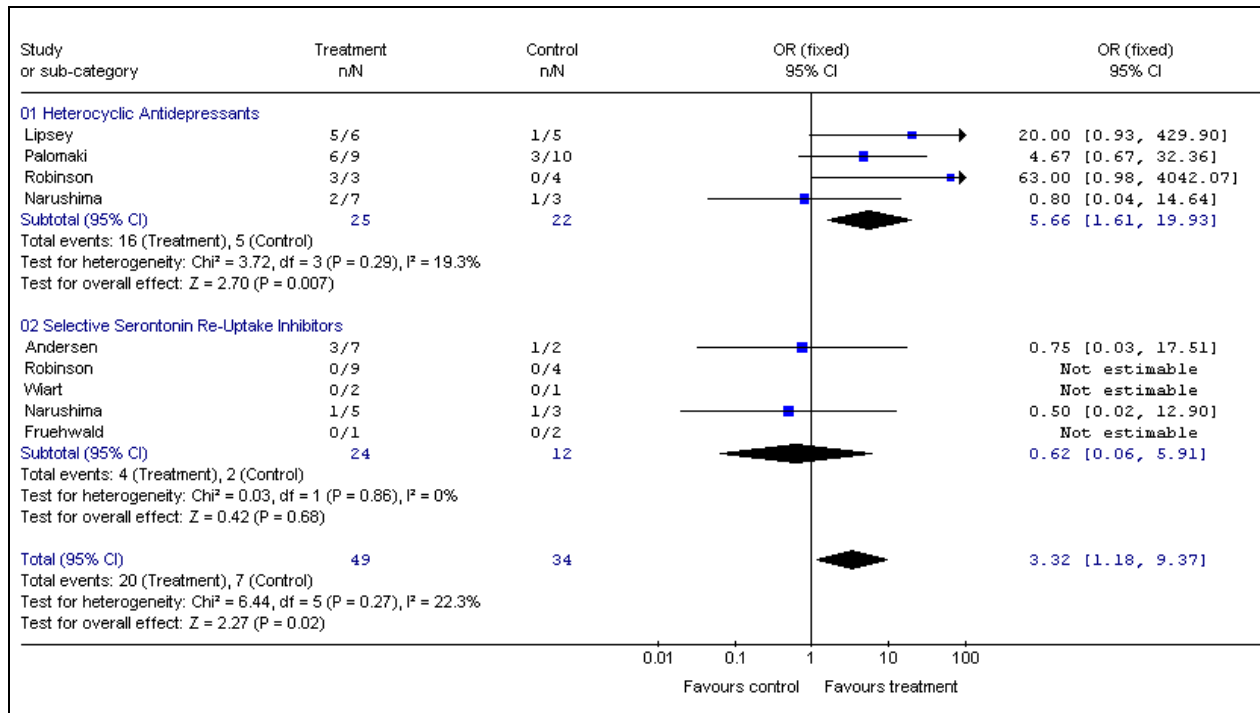
Authors/Year	PEDro Score	N	Drug	Result
Anderson et al. 1994	8	66	Citalopram	+
Robinson et al. 2000	8	104	Fluoxetine	-
Wiat et al. 2000	8	31	Fluoxetine	+
Fruehwald et al. 2003	9	54	Fluoxetine	+
Murray et al. 2005	9	123	Sertraline	-
Choi-Kwon et al. 2006	9	152	Fluoxetine	+ (QoL)
				-

Weighted Mean Difference and 95% Confidence Interval on Effect of Antidepressant Therapy on Mean Change Scores



Odds Ratio and 95% Confidence Interval of Patients Lost Due to Side Effects in Placebo Controlled Studies*

*Drop-outs due to side effects calculated by dividing the number of patients who dropped out because of side effects over the total number of drop outs of that treatment group.



Conclusions

Escitalopram or citalopram may be beneficial for improving post-stroke depression, anger, emotional lability and activities of daily living.

The literature is mixed concerning the efficacy of fluoxetine for post-stroke depression

7.3.4 Psychostimulants (Amphetamines)

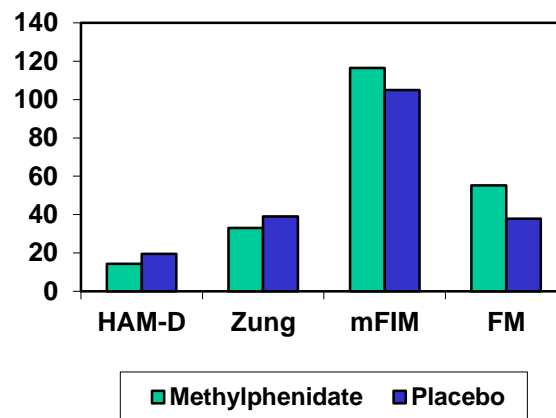
Methylphenidate, a psychostimulant approved for treating attention-deficit disorders, has also been used in the treatment of depression in the elderly as an alternative to other antidepressants. Depression in the elderly has been described as a "lack of interest and emotional involvement in one's surroundings", and psychostimulants have shown to be effective in treating such symptoms (Johnson et al. 1992). Methylphenidate has its effects in the cortical and subcortical areas of the brain. It is believed to heighten mood by affecting several neurotransmitter systems. It primarily acts as a dopamine and norepinephrine reuptake inhibitor.

Methylphenidate (Ritalin) stimulates the noradrenergic system, blocks reuptake of serotonin/noradrenaline and has dopaminergic activity. Methylphenidate has an early onset of treatment effect (2-10 days) vs. 2-4 weeks for other antidepressants.

Highlighted Study

Grade et al. (1998)		
RCT (7) N _{Start} =21 N _{End} =19 TPS=Acute	E: Methylphenidate (15mg, 2x/d) C: Placebo Duration: 3wks	<ul style="list-style-type: none"> Hamilton Depression Rating Scale (+) Zung Self-Rating Depression Scale (-) Modified Functional Independence Measure (+exp)

Only one RCT (n=21) has shown methylphenidate is more effective than placebo in improving depression and functional recovery (Grade et al. 1998).



Conclusion

Methylphenidate (a psychostimulant) may be effective in treating depression post-stroke and has an earlier onset of action than traditional antidepressants.

7.3.5 Summary of Effectiveness of Anti-Depressants

Drug Class	Example	Effectiveness
Heterocyclic Antidepressants	Nortriptyline	Yes – High side effect profile
Selective Serotonin Reuptake Inhibitors (SSRIs)	Sertraline, Fluoxetine, Celexa	Yes – May also improve neurorecovery (Chollet et al)
Selective Noradrenaline Reuptake Inhibitors (NARIs)	Reboxetine	
Serotonin and Noradrenaline Reuptake Inhibitors (SNRIs)	Venlafaxine	
Amphetamines	Methylphenidate	Less Certain – Earlier onset

Functional Recovery Associated with Treatment of PSD

PSD has a negative impact on function and cognitive recovery. Treatment of PSD should improve these outcomes. 6 RCTs examined the role of antidepressants on improvement of functional outcomes, ADLs, cognitive and neurological recovery. Four of the RCTs were positive and 2 had no effect. This is conflicting evidence with a trend towards the positive. Dam et al. 1996 (n=52) found fluoxetine associated with greater ADL performance, and significant impact on gait performance. Pariente et al. 2001 (n=8) found fluoxetine use associated with fMRI activation of the ipsilesional cortex and improved function after single dose. Zittel et al. 2008 (n=8), Acler et al. 2009 (n=30) found Citalopram associated with improved hand function. All these studies report functional impact independent of effect on depression since there was no significant difference between groups regarding depression diagnosis. Adverse events may include nausea, diarrhea, hepatic enzyme disorders, and bleeding (due to the role serotonin plays in platelet activation).

Antidepressants to Improve Neurological Recovery

The one unusual study was the FLAME trial (Chollet et al. 2011) which showed that early treatment with fluoxetine actually improved motor recovery as measured by the Fugl-Meyer scores. Budhdeo and DeLuca (2012) noted that fluoxetine administration upregulated BDNF (brain-derived neurotrophic factor) a neurotrophin which has been shown to promote neurogenesis and synaptic plasticity, thereby improving recovery from ischemic stroke (Binder & Scharfman 2004, Ploughman et al. 2009). Currently there are several larger trials of SSRIs on post-stroke recovery including the *Fluoxetine or Control Under Supervision* (FOCUS) trial, the *Australasian Assessment of Fluoxetine in Stroke Recovery* (AFFINITY) trial and the *Effectiveness of Fluoxetine – a Randomized Controlled Trial in Stroke* (EFFECTS) trial, and *Fluoxetine to Open the Critical Period Time Window to Improve Motor Recovery After Stroke* (FLOW) trial.

Summary of Stroke Recovery after Treatment with Antidepressant Medications

Study	Drug	Recovery	Outcome
Narushima et al. 2003	Nortriptyline or fluoxetine	Physical function	+ Early treatment vs. later treatment
Chemerinski et al. 2001	Nortriptyline	ADL	+ When depression remitted
Robinson et al. 2000	Fluoxetine or Nortriptyline	ADL	+ Nortriptyline
Wiat et al. 2000	Fluoxetine	ADL	-
Miyai & Reding 1998	Desipramine, Fluoxetine, or Trazadone	Functional	+ (Trazadone & Fluoxetine)
Dam et al. 1996	Maprotiline or Fluoxetine	ADL and neurological	+ Fluoxetine
Raffoele et al. 1996	Trazadone HCl	ADL	-
Gonzalez-Torrecillas et al. 1995	Nortriptyline or Fluoxetine	Functional	+ (Nortriptyline & Fluoxetine)
Reding et al. 1986	Trazadone	Functional	+ Pts with +ve dexamethasone suppression
Lipsey et al. 1984	Nortriptyline	Functional	-

Conclusions

There is strong evidence that heterocyclic antidepressants and SSRIs improve PSD.

Methylphenidate (a psychostimulant) may be effective in treating PSD with earlier onset of action.

Non-Pharmacological Treatments of PSD**7.3.6 Exercise for Depressive Symptoms Post Stroke**

Besides the more obvious physical benefits associated with exercise, psycho-social benefits also exist, and attempts are made to maximize these residual benefits as well (Saunders et al. 2014). Many studies

have shown how aerobic exercise can help improve cognitive function, and importantly protect it through ageing in healthy individuals (Quaney et al. 2009). It has also been found to significantly improve mood in non-stroke clinical populations (Altmann et al. 2016, Fritz & O'CONNOR 2016). Now, more work is needed to understand how exercise can improve mood related outcomes in stroke rehabilitation.

Highlighted Study

Aerobic training vs usual care		
Topcuoglu et al. (2015)		
RCT (6) N _{Start} =52 N _{End} =40 TPS=Subacute	E: Aerobic training (4wk) C: Usual care Duration: 4wks	<ul style="list-style-type: none"> • Beck Depression Inventory (+exp) • Functional Independence Measure (-) • Nottingham Health Profile (-)

Highlighted Study

Van de Port et al. (2012)		
RCT (8) N _{Start} =250 N _{End} =242 TPS=Subacute	E: Circuit training (24wk) C: Usual care Duration: 12wks	<ul style="list-style-type: none"> • Hospital Anxiety & Depression Scale - Anxiety (-) • Hospital Anxiety & Depression Scale – Depression (-) • Nottingham Extended Activities of Daily Living (-)

Highlighted Study

Harrington et al. (2010)		
RCT (7) N _{Start} =243 N _{End} =228 TPS=Chronic	E: Group exercise program (8wk) C: Usual care Duration: 8wks	<ul style="list-style-type: none"> • Hospital Anxiety & Depression Scale – Anxiety (-) • Hospital Anxiety & Depression Scale – Depression (-) • WHOQol-Bref (-) • Frenchay Activities Index (-)

Highlighted Study

Lai et al. (2006)		
RCT (8) N _{Start} =100 N _{End} =80 TPS=Subacute	E: Specialized exercise program (12wk) C: Usual care Duration: 3mo	<ul style="list-style-type: none"> • Geriatric Depression Scale (+exp) • Stroke Impact Scale – Emotion (+exp) • SF-36 – Emotion (+exp)

Eng and Reime (2014) conducted a review of 13 RCTs (n=1022) included in a meta-analysis. Exercise resulted in less depressive symptoms immediately after the exercise program ended (p=0.03) but the effects were not retained with longer term followup. Exercise had a positive effect on depressive symptoms across both the subacute (≤ 6 months post stroke) and chronic stage of recovery (> 6 months). There was a significant effect of exercise on depressive symptoms when higher intensity studies were pooled, but not for lower intensity exercise protocols. Antidepressant medication use was not documented in most studies and its potential confounding influence could not be assessed.

Conclusions

The literature is mixed concerning physical activity interventions for improving depression.

Physical activity does not seem to be beneficial for improving anxiety, activities of daily living or quality of life post-stroke.

7.3.7 Repetitive Transcranial Magnetic Stimulation

Repetitive transcranial magnetic stimulation (rTMS) applies a magnetic field to the head, inducing an electric current at the brain and delivering a series of magnetic pulses. Initially developed as an alternative non-invasive stimulation treatment for disorders of the CNS, it has since been shown effectiveness as a treatment for major depressive disorder (Grunhaus et al. 2003, Janicak et al. 2002) and treatment-resistant depression (George & Post 2011, Loo et al. 2003). In a recent systematic review, McIntyre et al. (2016) evaluated rTMS for the treatment of depression due to cerebrovascular disease (i.e. vascular depression and PSD). The authors reported that active rTMS demonstrated a greater decrease in depressive symptoms than sham stimulation. rTMS was also associated with greater rates of response and remission, without any significant side effects or adverse events. Systematic review evaluating the effectiveness of rTMS improving vascular depression (VD) and post stroke depression. Seven studies met inclusion criteria of which 4 were RCTs. Overall there appears to be a benefit of rTMS in treating post stroke depression.

Gu et al. (2017)		
RCT (9) N _{start} =24 N _{end} =24 TPS=Chronic	E: High frequency rTMS (10Hz) C: Sham stimulation Duration: 2.5hrs 6d/wk, 2wks	<ul style="list-style-type: none"> • Beck Depression Inventory (+exp) • Hamilton Depression Rating Scale (+exp)

Conclusion

High frequency rTMS may be beneficial for improving depression and apathy post-stroke, but not activities of daily living

7.3.8 Transcranial Direct Current Stimulation

Another form of non-invasive brain stimulation is transcranial direct-current stimulation (tDCS). This procedure involves the application of mild electrical currents (1-2 mA) conducted through two saline-soaked, surface electrodes applied to the scalp, overlaying the area of interest and the contralateral forehead above the orbit. Anodal stimulation is performed over the affected hemisphere and increases cortical excitability, while cathodal stimulation is performed over the unaffected hemisphere and decreases cortical excitability (Alonso-Alonso et al. 2007). Additionally, tDCS can be applied on both hemispheres concurrently, this is known as dual tDCS. In contrast to TMS, tDCS does not induce action potentials, but instead modulates the resting membrane potential of the neurons (Alonso-Alonso et al. 2007). It is a relatively newer form of non-invasive stimulation that has demonstrated efficacy and tolerability in treating major depressive episodes (Meron et al. 2015, Shiozawa et al. 2014).

Highlighted Study

Valiengo et al. (2017)		
RCT (8) N _{start} =48	E: Dual tDCS stimulation C: Sham stimulation	Hamilton Depression Rating Scale (+exp) Montgomery-Asberg Depression Rating Scale (+exp)

N _{end} =43 TPS=Chronic	Duration: 12 sessions, 30min, 5d/wk (first 2 weeks) then 7d/wk	Clinical Global Impression – Severity (-) Barthel Index (-)
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Conclusion

Dual tDCS could be beneficial for improving post-stroke depression

7.3.9 Cognitive-Behavioural Therapy (CBT) Post-Stroke

CBT is an active, directive, structured intervention based on emotion and behaviour as determined by experience. CBT concentrates on altering patient's interaction with environment and their interpretation of experiences. Cognitive behavioural therapy (CBT) has been well established as an effective intervention for depression and numerous other psychological disorders. It is founded on the notion that our thoughts affect our emotions and behaviours; whereby, dysfunctional thoughts lead to negative emotions and negative behaviours. Therefore, the aim of CBT is to evaluate, challenge and modify dysfunctional thoughts, through cognitive restructuring, to promote behavioural change and improve functioning. A psychoeducational approach is often utilized to teach individuals new ways of coping with stressful situations; however, emphasis is placed on homework assignments and activities completed outside of the therapy session (Cuijpers et al. 2013).

Highlighted Study

Cognitive Behavioural Therapy vs Standard Care		
Fang et al. (2017)		
RCT (5) N _{start} =42 N _{finish} =42 TPS=Acute	E: Constructive Integrative Psychosocial Intervention C: Standard Care Duration: 6months	<ul style="list-style-type: none"> Hospital Anxiety Depression Scale –depression (+exp) Hospital Anxiety Depression Scale – anxiety (-)

Highlighted Study

Visser et al. (2016)		
RCT (7) N _{start} =166 N _{end} =151 TPS=Chronic	E: Problem-solving therapy C: Usual care Duration: 1.5h/wk for 8wk	<ul style="list-style-type: none"> CES Depression Scale (-) Coping Inventory for Stressful Situations (-) Stroke-Specific Quality-of-Life Scale-12 (-) EuroQol EQ-5D-5l (-)

Highlighted Study

Thomas et al. (2013)		
RCT (7) N _{start} =105 N _{end} =89 TPS=Not reported	E: Behavioural therapy (aphasic) C: Usual care Duration: 20, 1h sessions over 3months	<ul style="list-style-type: none"> Stroke Aphasic Depression Questionnaire (+exp) Visual Analogue Self-Esteem Scale (+exp) Visual Analogue Mood Scale - Sad (+exp) Nottingham Leisure Questionnaire (-)

Highlighted Study

Cognitive Behavioural Therapy with Antidepressants vs Usual Care		
Mitchell et al. (2009)		
RCT (7) N _{start} =101	E: Psychosocial-behavioural intervention + Antidepressants	<ul style="list-style-type: none"> Hamilton Depression Rating Scale (+exp)

N _{End} =92 TPS=Subacute	C: Usual care + Antidepressants Duration: 9 sessions over 8wk	
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Highlighted Study

Motivational Interviewing vs Usual Care		
Watkins et al. (2007) Watkins et al. (2011)		
RCT (7) N _{Start} =411 N _{End} =340 TPS=Chronic	E: Motivational interviewing C: Usual care Duration: 1mo	<ul style="list-style-type: none"> General Health Questionnaire 28 (+exp) Yale Self-Report Screening Tool (+exp) Barthel Index (-)

Conclusions

The literature is mixed regarding the effectiveness of CBT for improving post-stroke depression. CBT does not appear improve activities of daily living or quality of life.

7.3.10 Care Provision and Educational Resources

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 caregivers, and among the caregivers themselves. How that care is delivered can take on any number of forms (education, home visits, weekly phone calls). The development of depression post-stroke may be influenced by the provision of regular contact, counselling, and support within various models of care. Therefore, some research has focused on which methods of provision and support can help ameliorate mood related disorders post-stroke.

Highlighted Study

Comprehensive Patient Follow-up and/or Care Coordination Programs vs Standard Care		
Graven et al. (2016)		
RCT (10) N _{Start} =110 N _{End} =94 TPS=Subacute	E: Intensive follow up + Goal Setting C: Standard care Duration: 12mo	<ul style="list-style-type: none"> Geriatric Depression Scale (+exp)

Highlighted Study

Wong et al. (2015)		
RCT (8) N _{Start} =108 N _{End} =99 TPS=Acute	E: Dedicated care coordination and follow up C: Standard care Duration: 4wk	<ul style="list-style-type: none"> CES Depression Scale (+exp) WHO Quality of Life, Spirituality, Religion and Personal Beliefs (+exp) SF-36 (+exp) Modified Barthel Index (-)

Highlighted Study

Goal Setting Structured Therapy Programs vs Standard Care or Education Program

Jones et al. (2016)

RCT (6) N _{Start} =78 N _{End} =66 TPS=Subacute	E: Self-management program C: Standard care Duration: 12wk	<ul style="list-style-type: none"> Hospital & Anxiety Depression Scale - Depression (-) Hospital & Anxiety Depression Scale - Anxiety (-) Stroke and Aphasia Quality of Life Scale (-) Nottingham Extended Activities of Daily Living Scale (-) Medical Outcomes Trust's Short Form 12 (-)
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Conclusions

Coordinated care and comprehensive follow-up may be beneficial for improving post-stroke depression, but not other mood related outcomes.

Goal-setting programs or home visits may not be beneficial for improving mood related outcomes post-stroke.

7.3.11 Art Therapy

Art therapy emerged from the combination of visual arts and psychotherapy. Creative expression is believed to help individuals with various psychosocial outcomes such as achieving goals, solving problems, and addressing trauma. One RCT was found that looked at art therapy for stroke survivors (Kongkasuwan et al. 2016).

Highlighted Study

Kongkasuwan et al. (2016)

RCT (7) N _{Start} =118 N _{End} =113 TPS=Not reported	E: Art therapy C: Standard care Duration: 2d/wk for 4wk	<ul style="list-style-type: none"> Hospital Anxiety & Depression Scale – Depression (+exp) Hospital Anxiety & Depression Scale – Anxiety (-) Modified Barthel Index Scale (+exp) Pictorial Thai Quality of Life Questionnaire (+exp)
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Conclusion

Art therapy may be beneficial for improving depression, activities of daily living and quality of life post-stroke, but not anxiety

7.3.12 Music Therapy in Depression

The benefits of music therapy have been well established in a variety of chronic diseases (Umbrello et al. 2019). However, in recent years the use of music therapy for stroke rehabilitation has gained attention. In stroke rehabilitation, music therapists utilize instruments, voice and music to address functional goals in areas such as emotion, communication, cognition, physical abilities and behaviour. In combination with the psychosocial benefits of music therapy, music has been shown to activate areas of the brain related to attention, affective processing, memory and motor control (Särkämö & Soto 2012). As such, activation and engagement of these brain regions likely contributes to the rehabilitating effect of music after stroke. A recent Cochrane review reported that music therapy significantly improves gait and upper extremity functioning, communication and overall quality of life following stroke (Magee et al. 2017).

Highlighted Study**Raglio et al. (2017)**

RCT (6)	E: Interactive Music Therapy (30min, 3x/wk)	• Functional Independence Measure (+exp)
N _{start} =38		• Hospital Anxiety and Depression Scale – Anxiety (-)
N _{end} =38	C: Standard Care	• Hospital Anxiety and Depression Scale – Depression (+exp)
TPS=Acute	Duration: 7wks	• McGill Quality of Life Questionnaire (-)

Conclusion

The literature is mixed regarding music therapies efficacy for improving mood related outcomes post-stroke.

7.4 Community Reintegration Post Stroke

Community reintegration is one of the most important and underrated areas of stroke care. Failure to mobilize adequate community supports can negate the best efforts of stroke rehabilitation. Community supports have a profound impact on quality of life. Throughout a stroke survivor's journey, they will transition through several setting 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, the stroke survivor and their caregivers should have an education plan that addresses their goal setting and learning needs (Mountain et al. 2020). 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). 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).

7.4.1 Social Support

Social support is defined as *“the experience or information that one is loved and cared for, valued and esteemed, and able to count on others should the need arise”*.

Social Support Domains

1. **Homefront** – composition of persons in the home and \$ means.
2. **Social Situation** – availability of care and quality of social network.
3. **Residence** – adaptability to the needs of the individual.

Glass and Maddox (1992) note the stroke experience:

1. Takes place in a short period of time.
2. Alters capacity for social role function.

3. Risk of loss of functional independence requires adjustment to new self with limitations of multiple and vital roles. The stroke experience requires both coping with loss and adaptation to change.

The goal of social support is to help the patient deal with the loss and move to that acceptance of their new self.

Importance of Social Support Post Stroke

Glass et al. (1993) conducted a prospective study (n=46). Patients with severe stroke and greatest social support attained an average Barthel Index score 65% greater than those with low levels of support. Higher levels of support associated with faster and more extensive recovery of functional status. Knapp and Hewison (2004) observed the availability of a close confiding relationship and social network relationships (emotional support) had a protective function against later depression and in turn resulted in improved functional outcomes. Meijer et al. (2004) in a review of 6 cohort studies found that the factors most predictive of discharge home were marital status and large social networks. Large social network and perceived social support associated with better physical function. There is limited but extensive evidence that social support systems provided through family and social networks associated with better outcomes (discharge home, better physical and functional outcomes).

Social Support and Quality of Life

Quality of life is a complex multidimensional concept. Bays (2001) conducted review of 39 articles focusing on Quality of Life.

- **Positive influence on Quality of Life:** independence in ADLs, functional ability, social support and healthcare resources.
- **Negative influence on Quality of Life:** depression, cognitive impairment, stroke severity and aphasia.

The presence and size of social support networks as well as perceived effectiveness of social support networks have a positive influence on physical recovery and Quality of Life post stroke. Higher levels of social support are associated with greater functional gains, less depression and improved mood and social interaction.

7.4.2 Family and Stroke

Who Does the Caregiving?

The brunt of long-term care of stroke survivor falls onto family caregivers. There is no family caregiving system, rather one family member occupies role of primary caregiver. There tends to be an order in North American society as to who does the caregiving. Usually it is the spouse and if not the spouse than a daughter, often the youngest daughter, followed by a son if there is no daughter available and if no children the role falls to other relatives and if no family available, friends. The key point is that care tends to fall onto one person with limited shared responsibilities. Although friends and family provide assistance with care shortly after discharge home, little help is forthcoming at one year. If new care demands develop, it is the family (primary caregiver) who must meet those demands.

Family Function and Stroke

Evans et al. (1987) noted that poor family functioning contributes to poor treatment compliance and deterioration in function. Poor family functioning is directly related to re-hospitalization (accounts for 28% of variance).

Good families:

- Communicate and exchange info clearly and directly.
- Effective problem solvers.
- Report strong emotional interest in one another.
- Caregivers and patients have different viewpoints of the patient's functioning which can create conflict.
- Patients generally rate their quality of life higher than the caregivers do.

Perceived family dysfunction is common post-stroke. Family function affects treatment adherence, performance of ADLs and social activity. Stroke patients do better with well-functioning families.

Effective communication, good problem solving or adaptive coping and strong emotional interest in each other characterizes well-functioning families.

The Impact of Caring for a Stroke Survivor Changes Over Time

Immediately following a stroke caregiver burden is influenced more by stroke severity. Caregivers are more preoccupied initially with physical limitations, medications and finances. Later (after 6-12 months), in part influenced by some continuing improvement, caregivers are more influenced by cognitive and emotional issues and may spend more time assisting with travel and leisure activities. Outpatient rehab and support has no influence on caregiver depression at 3 months post stroke but does at 12 months. Over the longer term (after 2 years), burden of care tends to decrease as does social support, while depression and quality of life remain stable.

Negative Impacts of Caregiving

Family members caring for stroke survivors often face their own adjustment difficulties. Caregivers must sacrifice their own personal needs to provide the needs of stroke survivors. Often times they find themselves having to provide skilled nursing care which they must learn by 'trial and error'.

Most commonly identified effects of caregiving:

- Increased caregiver stress/strain/burden.
- Decreased social contact and activity.
- Declines in psychological health (including increased risk for depression).
- Reduced quality of life.
- Individuals experiencing caregiver burden are at higher risk for depression and depression is also associated with deterioration of physical health (Schulz et al. 1997).
- Physical health may be compromised when the demands of caregiving are perceived to be great (Shaw et al. 1997).

Factors which Contribute to Caregiver Stress and Breakdown Post Stroke

Caring for a stroke survivor with severe disabilities can be a formidable task. Caregivers cope better with physical limitations than cognitive or emotional disorders. Lack of rest or time to fulfill obligations, the need for constant vigilance/supervision as well as lack of respite can have a negative impact on caregivers. Caregivers are often required to sacrifice their own personal needs. The chief reasons for

reports of less enjoyment of life on the part of caregivers include loss of companionship, increased domestic responsibility and interference with leisure and social activities.

Which Caregivers are at Risk?

Certain kinds of tasks are perceived as more stressful:

- Mood disturbances, bowel incontinence, memory impairments (Haley et al. 2009).
- Managing behavioural problems, providing emotional support (Bakas et al. 2004).
- “Most consistent patient and caregiver characteristics associated with burden are those relating to mental health” (Rigby et al. 2009).
- *“The consensus appears to be that whilst increasing primary demands (task assistance and time spent caring) do not consistently increase carer distress or burden, emotional or behavioural problems do”* (Morrison 1999).

Behavioural Problems Hinder Caregiver Adjustment

Caregiver adjustment is influenced by behavioral problems post-stroke. Personality changes noted by the caregiver post stroke is seen in 67% at 3-8 months:

- better in 5%
- worse in 82%
- not clear in 13%

Negative behavioural problems include:

- Irritability
- Loss of self control
- Lower frustration tolerance
- Emotional lability
- Self-centeredness
- Apathy
- Agitation

Summary of the Effects of Caregiving Post Stroke

Commonly identified effects of caregiving on the caregiver include decreased health (both physical and mental), decreased social contact and activity, increased risk for depression, increased carer stress, strain or burden and an overall decrease in quality of life. Decreased social contact and activity in itself may contribute to increased carer strain, increased risk of depression and decreased life satisfaction. Age, severity of stroke, stroke-related impairments, and functional and cognitive status have been reported as influencing caregiver outcomes.

Caregiver Depression

Stroke caregivers are more susceptible to depression. Caregivers of stroke survivors have high rates of depression (39-52%) when compared to normal population (12-16.5%); studies are on opportunistic samples with a self-selection bias. Chief causes were loss of companionship, increased domestic responsibility and interference with leisure and social activities. Factors which predict post-stroke depression include the stroke survivor's level of dependence, the amount of tangible support received, opportunities for socialization and a negative orientation towards problem solving.

Caregivers at highest risk of depression:

- Spouses of younger, more severely impaired strokes.

- Lower household incomes.
- Smaller social networks with whom they visit regularly.
- Lower levels of optimism and expectations.

Coughlan and Humphreys (1982) noted that 3-8 yrs post-stroke 32% of spouses reported “much less enjoyment of life”. Chief causes of reduced enjoyment were loss of companionship, increased domestic responsibility and interference with leisure and social activities. Webster and Newhoff (1981) noted that the wives of stroke patients had to assume duties formerly assigned to a spouse, had lack of people to confide in or talk to and lack of personal time alone.

Caregiver Burden

This term is used to describe the “load” carried by informal caregivers as a result of adopting this role. The reported prevalence of “significant burden” ranges from 25-54% (2009). **Objective Burden** is the physical assistance provided in the form of caregiving tasks. **Subjective Burden** is the psychological, social and emotional impact on caregivers as a consequence of objective burden (Montgomery et al. 1985).

Patient and Caregiver Support

Patient and family support can be divided into two types of support:

1. Social Support (mixture of various support types)
 - Social work interventions
 - Spec. social networking
 - Day services
 - Home-based support and care management
2. Education (primarily informational support)
 - Information packages
 - Education sessions
 - Skills training

Support given by caregiving peers may have a positive effect on the caregiver. It is important to include both the caregiver and stroke patient in social support interventions.

Psychological Disorders in Caregivers Less Likely to Get Support

Physical disabilities are more likely to receive assistance from formal sources than the harder to quantify behavioural and emotional disorders (Smith et al. 2004). Although behavioural and emotional problems may present the greatest difficulty, healthcare professionals may choose to ignore them. Simon et al. (2015) reported that caregivers with perceived poorer physical health received significantly more formal services following discharge. Psychological distress did not have a similar impact on service provision. 37% of carers were identified with significant psychological distress at discharge.

7.4.3 Patient Education Programs

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).

Highlighted Study

Rodgers et al. (1999)		
RCT (8) N _{Start} =204 N _{End} =154 TPS=Acute	E: Attend the Stroke Education Program C: Conventional care + access to pamphlets Duration: 6mo	<u>Patients</u> <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 (-) <u>Caregivers</u> <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)

Highlighted Study

Eames et al. (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	<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 (-)

	Duration: 3mo	<ul style="list-style-type: none"> • Satisfaction with information (+exp) • Caregiver Strain Index (-)
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Conclusion

Education programs may not benefit patient or caregiver outcomes.

7.4.4 Psycho-social and Emotional Support

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)

Highlighted Study

Glass et al. (2004)		
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 12wks	<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 (-)

Highlighted Study

Friedland & McColl (1992)		
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 (-)

Conclusion

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

7.4.5 Discharge Planning and Active Care Management

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. 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.

Highlighted Study

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 (-)

Highlighted Study

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)

Highlighted Study

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 (-)

Highlighted Study

Lincoln et al. (2003)		
RCT (5) N _{Start} = 250 N _{End} = 187 TPS=NR	E: The Stroke Family Support Organiser (FSO) service C: Conventional care Duration: 9mos	<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)

		<ul style="list-style-type: none"> • Satisfaction with information on stroke (-) • Satisfaction with information on community services (-) • Satisfaction with information on emotional support (+exp)
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Highlighted Study

Dennis et al. (1997)

RCT (8) N _{start} = 417 N _{end} =327 TPS=Acute	E: Post-stroke visits from a stroke family care worker C: Conventional care Duration: 6mo	<u>Patients</u> <ul style="list-style-type: none"> • Oxford Handicap Scale (-) • Barthel Index (-) • Frenchay Activities Inventory (-) • General health questionnaire – 30 (-) • Social adjustment scale (-) <u>Caregivers</u> <ul style="list-style-type: none"> • Caregiver hassle (-) • Frenchay Activities Index (-) • General health questionnaire – 30 (+exp) • Social adjustment scale (-)
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Conclusion

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

7.4.6 Self-Management Strategies

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).

Highlighted Study

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	<ul style="list-style-type: none"> • Chinese Self-management behaviour questionnaire • 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)
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Highlighted Study

Cadhilac et al. (2011)

RCT (7) N _{start} =143	E1: Attend a stroke specific self-management program (8wks)	<ul style="list-style-type: none"> • Irritability, Depression and Anxiety Scale (-) • Health Education Impact Questionnaire –
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N _{End} =122 TPS=Chronic	E2: Attend a generic self-management program (6wks) C: No management program Duration: 2.5hrs/wk, 6mo (follow up)	positive/active life engagement (-) • Assessment of Quality of Life (-) • Adherence (+exp)
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Conclusion

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

7.4.7 Caregiver and Training Programs

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. 2004).

Caregiver Skills Training

There is strong evidence that skills training is associated with a reduction in depression. There is moderate evidence that training in basic nursing skills improves outcomes of depression, anxiety and quality of life for both the caregiver and the stroke patient.

What social support interventions have been shown to help caregivers?

Support provided by caregiving peers may have a positive effect on the caregiver. It is important to include both the caregiver and stroke patient in social support interventions. There is moderate evidence that participation in an online program providing information and support through contact with both a nurse and other caregivers is not associated with improvements in perceived emotional support, physical help or caregiver health. Participation in a structured psychoeducational program (e.g. Powerful Tools for Caregiving) may improve well-being and reduce behaviours that could lead to problems with physical health.

Highlighted Study

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	<u>Patients</u> <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)

		<ul style="list-style-type: none"> Barthel Index (BI) (+exp) Caregiver Caregiver Burden Scale (-)
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Highlighted Study

Bakas et al. (2009)

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)
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Highlighted Study

Kalra et al. (2004)

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)
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RCT of 300 patients and caregivers. Intervention group received training in basic nursing and personal technique care vs. conventional care. Formal training of caregivers during patient's rehabilitation associated with:

- ✓ ***Less caregiving burden***
- ✓ ***Better psychological outcomes in patients and caregivers***
- ✓ ***Higher quality of life in patients and caregivers***
- ✓ ***Reduced overall costs of health and social care***

Highlighted Study

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)
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Conclusions

Caregiver training may not have specific benefits to carers.

Conclusions on Community Supports

Higher levels of social support are associated with greater functional gains, less depression, improved mood and social interaction as well as improved quality of life. Social support is predictive of discharge destination. Interventions to help access community support services is associated with increased social activity. It is important to include the caregiver as well in social support interventions.

7.4.8 Exercise and Physiotherapy Interventions

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).

Client Centered Home Exercise Program vs Conventional Care		
Bertilsson et al. (2016)		
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	<u>Caregivers</u> <ul style="list-style-type: none"> Caregiver burden scale (-) Provision of Informal care (-) Occupational Gaps questionnaire (-) Life satisfaction (-)

Conclusions

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

7.4.9 Sexuality, Aging, and Disability

In a study of individuals 50-92 years old, Gott et al. (2003) reported sex remained an important part of a close emotional relationship. However, sex may be assigned a lower priority, not due to aging per se, but rather due to increasing disability and health problems that are barriers to sexual activity.

Sexual Functioning Post Stroke

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.

Decreased sexual activity or abstinence is common post-stroke despite normal sexual libido. 70% of hemiplegic males and 44% of females report a decrease in frequency of sexual activity. This issue is often not well addressed in rehabilitation. Kerstan et al. (2002) interviewed 315 stroke survivors (18-65 years old) responded to questions regarding to changes in sex life post-stroke: 64% reported difficulties. Fugl-Meyer et al. studied 85 stroke victims who were sexually active pre-stroke. Post-stroke sexual activity was unchanged in 36%, decreased in 33% and discontinued altogether in 31%. Dysfunction was more significant in aphasia patients.

Decreased sexual activity post-stroke attributed to:

- Inability to discuss sexuality with spouse
- Unwillingness to participate in sexual activity
- Reduced body image and self-esteem
- Positioning problems due to disability

Most stroke patients agree resumption of sexual activity is important to them.

Treatment of Sexual Dysfunction Post-Stroke

There are no RCTs on treatment of sexual dysfunction post-stroke. Open discussion of the issue is critical. Personal care provision by the spouse reduces sexual intimacy. Both patient and partner need to recognize the need to adapt to physical disabilities. Patients and spouses need to be reassured that sexual activity will not result in another stroke. Importance of communication, sharing of concerns and development of adaptive approaches have been suggested.

Recommendations Re Sexuality (Dutch Clinical Guidelines – van Heughten et al. (2006)

- **Recommendation #1:** *Patients and spouses are often not satisfied with their sexual functioning after stroke; sexuality and intimacy should, therefore, be discussed with married couples.*
- **Recommendation #2:** *Changes in sexual function should be discussed with patients and spouses at different moments during the rehabilitation process, such as at discharge and at follow-up. Professional support should be offered when necessary.*
- **Recommendation #3:** *Sexuality and intimacy should be discussed during carer support groups. Information should be given about the nature and causes of these changes.*

Highlighted Study

Sansom et al. (2015)

RCT (6)	E: Structured sexual rehabilitation	• Changes in Sexual Functioning Questionnaire –
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NStart=10 NEnd=10 TPS=NR	program C: Usual care Duration: single 30min session (6wk follow up)	short form (-) • Depression, Anxiety and Stress Scale (-) • Functional Independence Measure (-) • Stroke and Aphasia Quality of Life Scale (-)
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Conclusions

A decrease in sexual activity is very common post-stroke and is likely related to a changed body image, reduced self-esteem and lack of communication with one's partner.

There is consensus opinion that sexual issues need to be addressed as an important part of community reintegration.

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

7.4.10 Driving Post-Stroke**Return to Driving**

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).

How might a stroke compromise driving ability?

- Visual field deficit.
- Inattention, particularly left neglect.
- Cognitive deficits (problem solving).
- Hemiplegia or hemiparesis.
- Apraxias.
- Language difficulties (receptive aphasia).

How important is driving to stroke survivors?

Driving represents the final step towards independence and reintegration into the community. Failure to resume driving negatively impacts social activities and overall wellbeing. The literature reveals very limited information about driving. Vision and attention are necessary elements for safe driving. These are often impaired post-stroke. Korner-Bitensky et al. (2000) have noted (motor free visual perceptual test) MVPT partially predicts driving ability. The ability of off-road tests to predict on-road results is questionable.

Are stroke survivors accurate judges of their own ability to drive?

- Most driving adults believe that they are better drivers than they are.
- Stroke survivors often are unaware of mistakes that they make in formal testing scenarios.
- Stroke survivors tend to rate their driving ability as “above average” and better than their spouses.

What assessment tools are available to assess a stroke survivor’s fitness to drive?

There are no specific assessment tools which are able to accurately predict who is able to drive and who cannot. Determination of ability to drive should not rely on neuropsychological testing or an on-road test evaluation. Cognitive tests such as the Trail Making Tests (A and B) and Rey-Osterreith Complex figure design have been consistently predictive of driving assessment outcomes. Other tests which have been identified as potentially useful include the Motor Free Visual Perceptions Test, the Useful Field of View test as well as tests of road knowledge (road sign and hazard recognition tests) and reaction time. Few studies have reported the development of cut-off points with appropriate sensitivity and specificity suitable for use within a stroke population.

In Ontario must report to Ministry of Transport if patient has valid driver’s license and concerned re driving; not all jurisdictions require reporting. Patient assessed by OT – MVPT >30/36 and brake reaction test within norms – go ahead for testing. Visual field testing needs to be done. On the road testing by professional driving instructor required for high-risk stroke survivors.

CMA Determining Fitness to Drive (2012)

- *“Patients who have experienced either a single or recurrent transient ischemic attack should not drive a motor vehicle until a medical assessment is completed.”*
- Detailed history and thorough physical examination, including assessment of cognition, insight and judgment are important.
- Assessment by an occupational therapist is ideal.
- Road test may help assess functional capacity to drive with concerns that such testing cannot always be relied on to reveal the true extent of the disability.
- *“Patients who have had a stroke should not drive for at least one month.”*
- *“Where there is residual loss of motor power, a driving evaluation ... can make recommendations for ... vehicle modification strategies, such as use of a steering wheel ‘spinner knob’ or left-foot accelerator.”*
- Patients with right hemispheric strokes are of particular concern because of visual perceptual disorders.
- Patients with a visual field deficit should have a visual field assessment conducted by an ophthalmologist or optometrist.

When a Stroke Patient Returns to Driving what Should they Avoid?

- Driving in an unfamiliar area.
- Driving at night.
- Driving when tired (includes long distances).
- Parallel parking.
- Driving in rush hour, particularly in a large city.
- Driving on busy multilane high speed expressways.

Treatment Interventions in Patients Not Able to Drive

There is moderate evidence that a visual attention retraining program is no more effective than traditional visuo-perception retraining in improving the driving performance of patients with stroke.

There is moderate evidence that a simulator training program involving the use of appropriate adaptations and driving through complex scenarios similar to real life is associated with improvement in driving fitness and successful on road evaluation. Driving fitness may be improved through the use of a stimulator training program.

Highlighted Study

Simulator Training vs Cognitive Training		
Akinwuntan AE, De Weerd W, Feys H, et al. Effect of simulator training on driving after stroke: a randomized controlled trial. Neurology 2005; 65:843-850.		
Devos et al. (2009)		
RCT (8) N _{Start} =83 N _{End} =73 TPS=Subacute	E: Simulator based training C: Driving related cognitive tasks 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)
<i>This RCT examined 83 patients < 3 months stroke with license and active driver pre-stroke. Randomized to simulator-based training (n=42) or control (driving-related cognitive tasks) (n=41) for 15 x 1 hr sessions over 5 weeks. Both groups demonstrated significant improvements (p<.05) from pre to post training assessments. While the simulator group showed more improvement than control group did not reach significance (p=0.08). 73% of treatment group passed their on-the-road assessment vs. 42% of controls (p=0.03).</i>		

Highlighted Study

Useful Field of View Training vs Computer Visuo-perceptual Training		
Mazer BL, Sofer S, Korner-Bitensky N, Gelinas I, Hanley J and Wood-Dauphinee S. Effectiveness of a visual attention retraining program on the driving performance of clients with stroke. Arch Phys Med Rehabil 2003; 84(4):541-550.		
RCT (7) N _{Start} =97 N _{End} =84 TPS=Subacute	E: Useful Field of View visual information processing training C: Visuo-perceptual 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 (-) Visuo-perception battery (-) Everyday attention (-)
<i>This RCT examined 97 patients with stroke < 6 months and license to drive prior to stroke. Randomized to visual information-processing training or to control visuo-perceptual training on computer x 20 sessions. No significant differences were noted on any outcomes. However, almost 2-fold increase (52.4% vs 28.6%) in rate of success for on-the-road testing of treatment group.</i>		

Conclusions on Driving Post-Stroke

Despite a lack of research, patients for whom there is a concern about their ability to drive post-stroke by law in Ontario need to be reported and properly assessed.

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

7.4.11 Return to Work Post Stroke

Observational studies suggest that many stroke patients could return back to work but most do not (less than half). 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 et al. 2003). The two major factors influencing RTW are the degree and nature of the stroke related impairment and the level of education/type of work. Despite a lack of research, there is consensus opinion that stroke survivors, if they were employed prior to the stroke, should be evaluated for their potential to return to work. A substantial proportion of stroke survivors who were employed prior to the stroke event do not return to work. Factors influencing return to work include the degree of physical and cognitive impairment, age, educational level and type of pre-stroke employment. There is consensus opinion that stroke survivors who worked prior to their stroke should, if their condition permits, be encouraged to be evaluated for their potential to return to work.

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.

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 (-)

Conclusions

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

7.4.12 Leisure/Socialization

Leisure Activities Post Stroke

A reduction in social and leisure activities has been reported following stroke. Neimi et al. (1988) noted that stroke patients in a survey reported an 80% reduction in leisure domains. Belanger et al. (1988) reported 6 months after returning home, < 50% participated in regular physical activities and < 50% in leisure activities outside of home; more time spent watching TV in home. Labi et al. (1980) noted women and those with higher education were most often affected in terms of leisure activities. This was attributed to greater value placed on body image and social status in social activities. Davidson and Young (1985) noted younger patients were more likely to be affected.

Lawrence and Christy (1979) observed physical disability in itself was less important to stroke patient than others response to disability. Patients with a caregiver that lived with them were less inclined to socialize even though they are generally unoccupied throughout the day. Even after return of physical

abilities, patients do not return to premorbid social activities. Often times, lack of socialization is avoided because of fear of managing outside of the home. For instance, toileting in strange and sometimes difficult facilities is often enough to keep the stroke patient isolated at home. Stroke leads to social isolation, loneliness and depression.

Three RCTs examining the effect of leisure therapy (always occupational therapist) found mixed results with only one RCT able to demonstrate beneficial and lasting effects of leisure therapy. All were outpatient interventions; difficulty distinguishing between ADL and leisure activities, and limited number of interventions, often with small numbers. A recent meta-analysis pooling data from 3 RCTs found modest improvement in leisure activity with leisure therapy.

Conclusions Regarding Leisure Activities Post-Stroke

Deterioration in social and leisure activities is common post-stroke and is greatest in women, the young and those who are better educated.

Perceptions about how others view their disabilities and perceptions about how they will be able to cope post-stroke may influence the degree of social isolation experienced.

Research is limited in this area.

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