Community Reintegration
Evidence Tables

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## 19. Social Support and the Stroke Patient

### 19.1.1 Social Support and Discharge Destination

<table>
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<tr>
<th>Author, Year Country PEDro Score</th>
<th>Population: Stroke Patient Group (SPG, N=5): Mean age=65.4yr; Gender: Males=1, Females=4. Carer Group (CG, N=5): Mean age=NA; Gender: Males=2, Females=3. <strong>Intervention:</strong> Semi-structured interviews with stroke patient (SP)/carer dyads were conducted 1m after discharge from stroke rehabilitation to enhance the understanding of this transitional period. <strong>Outcomes:</strong> Thematic analysis relating to the transitional experience.</th>
<th>Outcomes</th>
<th>1. Client experience  • Preparation for home-“rehabilitation was okay”  • Personal experience of being home- “it’s a struggle”  • Descriptions of home supports- “supports and assistance” 2. Carer experience  • Preparation of the SP for home- “the purpose of rehab”  • Descriptions of home life with the SP- “life is different now”  • Importance of “looking to the future”</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gustafsson et al. (2013)</strong> Australia Qualitative Study No Score TPS=mean=NA N_start=5 N_end=5</td>
<td><strong>Pohl et al. (2013)</strong> USA Retrospective No Score TPS=mean=NA N_start=31910 N_end=31910</td>
<td>Population: Mean age=77±7.3yr; Gender: Males=43%, Females=57%. <strong>Intervention:</strong> To determine whether functional ability at admission and demographics predict discharge placement after inpatient rehabilitation for older adults recovering from stroke. <strong>Outcomes:</strong> Discharge placement.</td>
<td>1. Results from logistic regression analyses showed that admission, FIM, age, and marital status were significantly associated with the likelihood of discharge to residential care (p&lt;0.001). The odds of discharge to residential care was 5.8 times greater for those who had an admission FIM score lower than 60, 1.6 times greater for those who were above the mean age of 77.7 years, and 1.9 times greater for those who were unmarried.</td>
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<tr>
<td><strong>Timbeck et al. (2013)</strong> Canada Retrospective No Score TPS=mean=NA N_start=16 N_end=16</td>
<td>Population: Participants had right brain damage and visuospatial neglect deficits, or right brain damage and no neglect. (n=10). No neglect group (N=6): Mean age=76.10±11.74yr; Gender: Males=3, Females=3; TPS=20.30±15.15d. Visuospatial Neglect Group (N=10): Mean Age=77.00±5.51yr; Gender: Males=6, Females=4. <strong>Intervention:</strong> To evaluate the effect of visuospatial neglect on functional outcome and discharge destination in individuals with right brain damage. <strong>Outcomes:</strong> Rivermead Behavioural Inattention Test; Functional Independence Measure (FIM); the Mini-Mental State Examination (MMSE); the Berg Balance Scale (BBS); Chedoke-McMaster Impairment Inventory.</td>
<td>1. Admission and discharge FIM scores were statistically significantly different between patients with and without visuospatial neglect (p&lt;0.05). 2. Results showed that a higher proportion of patients with visuospatial neglect were discharged to supportive housing.</td>
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<tr>
<td><strong>Obembe et al. (2013)</strong> Nigeria Post-Test</td>
<td><strong>Population:</strong> Mean age=58.3±7.8yr; Gender: Males=56, Females=34. <strong>Intervention:</strong> Stroke survivors attending the</td>
<td>1. Community reintegration had a significant correlation with age (r=-0.221, p=0.036), motor function (r=0.084, p=0.001), and PSD</td>
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<tr>
<td>Study</td>
<td>Population</td>
<td>Intervention</td>
<td>Outcomes</td>
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<tr>
<td>TPS Mean = 2.2 ± 1.2 yr  N&lt;sub&gt;Start&lt;/sub&gt;=90 N&lt;sub&gt;End&lt;/sub&gt;=90</td>
<td>Yes</td>
<td>Physiotherapy clinics of selected hospitals were assessed to determine the association of community reintegration with motor function and post-stroke depression (PSD). Outcomes: Motor Assessment Scale (MAS); Hamilton Depression Scale (HSD); Reintegration to Normal Living Index (RNLI).</td>
<td>(r = -0.373, p = 0.006). Age (p = 0.016), motor function (p = 0.000), and depression (p = 0.008) were significant predictors of community reintegration, accounting for 41% of the variance in the RNLI scores (p &lt; 0.001).</td>
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<td>Gustafsson et al. (2014) Qualitative No Score TPS Mean = 28.86d N&lt;sub&gt;Start&lt;/sub&gt;=7 N&lt;sub&gt;End&lt;/sub&gt;=7</td>
<td>Yes</td>
<td>Population: Mean age = 61 ± 13.9 yr; Gender: Males = 3, Females = 4. Intervention: To investigate the experiences and expectations of people with stroke, during transition from hospital to home, after participating in a novel inpatient outreach program, entitled Stroke Rehabilitation Enhancing and Guiding Transition Home (STRENGTH) program. Outcomes: Derivation of themes from interviews.</td>
<td>1. The first theme was “Hospital and home” and described clients’ experiences of therapy and the hospital environment. 2. The second theme was “Life will never be what it was before” and elaborated on the adaptations and changing expectations that clients had before and after discharge. 3. Overall, the patients valued STRENGTH and felt that it better prepared them for their discharge home.</td>
</tr>
<tr>
<td>Tanwir et al. (2014) Canada Observational No Score TPS Mean = NA N&lt;sub&gt;Start&lt;/sub&gt;=268 N&lt;sub&gt;End&lt;/sub&gt;=268</td>
<td>Yes</td>
<td>Population: Mean Age = NA; Gender: Male = 137, Female = 131. Intervention: Patients admitted for stroke rehabilitation from 2011 to 2012 were included. Outcomes: Functional Independence Measure (FIM): motor, cognitive; Living situation prior to stroke; Time from onset to admission in an inpatient rehabilitation unit; Stroke etiology.</td>
<td>1. Intermediate functioning patients according to motor FIM scores had an adjusted odds ratio of 2.48 (95% CI 1.04-5.90) for discharge home compared to low functioning patients (p = 0.04). 2. High functioning patients according to motor FIM scores had an adjusted odds ratio of 4.75 (95% CI 2.14-10.52) for discharge home compared to low functioning patients (p &lt; 0.01). 3. Patients who lived with a spouse, partner or family member prior to their stroke had an adjusted odds ratio of 4.07 (95% CI 2.05-8.06) for discharge home compared to patients who lived alone (p &lt; 0.01). 4. Intermediate functioning patients according to cognitive FIM scores had an adjusted odds ratio of 2.88 (95% CI 1.39-5.95) for discharge home compared to low functioning patients (p &lt; 0.01). 5. High functioning patients according to cognitive FIM scores had an adjusted odds ratio of 3.02 (95% CI 1.13-8.05) for discharge home compared to low functioning patients (p = 0.03). 6. Younger patients &lt; 65 yr had an adjusted odds ratio of 2.80 (95% CI 1.09-7.22) for discharge home compared to patients ≥ 85 yr (p = 0.03). 7. No significant differences in discharge destination were observed between patients 65-84 yr and ≥ 85 yr. 8. No significant differences in discharge destination were observed between gender, time from onset to admission in an inpatient rehabilitation unit; Stroke etiology.</td>
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<td>Study</td>
<td>Location</td>
<td>Study Type</td>
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<tr>
<td>Stineman et al. (2014)</td>
<td>USA</td>
<td>Longitudinal</td>
<td>No Score</td>
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<td>Nanninga et al. (2015)</td>
<td>Netherlands</td>
<td>Qualitative</td>
<td>No Score</td>
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<tr>
<td>Saji et al. (2015)</td>
<td>Japan</td>
<td>Retrospective</td>
<td>No Score</td>
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1. More than 85% of patients were discharged home and 14.4% were discharged to other locations, which included 1.2% to a non-VA hospital, 8.3% to an extended care facility, and 1.7% to a different location.
2. Achievement of physical grades IV and VI and cognitive stages II and VI by final PM&R assessment remained strong independent determinants of home discharge after adjusting for 6 additional independently predictive demographic and clinical factors.
3. The probability of discharge home alive in the derivation cohort was 65.03% in the group with sum scores of ≤21 points, 84.10% in the group with sum scores of 22-23 points, 9.36% in the group with sum scores of 24-26 points and 98.24% in the groups with sum scores of ≥27 points.

1. Participants longed for recovery and domestic places in the clinical phase, for pre-stroke activities and the roles in the post-discharge phase, for recognition and a sense of belonging in the reintegration phase.
2. The participant’s selves had changed, while the spatial and social contexts of their homes had remained the same.
3. The spatial score became smaller in both a social and a geographical sense.
4. It was difficult to achieve a feeling of being at home in their bodies and own living environment again.
5. The complexities that needed to be dealt with to engage with the outside world, turned participants unintentionally inwards. In particular, family members of participants with cognitive problems, longed for support and recognition in dealing with the changed personality of their spouses.

1. A total of 984 patients (78%) were discharged home, 42% of which were assessed as mRS 0–2, and 39% were certified with Long Term Care Insurance (LTCI) care levels 0–2.
2. Patients who were discharged home were assessed as mRS 0–2 and LTCI care level 0–2. They were more likely to be younger, male, have higher FIM scores on admission, greater FIM gain during admission, and higher FIM
gain per day. There were no significant differences between stroke subgroups.

3. Multivariable analyses showed that age (OR=0.96, 95%CI: 0.95-0.98) and FIM scores (OR=1.06, 95%CI: 1.05-1.07) were significant, independent predictors of LTCI care levels 0-2, after adjusting for sex, stroke subtypes, and other risk factors.

### 19.1.2 Social Support and Functional Status

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<th>Author, Year Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tr>
<td>Glass and Maddox (1992) USA No Score</td>
<td>This study was an inception cohort design of 64 stroke patients examining various types of supportive action in promoting functional independence. Patients were excluded if they had a significant history of heart disease or did not receive rapid medical attention after onset of symptoms (&lt;24 hours). Severity of stroke was assessed using the Oxbury Level of Consciousness (LOC) Scale and functional independence measured by the Barthel Index. Social support received was assessed using the Inventory of Social Supportive Behaviour (ISSB). Patients were followed for 6 months.</td>
<td>46 patients completed the study. Emotional, instrumental and informational supports were significantly related to functional capacity recovery; however, the effect of each support was different. The impact of social support does not appear during the first month of stroke; however, those who received emotional support demonstrated a dramatic improvement despite having the lowest baseline functional status. Instrumental support is most closely related to positive outcomes when provided in moderate amounts. Instrumental support appears to be mediated by disease severity.</td>
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<tr>
<td>Glass et al. (1993) USA No Score</td>
<td>Prospective cohort study of 46 patients examining the impact of social support on outcomes after a first stroke. Patients were divided into two groups according to their level of severity and level of social support received (low, medium and high). The Barthel Index measured changes in functional status.</td>
<td>Patients with more severe stroke and the largest amount of social support attained an average Barthel Index that was 65% higher than the groups reporting the least support. High levels of social support were associated with faster and more extensive recovery of functional status after stroke.</td>
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<td>Colantonio et al. (1993) USA No Score</td>
<td>Assessment results of 87 community dwelling survivors of first stroke over the age of 65 who were part of the Yale Health and Aging Project survey were examined to determine the relationship between premorbid psychosocial factors and post stroke outcomes of physical function and institutionalization.</td>
<td>Individuals with more social networks (measured via the social networks index) demonstrated fewer physical limitations 6 weeks post discharge from hospital (p&lt;0.05). Linear regression analysis revealed social network to be a significant predictor of physical function 6 weeks post stroke (p=0.01). Social network was also significantly related to risk of institutionalization (p&lt;0.05).</td>
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<td>Knapp &amp; Hewison (1998) UK No Score</td>
<td>Prospective study of 30 hospitalized stroke survivors followed for 6 months and assessed by The Hospital Anxiety and Depression Scale and the Interview Schedule for Social Interaction. The Barthel Index measured functional independence.</td>
<td>Pre-stroke support availability was correlated with measures of anxiety and depression. Mood was not correlated with ratings of satisfaction with support. Stroke survivors became isolated from social networks.</td>
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43 stroke patients were assessed repeatedly (at 1, 3 & 6 months) following onset of first ever stroke. Results from the Family Social Support Scale assessment were used to classify patients into two groups: high vs. moderate/low family support. Between group differences were examined in terms of changes in functional status, psychological /depression status and social status. All patients made significant functional gains over time ($p=0.001$). A significant interaction was identified between functional status, support & time ($p=0.019$) such that patients who received more family support improved more over time than those who received less support. Patients receiving more support were less depressed than those receiving moderate/low family support ($p=0.002$). Social status (general mood & social involvement) was higher in patients receiving more support ($p=0.001$). No significant interactions were identified between depression, social support and time or social status, social support and time. Stroke severity was significantly associated with all rehabilitation variables: functional status ($p=0.021$), depression status ($p=0.001$) and social status ($p=0.002$). High levels of instrumental support had a positive effect on functional status and social status at all assessments ($p<0.05$), but had a significant impact on depression at only the first month assessment. High levels of emotional support had a positive & significant impact on depression and social status at 1 & 3-month assessments ($p<0.05$) and on functional status at 3 & 6-month assessments ($p<0.05$).

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<td>Greece</td>
<td>No Score</td>
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<tr>
<th>Jaglal et al. (2013)</th>
<th>1. In total, 71 (31.5%) participants attended all sessions, 158 (70.2%) attended 4 or more sessions, and 20 (8.9%) dropped out of the program. Of the enrolled participant, 186 (87%) completed the 4m follow-up telephone questionnaires.</th>
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<tr>
<td>Canada Pre-Post No Score TPSmean=NA NStart=213 NEnd=186</td>
<td>2. The tele-CDSMP intervention significantly improved self-efficacy ($p=0.01$), all health behaviors (stretching and strengthening: $p&lt;0.001$; aerobic exercise: $p&lt;0.001$; cognitive symptom management: $p&lt;0.001$; communication with physicians: $p&lt;0.001$), and the majority of health status subsections (social role function: $p=0.015$; psychological well-being: $p=0.001$; energy/fatigue: $p=0.04$; health distress: $p&lt;0.001$; self-reported health: $p=0.004$) but not disability ($p=0.083$) and pain/physical discomfort ($p=0.191$) from baseline to 4mo.</td>
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<td>Intervention: Two telehealth models were used to examine whether a telehealth chronic disease self-management program (CDSMP) would lead to improvements in self-efficacy, health behaviors, and health status for chronically ill adults living in Northern Ontario: (1) single site, groups formed by participants at one telehealth site, and (2) multi-site, participants linked from multiple sites to form one telehealth group, as a strategy to increase access to the intervention for individuals living in rural and remote communities. Assessments were conducted at baseline, and at 4m.</td>
<td>3. There was no significant difference between the two groups regarding the change in improvement on any of the outcomes measured.</td>
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<tr>
<td>Outcomes: Self-efficacy; Health Behavior; Health Status.</td>
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</table>

| Hill et al. (2014) | Population: Intervention Group (N=49): Mean age=59.67±13.14yr; Gender: Male=31, Female=18. | 1. COPM scores above the median were significantly associated with greater hand |
|---------------------|--------------------------------------------------|
| USA | 2. |
Observational
No Score
TPS\text{mean}=72\pm58.8\text{mo}
N\text{start}=50
N\text{end}=49

\textbf{Intervention}: Patients who had returned to community living completed two sets of assessments to investigate the relationship between touch sensation and performance in valued activities. The assessments were conducted once only.

\textbf{Outcomes}: Canadian Occupational Performance Measure (COPM: Performance, Satisfaction); Touch Test (TT).

sensation on the TT (p<0.05).
2. COPM scores below the median were not significantly associated with greater hand sensation on the TT (p=0.97).
3. TT scores did not reveal a significant relationship between both groups (above/below median COPM score) and specific hand testing location (p=0.14); indicating COPM scores and sensation of specific hand testing locations were not associated.
4. COPM Performance and Satisfaction subtest scores were significantly correlated (p<0.0001) within the sample.

19.1.3 Social Support and Quality of Life

\textbf{Table 19.1.3 Social Support and Quality of Life}

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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</thead>
<tbody>
<tr>
<td>King, (1996)</td>
<td>USA</td>
<td>No Score</td>
<td>86 community dwelling stroke survivors who had experienced a stroke 1 to 3 years prior to assessment. Participants had no previous psychiatric history and had no communicative or cognitive impairment that would prevent their participation. A comparison group was drawn via a random sample from the telephone book. Participants were assessed using the Ferrans and Powers Quality of Life Index (QLI), FIM, estimates of motor impairment, CES-D and SSE (perceived social support)</td>
<td>Quality of life scores overall were comparable to those for the comparison group. General life satisfaction was reported to be moderate. Social support was identified as a predictor of overall quality of life and of the 4 domains identified within the QLI (health and functioning, socio-economic, psychological and family).</td>
</tr>
<tr>
<td>Wyller et al., (1998)</td>
<td>Norway</td>
<td>No Score</td>
<td>1417 stroke survivors and 1439 reference subjects were assessed via the Nord-Trondelag population health survey. This survey included items to assess subjective well being (SWB).</td>
<td>Stroke survivors reported lower subjective wellbeing than comparison subjects of a similar age (p=0.0004). Linear regression revealed that presence of stroke, gender, age, perceived health, nervousness, sleep problems, help and support as needed and loneliness explained 50.3% of variance in SWB.</td>
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<td>Kim et al., (1999)</td>
<td>Canada</td>
<td>No Score</td>
<td>Assessed 50 community dwelling stroke survivors 1 to 3 years post discharge from rehabilitation. Survivors included had no aphasia, psychiatric illness or cognitive impairment. Assessment included Ferrans and Powers Quality of Life Index (QLI), FIM, Frenchay Activities Inventory, Social Support Inventory for Stroke Survivors, Perceived Health Status question, CES-D and collection of demographic variables.</td>
<td>Multiple regression analysis revealed that marital status, quality of social support and IADL status (assessed via the Frenchay Activities Inventory) were significant predictors of QOL accounting for 60.1% of variance in QLI. Depression and quality of social support were stronger predictors of quality of life than functional status.</td>
</tr>
<tr>
<td>Gottlieb et al., (2001)</td>
<td>Israel</td>
<td>100 stroke patients living in the community were assessed using a post-stroke impairment rating</td>
<td>Social support as measured on the Tel-Aviv Social Support Scale was reported to have a</td>
<td></td>
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<tr>
<td>Study Authors</td>
<td>Country</td>
<td>Sample Description</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>MacKenzie and Chang, (2002)</td>
<td>China</td>
<td>215 stroke patients with neither depression or cognitive impairment and the ability to communicate with the interviewer, admitted to rehabilitation were assessed after 48 hours, 2 weeks and at 3 months via Sickness Impact Profile (used as QoL measure), modified BI, Social Support Questionnaire</td>
<td>Significant, positive association with both handicap (r=0.41; p&lt;0.01) and quality of life (r=0.45; p&lt;0.01). No significant relationship was demonstrated between social support and impairment (impairment rating scale) or disability (FIM score). On regression analysis, social support was demonstrated to be a significant independent predictor of quality of life (p&lt;0.01).</td>
<td>At 3 months, quality of life, as measured on the SIP, was associated with functional ability, satisfaction with social support and number of support persons available to the patient.</td>
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<td>Clarke et al. (2002)</td>
<td>Canada</td>
<td>282 community dwelling stroke survivors without significant cognitive impairment and 4524 community dwelling seniors (without stroke) were included as part of the Canadian Study of Health and Aging. Survey included Ryff measure of well-being, MMSE, demographic items, general health status, a measure of ADL, 7-item measure of IADL, item re: size of and satisfaction with social networks, 5 questions from mental health component of SF36.</td>
<td>Survivors reporting adequate social support were less likely to report negative effects on wellbeing (defined as environmental mastery, positive relations, and self-acceptance). Size of the social network was positively related to aspects of wellbeing (positive relations and personal growth).</td>
<td>Quality of life was significantly lower for the stroke survivor groups than for the comparison group. Three variables were identified as predictors of quality of life: emotional support, depression and functional status. This model accounted for 38% of the variance in quality of life scores.</td>
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<tr>
<td>Jaracz et al. (2003)</td>
<td>Poland</td>
<td>72 community—dwelling stroke survivors (6 months post stroke) and 110 ADL-independent, community dwelling elderly (comparison group) were assessed using the Ferrans and Powers QLO scale, the Scandinavian Stroke Impact Scale, the Barthel Index, the QLI emotional support item, and the Zung depression scale.</td>
<td>Quality of life was significantly lower for the stroke survivor groups than for the comparison group. Three variables were identified as predictors of quality of life: emotional support, depression and functional status. This model accounted for 38% of the variance in quality of life scores.</td>
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<tr>
<td>Haslam et al. (2008)</td>
<td>UK</td>
<td>The relationship between subjective well-being and # of group memberships &amp; sustained group membership following stroke was examined in 53 individuals (mean 8.6 months post stroke). Assessments included # of group memberships, ratings of group affiliations (Exeter Identity Transition Scales- EXITS – extend of participation, maintenance of membership, new group affiliations), Cognitive Failures Questionnaire (CFQ), Life satisfaction and chronic stress.</td>
<td>Multiple pre-stroke memberships (group listings and group affiliation ratings) was associated with greater life satisfaction post-stroke (r=0.27, p&lt;0.05), but was not related to chronic stress. Maintenance of memberships was positively correlated with life satisfaction (r=0.47, p&lt;0.01) and negatively with chronic stress (r=-0.44, p&lt;0.01). Well-being was not associated with new group membership. Perceived cognitive failures were negatively associated with life satisfaction (r=-0.36, p&lt;0.05) &amp; maintaining group memberships (r=-0.30, p&lt;0.05) and positively associated with chronic stress (r=0.26, p=0.06).</td>
<td>The relationship between subjective well-being and # of group memberships &amp; sustained group membership following stroke was examined in 53 individuals (mean 8.6 months post stroke). Assessments included # of group memberships, ratings of group affiliations (Exeter Identity Transition Scales- EXITS – extend of participation, maintenance of membership, new group affiliations), Cognitive Failures Questionnaire (CFQ), Life satisfaction and chronic stress.</td>
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<tr>
<td>Doble et al. (2009)</td>
<td>Canada</td>
<td>54 individuals with stroke were grouped according to their perceived satisfaction with ‘time use’ (that is, their participation in whatever activities they choose). Between group differences in social support (MOS Social Support Scale) and depression</td>
<td>64.8% of participants indicated that they were satisfied with how they spend their time. There were no significant differences between the satisfied and dissatisfied groups in terms of emotional/informational or tangible support</td>
<td>54 individuals with stroke were grouped according to their perceived satisfaction with ‘time use’ (that is, their participation in whatever activities they choose). Between group differences in social support (MOS Social Support Scale) and depression</td>
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<td>Hilari et al. (2010)</td>
<td>87 individuals with first stroke were assessed at baseline (while still in acute care), 3 months and 6 months post stroke. Psychological distress was assessed using the GHQ-12. Other assessments included NIHSS (severity), BI, Frenchay Aphasia Screening Test (FAST), Frenchay Activities Index, MOS Social Support Scale and social network indicators. Logistic regression was used to identify factors associated with distress at each assessment point. In addition, prediction of distress at 6 months was examined using baseline variables.</td>
<td>At study entry, stroke severity was a significant predictor of distress on logistic regression (p&lt;0.01); however, age, and loneliness were also significantly correlated with distress. At three months, low social support was predictive of distress on regression (significant correlations included severity, presence of aphasia, functional dependence, loneliness, low satisfaction with social network and low perceived social support). At 6 months, variables significantly correlated with distress were severity, functional dependence, loneliness, low satisfaction with social network and low perceived social support. Logistic regression revealed that both loneliness and low satisfaction with social networks were significant predictors of distress while the model including all variables accounted for 51% variance in distress. Baseline variables significantly correlated with distress at 6 months were psychological distress (at baseline), loneliness and low satisfaction with social networks. On regression, all three of these variables were significant predictors of 6-month distress.</td>
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<tr>
<td>Huang et al. (2010)</td>
<td>102 individuals with stroke completed interviews at a single time point during which social support (Social Support Inventory), depression (CES-D), physical function (BI), extended activities of daily living (Lawton-IADL) and quality of life (quality of life index) were assessed. Regression analyses were used to examine mediating roles of social support (emotional, information and tangible) on study outcomes of depression, function and quality of life.</td>
<td>The receipt of tangible support was identified as a partial mediator in the relationship between functional ability and depression. (p=0.02). In addition, tangible support was identified as a significant mediator in the relationship between age &amp; function and mental/physical quality of life.</td>
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<td>Haley et al. (2009)</td>
<td>136 individuals with incident stroke and 136 matched stroke-free control participants completed the SF-12 and CES-D at baseline and 1,231 days later. Between group differences in change scores were examined using multiple linear regression. Covariates used included age, gender, race, income, living alone.</td>
<td>Individuals with stroke demonstrated a co-variate adjusted decreased of 1.97 points on the mental component summary(MCS) score of the SF-12, whereas controls demonstrated an adjusted increase of 1.01 pts (F=8.18, p=0.005). On the PCS, stroke participants showed an adjusted decrease of 2.18 points (F=12.87, p=0.004). Living alone</td>
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<tr>
<td>Study</td>
<td>Population</td>
<td>Intervention</td>
<td>Outcomes</td>
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<tr>
<td><strong>Baumann et al. (2012)</strong></td>
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<td>Luxembourg</td>
<td>A retrospective chart audit was performed on all stroke patients admitted to hospitals in Luxembourg. 94 individuals consented to have their hospital charts audited and to participate in face to face interviews along with 62 caregivers. Participants and caregivers completed questionnaires on their life satisfaction, quality of life, and demographic characteristics.</td>
<td>Life satisfaction was positively correlated with scores of quality of life in the domains of feelings, sleep, emotion, cognition, and pain (r=0.2-0.31)</td>
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<td><strong>Kubina et al. (2013)</strong></td>
<td>Population: Mean age=58yr; Gender: Males=3, Females=3. <strong>Intervention</strong>: Community dwelling individuals recovering from their first stroke were interviewed at 6, 9, 12, 18 and 24m post-stroke to explore the process of re-engagement in personally valued activities that would be helpful to those designing interventions to address participation post-stroke. <strong>Outcomes</strong>: Themes of re-engagement in valued activities.</td>
<td>1. “Social connection” and “being in charge” appeared to operate simultaneously as participants resumed their occupations following stroke. 2. Social connection had several dimensions: belonging, reciprocity, doing one’s share and support. 3. Being in charge was described as: being in charge of the activity, being in charge of activity adaptations, and being in charge of the reassessment of activity priorities. 4. Both themes led to activity engagement and risk taking to test abilities. These led to lowering of current expectations and activity adaptation which supported hope for recovery and further testing. Difficulties perceived to be related to ageing led to disengagement.</td>
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<td><strong>Shao et al. (2014)</strong></td>
<td>Population: Mean age=70.29±7.64yr; Gender: Males=128, Females=86. <strong>Intervention</strong>: Data from community-dwelling older stroke survivors was analyzed to examine the roles of meaning in life as a mediator for the relationship of physical functioning, social support, and optimism with well-being. <strong>Outcomes</strong>: Functional Independence Measure (FIM); Chinese version of the Revised Life Orientation Test (LOT; measuring optimism); Chinese version of the Social Support Questionnaire for Transactions (SS; measuring social support); Meaning of Life Scale (measuring: will to meaning (WM), existential vacuum (EV), life purpose (LP), life control (LC), suffer acceptance (SA), death acceptance (DA)); Subjective Well-being Questionnaire (SWB).</td>
<td>1. Physical functioning, optimism, and social support were significantly related to subjective well-being (all p&lt;0.05). 2. Physical functioning, optimism, and social support were significantly correlated with meaning of life, as well as between meaning of life and subjective well-being (all p&lt;0.05). 3. Using Structural Equation Modeling (SEM) for analysis of the data, the standardized path coefficient of physical functioning in the model was 0.20 (p&lt;0.001) and social support to meaning in life was 0.31 (p&lt;0.001), whereas that for optimism to meaning in life was 0.55 (p&lt;0.001). 4. This indicates that meaning of life mediates relationship of physical functioning, social support, and optimism with subjective well-being. The life phase of patients is also an important factor in influencing subjective well-being.</td>
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<tr>
<td><strong>Johansson et al. (2014)</strong></td>
<td>Population: Age range=62-88yr; Gender: Males=7, Females=10.</td>
<td>1. Living with the effects of a stroke had not affected the relationship with the animal.</td>
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</tbody>
</table>
Sweden
Qualitative
No Score
TPS Mean=2yr
N Start=17
N End=17

**Intervention:** Structured individual interviews were performed on stroke individuals to explore older people's experience of living with companion animals after stroke, and their life situation with the animals in relation to the physical, psychological, and social aspects of recovery after stroke.

**Outcomes:** Overarching themes regarding the contribution of animal companion to the meaning of life.

On the contrary, the presence of the animal companion motivated the stroke patients to recovery physically and psychologically after the stroke.

1. Participants indicated that animals could show them warmer feelings than close friends. This relationship was explained as "someone to care for who cares for you".
2. The animals were seen as family members and the participants talked about their personalities and behavior.
3. Animals were also perceived as providers of safety and protection when the family is not at home.

Kristensen et al. (2014)
Denmark
Observational
No Score
TPS Mean=NA
N Start=41
N End=41

**Population:** Mean age=69yr; Gender: Males=25, Females=16.

**Intervention:** Activities of daily living interviews (ADL-I) were administered to mild stroke patients in hospital and 1m after discharge. The last 8 interviews (1m after discharge) were extended with semi-structured interviews (SSIs) lasting no more than 30min.

**Outcomes:** Activities of Daily Living.

1. Independence in personal ADL (PADL) and instrumental ADL (IADL) was maintained in the majority of patients both during hospitalization and after discharge.
2. During PADL, patients independently overcame difficulties using alternative strategies such as assistive devices, by spending more time on the activities and/or through experiencing fatigue.
3. Some participants faced difficulties while performing IADL (especially household activities), which were overcome with increased fatigue.
4. 3 main themes and 7 subthemes arose from the semi-structured interviews concerning subjective experiences while attempting to resume everyday life.
   - Occupational balance
     - Some participants found they would be able to maintain ordinary occupational balance but with challenging occupations in the future.
     - Others found that ongoing adjustments had to be made in their expectations and planning of the future.
   - Adaption
     - Some participants had less energy and because of this were forced to adapt to their post-stroke condition which included managing demands that challenged the structure of their daily lives.
   - Emotional reactions
     - Difficulty coping with fatigue and physical limitations, worry of having a serious medical condition, and
the risk of a new stroke all contributed to feelings of anxiety and uncertainty of the future.

- Priorities of health/ wellbeing and family/ friends became more important after the stroke.

**Vincent-Onabajo et al. (2016)**

**Nigeria**

**Observational No Score**

| TPS | Mean=19.0±24.6mo | NStart=96 | NEnd=96 |

**Population:** Mean Age=56.6±12.0yr; Gender: Males=36, Females=60.

**Intervention:** Community-dwelling stroke survivors from two outpatient physiotherapy departments were surveyed to investigate the impact of social support on participation.

**Outcomes:** London Handicap Scale(LHS, Domains: Total, Orientation, Economic self-sufficiency); Multidimensional Scale of Perceived Social Support (MSPSS); Age; Gender; Martial status; Post-stroke employment status; Educational level; Living arrangement; Post-stroke duration; Type of stroke; Side of hemiplegia/hemiparesis; Modified Rankin Scale (mRS); Social support.

1. In the regression model for overall participation (LHS), only functional disability, post-stroke duration, and side of hemiplegia/hemiparesis were significant predictors. MSPSS was not significantly associated with LHS.

2. In the regression model for LHS-orientation, MSPSS and all other independent variables were not significant predictors.

3. In the regression model for LHS-economic self-sufficiency, MSPSS was a significant predictor (β=0.23, p<0.0001) of better participation. Type of stroke was the only variable significantly associated with LHS-economic self-sufficiency.

### 19.1.4 Social Support Interventions

**Table 19.1.4.1 Social Work Interventions**

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Christie and Weigall, (1984)</td>
<td>Australia</td>
<td>5 (RCT)</td>
<td>213 stroke survivors, 2 years post stroke, were randomised allocated to treatment group and control groups. 110 of the 213 participating individuals received client-centred social work intervention consisting of 7 planned contacts over a 12-month period. Each contact included a home visit of approximately 1 hour duration, follow-up actions and a phone call to the patient to discuss the outcome. Outcomes included death, independence in ADLs (assessed via a study-specific tool) and reported use of health &amp; community resources.</td>
<td>At the end of treatment, there was no difference between groups in terms of activity-independence scores. There was a non-significant trend toward increased mortality in the control group. Overall, while there was no evidence that the intervention altered use of community or acute care health resources, it may have had therapeutic effects for individual stroke patients. More than 70% of patients expressed satisfaction with the range and quality of the intervention.</td>
</tr>
<tr>
<td>Towle et al. (1989)</td>
<td>UK</td>
<td>7 (RCT)</td>
<td>44 stroke patients suffering from depression were allocated to either a treatment or control group. Both groups received information booklets containing information of interest to stroke patients and their families. In addition to this, the treatment group received visits from a social worker twice a week for up to 16 weeks. The social worker provided counselling and additional information regarding services and benefits as</td>
<td>The intervention and control groups did not differ with regard to level of social independence or social activity. Social work intervention was not associated with increased use of community services or aids received. Information contained in the booklets distributed to both groups may have contributed to change in both groups and minimized group differences.</td>
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required by participants. Participants in both groups were assessed at baseline, 8 weeks and 16 weeks.

<table>
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<tr>
<th>Study</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes</th>
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</table>
| Anderson and Whitfield (2013)      | Mean age=58.22±3.49yr; Gender: Males=6, Females=3. | Individual interviews were conducted on survivors of stroke to understand the ways in which family, social, and community resources might enhance stroke survivors’ participation in personally meaningful activities over the long term. | 1. Participants all noted that they lost confidence and at times were unsure how they might cope in commonplace situations. All stressed they were motivated to do what they could to recover but were often unsure how to proceed or were forced to wait for assessment or therapy and in the process lost their confidence in their ability to participate in the ordinary pre-stroke activities.  
2. Participants noted they were surprised by how interactions with other people changed after stroke and that they believed they were vulnerable to any rejection of their goals, because they did not have the resources or a position to confront the other person’s assessments.  
3. All stroke survivors found that stroke impairments and other people’s perceptions of their impairments made it difficult to gain control as they had pre-strike.  
4. Participants were unable to position their goals as a priority because they felt the rehabilitation professionals lacked to recognize their goals (i.e. returning back to work or other long-term complex activities).  
5. Participants discovered that impairments made it difficult to make their case or the other person in the interaction did not take them seriously as they might have pre-strike. In most cases, emotional and practical support received from someone allowed them to increase their control.  
6. Participants stressed that they were constantly fighting stereotypes about what people with stroke could do and a general stigma of stroke disability. |
| Saal et al. (2015)                  | Experimental Group (EG=130): Mean Age=68.1±12.6yr; Gender: Males=64, Females=66; Control Group (CG, N=135): Mean Age=68.4±12.7yr; Gender: Males=73, Females=62. | EG and CG received optimized standard care, with assessments prior to discharge, 4wk after discharge (baseline), and 12mo. EG received a stroke support service carried out by two stroke support organizers, consisting of an in-depth assessment to identify any ongoing rehabilitation needs, stroke outreach support, educational sessions, and written | 1. After 12mo, no significant differences were found between EG and CG in terms of SIS, WHOQOL-BREF, GDS, SCL-90-R.  
2. EG had a significantly lower chance of death than CG (RR=0.34, 95%CI=0.13-0.90). |
patient information.

**Outcomes:** Stroke Impact Scale (SIS); World Health Organisation Quality of Life short version (WHOQOL-BREF); Geriatric Depression Scale (GDS); Symptom Checklist 90 revised (SCL-90-R); Death.

### 19.1.4.2 Specialized Social Support Network Interventions

<table>
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<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tr>
<td>Friedland and McColl (1992) Canada 5 (RCT)</td>
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<td>88 patients randomized to receive either Social Support Intervention (SSI) program (6-12 sessions that involved the subjects and/or members of their supportive system) or to receive no specific intervention (although they were free to engage in any supportive relationships or groups available to them). Social support was assessed using the Social Support Inventory for Stroke Survivors (SSISS) and the Interpersonal Support Evaluation List (ISEL). Additional assessments included the GHQ-28, and the SIP. Assessments were conducted at baseline (time 1), at the end of treatment (time 2) and 3 months post-treatment (time 3).</td>
<td>There were no significant between group differences reported on social support scores at time 2 or at time 3. However, individuals in the treatment group did report more support on 3 individual items from the ISEL. There were also no significant between group differences reported on the GHQ-28 or SIP at either time 2 or 3.</td>
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<tr>
<td>Glass et al. (2004) USA 7 (RCT)</td>
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<td>291 stroke patients were randomized, within 28 days of the stroke event, to receive either usual care or a psychosocial intervention (PSI). Usual care consisted of provision of standard educational material regarding stroke recovery. The PSI consisted of up to 16 home sessions over a period of 6 months conducted by a mental health worker (psychologist or social worker). The intervention focussed on 4 domains of challenge in families after stroke: informational, social, emotional and behavioural and was supervised by a consulting psychologist. Where possible sessions included the patient’s entire support system (e.g. survivor, primary carer, family friends, and professional caregivers). Outcomes (BI, OARS-IADL, Physical Performance Test, global cognition) were assessed at 6 months post randomization.</td>
<td>Using intention-to-treat analysis, there was no significant difference (p=0.56) between groups in terms of functional recovery as measured by the Barthel Index (the primary study outcome). However, more than 40% of patients reported maximum scores on the BI by 6 months. Subgroup analysis demonstrated that PSI was more effective for patients with the fewer depressive symptoms (p=0.03) and better cognitive function (p=0.08).</td>
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<tr>
<td>Ertel et al. (2007)</td>
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<td>FIRST study (Glass et al. 2004) subgroup</td>
<td>Overall, the authors identified a trend such that the</td>
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analyses defined by the following variables (assessed at study baseline): age, sex, education, social network size, depressive symptoms, MMSE, NIHSS scores, rehabilitation days, co-morbid conditions, frailty. Possible mediators of treatment effect were also assessed (efficacy, social support and social networks).

intervention tended to be associated with improved outcome in individuals who were healthier (less severe stroke, fewer comorbid conditions, non-frail). Assignment to the psychosocial intervention was associated with better cognition in individuals with less severe stroke (NIHSS ≤5; p=0.05), better instrumental ADL scores and physical performance in non-frail individuals (p<0.01 and p=0.02, respectively) and in those with 3 or fewer co-morbid conditions (p=0.01 and 0.04, respectively). In addition, in non frail individuals and those without possible depression, intervention vs. usual care was associated with reduction in risk for mortality. However, for frail or depressed individuals there was an increased risk associated with intervention.

**Tregia et al.** (2013)

*Population:* People with Aphasia (N=19): Mean age=64.8±12.9yr; Gender: unspecified. Family Members (N=7): Mean age=58.3±9.0yr; Gender: unspecified.

*Intervention:* Data from people with aphasia and family members was collected via participant observation, focus group discussion, individual interviews and written artefacts to understand and interpret the functioning of peer-led aphasia support groups in the community.

*Outcomes:* Themes important for the successful functioning of a peer-led aphasia support group.

1. Themes such as friendship, informality, a supportive communication environment, providing support and practical considerations for the timing and location of meeting.
2. Factors that facilitated peer leaders to start and run groups included information support, practical support, attracting new members, time and organization, and particular personal qualities.

**Brown et al.** (2014)


*Intervention:* 35 participants underwent a standardized aerobic fitness program during inpatient rehabilitation, while 26 did not. During the 6m after discharge, further engagement in physical activity was assessed.

*Outcomes:* The Physical Activity Scale for Individuals with Physical Disabilities (PASIPD); Adherence to the American College of Sports Medicine (ACSM) guidelines.

1. There were no significant group-by-time interaction effects for PASIPD scores (p=0.50) or rates of adherence to ACSM guidelines with or without walking (p=0.46; p=0.13).
2. There were no significant differences in PASIPD scores (p=0.18) or rates of adherence to ACSM guidelines with or without walking (p=0.89; p=0.81) between groups for all time points combined.
3. There was no significant correlation between volume of activity performed in the fitness program and PASIPD scores (p=-0.23, p=0.18).
4. There was no significant increase in the likelihood of adherence to ACSM guidelines with increased volume of exercise during the fitness program. For every 1 unit increase in exercise volume, the odds ratio (OR) for adherence to ACSM guidelines with walking was 1.00 (p=0.97), and without walking the OR was 0.98 (p=0.62).
<table>
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<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tr>
<td>Forster and Young (1996) UK 6 (RCT)</td>
<td>240 community dwelling stroke survivors with new stroke (either prior to discharge or within 6 weeks of acute stroke event) and over the age of 60. Participants were randomised to receive usual care or usual care plus visits over 12 months from specialized nurses who would provide information, advice and support. A minimum of 6 visits was to occur during the first 6 months following randomisation. Patients were assessed at 3, 6 and 12 months. Caregiver stress was also assessed.</td>
<td>Overall, no difference between groups was demonstrated with regard to social activities, perceived wellbeing or physical abilities. Both intervention and control groups demonstrated increased social activity and improved physical functioning over the 12-month period. In a subgroup of mildly disabled patients (BI=15 – 19), participation in the intervention was associated with increased social activity (FAI score) at 3 (p=0.04), 6 (p=0.03) and 12 months (p=0.01).</td>
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<td>Dennis et al. (1997) Scotland 8 (RCT)</td>
<td>A single blind trial of 417 patients randomized to receive either post stroke visits by a stroke family care worker who identified unmet needs and aimed at fulfilling them or usual care (no family care worker) for 6 months.</td>
<td>Patients were assessed 6 months after randomisation using the Oxford Handicap Scale, the Frenchay Activities Inventory (FAI), a general health questionnaire and social adjustment scale. No significant beneficial effect on social activity or social adjustment was associated with the intervention for either the stroke patients or their carers. The only positive effect noted was higher caregiver mood scores and lower caregiving hassle scores in intervention participants vs. the control group.</td>
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<td>Mant et al. (2000) UK 8 (RCT)</td>
<td>Single blind trial of 520 patients and their carers (n=323) randomized to receive either family-support care with the use of an information package or usual post-stroke care. The nature and frequency of contact with the stroke patient and his/her family was at the discretion of the family support organizer. Participants randomized to the intervention group received, on average, one hospital visit, one home visit, 3 telephone calls and one liaison with one other service over a 6-month period.</td>
<td>Carers in the intervention group had significantly better Frenchay activity indices, and SF-36 scores of energy, health, pain and physical function. Carers of the intervention group were more satisfied with their understanding of stroke, its causes, and how to prevent another stroke. A further analysis of this study based on data collected at one year post stroke (Mant et al. 2000) demonstrated no evidence of benefit to the stroke patients. Patients with greater contact with the family support organizer were more likely to be followed up. Benefits to carers seen at 6 months (Mant et al. 2000) persisted at one year, although this was no longer significant (Mant et al. 2005).</td>
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<td>Lincoln et al. (2003) UK 5 (RCT)</td>
<td>250 stroke patients and their informal caregivers were randomized to receive either the Stroke Family Support Organiser (FSO) service which provided support, information to patients and carers and liaised with hospital or to standard care. Intervention was provided for up to 9 months and participants were assessed at 4 and 9 months.</td>
<td>There were no significant differences between groups on patients’ mood, independence in personal or instrumental activities of daily living, caregivers’ mood, strain or independence. The FSO group had better knowledge of stroke and was more satisfied with the service they received than the control group. Further studies have reported that the FSO service, in general, primarily functioned to provide information and assist in practical activities rather than provide emotional support (Harding et al, 2000; Lilley et</td>
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<td>Study (Year)</td>
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<td>Design</td>
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<tr>
<td>Boter et al. (2004)</td>
<td>Netherlands</td>
<td>6 (RCT)</td>
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<td>Burton and Gibbon (2005)</td>
<td>UK</td>
<td>7 (RCT)</td>
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<tr>
<td>Tilling et al. (2005)</td>
<td>UK</td>
<td>7 (RCT)</td>
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but this did not reach significance. Analysis of randomly selected FSO reported demonstrated that, while needs were identified, specific intervention were not targeted to needs. Information about stroke, secondary prevention, medications and social service entitlements and FSO’s acted as liaisons between clients and other service providers.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>N (RCT)</th>
<th>Intervention Details</th>
<th>Outcome Measures</th>
<th>Results</th>
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<tr>
<td>Claiborne (2006) USA 5 (RCT)</td>
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<td>28</td>
<td>28 patients with stroke were randomly allocated to either the intervention (n=16) or control conditions (n=12). The intervention condition was receipt of care coordination provided by a social worker. Care coordination consisted of a home visit (1 – 2 weeks following discharge from rehabilitation) followed by weekly telephone appointments 20 min. – 1hr in length over a 3-month period. Care coordination was characterized by ongoing monitoring of patient progress (biopsychosocial, service needs, self-care practices) and use of a problem-solving approach. Control received usual care.</td>
<td>SF-36 mental components scale, Geriatric Depression Scale, adherence to prescribed regimens</td>
<td>No significant group differences on the SF-36 mental components scale. Significant differences were reported for the Geriatric Depression Scale (p&lt;0.001) and adherence to prescribed regimens (p&lt;0.05).</td>
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<td>Mayo et al. (2008) Canada 8 (RCT)</td>
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<td>190</td>
<td>190 individuals returning home post stroke from an acute care facility were randomly assigned to receive either usual care (n=94) or a case management intervention (n=96). The case management intervention consisted of home visits and telephone contacts over a period of 6 weeks in order to establish contact (arrange appointments and delivery of documentation) with the primary care physician, and provide other actions and interventions based on patient needs. Primary study outcome was the Physical Component Summary (PCS) score of the SF36 at 6 weeks (end of treatment).</td>
<td>SF-36 PCS, Mental Component Summary, EQ5D, Preference-based Stroke Index, RNLI, BI, Geriatric Depression Scale, Gait speed, Timed Up and Go</td>
<td>Average number of contacts reported: 4.8 home visits &amp; 7.8 telephone calls. Interventions reported by the case managers included surveillance, information exchange &amp; teaching, health system guidance, active listening, family support, medication management and risk identification. There were no statistically significant between group differences on the primary outcome at either 6 weeks or 6 months. There were no significant between group differences reported for any of the secondary outcomes assessed (Mental Component Summary, EQ5D, Preference-based Stroke Index, RNLI, BI, Geriatric Depression Scale, Gait speed, Timed Up and Go).</td>
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<tr>
<td>Forster et al. (2009) UK 8 (RCT)</td>
<td></td>
<td>265</td>
<td>265 stroke patients and their carers were randomly assigned to receive either existing care + structured patient/carer assessment at 5 – 6 months or usual care + a service information package. Structured assessment was conducted either as a home visit assessment performed by a stroke nurse (with discussion and case review by a multidisciplinary stroke team) or by a stroke nurse in a medical stroke review clinic. Patients and carers were assessed together. Primary outcome was change from study baseline (4 months post stroke) to 12 months post stroke in extended activities of daily living (Frenchay Activities Inventory; FAI). Primary carer outcome was change from baseline to 12 months in psychological distress (General Health Questionnaire 28; GHQ-28). Activities of daily living, mood, satisfaction with services, carer strain and</td>
<td>FAI, GHQ-28</td>
<td>There were no significant between-group differences for patient scores on the FAI (p=0.259 – Mann-whitney U test) or for carer scores on the GHQ-28 (p=0.945). Similarly, there were few significant differences on secondary analyses. Individuals in the intervention condition were more likely to feel that they were given all the information they needed at the time of discharge from hospital (p=0.04) and that they were well-prepared for the return home (p=0.015) than individuals assigned to the control condition. The authors note that this was not likely due to the intervention as the question referred to the time of hospital discharge rather than the time of structured assessment. There were no differences in terms of carer strain or mood. Patients assigned to the</td>
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resource use were also assessed. Structured assessment condition used fewer hospital bed days and home bed care days than those in the control group. This offset costs associated with delivery of the intervention making service costs per patient similar between groups.

<table>
<thead>
<tr>
<th>Allen et al. (2009)</th>
<th>USA 9 (RCT)</th>
<th>380 stroke patients in an acute stroke unit were randomly assigned to receive either post-discharge intervention + enhanced discharge planning or only enhanced discharge planning. Within 7 days of discharge, patients in the intervention group received an in-home assessment conducted by a case management nurse. Results of the assessment were reviewed by an interdisciplinary team who developed a specific care plan. Copies of the plan and pertinent information (evidence, guidelines, etc.) were provided to the family physician. The case management nurse &amp; physician implemented the recommendations and provided monitoring (via home visits and telephone calls) over a 6 month period. Outcomes were assessed in the areas of neuromotor function, LOS &amp; death, QOL, management of risk and stroke knowledge and lifestyle modification. Although the number of contacts and frequency of contacts per patient were not noted, care managers spent a median of 197 minutes in contacts/education/meetings, 135 minutes in medical follow-up, 70 minutes in clerical activities, 0 minutes addressing issues with allied health and 9 minutes addressing psychosocial issues over the course of the study. In examining between group differences in each of the outcome domains, treatment effect associated with the intervention was close to 0 for all domains with the exception of stroke knowledge and lifestyle modification. In this domain, there was a significant effect associated with the intervention (p=0.003). Note that this domain was assessed using a study-specific questionnaire written by the authors to measure knowledge of stroke risk factors, appropriate behaviours for risk reduction, appropriate response to stroke symptoms, objective health indicators, alcohol use and smoking.</th>
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<tr>
<td>Drummond et al. (2013)</td>
<td>UK RCT and Cohort PEDro=6 TPS\text{mean}=NA RCT: N\text{start}=43 RCT: N\text{end}=31 Cohort: N\text{start}=173 Cohort: N\text{end}=86</td>
<td><strong>Population</strong>: RCT (N=173): Experimental Group (EG, N=47): Mean age=70.64±14.29yr; Gender: Males=26, Females=21; Control Group (CG; N=46): Mean age=73.65±15.06yr; Gender: Males=24, Females=22. Cohort Study (N=43): Mean age=71.73±12.72yr; Gender: Males=15, Females=18; <strong>Intervention</strong>: Patients who were recruited to the RCT were allocated to either a control group (no visit) or to the intervention group (home visit by occupational therapist). Patients in the cohort study received a home visit under the same protocol as patients in the RCT intervention group. <strong>Outcomes</strong>: Nottingham Extended Activities of Daily Living Scale; Stroke Aphasic Depression Questionnaire: mood; quality of life, costs at one week and one month after discharge. 1. There were no significant differences between the EG and CG in the RCT for any measure except mood (EG&gt;CG) and readmissions to hospital at one month (CG&gt;EG). A greater proportion of participants in the EG were readmitted to hospital by one month after discharge than in the CG (p=0.04). 2. On average, the main resource use associated with home visits (amount of staff time required) was greater for the RCT participants than the cohort study participants.</td>
</tr>
</tbody>
</table>
| Gustafsson et al. (2014) | Australia Qualitative TPS\text{mean}=NA N\text{start}=NA N\text{end}=NA | **Population**: No demographic information available. **Intervention**: Participants completed a questionnaire on their agreement with 12 statements about the Stroke Rehabilitation Enhancing and Guiding Transition Home (STRENGTH) program. **Outcomes**: Influences of context on team function; 1. Results from the qualitative analysis showed that there were 2 main themes that emerged: 1) influence of context on team functioning; and 2) experiences of the program 2. Participants identified that an important element of STRENGTH was option to
Impact on communication; Impact on therapy; Impact on goals; Experiences of the program.

3. Benefit of the program was that it encouraged therapists to find time to communicate more with each other.

4. An increase in shared treatment sessions (client and carer worked on activities together within the home environment).

5. Overall, a valued and beneficial experience, though a major impediment was that the program would end after funds for study were finished – a huge loss for patients.

### 19.1.4.4 Active Case Management

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goldberg et al. (1997)</strong> USA 5 (RCT)</td>
<td>55 patients post stroke, 65 years of age or older with no residual cognitive or language impairment able to return home, were randomly allocated to received STAIR (Stroke Transition after Inpatient Rehabilitation) intervention. The STAIR intervention was to provide home-based case-managed care including weekly telephone contact and monthly home visits, home-based therapeutic recreational treatment as needed, social work and psychology consultations, as well as access to educational resources and to a stroke “hot line”. The program was designed to identify problems promptly, direct appropriate interventions and advocate for the patient/family in accessing resources. Both groups received usual outpatient follow-up.</td>
<td>Assessments were completed post discharge from inpatient services at 1 week (baseline), 6 months and 1 year. Significant improvement in functional independence (FIM; p&lt;0.001) and IADL ability (FAI; p&lt;0.001) was reported for the entire sample between baseline and 6 months, and baseline and 1 year. There was a trend identified for participation in the study group to be associated with an increase in FAI (social activity) scores at 1 year (p=0.063). Addition of “sense of effectiveness” to inclusion in the experimental groups significantly predicted increased FAI scores at one year (p&lt;0.01). Comparison with the control group demonstrated that neither quality of life nor psychosocial functioning was improved by involvement in the STAIR intervention.</td>
</tr>
</tbody>
</table>

| **Ostwald et al. (2014)** USA RCT PEDro=5 TPS<sub>EG</sub>≤12mo TPS<sub>CG</sub>≤12mo N<sub>Start</sub>=159 N<sub>End</sub>=134 | **Population:** Experimental Group (EG, N=80): Mean age=66.98±9.04yr; Gender: Male=55, Female=25. Control Group (CG, N=79): Mean age=65.75±9.26yr; Gender: Male=64, Female=15. **Intervention:** EG received mailed letters with information on stroke, resources and advice plus home visits from nurses and therapists. CG received mailed letters with information on stroke, resources and advice only. The intervention was provided 1/mo for both groups but EG also were provided with a mean of 16 home visits lasting 70min each for the first 6mo of the study. Assessments were conducted at baseline, 3mo, 6mo and 12mo follow-ups. | 1. GDS and PSS scores did not differ significantly between groups at any time point but when both groups were combined, a significant decreases in depression and stress were found (p<0.05).

2. SF-36 improved significantly for EG from baseline to 6mo (p=0.03) but no improvements were reported from 6mo to 12m follow-ups.

3. SF-36 improved significantly for caregivers of both EG and CG (both p=0.041) at 6mo follow-up but no significant improvement |
6mo, 9mo and 12mo follow-ups.

Outcomes: Geriatric Depression Scale (GDS); Perceived Stress Scale (PSS); Short Form Health Survey (SF-36); Stroke Impact Scale (SIS: Memory, Social Participation); Functional Independence Measure (FIM: Cognitive).

was noted at 12mo.

4. FIM Cognitive improved for both groups from baseline to 6mo (both p=0.03) but no differences were reported groups.
5. The SIS Memory and Social Participation subscales revealed significant improvements for all patients combined (both p<0.05) at 6mo and 12mo but no significant differences were found between groups for either subscale.

19.1.4.5 Discharge Planning Programs

Table 19.1.4.5 Discharge Planning and Transition Programs

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
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<tbody>
<tr>
<td>Shyu et al. (2008)</td>
<td>Taiwan</td>
<td>5 (RCT)</td>
<td>201 carer/stroke patient dyads received either the caregiver-oriented discharge planning program (n=97) or usual care (n=104). The discharge planning program was conducted by trained research nurses who evaluated caregiver needs within 48 hours of admission. The results of this assessment were used to supplement routine information provision that was not based on individual carer needs. Bedside instruction was provided on 4-5 occasions for approximately 30 minutes per session over the course of the admission. The competing needs checklist was used to help caregivers identify/anticipate competing care needs and advice/counselling was provided during bedside instruction. Once discharged, carers were contacted within one week by telephone and two home visits were made (one week, one month) to advise and support caregivers in the home environment. Study outcomes included nursing and self-evaluations of caregiver preparedness, satisfaction with discharge needs being met, &amp; balance in competing needs.</td>
<td>158 dyads completed the trial and all follow-up (n=72 in the experimental group, 86 in the control group). From baseline to the first assessment (at the time of discharge), individuals in the treatment group demonstrated significant improvement in caregiver preparedness (p&lt;0.001). The nursing evaluation of preparedness also suggested improvements in the control group (p&lt;0.01). However, between group comparisons demonstrated that, at the time of discharge, caregivers assigned to the discharge planning program demonstrated significantly greater levels of caregiver preparedness on both nursing and self-reported evaluations (p=0.004 &amp; 0.008, respectively). In addition, at 1 month, caregivers allocated to the intervention group demonstrated greater satisfaction with discharge needs than those in the control group (p&lt;0.001). There were no between group differences in terms of balancing competing needs.</td>
</tr>
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</table>

| Shyu et al. (2010) | Taiwan | 5 (RCT) | In this long-term follow-up to Shyu et al. 2008, HRQOL (SF-36), quality of care (assessed using the Family caregiving consequence inventory which evaluates the degrees to which needs of the care recipient are met), and health service utilisation were assessed at 3, 6 and 12 months after discharge. 61 dyads in the experimental group | There were no significant between group differences on any subscale of the SF-36 for either patients or carers. Quality of care given by carers assigned to the intervention group appeared better than the control group at 6 months. Further analysis (generalised estimating equation), demonstrated that over the 12-month period, quality of care or the fulfillment of care recipient needs was greater in the intervention group |
and 75 in the control group completed all evaluations to 12 months. than in the control group (p=0.03). In terms of hospital readmissions, the two groups did not differ significantly; however, more patients assigned to the control group were institutionalised between 6 and 12 months post-discharge than those in the experimental condition (p=0.03).

**Wei et al. (2014)**
Singapore Qualitative descriptive No Score TPS\_Mean=NA N\_Start=68 N\_End=48

**Population**: Continued with rehabilitation (N=20): Mean age=62.25±9.79yr; Gender: Males=13, Females=7. Did not continue with rehabilitation (N=28): Mean age=66.46±12.01yr; Gender: Males=14, Females=14.

**Intervention**: Semi-structured telephone interviews were undertaken and analyzed using inductive thematic analysis, from patients who have been discharged from the hospital after inpatient rehabilitation. Participant were divided in groups based on their continuation with rehabilitation.

**Outcomes**: Recurrent themes regarding obstacles that deter patients from continuing stroke rehabilitation after discharge from hospital.

1. 5 themes emerged: (1) the means to access rehabilitative services, (2) lapse in discharge coordination, (3) family member’s views and actions, (4) discrepancies in expectation, and (5) the perception that rehabilitation is simple.

2. (1) The lack of means of transport and the associated costs were the chief barriers that hindered adherence to continuing post-stroke rehabilitation.

3. (2) Existing gaps in the transition from inpatient to outpatient services is where some participants fell through and were left waiting for follow-up rehabilitation.

4. (3) In some cases, where the patient was generally reluctant to continue their rehabilitation, the patient’s children acted to implement rehabilitation based on their own beliefs that participation in rehabilitation is beneficial. Some felt stranded and expressed their helplessness and need of assistance.

5. (4) While some participants felt discouraged from continuing rehabilitation due to unmet needs during their rehabilitation, others reported that the therapy intensity was not comparable to their expectations, leading them to seek alternatives to their therapy recommendations.

6. (5) The expertise of exercise prescription and activity grading by the clinicians was undermined as participants did not understand the reasoning behind their therapy prescription. The use of medications and acupuncture was believed to be contributing more to their recovery compared to rehabilitation.

### 19.1.5 Patient Education Programs

**Table 19.1.5 Patient Education Programs**

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tr>
<td><strong>Bek et al. (2016)</strong> United Kingdom RCT PEDro=6 TPS_Mean=34.5±39.8m</td>
<td><strong>Population</strong>: Experimental Group (EG, N=41): Mean Age=60.4±12.6yr; Gender: Males=25, Females=16; Control Group (CG, N=36): Mean Age=64.3±13.2yr; Gender: Males=21, Females=15.</td>
<td>1. BI increased from 16.3±3.3 to 16.9±3.0 in IG and 15.1±4.9 to 14.8±5.0 in CG. 2. TUG(s) increased from 34.9±21.6 to 38.0±23.7 in IG and 31.5±17.7 to 47.4±78.8 in CG. 3. 10m walk(s) increased from 27.7±20.5 to</td>
<td></td>
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### Intervention: Conductive Education (CE)

- **TPS Mean**: 31.7±34.1m
- **Start**: 77
- **End**: 70

- **Intervention**: IG received Conductive Education, an approach to rehabilitation that views stroke as a learning process and consists of 10 weekly 1.5h sessions. CG were invited to two introductory meetings during the 10wk waiting list period.

- **Outcomes**: Barthel Index (BI); Stroke Impact Scale (SIS); Timed Up and Go Test (TUG); 10metre walking test (10m walk); Hospital Anxiety and Depression Scale (HADS).

- **Forster et al. (2013)**
  - **UK**
  - Multicentre cluster RCT
  - **PEDro=5**
  - **TPS Mean**: NA
  - **Start**: 1856
  - **End**: 1247

- **Population**: LSCTS Patient group (N=450): Mean age=71.0±12.76yr; Gender: Males=47%, Females=43%. LSCTS Caregiver group (N=450): Mean age=61.1±14.64yr; Gender: Males=31%, Females=69%. Control Patient group (N=478): Mean age=71.3±12.18yr; Gender: Males=55%, Females=45%. Control Caregiver group (N=478): Mean age=60.8±13.91yr; Gender: Males=32%, Females=68%.

- **Intervention**: 49 Stroke units were randomly assigned to either the London Stroke Carers Training Course (LSCTC) or to usual care (control group), stratified by geographical region, and quality of care. Patients were recruited along with their caregiver. Assessments were conducted at 6mo.

- **Outcomes**: Nottingham Extended Activities of Daily Living (NEADL); Caregiver Burden Scale (CBS).

- **Norris et al. (2013)**
  - **UK**
  - Pre-Post
  - **Score TPS Mean**: 1.7yr
  - **Start**: 30
  - **End**: 22

- **Population**: Mean Age=62yr; Gender: Male=13, Female=8.

- **Intervention**: All patients were enrolled into the Action for Rehabilitation in Neurological Injury (ARNI) training program. The ARNI program consisted of 1.5hr/wk group sessions for 12wk where patients learned to become functionally independent through both physical and psychological interventions.

- **Outcomes**: Personal experiences with the program recorded during conversations with the program administrators.

- **Norris et al. (2013)**: The NEADL scores or the CBS scores did not differ between the two groups at 6mo (p=0.866, p=0.66).

- **Forster et al. (2013)**
  - **UK**
  - Multicentre cluster RCT
  - **PEDro=5**
  - **TPS Mean**: NA
  - **Start**: 1856
  - **End**: 1247

- **Population**: LSCTS Patient group (N=450): Mean age=71.0±12.76yr; Gender: Males=47%, Females=43%. LSCTS Caregiver group (N=450): Mean age=61.1±14.64yr; Gender: Males=31%, Females=69%. Control Patient group (N=478): Mean age=71.3±12.18yr; Gender: Males=55%, Females=45%. Control Caregiver group (N=478): Mean age=60.8±13.91yr; Gender: Males=32%, Females=68%.

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- **Outcomes**: Nottingham Extended Activities of Daily Living (NEADL); Caregiver Burden Scale (CBS).

- **Forster et al. (2013)**: The NEADL scores or the CBS scores did not differ between the two groups at 6mo (p=0.866, p=0.66).

- **Forster et al. (2013)**: The NEADL scores or the CBS scores did not differ between the two groups at 6mo (p=0.866, p=0.66).

1. Patients reported improvements in physical domains including balance, muscle strength and mobility.
2. These physical improvements in addition to an increase in confidence were associated with increases in their ability to complete daily activities such as walking and household activities.
3. The program was frequently reported as challenging however some patients expressed a desire for an increase in intensity.
4. Group activities were reported by all patients as critical for providing a challenge but some patients who received individual sessions felt that the one-on-one training was better targeted at their personal needs.
5. Several patients reported the introduction of challenging goals into their lives following training including the resumption of pre stroke activities.
6. Some patients reported that the duration of the program was not sufficient for the resumption of previous roles.
The majority of patients felt that there should have been a form of continuation following the initial program.

Patients also reported that having the program outside of the hospital was beneficial and allowed for a more positive approach to training.

**Wang et al. (2013)**
Taiwan  
RCT  
PEDro=4  
TPS\text{mean}=NA  
N\text{Start}=170  
N\text{End}=127  

**Population:** Experimental group (N=65): Mean age=67.3±12.8yr; Gender: Males=43, Females=22.  
Control group (N=62): Mean age=67.2±10.4yr; Gender: Males=40, Females=22.

**Intervention:** The experimental group consisted of patients randomly selected from seven communities to received 3 3hr stroke interventions per week for 8wks. The control group consisted of stroke patients randomly selected from a medical centre who received a general stroke education programme.

**Assessments:** were conducted at baseline (t0), after the intervention after 3m (T2), and at 6m follow-up (T3).

**Outcomes:** Questionnaires containing questions regarding demographic characteristics, lifestyle, personal chronic diseases, behavior of patients with stroke, and self-efficacy (including dietary control, continuous rehabilitation, physical activities, exercise, positive attitude in social participation and stress management).

1. There was no significant improvement across any time points in the control group regarding the knowledge (i.e. warning signs and medical treatment, risk factors of stroke, and dietary) the behavior (i.e. warning, risk factors of stroke, and social participation) or the self-efficacy sections of the questionnaires.
2. The experimental group improved significantly from T0 to T1 and from T0 to T2 on all knowledge subsection (warning signs: p<0.001, p=0.03; risk factors: p<0.001, p<0.001; dietary: p=0.04 from T0 to T1 only), on the social participation subsection of behavior (p<0.001, p<0.001), and on the self-efficacy section (p<0.001 p<0.001).
3. The experimental group had a significantly different mean knowledge score of risk factors, increasing at the 6m follow-up in comparison with the baseline and scores in the control group (0.9 vs. 0.2, p=0.04).
4. Self-efficacy was correlated significantly with knowledge of risk factors after the intervention (r=0.31, p=0.02), knowledge of risk factors after 6m (r=0.42, p<0.01), and social participation after 6m (r=0.29, p=0.04) in the experimental group.

**Skidmore et al. (2014)**
USA  
PCT  
No Score  
TPS\text{yr}=15±8d  
TPS\text{AC}=14±4d  
N\text{Start}=10  
N\text{End}=10

**Population:** Strategy Training Group (ST; N=5): Mean age=64±17yr; Gender: Males=4, Females=1.  
Attention Control Group (AC; N=5): Mean age=72±13yr; Gender: Males=3, Females=2.

**Intervention:** Participants received strategy training or attention control sessions in addition to usual care. Sessions in both groups were 30-40m/d, 5d/wk, for the duration of inpatient rehabilitation. Assessments for disability were conducted at study admission, inpatient rehabilitation discharge, 3 and 6m after.

**Outcomes:** Functional Independence Measure (FIM).

1. A significant group x time interaction (p=0.001) as well as a non-significant main effect of group (p=0.35), and a significant main effect of time (p<0.001) were found.
2. The ST group demonstrated significantly greater reduction in disability between baseline and the 6m follow-up compared to the AC group (mean difference: 20points, p=0.02), despite the fact that both groups improved significantly over time.

**Taricco et al. (2014)**
Italy  
PCT  
No Score  
TPS\text{APA}=287.3d

**Population:** Adapted physical activity (APA) group (N=126): Mean age=71.8±10.5yr; Gender: Males=85, Females=41.  
Control group (N=103): Mean age=70.1±10.7yr; Gender: Males=62, Females=41.

1. The APA group improved significantly on the 6MWT (p<0.002), BBS (p<0.001), SPPB (p<0.001), M1 (p<0.001), GDS (p<0.001), and the SF-12 (p<0.001).
2. The control group showed no significant
Intervention: Participants were allocated either to the experimental group and received 16 adapted physical activity (APA) sessions and 3 therapeutic patient education (TPE) sessions, or to the control group and received usual care. Assessments were conducted before and after the intervention. Outcomes: Short Physical Performance Battery (SPPB); Berg Balance Scale (BBS); Barthel Index (BI); Geriatric Depression Scale (GDS); 12-Short-Form Health Survey (12SF); Caregiver Strain Index (CSI); 6 Minute Walk Test (6MWT).

1. There was no statistically significant difference between groups on the mean total RNLI score: (p=0.87).
2. Multivariable regression analyses showed that demographic and intervention variables were not significantly related to the RNLI total scores (p>0.072).
3. For the qualitative analysis, EG participants revealed that they felt the CRCATT found it helped to facilitate communication between themselves and family members concerning ‘hidden worries’.
4. Participants described that the CRCATT was useful for accessing formal supports to resume activities and participate in their community.
5. EG participants described more positive experiences with health care providers than CG, who described they felt that they were left to figure things out on their own.
6. EG and CG differed in terms of the questions they asked: the EG asked questions related to CR needs while control group asked questions related to cause risk factors, recurrence of stroke, time to recovery.

McKellar et al. (2015)
Canada
RCT
PEDro=2
TPS\textsubscript{mean}=NA
N\textsubscript{Start}=77
N\textsubscript{End}=57

Population: Experimental Group (EG; N=39):
Mean Age=57yr; Gender: Males=24, Females=15.
Control Group (CG; N=38):
Mean Age=58;
Gender: Males=24, Females=14;

Intervention: The EG received a Heart and Stroke Foundation booklet, a tip sheet on how to communicate with healthcare providers and the Cue to Action Trigger Tool (CRCATT), which is a patient mediated question-prompt list covering eight area for community re-engagement (CR). The EG received a 20min visit from a research coordinator at week 2 and week 3, following rehab admission. The CG only received the Heart and Stroke Foundation booklet during a brief in-person visit.

Outcomes: Self-reported re-engagement in activities: Reintegration to Normal Living Index (RNLI).

1. A significant difference between groups was found 6MWT (p=0.01), BBS [p<0.001], SPPB (p<0.001), and on the physical composite scale of the SF12 (p<0.001).
2. No significant difference was found on the remaining scales.

Robinson-Smith et al. (2016)
USA
RCT
PEDro=4
TPS\textsubscript{mean}<2wk
N\textsubscript{Start}=10 dyads
N\textsubscript{End}=8 dyads

Population: Experimental Group (EG; N=10):
Stroke survivor: Mean age=65.2±14.9yr; Gender: Males=3, Females=2;
Spouse: Mean age=65.4±15.0yr; Gender: Males=3, Females=2.
Control Group (CG; N=10):
Stroke survivor: Mean age=75.6±7.4yr; Gender: Males=3, Females=2;
Spouse: Mean age=75.6±10.1yr; Gender: Males=3, Females=2.

Intervention: Couples were randomly assigned to the experimental group which received a psychoeducational intervention (PEI) over the course of 6 sessions, or to the control group which did not receive the intervention. Outcomes were assessed at baseline and after the intervention.

1. Repeated measures ANOVA demonstrated some statistically significant differences when experimental versus control group responses of stroke survivors were compared over time for: depression (F = 7.46, df = 1, p = .026); quality of life (F = 11.55, df = 1, p = .009); and dyadic coping by oneself (subscale) (F = 7.19, df = 1, p = .028).
2. No significant differences were noted for comparisons of stroke spouse experimental and control groups on total dyadic coping and depression.
3. Repeated measures ANOVA demonstrated statistically significant differences over time in the experimental group versus the control
Outcomes: Dyadic coping instrument (DCI); Quality of life index-Stroke Version (QLI); Centre for Epidemiologic Studies-Depression (CES-D); Strategies Used to Promote People’s Health (SUPPH); Activity Measure for Post-Acute Care (AM-PAC).

Kamal et al. (2015) Pakistan RCT PEDro=7 TPS\text{EGMedian}=2 (IQR=1-5)? TPS\text{CGMedian}=2 (IQR=1-4)? N\text{Start}=200 N\text{End}=162

Population: Experimental Group (EG, N=100): Mean Age=56.07±1.5yr; Gender: Males=64, Females=36; Control Group (CG, N=100): Mean Age=57.62±1.3yr; Gender: Males=71, Females=29.

Intervention: In addition to the usual care received by CG, EG received automated SMS reminders customized to their individual prescription and twice weekly health information SMS. Outcomes assessed at baseline and 2mo.

1. High patient satisfaction and acceptability of intervention reported.
2. Adjusting for baseline adherence score, number of pills, dosing frequency, age, gender, employment status, education, use of alarms, and missing physician appointments in the past year, EG had a significantly higher improvement in MMAS compared to CG (adjusted difference=0.54, p<0.01).
3. No significant differences in systolic blood pressure observed, but mean diastolic blood pressure in EG was 2.6mmHg (p=0.06) lower compared to CG after the intervention.

19.1.6 Community-Based Rehabilitation Programs

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Kim et al. (2014)</td>
<td>Korea</td>
<td>RCT</td>
<td>PEDro=8</td>
<td>population: Mean age=50.18±10.29yr; Gender: Male=6, Females=5. Control group (CG) (N=11): Mean age=50.73±7.24yr; Gender: Males=7, Females=4. Intervention: Participants were randomly allocated either to the community walking training program (CWTP) group and participated (30 minutes per day, 5 times a week, for 4 weeks), or to the control group (CG) which did not participate in the social walking intervention. All participants received standard rehabilitation for 60 mins per day, 5 times a week, for 4 weeks. Assessments were conducted before and after the intervention period. Outcomes: 10 Meter Walk Test (10MWT); 6 Minute Walk Test (6MWT); Stroke Impact Scale (SIS); Community walking test.</td>
</tr>
<tr>
<td>Corr et al. (2004)</td>
<td>UK</td>
<td>6 (RCT)</td>
<td>26 patients referred to the Cardiff Day Service were randomly allocated to group A (attend service immediately for 6 months and then not attend for 6 months; n=14) or group B (attend service for 6 months after not attending for 6 months; n=12) in a cross-over design.</td>
<td>1. Assessment at 6 months demonstrated a significant difference in SF36 physical functioning scores (p=0.04) such that patients in group B (late attendance) had higher physical functioning. 2. There were no other significant between...</td>
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</table>
service was designed to provide access to recreational and leisure activities as well as to help stroke survivors identify and pursue opportunities within the community. All participants were assessed at baseline, 6 months and again at 1 year using the Extended ADL scale, the Nottingham Leisure Questionnaire, SF-36 and the hospital Anxiety and Depression Scale.

3. Before and after treatment assessments for group A demonstrated an increase in ability to carry out occupations (p=0.05) and increased satisfaction with performance (p=0.03) on the COPM. There was a trend toward increased regular leisure activities (p=0.085) though not in number of activities.

4. For Group B, no change was identified over the control phase. The intervention phase was associated with increased number of leisure activities (p=0.028).

Shibuta et al. (2016)

Population: Stroke Group (SG, N=113): Mean Age=80±11yr; Gender: Males=41, Females=72; Other Group (OG, N=396): Mean Age=78±13yr; Gender: Males=119, Females=277.

Intervention: The study population consisted of patients admitted to a rehabilitation programme and discharged home, separated into two groups depending on their primary disease (Stroke or other). The study examined the interaction between rehabilitation during hospital stay, the use of community-based rehabilitation, and non-rehabilitation services and their effect on the patient’s subsequent functional abilities. Assessments were conducted at 3mo after hospital discharge.

Outcomes: Functional Independence Measure (FIM) change %.

1. In SG, use of community-based rehabilitation services and non-rehabilitation services were associated with significantly increased FIM change %.

2. There were also significant interaction terms between FIM change% and either type of service used.

19.1.7 Patient Self-Management Programs

Table 19.1.7 Patient Education Programs

<table>
<thead>
<tr>
<th>Author, Year Country</th>
<th>Methods</th>
<th>Outcomes</th>
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<tr>
<td>Kara et al. (2015) South Africa</td>
<td>Population: Experimental Group (EG=21): Mean Age=62.4±16.5yr; Gender: Males=11, Females=10; Control Group (CG, N=21): Mean Age=59.3±14.7yr; Gender: Males=9, Females=12. Intervention: Both groups received the standard home exercise programme, with the EG receiving an additional written and pictorial prescription of the home exercises to optimise the patients’ functional status. Study was conducted over a 4wk period with participants completing a logbook and the primary outcome being adherence. Outcomes: Adherence rate; Modified Rivermead</td>
<td>1. No significant differences between EG and CG groups in terms of adherence rate. 2. Both MRMI and BI increased from baseline to 4wk, though there were no significant differences between EG and CG. 3. Significant correlation between adherence rate and BI but not between adherence rate and MRMI.</td>
</tr>
</tbody>
</table>
| **McKenna et al. (2015)** | Mobility Index (MRMI); Barthel Index (BI). | **Population:** Experimental Group (EG=11): Mean Age=62.18±13.57yr; Gender: Males=7, Females=4; Control Group (CG, N=13): Mean Age=67.38±10.60yr; Gender: Males=6, Females=7.  
**Intervention:** In this feasibility RCT, both groups received the usual multidisciplinary stroke rehabilitation with assessments at baseline, 6wk (program completion), and 3mo follow-up. In addition, EG received one session of up to one-hour per week over six weeks of Bridges stroke self-management program (SSMP), consisting of one-to-one sessions using strategies to promote specific behaviors that exemplify the hallmarks of self-management.  
**Outcomes:** EuroQoL Index; EuroQoL VAS; Stroke-Specific Quality of Life (SSQOL); Stroke Self-Efficacy Questionnaire (SSEQ); Self-Efficacy Scale (SES); Barthel Index (BI); Nottingham Extended Activities of Daily Living (NEADL); General Health Questionnaire (GHQ-28); Subjective Index of Physical and Social Outcome (SIPSO).  
1. At 6mo, EG increased for EuroQoL Index (0.09), EuroQoL VAS (0.13), SSQOL (1.11), SSEQ (1.04), and SES (0.79).  
2. At 6mo, CG increased for EuroQoL Index (0.15), EuroQoL VAS (0.12), SSQOL (1.94), SSEQ (0.65), and SES (0.36).  
3. From 6wk to 3mo, EG showed decreases in EuroQoL Index, SSEQ, and SES, but increases in EuroQoL VAS and SSQOL.  
4. From 6wk to 3mo, CG showed decreases in EuroQoL Index, EuroQoL VAS, and SSEQ but increases in SES and SSQOL.  
5. Conflicting findings were observed among secondary outcomes. |
| **Hoffmann et al. (2015)** | | **Population:** Coping Skills (CS, n=11): Mean Age=63.6±13.0yr; Gender: Male=7, Female=4; Self-management (SM, n=12): Mean Age=60.8±11.7yr; Gender: Male=9, Female=3; Usual Care (UC, n=10): Mean Age=57.0±14.2yr; Gender: Male=6, Female=4.  
**Intervention:** Patients were randomized to receive CS, SM or usual care interventions for 8 1hr sessions. CS consisted of performing cognitive and behavioural exercises with the goal of improving self-awareness and coping skills. SM taught problem-solving skills, the ability to communicate with healthcare professionals and how to adjust to life post stroke in addition to addressing individualized concerns. UC comprised of multidisciplinary assessment and treatment in addition to basic education and advice.  
**Outcomes:** Stroke knowledge questionnaire; Hospital Anxiety and Depression Scale; Modified Barthel Index (MBI); Montgomery and Asberg Depression Rating Scale (MADRS); Self-efficacy questionnaire; Nottingham Extended Activities of Daily Living scale (Nottingham EADL); Stroke and Aphasia Quality of Life Scale (SAQoL): psychosocial, physical, communication.  
1. Depressive symptoms according to HADS were significantly more prevalent in the CS group compared to the UC group post intervention (mean UC=6.4±0.5, CS=7.9±0.5) (p=0.034).  
2. Stroke knowledge post intervention was significantly greater in the CS group compared to the UC group (mean UC=19.9±0.4, CS=21.2±0.4) (p=0.036).  
3. MBI scores post intervention were not significantly greater in the SM group compared to the UC group (mean UC=19.9±0.4, CS=21.2±0.4) (p=0.036).  
4. No other significant differences were observed between the CS and UC groups and the SM and UC groups post intervention.  
5. No significant differences were observed between the CS and UC groups and the SM and UC groups at 3-5mo post intervention. |
| **Tielemans et al. (2015)** | | **Population:** Mean Age=57.1±8.9yr; Gender: Males=59, Females=53.  
**Intervention:** Stroke patients participating in the Restore4Stroke Self-Management study had their UPCC was found to have a significant positive correlation with USER-Participation satisfaction (r=0.34, p<0.001), 2LS (r=0.36, p<0.001), SS-QOL-12 (r=0.38, p<0.001), GSES |
Baseline data analyzed to examine associations of proactive coping and self-efficacy with psychosocial outcomes.

**Outcomes**: Utrecht Proactive Coping Competence scale (UPCC); General Self-Efficacy Scale (GSES); USER-participation (restriction and satisfaction subscales); Hospital Anxiety and Depression Scale (HADS); 2 Life Satisfaction Questions (2LS); Short Stroke-Specific Quality of Life scale (SS-QOL-12).

1. A total of 4 themes emerged: (1) self-management: a difficult word, (2) self-management: a complex and long-term learning process, (3) influence of relatives on the self-management process, and (4) persons with stroke feel neglected in their needs.
2. Participants described their self-management as a complex, long-term, personal learning process.
3. Post-discharge, participants were not ready to self-manage.
4. Relatives could provide support, but they also limited the development of participants’ self-management skills.
5. Participants missed having professional support post-discharge and would have appreciated additional psychological and emotional support in the process of self-management.

**Satink et al. (2015)**
Netherlands Qualitative No Score TPS/start=NA N/start=16 N/end=16

- **Population**: Mean age=70.81±9.22yr; Gender: Males=7, Females=9.
- **Intervention**: Focus group interviews were conducted on community living stroke survivors to explore the reflections of persons post-stroke on self-management, readiness, and needs in self-management support.
- **Outcomes**: Emerging themes regarding self-management, readiness, and self-management support.

**Boger et al. (2015)**
UK Qualitative No Score TPS/start=57.9±60.8mo N/start=31 N/end=28

- **Population**: Mean age=65.67yr; Gender: Males=11, Females=17.
- **Intervention**: Participants were recruited from rural and urban community stroke support groups to investigate the factors which facilitate or hinder self-management by means of semi-structured interviews which were conducted during 5 focus group sessions.
- **Outcomes**: Emerging themes regarding the ability to self-manage.
Population: Experimental Group (EG=15): Mean Age=56.3±8.7yr; Gender: Males=7, Females=8; Control Group (CG, N=8): Mean Age=55.3±12.6yr; Gender: Males=4, Females=4.

Intervention: Both groups received usual care, with EG also received a mobile phone with the STARFISH app, where their “fish” was rewarded if step count targets were reached. Assessments at baseline and week 6.

Outcomes: Mean number of steps per day; Sedentary time; Upright time; Walking time; Fatigue Severity Scale (FSS); Instrumental Activities of Daily Living Scale (IADL); Stroke Specific Quality of Life Scale (SS-QOL); Psychological General Well-Being Index (PGBWI); Ten-Meter Walking Test (10 MWT).

1. Mean number of steps per day increased by 39.3% in EG and decreased by 20.2% in CG (p=0.005).
2. Walking time increased by 20min in EG and decreased by 14min in CG (p=0.002).
3. No significant differences between EG and CG for Sedentary time or Upright time.
4. FSS was reduced in EG and increased in CG (p=0.031).
5. No significant differences observed between EG and CG for IADL, SS-QOL, PGBWI, or 10MWT.

Population: Experimental Group (EG=11): Mean Age=62.1±10.0yr; Gender: Males=9, Females=2; Control Group (CG, N=15): Mean Age=67.1±13.4yr; Gender: Males=6, Females=9.

Intervention: Both groups were either enrolled in outpatient rehabilitation or on a waiting list to start. The EG participated in the PROPEL program, a supervised and individualized aerobic training group available 3 times a week with self-management components. Assessments occurred after intervention or 6 weeks after discharge.

Outcomes: Accelerometer (steps with or without low frequency extension (LFE)); Heart Rate monitor; Physical Activity Scale for Individuals with Physical Disabilities (PASIPD); Short Self-Efficacy for Exercise (SSEE); Short outcome expectations for exercise (SOEE); Barriers to Being Active Quiz (BBAQ).

1. EG had higher PASIPD (Hedge’s g=0.75), Steps without LFE (Hedge’s g=0.09), Steps with LFE (hedge’s g=0.14), Heart rate (hedge’s g=0.63), SOEE (hedge’s g =0.50) than CG.
2. No differences for SSEE between both groups.
3. EG had fewer significant barriers (BBAQ) than CG.

Population: Experimental Group (EG, N=40): Mean Age=61.79±16.03yr; Gender: Males=20, Females=20; Control Group (CG, N=38): Mean Age=68.82±10.28yr; Gender: Males=25, Females=13.

Intervention: Feasibility cluster-randomised design with EG receiving a self-management programme (Bridges) in addition to the usual community stroke rehabilitation that CG received. The intervention integrated seven key principles (problem solving, reflection, goal setting, assessing resources, self-discovery, activity, and knowledge) and utilized a stroke workbook. Outcomes assessed at baseline (within 2wk of starting rehabilitation), 6wk, and 12wk.

Outcomes: Stroke Self-Efficacy Questionnaire (SEQ); Hospital Anxiety Depression Scale (HADS);

1. No significant differences between EG and CG were observed at 6wk, 12wk in terms of NEADL, HADS, SAQOL, SF-12, or SEQ.
2. Feasible to integrate a stroke self-management programme into community rehabilitation and use outcome measures.
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Design</th>
<th>PEDro</th>
<th>TPS Median</th>
<th>N Start</th>
<th>N End</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Jones et al. (2016)</td>
<td>Australia</td>
<td>Pre-Post</td>
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<td>24</td>
<td>22</td>
<td>Mean Age=51.13±16.52y; Gender: Males=10, Females=14; ABI Type: Stroke=20, TBI=4.</td>
<td>ABI adult survivors received a remotely delivered self-management program (myMoves) aimed at increasing physical activity and consisting of 6 email modules over 8 weeks. Assessments performed at baseline (prior to intervention), after the intervention, and 3mo.</td>
<td>Feasibility; Acceptability; Average daily step count; Average daily time spent sitting/lying down; Average daily time spent in moderate to vigorous physical activity; Spinal Cord Injury Exercise Self-Efficacy; Kessler Psychological Distress Scale (K-10); modified Reintegration to Normal Living Index (mRNLI).</td>
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</table>
| Wolf et al. (2016)                        | United States    |        | 5     |            | 185     | 78     | Experimental Group (EG=66): Mean Age=57±10y; Gender: Males=31, Females=35; Control Group (CG, N=31): Mean Age=59±7.7y; Gender: Males=15, Females=16. | At two University settings, patients were assessed at baseline, post-intervention, and 6-9mo post-intervention. CG was placed on a wait list while EG received the Improving Participation after Stroke Self-Management Program (IPASS) intervention. This consisted of 12 small-group sessions intended to help participants build self-efficacy and problem-solving skills. | 1. Good feasibility and acceptability reported.  
2. No significant differences in the Amounts of sedentary time, Average number of steps taken per day, Average daily time spent in physical activity, or Spinal Cord Injury Exercise Self-Efficacy Scale between any time points.  
3. There was a significant reduction in K-10 before and after intervention (2.76pts, p=0.001).  
4. There was a significant increase in mRNLI before and after intervention (2.8pts, p=0.008). |
| Sit et al. (2016)                          | Hong Kong        | RCT    | 8     |            | 210     | 175    | Experimental Group (EG=105): Mean Age=67.8±14.2y; Gender: Males=55, Females=50; Control Group (CG, N=105): Mean Age=70.7±13.9y; Gender: Males=55, Females=50. | EG and CG received usual care, with assessments at baseline (pretest), 1wk after intervention, 3mo after intervention, and 6mo after intervention. In addition, EG received the 13wk Health Empowerment Intervention for Stroke Self-Management (HEISS), consisting of small group sessions and home-based implementation. | Chinese Self-Management Behavior Questionnaire (self-efficacy in illness management, cognitive symptom management, communication with physicians); Medication adherence; Self-BP monitoring record; Barthel Index (BI); Chinese Lawton instrumental Activities of Daily Living (IADL); | 1. EG had significantly better self-efficacy in illness management at 3mo and 6mo compared to CG (p=0.011, p=0.012).  
2. EG had significantly better cognitive self-management than CG at all time points (p<0.001).  
3. EG had significantly better communication with physicians at 1wk (p<0.001) and 3mo (p=0.002), but not at 6mo.  
4. There were no significant differences between EG and CG in terms of medication adherence.  
5. EG had significantly better self-BP monitoring at all time points (p=0.005, p=0.005, p=0.025).  
6. EG had significantly improvement in BI and IADL compared to CG at 1wk (0.005, p<0.001), 3mo (p=0.016, p<0.001), and 6mo (p=0.03, p<0.001). |
|                                           |                  |        |       |            |         |        | Control Group (N=105): Mean Age=67.8±14.2y; Gender: Males=55, Females=50. | Control Group (CG, N=105): Mean Age=67.8±14.2y; Gender: Males=55, Females=50. | Control Group (CG, N=105): Mean Age=67.8±14.2y; Gender: Males=55, Females=50. | Control Group (CG, N=105): Mean Age=67.8±14.2y; Gender: Males=55, Females=50. | Control Group (CG, N=105): Mean Age=67.8±14.2y; Gender: Males=55, Females=50. |
Outcomes: Chronic Disease Self-efficacy Scale (CDSES); Participation Strategies Self-efficacy Scale (PS-SES); Community Participation Indicators (CPI); Reintegration to Normal Living (RNL); Activity Card Sort (ACS); WHO Quality of Life Scale (WHOQOL-BREF); Stroke Impact Scale (SIS).

2. EG had significantly improved PS-SES compared to CG post-intervention for the following domains: managing home (p=0.004), staying organized (p=0.023), managing community (0.000), managing work and productivity (0.043), and advocating for resources (0.002). No significant differences between groups for managing communication domain.

19.2 Family and Stroke

19.2.1 Effects of Caregiving on the Caregiver

<table>
<thead>
<tr>
<th>Author, Year Country</th>
<th>Study Summary</th>
<th>Study Summary</th>
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<tbody>
<tr>
<td>Brocklehurst et al. (1981) UK</td>
<td>Study of the effect of stroke on the chief carer in 97 stroke patients over a 4-year period.</td>
<td>The largest group of main carers was women. 25% of them were responsible for other people as well. Deterioration of chief carer’s health was common during the first year post-stroke and 14% of those in employment gave up their jobs. 27% of patients being cared for in the community were dependent on the carer.</td>
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<tr>
<td>Silliman et al. (1986) UK</td>
<td>101 patients &amp; 89 family caregivers were interviewed to determine health effects on the family caregiver; whether or not caregivers actually providing home care experience different effects than caregivers whose family members live in a nursing home; and factors associated with any observed deleterious effects of care-giving.</td>
<td>Patient functional status was associated with a decrease in social activity and emotional health for the caregiver. No differences were found between actual caregivers and those caregivers whose family members were in institutions.</td>
</tr>
<tr>
<td>Schulz et al. (1988) USA</td>
<td>The prevalence of depression in caregivers were studied.</td>
<td>Prevalence of depressive symptoms was 2.5 to 3.5 times higher in stroke caregivers than that of general population. Levels of optimism significantly declined over time. Caregiver depression and perceived burden were associated with patient’s stroke severity. Caregivers of good health, older and of higher income were least depressed.</td>
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<tr>
<td>Tompkins et al. (1988) USA</td>
<td>162 stroke patient/primary support person pairs were recruited. Subjective health, socio-support network functions, psychological well-being &amp; level of optimism were assessed.</td>
<td>Caregivers at risk for developing depression had higher initial depression scores, were less optimistic, were more likely to be married to the patient, named fewer social network members for the period preceding the stroke and their stroke partners were younger and more impaired in physical activities of daily living.</td>
</tr>
<tr>
<td>Draper et al. (1992) Australia</td>
<td>Cohort study of 99 co-resident caregivers of dementia and stroke patients.</td>
<td>Caregiver burden and psychological distress were assessed. 46% of caregivers had significant psychological morbidity which was associated with caregiver burden. There were no significant</td>
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<td>Study</td>
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<tr>
<td>Kotila et al. (1998) Finland</td>
<td>Incidence and severity of depression were compared at 3- and 12-months post-stroke in patients and their chief caregivers (spouses 63% and children 37%) in four districts: two with active discharge intervention programs and two without.</td>
<td>Fewer patients were depressed in districts with active programs than in districts with no program at 3 and 12 months; however at 3 months, this difference was not significant. By 12 months, there were significantly more depressed caregivers in no-program districts. Poor patient Rankin Scale scores and Scandinavian Stroke Scale scores were associated with depression in caregivers at 3-months.</td>
</tr>
<tr>
<td>Hop et al. (1998) Netherlands</td>
<td>51 partners of patients interviewed 4 months post SAH event. Data collected included patient function, quality of life, health-related quality of life and a rating of general wellbeing (both retrospective and current).</td>
<td>Quality of life was unaffected for partners of patients who were completely recovered in all domains except emotional. In partners of patients with Rankin scores from 1 – 5, reductions in quality of life occurred in emotional behaviour, social interaction, work and recreation and past-times. Wellbeing rated on the VAS was decreased in both patients and partners – partners of patients with the greatest functional limitations, reported an estimated 50% reduction in QOL.</td>
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<tr>
<td>Bugge et al. (1999) Scotland</td>
<td>110 patient/informal caregiver pairs were studied. Stroke patients who were alive at 1 month and agreed to participate were asked to nominate their principal informal caregiver that was defined as “the person who helps you the most but who is not paid to do so.” The pairs were then assessed on the Caregiver Strain Index and the SF-36 at 1, 3, and 6 months.</td>
<td>At 6 months, 37% of the caregivers experienced considerable strain. The amount of time spent by the caregiver helping the stroke patient, the amount of time spent with the patient, and the caregiver’s health were significantly associated with the level of strain experienced.</td>
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<tr>
<td>Blake &amp; Lincoln (2000) UK</td>
<td>222 carers of stroke patients were surveyed via mailed questionnaires to assess strain, stress, mood (patient and carer), HRQOL, extended activities of daily living, locus of control, affect, emotional control, life orientation and satisfaction with life. 37% of respondents demonstrated significant strain.</td>
<td>Significant associations were identified between high levels of strain and poor carer mood, poor perceived mood and low levels of EADL in the patient and increased levels of carer handicap (LHS score). Carers reporting strain demonstrated low self-esteem, decreased positive affectivity and increased negative affectivity. On logistic regression, carer mood, perceived patient EADLs and negative affectivity were significant, independent predictors of carer strain.</td>
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<tr>
<td>Teel et al. (2001) USA</td>
<td>83 primary caregivers of stroke patients were interviewed at 1, 3 and 6 months following the stroke event. Assessments included fatigue and energy level, spiritual perspective, recurrent sorrow, perceived stress, depression, caregiver reaction and number of hours of care required per day.</td>
<td>Caregivers reported fatigue, reduced vigour &amp; perceived health, recurrent sorrow, stress, difficulties with finances and availability of family support, and depressive symptoms at all evaluation periods. At 3 months, carer physical health was predicted by depressive symptoms, fatigue and recurrent sorrow. Mental health was predicted by vigour &amp; perceived stress. At 6 months, physical health was predicted by depressive symptomatology and scheduling difficulties, whereas mental health was predicted by perceived stress. At both time periods, carer health (physical &amp; mental) were associated with relationship differences in burden or psychological distress between stroke and dementia. Behaviour and mood disturbances in patients were significant contributors to caregiver burden and psychological morbidity.</td>
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<td>Study</td>
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<td>Thommessen et al. (2002) Norway</td>
<td>Throng patient/spouse carer couples, 92 mild dementia patient/spouse carer couples and 58 Parkinson patient/spouse carer couples were interviewed. Assessment included Relative Stress Scale, MMSE, ADL measures (specific to patient group) to assess independence and the Montgomery Asberg Depression Rating Scale.</td>
<td>Stress associated with caregiving did not vary between groups. However, examination of individual items revealed that worry about accidents happening to the loved one was greatest among carers of stroke patients. Patient characteristics that predicted the psychosocial burden on spouses were cognitive function, ADL function, and gender.</td>
</tr>
<tr>
<td>Wyller et al. (2003) Norway</td>
<td>Interviews 54 patients 1 year after stroke and their closest relatives were compared to a reference population (n=419 elderly people drawn by random from census files) to identify variables related to the well being of the relatives.</td>
<td>Relatives rated their well being lower than the reference group rating. There was no association between relatives' well being and the motor, cognitive and personal- and instrumental activities of daily living characteristics of the patients.</td>
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<tr>
<td>Adams (2003) Australia</td>
<td>Interviewed 22 stroke survivor/informal carer dyads at discharge from hospital and at 1 month post discharge. Quality of life, social support, use of services and burden of care were assessed.</td>
<td>Caregivers reported no change in quality of life during the first month. The only noted declines occurred at the time of the second evaluation. Caregivers experienced the greatest change in social function. There were decreases noted in relationships, social companionship and daily emotional support.</td>
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<tr>
<td>Morimoto et al. (2003) Japan</td>
<td>Interviewed 100 family caregivers. Outcomes assessed included burden, health related quality of life (SF-12), functional status of the patient &amp; depression. The duration of caregiving, hours of caregiving per day and the availability of respite care was also noted.</td>
<td>Increased caregiver burden was significantly related to lower health-related quality of life. Lowest SF-12 scores were in the areas of general health, vitality and mental health. Depressive symptomatology was identified in 52% of caregivers. Caregiver burden was related to daily hours of care provides but not to patient functional status or to social support (presence of respite caregiver). There was no relationship identified between increased burden and physical function of caregiver or role-physical (SF-12). Caregiver age was more predictive of the physical functioning of the caregiver than burden.</td>
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<tr>
<td>White et al. (2003) Canada</td>
<td>97 stroke patient/caregiver dyads were interviewed an average of 7 months and 23 months post stroke. Functional status of the patient was noted (by proxy). Caregivers were assessed for physical symptoms, burden, health-related quality of life and a global rating of quality of life was elicited on a scale of 1 – 10. Mental health of caregivers was, on average, 10 points lower than for age-matched population (SF-36).</td>
<td>Women were more affected than men and while male scores tended to improve over time, female scores did not. Women reported increasing burden over time (men did not). Women were less likely to obtain information support and reported more stress relative to balancing demands. Increasing age and physical symptoms were associated with decreased physical component scores of the SF36. Older age, less burden and fewer physical symptoms were associated with increases in mental component score (SF36). No patient characteristics were associated with caregiver HRQOL. Initially QOL was associated with patient’s functional status, caregiver age, vitality and both physical and mental aspects of health-related quality of life. At 12 months, the patient’s functional status was no longer associated with QOL, but the presence of aphasia was.</td>
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<td>Study</td>
<td>Country</td>
<td>Sample Description</td>
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<tr>
<td>Wyll et al. (2003)</td>
<td>Norway</td>
<td>54 stroke patient/family caregiver dyads were assessed one year post stroke for well being, caregiver strain, functional status (patient), social activity, motor function (patient), and cognitive/neurological impairments (patient). A reference group was drawn from census data.</td>
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<tr>
<td>Blake et al. (2003)</td>
<td>UK</td>
<td>116 caregivers (co-resident spouses) of stroke patients completed assessments at 3 and 6 months after the stroke event. The accuracy of the predictive model of carer strain developed by Blake &amp; Lincoln (2000) was evaluated. Assessments included the Caregiver Strain Index (at 3 and 6 months), the GHQ-12 (at 3 months), the EADL (at 3 months – perceived patient functional ability), and the Positive and Negative Affectivity Schedule (at 3 months).</td>
</tr>
<tr>
<td>Grant et al. (2004)</td>
<td>USA</td>
<td>74 caregivers were interviewed 1 – 2 days prior to the discharge of their family member admitted for stroke. Participants were evaluated for social problem-solving skills, health status, satisfaction with health care, social support, caregiver preparedness, caregiving burden and depression. The functional status of the stroke survivor was also assessed (FIM).</td>
</tr>
<tr>
<td>Forsberg-Warleby et al. (2004)</td>
<td>Sweden</td>
<td>67 spouses of stroke survivors were assessed using the Life Satisfaction Checklist 10 days, 4 months and 1 year following the stroke event. Stroke patients were assessed for neurological and emotional impairments as well as for functional independence.</td>
</tr>
<tr>
<td>Grant et al. (2004)</td>
<td>USA</td>
<td>Data was collected from 52 caregiver/patient dyads 1-2 days prior to discharge from rehabilitation and then at 5, 9 and 12 weeks following discharge.</td>
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<td>Study</td>
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<td>Sample Description</td>
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<tr>
<td>Sit et al. (2004)</td>
<td>China</td>
<td>102 family caregivers of stroke survivors were interviewed (re: demographics, stroke survivor's health &amp; functional status, social support and general health) 12 weeks following discharge of the survivor from rehabilitation.</td>
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<tr>
<td>Clark et al. (2004)</td>
<td>USA</td>
<td>132 family caregivers of stroke survivors at 6 rehabilitation centers in the USA were assessed using the SF-36, the 12-item General Family Functioning Scale and the Family Caregiver Conflict Scale.</td>
</tr>
<tr>
<td>Smith et al. (2004)</td>
<td>UK</td>
<td>90 patients and informal carers were visited at home one year post stroke. Carer stress and coping (via general health, anxiety depression and perceived stress) were examined.</td>
</tr>
<tr>
<td>Van Exel et al. (2005)</td>
<td>Netherlands</td>
<td>145 patients and informal caregivers were interviewed 6 months after the stroke event to assess objective/subjective burden and HRQOL.</td>
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<td>Study</td>
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<td>Methodology</td>
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<tr>
<td>McCullagh et al. (2005)</td>
<td>UK</td>
<td>Caregiver burden, HRQOL, functional ability and depression/anxiety were assessed in 232 stroke patients and caregivers enrolled in a study of caregiver training conducted by Kalra et al. (2004).</td>
</tr>
<tr>
<td>Berg et al. (2005)</td>
<td>Finland</td>
<td>Depression and caregiver exhaustion were assessed in 98 caregivers/patient dyads during the acute phase, at 6 and 18 months post stroke.</td>
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<tr>
<td>Tooth et al. (2005)</td>
<td>Australia</td>
<td>Stroke patients and carers were interviewed 6 months (n=71) and 12 months (n=57) months following discharge from rehabilitation. Carer assessments included caregiver burden, amount of time spent in providing care and health status. Patient function and health status were also assessed.</td>
</tr>
<tr>
<td>Larson et al. (2005)</td>
<td>Sweden</td>
<td>100 spouses of stroke patients were assessed while on a stroke unit, and at 6 QOL was lowest at baseline and increased gradually over the next year. Ratings at 12 months did not reach</td>
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</table>
months and 12 months for QOL, well-being, life situation, sense of coherence, social interaction, psychological health and health status.

the same level as retrospective ratings of QOL prior to the stroke event. Life situation was a significant predictor of QOL at all assessment points. Other significant factors included general well-being (baseline & 6 months), carer illness (baseline) and economic situation (12 months). Poor life situation may be interpreted as equivalent to high levels of burden.

<p>| Singh &amp; Cameron (2005) Canada | 48 carers of stroke patients (64.6% spouses, 75% women) were assessed for caregiver characteristics, burden, self-efficacy, support, impact, mastery and well-being. The average duration of caregiving was 83.5 weeks (±164 weeks); however, the majority of carers had been in this role for less than 1 year. Mastery was reported to moderate the association between lifestyle impact and emotional well-being and also between caregiver satisfaction and well-being. (Mastery describes perceived control over one’s life and well-being). In addition, support was found to moderate the relationship between behaviour and bother (i.e. support received by the carer could affect the amount that the patient’s behaviour was perceived as bothersome). Bother, in turn, was found to be the best predictor of emotional well-being. |
| Jonsson et al. (2005) Sweden | 304 stroke patients and 234 informal carers completed assessments of HRQOL, 4 &amp; 16 months following stroke. Social participation and depression were also assessed as were patient physical and cognitive status. There were no significant decreases in HRQOL (SF-36) between the first &amp; second assessments. At 16 months, caregivers had significantly higher scores in 6 of 8 domains (all but bodily pain and mental health). Scores in physical and emotional domains, general health and bodily pain were associated with increasing age. Social and mental domains, and bodily pain, were influenced by patient functional status. Social function and vitality were negatively influenced by increasing patient age. |
| Bakas et al. (2006) USA | 159 family caregivers completed questionnaire assessments of caregiver related outcomes at 1 and 4 months post stroke. Female caregivers had more difficulty with tasks (p&lt;0.01), more depressive symptoms (p&lt;0.001) and more negative stroke-related outcomes (decreased social functioning, subjective well-being and physical health, (p&lt;0.01)) than male caregivers. More severe communication problems were related to increased task difficulty (p&lt;0.001), caregiver depression (p&lt;0.05) and negative stroke-related outcomes (p&lt;0.01). While tasks were perceived as more difficult among carers of patients with aphasia (p&lt;0.05), for all carers tasks were less difficult at 4 months than at 1 month. In addition to female carers, carers of survivors with more self-care deficits were more likely to experience depression (p&lt;0.05) as well as other negative caregiver outcomes (p&lt;0.05). |
| Grant et al. (2006) USA | 52 family caregivers of individuals with stroke were assessed at 1-2 days prior to discharge from inpatient rehabilitation and then again at 5, 9 and 13 weeks post-discharge. Assessments included interpersonal support evaluation, social Negative orientation to problem-solving and lower levels of social support were significantly associated with increased depression (p&lt;0.001 for both) and reduced sense of well-being (p&lt;0.001 &amp; p=0.014, respectively). Lower levels of social support were also significantly associated with lower levels of general |</p>
<table>
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<tr>
<th>Study</th>
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<tr>
<td>Cameron et al. (2006)</td>
<td>Canada</td>
<td>94 informal caregivers</td>
<td>Brain Impairment Behavior Inventory – revised (behavioural and psychological symptoms), Caregiver Assistance Scale (amount of assistance provided by the carer), Caregiver Impact Scale (lifestyle interference), CES-D (depression)</td>
<td>Pearlin’s 7-item measure of mastery. 44.7% of caregivers were at risk for clinical depression. More depressive symptoms were associated with female gender, more lifestyle interference, lower levels of mastery (sense of control), provision of less care, presence of more behavioural and psychological symptoms related to memory and comprehension in the individual with stroke.</td>
</tr>
<tr>
<td>White et al. (2006)</td>
<td>Canada</td>
<td>52 caregivers</td>
<td>Stroke Impact Scale, Brain Impairment Behaviour Scale, Caregiver Assistance Scale, SF-36 (caregiver HRQOL), Pearlin Mastery Scale, 4 questions from the Longitudinal Study of Three-Generation families (general closeness, communication, similarity of views about life and degree of getting along) and the Stroke Caregiver Quality of Life Measure.</td>
<td>Few caregivers accessed services to assist with care over time. Recovery of the stroke survivor did not change significantly over time. There was a significant decrease in behavioural disturbances over time and caregivers reported providing less assistance over time. HRQOL and QOL scores of the caregiver did not change significantly between the 2 interviews; however, comparison of the caregiver’s SF-36 scores with Canadian norms demonstrated that caregivers scored significantly lower on vitality, social function and mental health subscales at both assessment points. 33% of variation in caregiver health (Stroke Caregiver Quality of Life Measure) was explained by caregiver age, social participation of the stroke survivor and quality of relationship between the caregiver and the survivor. At the second interview, this model explained 29% of variance. Overall, caring for a survivor with behavioural changes had a negative impact on caregiver QOL, while social participation of the survivor had a positive impact.</td>
</tr>
<tr>
<td>Larson et al. (2008)</td>
<td>Sweden</td>
<td>80 female and 20 male spouses</td>
<td>QOL, patient’s level of self-care, well-being, life situation, health state, sense of coherence, perceived social support, and psychological health.</td>
<td>Female caregivers are more negatively affected by the caregiving role than male caregivers. Female spouses experienced significantly lower well-being (p=0.02) and energy (p=0.03) at baseline – though women had greater availability of emotional attachments/contacts than men (p=0.02). At 6 months, female spouses continued to have lower general well-being (p&lt;0.01), energy (p=0.04) and sense of coherence (p=0.02) than male spouses. In addition, women experienced greater negative well-being (p=0.04), emotional attachments (p&lt;0.01) and psychological distress (p=0.04). By 12 months, female spouses continued to have higher negative well-being (p=0.02) and emotional attachment (p=0.02).</td>
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<tr>
<td>Franzen-Dahlin et al. (2007)</td>
<td>Sweden</td>
<td>100 spouses</td>
<td>Quality of life, well-being, social situation/network, life situation, sense of coherence, physical function, health state of patient &amp; spouse and stroke knowledge.</td>
<td>32% of spouses were above the cut-off for depression at baseline, 26% at 6 months and 37% at 12 months. At baseline, predictors of psychological health were well-being, age and own health or illness. Less knowledge was associated with reduced psychological health. At six months, psychological health was positively predicted by well-being as were spouse’s need for assistance from GP &amp; district nurse and</td>
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<tr>
<td>Study</td>
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<td>Design</td>
<td>Participant details</td>
<td>Findings</td>
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<tr>
<td>Ski &amp; O’Connell (2007)</td>
<td>Australia</td>
<td>Survey &amp; Structured Interviews</td>
<td>13 stroke survivors &amp; their carers assessed at 3 weeks &amp; 3 months post discharge</td>
<td>Both stroke survivors and carers demonstrated QOL lower than population norms. QOL did not deteriorate over time. Although depression ratings exceeded population standards, this was not significant.</td>
</tr>
<tr>
<td>Rochette et al. (2007)</td>
<td>Canada</td>
<td>Interviews</td>
<td>54 spouses of individuals with first stroke were interviewed at 2 weeks following stroke and 6 months later</td>
<td>There were significant increases noted re: participation in nutrition (meal prep, food selection, etc) and responsibilities. The most notable changes in participation were reductions in personal relationships, employment and recreation from pre-stroke to 2 weeks post stroke and 6 months. These changes were associated with increased caregiver strain, but not with depression.</td>
</tr>
<tr>
<td>Visser-Meily et al. (2008)</td>
<td>Netherlands</td>
<td>Interviews</td>
<td>119 stroke patients and their carers interviewed at 1 year and 3 years post stroke</td>
<td>51% of carers reported strain, 46% were not satisfied with their lives and 51% experienced symptoms of depression at one year post stroke. With the exception of burden and depression, scores deteriorated between 1 and 3 years (life satisfaction, harmony in the relationship and social support). Reports of depression remained stable, while burden improved from 51% reporting substantial burden to 44%.</td>
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<tr>
<td>Parag et al. (2008)</td>
<td>New Zealand</td>
<td>Interviews</td>
<td>159 stroke patient/carer pairs were interviewed at 6 months post stroke</td>
<td>All SF36 domain scores of carers were significantly lower than age and sex-matched normative scores for New Zealand with the exception of physical functioning. In addition, most carers (72%) did not consider their health to be worse than prior to assuming the caregiving role. By 18 months, scores had improved, with the exception of general health. Scores on the Bakas Caregiving outcomes scale were stable over time.</td>
</tr>
<tr>
<td>Visser-Meily et al. (2009)</td>
<td>Netherlands</td>
<td>Interviews</td>
<td>Patients/spouses were interviewed conducted at admission to rehabilitation</td>
<td>Over time, caregiver strain decreased, but so did harmony in the relationship between spouses and social support. Depression scores improved between the first &amp; second and second &amp; third assessments, and then remained stable. Reduction in strain was associated with less passive coping and more avoidant coping and higher patient BI scores. Less depression was associated with less passive coping and more expression of emotion. Better relationships were associated with being male (spouse), having no young children, more active coping and more seeking of support. There were 6 significant predictors of better social support – female gender, active coping, more palliative coping, more support seeking, less expression of emotions and better communicative harmony.</td>
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</table>
**Simon et al. (2009)**
UK

105 carers of individuals with stroke were interviewed prior to discharge from hospital, at 6 weeks and 15 months post discharge. Assessments included measures of psychological health, physical health, and social well-being. Carer responses were compared to a control cohort of 50 matched non-carers assessed over the same time period.

Psychological distress was common and seemed to begin early. At first interviews, 37% of carers had significant distress vs. 16% of non-carers. Although psychological health declined between the first and second interviews, there was no further deterioration by 15 months. However, they did continue to have significantly poorer psychological health than non-carers (p=0.001). At 15 months, only 10% of individuals with significant psychological distress had received treatment. Availability of social support declined significantly over the 15-month period (p<0.001) as did quality of support (p<0.001). Although there was a trend toward deterioration in physical health over time, only one marker reached significance (number of health problems reported, p=0.049). The only significant predictor of self-rated health was carer’s morale; higher morale resulted in higher ratings of health.

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**Nir et al. (2009)**
Israel

140 informal caregivers were assessed within 2 weeks of stroke (during inpatient rehabilitation), and at 3 & 6 months post stroke. Assessments included perceived health, depression social support (sources of support and perceived support), caregiver burden and QOL.

Perceived health status improved over time (p<0.05), depression also improved by 3 months and remained stable at 6 months. Burden decreased at 3 and 6 months (p<0.01). Instrumental support decreased at 3 months (p<0.05) and support within the home decreased at both 3 & 6 months (p<0.05, p<0.01, respectively). Satisfaction with family relationships also decreased at 3 & 6 months. Levels of support correlated with satisfaction with relationships (p<0.01). QOL decreased at 3 months but increased by 6 (p<0.05). Decreases were correlated with levels of instrumental support and satisfaction with support.

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**Hayes et al. (2009)**
USA

275 individuals with stroke and their caregivers were surveyed using items from the National Alliance for Caregiving Survey, the CES-D and the Behavioural Risk Ractos Surveillance Survey.

Caregivers who reported a physical injury were more likely to report higher levels of burden, more hours of care per week, more depressive symptoms and fewer healthy days per month compared to carers reporting no injury. The most common type of injury reported was a back injury and 53% of injured carers stated that the injury interfered with their ability to provide care. Significant predictors of injury were caregiver burden (p=0.008) and depression (p=0.001).

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**Carod-Artal et al. (2009)**
Spain

In a cross-sectional study, 200 patient/carer dyads were assessed using the HADS, the Zarit caregiver burden interview (ZCBI) and EQSD. Additional patient assessments included the BI, the NIHSS, mRS and HADS.

22.6% and 12.1% of caregivers scored ≥11 points on the HADS-anxiety and HADS-depression scales respectively. Female carers scored significantly worse on the anxiety scale than male. Depression scores were significantly correlated with both caregiver burden and health-related quality of life. On multivariate regression analysis, patient disability, female sex and depression were significant predictors of caregiver burden, while caregiver education and burden were significant predictors of HRQOL. Patient cognitive impairment, caring for one’s spouse and caregiver depression were significant predictors of...
<table>
<thead>
<tr>
<th>Author et al. (Year)</th>
<th>Location</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
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</table>
| **Chen et al. (2010)**  
China | 123 stroke patient/carer dyads were assessed approximately 2 years following the stroke event (mean = 27.9, SD=5). Patient and carer assessments included HRQOL (SR36), the cumulative illness rating scale (comorbidities) and depression (GDS). Patient disability was assessed using the BI, MMSE and IADL. Caregiver level of support and recent life events were also assessed. | On multiple linear regression analysis, caregiver depression was predictive of both psychological & physical aspects of HRQOL. Caregiver depression was also predictive of the Mental Component Score of the patients’ SF-36. |
| **Cameron et al. (2011)**  
Canada | 399 stroke patient/carer dyads were assessed at 1, 3, 6, and 12 months post stroke. A subset of 80 dyads consented to additional follow-up at 18 and 24 months. Assessments included behavioural and psychological symptoms (apathy, depression, memory/comprehension and irritability assessed on the Brain Impairment Behavior Inventory), physical disability (SIS), cognitive impairment (SIS + MMSE), co-morbidity (Charlson Index), amount of care (Caregiver Assistance Scale), burden (Caregiving Impact Scale) and caregiving mastery (Pearlin’s 7-item mastery index). | Statistical modeling demonstrated that increased emotional distress is experienced by caregivers who provide care to stroke survivors who are depressed or cognitively impaired. In addition, more caregiver distress was associated with age (younger) and sex (female), poorer physical health, greater lifestyle interference due to the caregiving role, caring for one’s spouse and lower levels of mastery. Caregiver distress was not associated with severity of survivor disability, illness severity or the presence of co-morbid conditions. |
| **Baumann et al. (2011)**  
France | 215 individuals with stroke and their informal main caregivers participated in face-to-face interviews. In addition to sociodemographic information, responses to a study-specific list of “stroke-related repercussions” were collected. Information regarding domains of stroke-related impairments and functional status (Katz ADL) was also collected. | Functional dependence and the presence of impairments in more than 2 domains was associated with social repercussions such as loss of friends, inability to resume social life, bothering friends as well as feelings of abandonment (dependence) & isolation (dependence). In male carers, presence of impairment in 2 or more domains was also associated with feelings of injustice. |
| **Adriaansen et al. (2011)**  
Netherlands | 180 spouses of individuals with stroke were assessed at the time of patient discharge from stroke rehabilitation (T1), at one year (T2) and 3 years (T3) post stroke for social support (Social Support List – everyday social support, support in problem situations and esteem support), life satisfaction (Life Satisfaction Questionnaire) and caregiver strain (Caregiver Strain Index). | Perceived social support declined significantly over time. At time one and 2, life satisfaction was significantly and positively correlated with all forms of social support assessed. At 3 years post-stroke, only “support in problem situations” (instrumental, informative and emotional support in times of trouble) was significantly associated with life satisfaction. At all time points, there was a significant negative correlation identified between caregiver strain and life satisfaction; however, strain was not significantly correlated with social support. No interaction between strain and social support was identified. Social support was important for life satisfaction regardless of level of strain experienced. |
| **Achten et al. (2012)**  
Netherlands | Individuals with stroke and their spouses (n=78 couples) were assessed 3 years following a stroke event to explore the association between the life satisfaction of the individual with stroke and that of her/his | Based on the Life Satisfaction Questionnaire, most patients (92%) expressed satisfaction with their relationship with their partner (vs. only 64% of carers). Most spouses (85%) were satisfied with their “ability in self-care”. Neither group was satisfied with their sex |
spouse. Assessments included the Life Satisfaction Questionnaire, the MMSE (patient only), Token Test (short version, patient only), Utrecht Communication Observation (short version, patient only), Barthel Index (patient only), the Frenchay Activities Index (patient only) and the Caregiver Reaction Assessment (carer only).

Factors significantly associated with major caregiver stress were long caregiving hours (avg. = 8.4 hrs/day), anxiety, disturbed night sleep, financial stress, younger age (<45 years) and familial relationship (daughter-in-law). In addition, patient factors such as sex (female), moderate to severe neurological deficit, poor functional recovery (BI <50 at day 28) and urinary incontinence were associated with increased caregiver stress.

Kruithof et al., (2012) Netherlands

121 patients and their spouses were recruited in an inpatient rehabilitation centre after stroke. Assessments occurred at recruitment and 3 years after stroke. Objective burden (number of new caregiving tasks) was assessed using the 16-item Care Task List, the Caregiver Reaction Assessment (CRA) was used to assess burden (by combining the four negative subscales) and self-esteem (positive subscale), and life satisfaction was assessed using the Life Satisfaction Questionnaire (LiSat-9).

Level of caregiver burden and life satisfaction was associated with patient cognitive and physical functioning as well as caregiver health and objective burden (P<0.01). Life satisfaction was also associated with the caregivers level of education (rho=-0.22, P<0.05). Multivariate regression analysis found spousal age, education level, health, objective and subjective burden, and self-esteem as significant predictors of caregiver life satisfaction (P<0.05). Patient level of cognitive and physical functioning and spousal age were not significant predictors of spousal life satisfaction. Spousal age and parental status were not significant in the bivariate analysis. There was an interaction effect between the positive experiences of caregiving (caregivers self-esteem) and level of burden. At a higher level of burden, caregivers had a higher level of life satisfaction if their self-esteem was higher (interaction term β=0.17, p=0.06).

Jaracz et al., (2012) Poland

150 patients and their caregivers were recruited from hospital after stroke. Assessments occurred at recruitment and at 6 months after discharge. The Caregiver Burden Scale (CB Scale) was used to assess caregiver burden, the Hospital Anxiety and Depression Scale (HADS) was used to assess anxiety and depression, the Sense of Coherence Questionnaire (SOC-29) to assess sense of coherence, and the Berlin Social Support Scale (BSSS) to assess social support. Path analysis was used to assess the patient and caregiver factors that were predictive of caregiver emotional state and caregiver burden, and to determine if sense of coherence acts as a mediator between

Caregiver age, level of social support, presence of caregiver illnesses and patient functional status were included in the final model, either directly or indirectly (mediated by sense of coherence) associated with caregiver emotional state and caregiver burden. The model explained 62% of the variance for caregiver burden and 52% of the variance for caregiver emotional state.
Peyrovi et al. (2012) Iran

60 caregivers who had been providing care to stroke survivors for at least 1 month were included in the study. Assessment took place as soon as possible following recruitment. The Bakas Caregiving Outcomes Scale (BCOS) was used to assess life changes in response to caregiving. Depression was assessed using the Center for Epidemiologic Studies Depression (CES-D) scale. The relationship between patient and caregiver characteristics and caregiver outcomes was assessed using linear regression models.

The correlation between caregiver life changes (measured with the BCOS) and caregiver depression (CES-D) was significant (p<0.001). Patient’s level of functional disability was the only significant independent predictor of caregiver life changes and caregiver depression (P<0.001), with 60% and 54% of variance explained by each model respectively. Patient and caregiver age and gender, and duration of caregiving were not significant predictors of caregiver outcomes.

Sreedharan et al. (2013) India

150 individuals recovering from stroke and their caregivers were recruited from an outpatient clinic. Employment status, social functioning and caregiver burden were assessed. Patients were between 3 months and 2 years since stroke.

There were no significant changes in the percentage of caregivers employed before vs. after stroke (34.7% before, 33.3% after). A decline in social functioning for caregivers was significantly correlated with an increase in the number of visits to a religious institution (P=0.023 – HADS anxiety score >11). It was also found that carers of patients with aphasia or experiencing seizures were more likely to have depression (P=0.026; P=0.033 respectively).

Godwin et al. (2013a) USA

30 patients and their caregivers who were enrolled in the CARes intervention study (a support program for patients recovering from stroke and their caregiver) were included. Assessments occurred at a time point greater than 2 years after stroke. Health related quality of life was measured using the Short Form Health Survey (SF-36), the Stroke Impact Scale was used to measure patient quality of life, the Geriatric Depression Scale (GDS) was used to measure depression, the mutuality scale of the Family Caregiving Inventory was used to measure mutuality, and the Zarit Burden Interview was used to measure caregiver burden.

Over time, there were no significant differences in caregiver burden or mutuality (p=0.056). Conversely, caregivers experienced a decrease in depression from baseline at all time points (p=0.015). Older age and number of illnesses were associated with statistically significantly lower SF-36 physical domain subscore (F=7.30, p=0.004), while higher levels of depression was associated with statistically significantly lower SF-36 mental domain subscore (F=10.97, p=0.003).

Denno et al. (2013) USA

153 of respondents to the U.S. National Health and Wellness survey were identified as providing care to a stroke survivor with spasticity and met inclusion criteria. The Oberst Caregiving Burden Scale (OCBS) was used to measure objective burden based on caregiving tasks. The Bakas Caregiving Outcomes Scale (BCOS) was used to measure life changes in response to caregiving. In addition to the use of the Patient Health Questionnaire-9 (PHQ-9) as a measure for assessing the presence of depressive symptoms, patients were asked to self-

A series of logistic regression analyses were conducted to assess the effect of caregiving on presence of anxiety or depression. Caregivers had a greater likelihood of having anxiety, depression, or a higher severity of depression, as the level of caregiving task difficulty increased (OR 2.57, 95% CI 1.57-4.21; OR 1.88, 95% CI 1.19-2.99; OR 2.48, 95% CI 1.72-3.56). Likewise, there was a greater likelihood of having anxiety, depression, or a higher severity of depression as caregivers experienced greater negative life changes as a result of caregiving (OR 2.43, 95% CI 1.47-4.16; OR 2.27, 95% CI 1.35-3.70; OR 4.55, 95% CI 2.94-7.14). The odds of experiencing a higher severity of...
report any history of diagnosis for anxiety or depression.

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<th>Study</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes</th>
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<tr>
<td>Chen &amp; Botticello (2013) USA</td>
<td>146 caregivers of spouses who had a stroke and 3,710 non-caregivers were identified from the Health and Retirement Study, a longitudinal study based in the United States, and included in this study. Assessments occurred in 2 year intervals, and data for this study was derived from the 1996 data, and included caregivers who had provided care to a spouse experiencing a stroke between 1992 and 1996. Measures of cognitive functioning included: time orientation, working memory, semantic memory, learning, and episodic memory. Multivariate regression was used to assess the risk of experiencing cognitive deficits as a caregiver vs. non-caregiver.</td>
<td>The risk of episodic memory (delayed recall) was significantly greater for caregivers compared to non-caregivers (RR=0.91, 95% CI 0.84-0.98, p=0.018). The outcomes for all other cognitive domains did not differ significantly between caregivers and non-caregivers with adjustment for patient and caregiver characteristics.</td>
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<td>Clay et al. (2013) USA</td>
<td>Baseline data for 146 survivors of stroke and their caregivers from the CARES (Caring for Adults Recovering from the Effects of Stroke) study was used in this study. Multiple regression models were used to assess the impact of the availability of resources, number of impairments or stressors and the caregivers appraisal of these stressors on caregiver quality of life. The significance of each factors association with caregiver quality of life was determined by the change in R^2 after their addition to the model. Caregiver quality of life was measured using the SF-12 (Physical and Mental component).</td>
<td>The total number of stroke survivor problems (stressors), the caregivers appraisal of these stressors, and the amount of social support recieved were significantly associated with the caregivers quality of life (physical component) (p&lt;0.05, p&lt;0.05, p&lt;0.0001). The number of impairments (stressors) experienced by the stroke survivor was the only significant factor associated with the mental component of the caregivers’ quality of life.</td>
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<td>Grant et al. (2013) USA</td>
<td><strong>Population:</strong> Stroke Group (N=146): Mean Age= 74.7±7.8yr; Gender: Males=72, Females=74. Caregiver Group (N=146): Mean Age=63.7±13.4yr; Gender: Males=32, Females=114. <strong>Intervention:</strong> All data for the analyses of the relationship between caregiver/stroke participant dyads was drawn from the REasons for Geographic and Racial Differences in Stroke (REGARDS) study. Data from patients and caregivers recruited from 2005 to 2010 was used to assess whether caregiver well-being is a factor in stroke survivor depressive symptoms. Assessments within the study were conducted after a mean of 9mo post-stroke. <strong>Outcomes:</strong> Center for Epidemiologic Studies Depression Scale (CES-D); Caregivers’ report</td>
<td>1. A greater number of SSIs were associated with higher patient CES-D scores (p&lt;0.0001). 2. Caregiver CES-D accounted for 32.95% of the relationship between SSIs and patient CES-D scores. 3. Caregiver LSI-Z scores accounted for 29.29% of the relationship between SSIs and patient CES-D scores. 4. Caregiver LSI-Z and CES-D scores together account for 40.50% of the direct relationship between SSIs and patient CES-D scores, while this relationship remained significant (p&lt;0.05).</td>
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of the occurrence of stroke survivor impairments and problems (SSIs); Life Satisfaction Index (LSI-Z).

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<th>Study</th>
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<th>Study Design</th>
<th>Score</th>
<th>TPS Mean</th>
<th>Start</th>
<th>End</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Impact of the Stroke</th>
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<tbody>
<tr>
<td>Cecil et al. (2013)</td>
<td>UK</td>
<td>Qualitative Descriptive</td>
<td>No Score</td>
<td>Mean=NA</td>
<td>30</td>
<td>30</td>
<td>Age range=36-84yr; Gender: Males=7, Females=23.</td>
<td>Semi-structured interviews with primary carers were conducted approximately 6wk after stroke survivor (SS) discharge from hospital regarding carer coping and identification of factors impacting their lives.</td>
<td>Impact of stroke on the carers, extrinsic factors that support the caring scenario, intrinsic factors that help the carers cope.</td>
<td>1. Changes to lifestyle (Restrictions to life (eg., giving up work), loss of social life, carer taking on responsibilities of the stroke survivor (eg., finances) 2. Concerns and Worries (Health of the SS, well-being of others involved, own (Carer) health, financial worries, large number of appointments) 3. Mental health issues (carer’s major concern was emotional and mental health of the SS, own mental health) 4. Extrinsic factors that support the caring scenario (Health professionals, information and knowledge, family support) 5. Intrinsic factors that help the carers cope (own health and well-being, gratitude and faith, the dyadic relationship)</td>
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<tr>
<td>Vincent-Onabajo et al. (2013)</td>
<td>Nigeria</td>
<td>Observational</td>
<td>No Score</td>
<td>Mean=11.9±11.26mo</td>
<td>59</td>
<td>59</td>
<td>Mean age=29.24±9.68yr; Gender: Male=33, Female=26.</td>
<td>Caregivers assisting patients with stroke in the community completed a questionnaire examining quality of life. The assessment was conducted once only.</td>
<td>WHOQoLBREF scores for each of the four subscales were above average. WHOQoLBREF Physical (p&lt;0.00), Social Relationships (p=0.02), and Environment (p=0.01) subscores were significantly higher for caregivers aged 14-30yr compared to caregivers aged 31-55yr. WHOQoLBREF Environment subscores were significantly lower for caregivers of patients who were 1-2yr post stroke compared to &lt;1yr and &gt;2yr post stroke (p=0.05). WHOQoLBREF scores did not differ significantly based on relationship status between the caregiver and the patient with acquaintances of stroke survivors reporting higher mean scores on the Physical and Social Relationships subscales but family members reported higher means scores on the Psychological and Environment subscales. WHOQoLBREF scores were not significantly associated with gender.</td>
<td>1. WHOQoLBREF scores for each of the four subscales were above average. 2. WHOQoLBREF Physical (p&lt;0.00), Social Relationships (p=0.02), and Environment (p=0.01) subscores were significantly higher for caregivers aged 14-30yr compared to caregivers aged 31-55yr. 3. WHOQoLBREF Environment subscores were significantly lower for caregivers of patients who were 1-2yr post stroke compared to &lt;1yr and &gt;2yr post stroke (p=0.05). 4. WHOQoLBREF scores did not differ significantly based on relationship status between the caregiver and the patient with acquaintances of stroke survivors reporting higher mean scores on the Physical and Social Relationships subscales but family members reported higher means scores on the Psychological and Environment subscales. 5. WHOQoLBREF scores were not significantly associated with gender.</td>
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<tr>
<td>McLennon et al. (2014)</td>
<td>Population: Intervention Group (N=242): Mean age=54.2±12.1yr; Gender: Male=52, Female=190.</td>
<td>1. PHQ-9 scores for depression were significantly higher for female caregivers (p&lt;0.001) and caregivers of patients with lower SSSQL Mobility and Thinking scores (both p&lt;0.001).</td>
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<td>Intervention: Caregivers completed a set of questionnaires via telephone interview examining depressive symptoms, task difficulty, life changes, and patients’ quality of life and impairment. Assessments were conducted once only.</td>
<td>2. OCBS total scores were significantly higher for caregivers who reported depressive symptoms according to PHQ-9 (p&lt;0.001).</td>
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<td>Outcomes: Patient Health Questionnaire (PHQ-9); Oberst Caregiving Burden Scale (OCBS: Arranging care while away, Providing personal care, Giving emotional support, Watching and monitoring the patient); Bakas Caregiving Outcomes Scale (BCOS: Self-esteem, Ability to cope with stress, Physical health, Emotional well-being, Financial well-being, Level of energy).</td>
<td>3. Eight of 15 OCBS subscales among caregivers with depressive symptoms reported significantly greater difficulty compared to caregivers without depressive symptoms with the most significant being Arranging care while away (p&lt;0.001), Providing personal care (p=0.003), Giving emotional support (p=0.007), and Watching and monitoring the patient (p=0.009).</td>
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<td>4. BCOS total scores were significantly higher for caregivers who reported depressive symptoms according to PHQ-9 (p&lt;0.001).</td>
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<td>5. 14 of 15 BCOS subscales were significantly lower among caregivers with depressive symptoms compared to caregivers without depressive symptoms with the most significant being Self-esteem, Ability to cope with stress, Physical health, Emotional well-being, Financial well-being, and Level of energy (all p&lt;0.001).</td>
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</table>

| Chow et al. (2014) | Population: Age range=42-87yr; Gender: Males=8, Females=21. | 1. Factors contributing to carer stress: |
| | Intervention: 6 focus groups using a semi-structured interview, consisting of 3 to 6 carers of stroke survivors (SSs), and lasting 60-90 min was conducted based on the experiences of family carers, services that do or do not help the carers manage their role, and the review of the literature on caregiver stress and elder abuse. | • Adverse impact on physical health (demands due to strenuous physical work, common chronic pain, pains/aches or injuries were common, many carers were consistently tired/exhausted) |
| | Outcomes: Factors contributing to carer stress, factors that have a buffering effect on carer stress, identification of unmet needs. | • Adverse impact on psychological health (feelings of anxiety, loneliness, depression, social isolation, helplessness, fatigue and burnout, (many carers dealt with psychological stress when dealing with SS’s suicidal thoughts or verbal aggression) |
| | | • Financial hardship (due to increases in expenditure and loss of income) |
| | | • Pressure created by cultural expectation (female carers were expected to focus on their role as a caregiver, and had to worry about criticism for not performing this role well, male carers were expected to act strong) |
| | | • Environment not friendly to the disabled (many barriers in transporting the disabled) |
| | | 2. Factors that have a buffering effect on carer stress: |
| | | • Tailor-made programmes (tailor-made rehabilitation exercises contributed to the improvement and maintenance of SS’s... |
health, visiting therapists/staff gave carers a much needed break and their presence produced better compliance of the SSS to their rehabilitation exercises, meal service, special outings, day-care respite service, and installation of home transportation equipment were all identified as important tailor-made support programs to carers.

- Peer support (support from peers (family/friends) was considered the most effective solution to loneliness/social isolation)
- Resilience (carers with a positive mindset were better equipped to deal with problems effectively in stressful situations)
- Identification of unmet needs (need of improvement of existing services, need of provision of education and training on how to care for SSS, need of a friendly environment towards SSS, need of an improvement in the general public’s attitudes toward the disabled

| Zawadzka & Domanska (2014) | Population: Experimental Group 1 (EG1, N=36): Mean Age=65.2±7.5yr; Gender: Unspecified. Experimental Group 2 (EG2, N=29): Mean Age=66.2±10.0yr; Gender: Unspecified. Control Group (CG, N=35): Mean Age=70.7±5.4yr; Gender: Unspecified. | 1. NBAP Indifference, Depression and Inappropriateness (all p<0.000) and Mania (p=0.003) differed significantly between all three groups, with EG1 scoring higher than EG2 and the CG. |
| Poland Prospective Observational No Score TPSExp1=6.1wk TPSExp2=38mo TPSCon=NA NStart=100 NEnd=100 | Intervention: EG1 (short-term stroke), EG2 (long-term stroke) and the CG (spinal cord injury patients) all completed self-reports of depression, as did relatives of patients in all three groups. Assessments were conducted once only. | 2. Relatives scores for NBAP Indifference, Depression and Inappropriateness (all p<0.000) and Mania (p=0.002) differed significantly between all three groups, with EG1 scoring higher than EG2 and the CG. |
| | Outcomes: Neuropsychology Behavior and Affect Profile (NBAP: Mania, Indifference, Depression, Inappropriateness); State and Trait Anxiety Inventory (STAI: State, Trait). | 3. NBAP Mania and Inappropriateness were significantly higher among patient ratings compared to relatives ratings in EG1 (p=0.001 and p=0.007 respectively). |
| Oosterveer et al. (2014) | Population: Intervention Group (N=179): Mean age=Unspecified; Gender: Unspecified. | 4. NBAP ratings for EG2 and the CG did not differ significantly between patients and relatives for any subscales. |
| The Netherlands Observational No Score TPSmean=NA NStart=284 NEnd=179 | Intervention: Caregivers completed a questionnaire that examined burden, and patients completed a set of questionnaires at home that examined anxiety, depression, | 5. STAI Trait scores were positively correlated with NBAP Depression patient scores for EG1 (p<0.000). |
| | 1. High CSI scores were significantly associated with high HADS Anxiety and low LiSat-9 scores (p=0.023 and p=0.0012 respectively) according to the model. | 6. STAI State and Trait scores were positively correlated with NBAP Depression patient scores for EG2 (both p<0.000). |
| | 2. Presence of stairs in the patient’s house (p=0.16), HADS Depression (p=0.89), FSS (p=0.49) and FAI (0.34) scores were not associated with higher CSI | |
fatigue, life satisfaction, and type of home. The assessments were conducted 6wks after the patient’s discharge from hospital or rehabilitation. 

**Outcomes:** Caregiver Strain Index (CSI); Hospital Anxiety and Depression Scale (HADS: Anxiety, Depression); Life Satisfaction Questionnaire (LiSat-9); Fatigue Severity Scale (FSS); Frenchay Activities Index (FAI); Presence of stairs in patient’s home.

3. High CSI scores were significantly and independently associated with high HADS Anxiety and low LiSat-9 scores (p=0.0031 and p=0.000007 respectively) after stepwise backward regression.

4. High CSI scores were independently associated with the presence of stairs in the patient’s home, but this did not reach statistical significance (p=0.059) after stepwise backward regression.

**Jessup et al. (2015)**
USA Observational No Score
TPSmean=NA
NStart=243
NEnd=243

**Population:** Intervention Group (N=243): Mean age=54.8±12.1yr; Gender: Male=52, Female=191.

**Intervention:** Caregivers completed a set of questionnaires via telephone examining depressive symptoms, task difficulty, life changes, and patients’ quality of life and impairment. Assessments were conducted once only.

**Outcomes:** Oberst Caregiving Burden Scale (OCBS); Patient Health Questionnaire (PHQ-9); Bakas Caregiving Outcomes Scale (BCOS); Stroke Specific Quality-of-Life Scale (SSQoL Proxy: Mobility, Self-care, Language, Thinking, Personality).

1. OCBS scores were significantly higher among female caregivers (p<0.001) and African-American spouses (p=0.048).

2. PHQ-9 scores were significantly higher among female caregivers (p<0.001), Spouses (p=0.003), Non-African-Americans (p=0.047), and African-American spouses (p=0.010).

3. BCOS scores were significantly higher among female caregivers (p=0.008) and African-Americans (p=0.033).

4. SSQoL Proxy scores on average were rated as moderate on all five subscales; Mobility, Self-care, Language, Thinking, and Personality.

**Guo & Liu (2015)**
China Observational No Score
TPSmean=NA
NStart=196
NEnd=180

**Population:** Caregivers (N=180); Age=57.60±14.4yr; Gender: Males=42, Females=138.

**Intervention:** Caregivers answered questionnaires to assess family functioning and depression in caregivers of stroke patients.

**Outcomes:** Family Assessment Device (FAD); Center for Epidemiologic Studies Depression Scale (CES-D); Barthel Index (BI).

1. Following a stroke of a family member 71% of caregivers had depressive symptoms.

2. Higher depression severity in caregivers was linked to caregiver education, stroke survivor ADLs and family functioning.

**Jeong et al. (2015)**
Korea Observational No Score
TPSmean=NA
NStart=280
NEnd=238

**Population:** Caregivers (N=238); Age=52.41±11.63yr; Gender: Males=73, Females=165; Stroke Survivors (N=238); Age=55.09±15.11; Gender: Males=148, Females=90.

**Intervention:** Caregivers were interviewed using questionnaires to investigate the effect of caregiver burden.

**Outcomes:** Zarit Burden Interview (ZBI); World Health Organization Quality of Life-BREF (WHOQoLBREF).

1. The negative predictors of QoL in caregivers with high caregiver burden were the patient characteristics of being unemployed and the caregiver characteristics of poor health status, lower income, and being a spouse.

2. The negative predictors of QoL in caregivers with low caregiver burden were poor health status and the patient characteristics of being hospitalized for a long duration of time.

**Jaracz et al. (2015)**
Poland Observational No Score

**Population:** Caregivers (N=88); Age=53.6±12.1yr; Gender: Males=15, Females=73. Stroke Survivors (N=88); Age=61.1±12.2; Gender: Males=50.

1. At 6 mo, caregiver burden was reported by 44% of caregivers and 30% after 5 yr.

2. Caregiver burden was associated with caregivers’ sense of coherence and amount of caregiving at 6 mo.

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19. Community Reintegration

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<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Study Design</th>
<th>No Score</th>
<th>TPS Mean</th>
<th>N Start</th>
<th>N End</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haley et al. (2015)</td>
<td>United States</td>
<td>Cohort</td>
<td>235</td>
<td>NA</td>
<td>150</td>
<td>88</td>
<td>Caregivers (N=235); Age=61.81±13.55yr; Gender: Males=50, Females=185; Non-caregiving Control (N=235) Age=59.98±13.35yr; Gender: Males=50, Females=185</td>
<td>Family caregivers of REGARDS participants who experienced a stroke event and non-caregivers completed telephone interviews assessing depressive symptoms, mental and physical health quality of life(QOL), life satisfaction, and leisure satisfaction at approximately 9, 18, 27, and 36 months.</td>
<td>Caregiver Burden Scale (CBS); Hospital Anxiety and Depression Scale (HADS); Berlin Perceived Social Support Scale (PSS); Sense of Coherence Scale (SOC); World Health Organization Quality of Life-BREF (WHOQoLBREF) Scandinavian Stroke Scale (SSS); Barthel Index (BI).</td>
</tr>
<tr>
<td>Akyuz et al. (2015)</td>
<td>Turkey</td>
<td>Observational</td>
<td>51</td>
<td>42.61±14.76yr</td>
<td>51</td>
<td>51</td>
<td>Patients: Mean Age=57.35±12.71yr; Gender: Males=34, Females=17; Caregivers: Mean=48.24±14.76yr</td>
<td>Community-dwelling patients and their caregivers were surveyed to investigate the correlation between function of the upper extremity and the quality of life of their primary caregiver.</td>
<td>Brunnstrom grade for upper extremity/hand; Short Form-36 (SF-36).</td>
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<tr>
<td>Bergstrom et al. (2015)</td>
<td>Sweden</td>
<td>Observational</td>
<td>105</td>
<td>3-6mo</td>
<td>105</td>
<td>105</td>
<td>Survivors (N=105): Median Age=70(range=46-90)yr; Gender: Males=77, Females=28; Caregivers (N=105): Median Age=68(range=18-88)yr; Gender: Males=25, Females=80</td>
<td>Stroke survivors and their live-in caregivers from multiple centres were surveyed to explore the relationship between participation restrictions and global</td>
<td>Survivor OGQ was significantly associated with survivor LiSat-11 (OR=1.1, p=0.03); caregiver OGQ was not significantly associated with survivor LiSat-11.</td>
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</table>

In Haley et al. (2015) study, caregivers showed poorer well-being at 9 mo post-stroke than controls on all measures except physical health QOL. Significant differences were sustained for 22 mo after the stroke event for depressive symptoms, 31 mo for mental health QOL, and 15 mo for life satisfaction. For leisure satisfaction, differences were still significant at 36 mo post-stroke.

In Akyuz et al. (2015) study, high Brunnstrom grade was significantly associated with higher vitality (p<0.005), mental health (p<0.005), social functioning (p<.05), and role emotional (p<0.05) domains of SF-36. There were no significant associations in terms of general health, role physical, bodily pain, and physical functioning.

In Bergstrom et al. (2015) study, survivor OGQ was significantly associated with survivor LiSat-11 (OR=1.1, p=0.03); caregiver OGQ was not significantly associated with survivor LiSat-11. Caregiver OGQ was significantly associated with caregiver LiSat-11 (OR=1.2, p=0.04); survivor OGQ was not significantly associated with caregiver LiSat-11. Survivor OGQ was significantly correlated.
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Design</th>
<th>TPS Score</th>
<th>Sample Size</th>
<th>Sample Characteristics</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| Gbiri et al. (2015)          | Nigeria     | Observational  | No Score  | N=157        | Age=39.2±12.8yr; Gender: Males=81, Females=76. Stroke Survivors: 59.6±14.6. | Caregivers answered were given a questionnaire as they arrived at the stroke clinic and completed before leaving the clinic.          | 1. The closer intimacy with the stroke survivors, the fewer number of caregivers for the stroke patient, the longer duration since the onset of stroke and more hours of caregiving per day affected the level of burden experienced by the caregiver (p<0.05).  
2. Caregiving had a negative significant influence (p<0.05) on the social, emotional, health and financial well-beings of the caregivers. |
| Ganapathy et al. (2015)      | USA         | Observational  | No Score  | N=153        | Age=51.6±12.6yr; Gender: Males=45, Females=108. | Caregivers participated in an Internet survey which measured caregiving time and difficulty, work productivity and activity impairment. | 1. Employed caregivers (n=71) had overall work restriction (32%), absenteeism (9%), and presenteeism (27%).  
2. Caregiver characteristics, lack of nursing home coverage, and stroke survivors’ disability predicted all work restriction outcomes.  
3. The mean total lost-productivity cost per employed caregiver was $835 per month (> $10,000 per year). |
| Limpawattana et al. (2015)   | Thailand    | Observational  | No Score  | N=101        | Mean age=49.7±11.8yr; Gender: Males=18, Females=83. | Caregivers of stroke patients were interviewed to determine the burdens of caring for stroke patients. | 1. There were no significant differences between males and females on the ZBI.  
2. 54.4% of caregivers reported no caregiver burden, 34.7% reported mild burden, 8.9% reported moderate burden, and 1.9% reported severe burden.  
3. Self-reported income was associated with caregiver burden based on the ZBI scores, suggesting lower income correlated with lower ZBI scores. Conversely, the numbers of basic ADL needing assistance by caregivers of patients with coexisting musculoskeletal conditions had a positive relation with ZBI scores.  
4. Factors such as caregiver age, gender, marital status, level of education, self-reported health status, types of illness, kinship, employment status, caregiver income, and duration of care did not influence caregiver burden. |
| Tsai et al. (2015)           | Taiwan      | Observational  | No Score  | Mean age=44.25±13.08yr; | 1. The greatest needs identified before transfer | | |
### Data Collection

**Gender:** Males=25, Females=35.

**Intervention:** This study aimed to explore the changing needs of family caregivers of stroke patients and factors related to the needs. Data were collected at four time points, which were before transferring out of the ICU, before discharge, 2 weeks post-hospitalization, and 3 months post-hospitalization.

**Outcome:** Needs of family caregivers and factors related to the needs.

1. From the ICU to the neurological unit (time 1) were for the following items: respect the patient when performing education, treatment or rehabilitation; providing information on disease progress; to have my question answered honestly; information on medication and treatment; information on the patient’s physical problems; and rehabilitation progress. All family caregivers had those needs in the health information domain.

2. The greatest needs before discharge (time 2) were for the following items: respect the patient when performing education, treatment or rehabilitation; information on medication and treatment; information on the patient’s physical problems in the health information domain; and being informed of how to handle the medical emergencies of the patients in the professional support domain. Most (98%) family caregivers had those needs.

3. At 2 weeks post-hospitalization (time 3), the greatest needs were for information on how to handle the medical emergencies and what to do when the patient became upset or acted strange in the professional support domain; information about physical problems and medication and treatment in the health information domain; and conveying advice with the help of professionals in the community networks domain. Around 88%–95% of family caregivers had those needs.

4. At 3 months post-hospitalization (time 4), the greatest needs were for information on how to handle the medical emergencies and what to do when the patient became upset or acted strange in the professional support domain; information about physical problems and medication and treatment in the health information domain; and conveying advice with the help of professionals and support from family and friends in the community networks domain. About 75%–93% of family caregivers had those needs.

5. The patient’s sex, religion, number of stroke episodes, number of diagnosed chronic diseases, and care needs of family caregivers in the four stages showed no significant correlations.

6. The NIHSS score at admission and length of stay had significant positive correlations with caregiver needs in the four stages.

7. Physical dependence (Barthel Index) had significant negative correlations with caregivers’ needs.

8. The caregiver’s sex, living status, occupation,
**Persson et al. (2015)**

Sweden
Cohort
No Score
TPS\textsubscript{mean}=NA
N\textsubscript{Start}=493 dyads
N\textsubscript{End}=493 dyads

**Population:** Stroke survivors (N=248): Mean age=64±11yr; Gender: Males=163, Females=85. Controls (N=245): Mean age=65±9yr; Gender: Males=161, Females=84. Spouses of stroke survivors (N=248): Mean age=63±11yr; Gender: Males=86, Females=162. Spouses of controls (N=245): Mean age=64±9yr; Gender: Males=84, Females=161.

**Intervention:** This is a 7yr follow-up of the Sahlgrenska Academy Study on Ischemic Stroke (SAHLSIS) whereby spouses of stroke survivors and spouses of controls were evaluated to explore the HRQoL of spouses of younger stroke survivors 7 years after stroke onset and to identify predictors of HRQoL of spouses based on demographic features and stroke-related variables.

**Outcomes:** Health-Related Quality of Life (HRQoL); Short Form-36 (SF-36).

1. The age of the spouses was correlated with their HRQoL, such that older spouses of stroke survivors scored significantly lower on all SF-36 domains than younger spouses of stroke survivors; however, older spouses of controls scored significantly lower on physical functioning (p<0.001) and general health (p=0.003) than younger spouses of controls.

2. The main predictors of the physical domain scores of the HRQoLs were the age of the spouses of stroke survivors and the global disability of the stroke survivors.

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**Dankner et al. (2016)**

Israel
Observational
No Score
TPS\textsubscript{mean}=NA
N\textsubscript{Start}=102
N\textsubscript{End}=102

**Population:** Caregivers (N=51); Age=65.6±8.3yr; Gender: Males=9, Females=42; Survivors (N=51): Median Age=68.1±6.7yr; Gender: Males=44, Females=7.

**Intervention:** Survivors and their caregivers were interviewed. The survivor’s disability level was assessed using scales and the caregiver’s burden was assessed using questionnaires.

**Outcomes:** Barthel Index (BI); Modified Rankin Scale (MRS); Short Form Survey (SF-36); Hospital Anxiety Depression Scale (HADS); Zarit Burden Interview (ZBI-12).

1. Caregiver’s anxiety level was higher than that of the survivors (7.7±5.1 vs. 5.8±4.5; p=0.02).

2. Anxiety was the only characteristic of caregivers that was associated with overall caregiver burden.

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**Byun et al. (2016)**

United States
Observational Longitudinal
No Score
TPS\textsubscript{mean}=NA
N\textsubscript{Start}=63
N\textsubscript{End}=40

**Population:** Stroke Survivors: Mean Age=75.60±7.80yr; Gender: Males=15, Females=25; Caregivers: Mean Age=57.70±14.22yr; Gender: Males=13, Females=27.

**Intervention:** Caregivers of stroke survivors were surveyed at baseline (within 2wk post-stroke) and 6wk post-stroke to explore caregiver uncertainty across the early weeks after a family member’s stroke.

**Outcomes:** Mishel Uncertainty in Illness Scale for Family Members (Uncertainty); Perceived Stress Scale (PSS); Patient Health Questionnaire (PHQ); Cumulative Illness Rating Scale (CIRS); Sense of Coherence tool (SoC); Multidimensional Scale of Perceived

1. From baseline to 6wk post-stroke, there were significant improvements in SoC (p=0.046) and patient-BI (p=0.002), significant worsening of CIRS (p=0.047) and MSPSS (p=0.014), and no significant changes in Uncertainty, PHQ, or PSS.

2. The following factors were significantly associated greater uncertainty across the first 6 weeks post-stroke: caregiver’s older age, being a spouse, worse CIRS, worse PSS, worse SoC, recurrent stroke, worse BI, and insurance type.
19.2.2 The Family Caregiver and Social Support Interventions

Table 19.2.2 Support Interventions for Family Caregivers

<table>
<thead>
<tr>
<th>Author, Year, Country, PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Stewart et al. (1998) Canada, No Score</td>
<td>20 female caregivers of persons with recent stroke received 2 home visits/week from peer visitors over 12 weeks. Peer visitors were volunteers who had experience caring for a relative or individual post stroke. Visitors attended a one-day training session (empathy training &amp; documentation of support). Visitors received support from health-professionals with whom they could confer on a regular basis. Results were derived from support diaries recorded by peer visitors and audiotaped post intervention interviews (at 3 and 6 months after intervention).</td>
<td>It was determined that peer visitors provided primarily emotional and informational support and occasional instrumental support. Professionals were seen as providing primarily informational support. Carers felt that the relationship with peer support visitors was positive. Carers reported increased self-esteem, confidence and reduced uncertainty and burden. Results of quantitative assessments of social support, caregiving confidence, perceived stress and use of health services were not</td>
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<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Location</td>
</tr>
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</tr>
<tr>
<td>Pierce et al.</td>
<td>2004</td>
<td>USA</td>
</tr>
<tr>
<td>Stewart et al.</td>
<td>2006</td>
<td>Canada</td>
</tr>
<tr>
<td>Won et al.</td>
<td>2008</td>
<td>USA</td>
</tr>
<tr>
<td>Steiner et al.</td>
<td>2008</td>
<td>USA</td>
</tr>
<tr>
<td>Study (year, country)</td>
<td>Description</td>
<td>Outcome Measures</td>
</tr>
<tr>
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<tr>
<td>[1] Franzen-Dahlin et al. (2008), Sweden 6 (RCT)</td>
<td>100 spouses of individuals with stroke were randomly assigned to intervention or control groups. Intervention consisted of group meetings led by specialist stroke nurses (10 participants in each group), 6 in 6 months and one follow-up meeting 6 months later. Each meeting consisted of a 20-30 minute lecture (symptoms of stroke, risk factors, treatment, prevention, personality changes, social aspects) followed by group discussion on topics chosen by the participants. In addition, intervention participants had telephone access to the nurses as needed. The primary outcome was caregiver psychological health at 12 months. Assessments included the Comprehensive Psychopathological Rating Scale Self-Affective (CPRS-SA), Interview Schedule for Social Interaction (social support), Sense of Coherence Scale (SOC), level of knowledge, BI (patient function), need for assistance and economic situation.</td>
<td>There was no significant differences in psychological health between treatment and control groups at either 6-month or 12-month evaluations (p= 0.991 and 0.280, respectively). The only significant between group difference demonstrated was for stroke knowledge at 12 months (p=0.041). However, within the treatment group, frequency of attendance appeared to influence outcome. Those that attended more sessions (5-6) had better psychological health than those who attended fewer sessions (1-4) (p&lt;0.05). In addition, improvements seen at 6 months, disappeared by 12 months only in the group attended 1-4 sessions. In both groups, knowledge increased significantly over time (p&lt;0.001) while number of emotional contacts decreased (p=0.007). After six and 12 months, psychological health was correlated with availability of social contacts such less availability resulted in poorer psychological health.</td>
</tr>
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<td>[2] Pierce et al. (2009), USA 5 (RCT)</td>
<td>In an update to an earlier report (Steiner et al. 2008), 103 carers were assigned at random to either the intervention or control groups. Intervention consisted of the use of “Caring Web” (online education and support including “Ask the Nurse” email service, “caretalk” email support group and “tip of the month” information about stroke and caring). The control group did not use Caring Web. Outcomes included depression (CES-D), satisfaction with life (Satisfaction with Life Scale – SWLS) and healthcare service use (self-reported visits to a provider and/or emergency department, re-admissions to hospital &amp; nursing home placement). Only subjects who completed 1-year of the study were included in the analyses (n=73). Measures of well-being were administered by telephone every 3 months; health care use was evaluated every 2 weeks.</td>
<td>On the average, intervention participants used Caring Web 1-2 hours per week. Novice computer users were able to use the service. There were no significant between group differences reported for depression or life satisfaction. Neither depression nor life satisfaction changed significantly within groups over time. There were significant differences noted in healthcare utilization such that individuals in the intervention group had significantly fewer visits to the emergency department over the course of the 1-year intervention period than individuals in the control group (p=0.001). Additionally, Care-Web users reported significantly fewer hospital re-admissions (p=0.0005).</td>
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<tr>
<td>[3] Smith et al. (2012), USA 6 (RCT)</td>
<td>38 stroke survivors and their caregivers were randomly allocated to either the intervention group (n=15) or the control group (n=17). The intervention consisted of educational videos, online chat sessions, e-mail and message boards, a resource Controlling for baseline depression scores, caregivers in the intervention group had statistically significantly lower depression scores post-intervention and at 1 month follow compared to the control group (F=6.13, p&lt;0.01).</td>
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</tbody>
</table>
room, and a professional guide to introduce, direct, and encourage caregivers to provide optimal support to the stroke survivor and to manage their personal distress. Outcomes of interest were depression (CES-D), mastery (Mastery Scale), self-esteem (10-item self-esteem scale), social support (MOS Social support survey), and treatment credibility, reported effort and perceived benefit (credibility/expectancy questionnaire). Outcomes were assessed at baseline, post-intervention and 1 month follow-up.

All other outcomes were not significantly different between the groups.

<table>
<thead>
<tr>
<th>Yu et al. (2013) China Observational No Score TPSmean=98.7±74.9mo NStart=142 NEnd=121</th>
<th>Population: Mean age=72.09±8.37yr; Gender: Males=75, Females=46. Intervention: Stroke survivors-caregiver dyads were recruited from 3 community health centres and 6 health service stations. Data was collected in face-to-face interviews at the participants' home using structured questionnaires. Outcomes: Demographic information; Barthel Index (BI); Multidimensional Scale of Perceived Social Support (MSPSS); Brief COPE Inventory (BCI); Short Form-36 (SF-36: Physical Component Summary (PCS), Mental Component Summary (MCS).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. The majority of caregivers (CGs) were women (72.7%), 73.6% had less than a senior middle school education. 2. The most chronic condition in CGs was hypertension (70.4%), heart disease (33.3%), bone and joint disease (16%), and diabetes mellitus (12.3%). 3. 52.1% of CGs spent more than 8hr/d providing care to the stroke survivor. 4. The most common coping strategies by stroke CGs were acceptance, active coping, positive reframing, and planning. 5. PCS scores were positively associated with CGs’ educational level (r=0.197, p&lt;0.05), and negatively associated with the number of chronic conditions (r=-0.453, p&lt;0.001) and relationship to stroke survivor (r=-0.284, p&lt;0.01). 6. MCS was positively associated with active coping (r=0.186, p&lt;0.05), planning (r=0.286, p&lt;0.01), and CG’s educational level (r=0.243, p&lt;0.01). 7. MCS correlated with BI scores of stroke survivors (r=0.399, p&lt;0.001), and were negatively correlated with hours of care/d (r=-0.376, p&lt;0.001), and number of CGs chronic conditions (r=-0.22, p&lt;0.05).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hayashi et al. (2013) Vietnam Observational No Score TPSmean=NA NStart=86 NEnd=86</th>
<th>Population: Age groups: N≤45yr=45, N≥46yr=41; Gender: Males=28, Females=58. Intervention: A survey was administered at a state-owned acute-care hospital in order to describe sociodemographic characteristics of stroke-patient (SP) caregivers and learn about their needs after SP discharge. Outcomes: Caregiver needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. There was a significant difference (p=0.04) between mean lengths of stay of respondents who did not indicate a concern about decreasing family income (4.4 days) and those who were concerned (6.3 days). 2. There was a significant difference (p=0.02) between mean lengths of stay of respondents who did not indicate a need for greater availability of hometown physiotherapists (4.33 days) and those who did indicate this need (6.41 days).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Olaleye et al. (2014) Nigeria</th>
<th>Population: Mean Age=60.6y; Gender: Male=7, Female=18.</th>
</tr>
</thead>
</table>
| | 1. Significant increases in motor function scores (p=0.01), postural balance (p=0.01),}
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Study Design</th>
<th>PEDro Score</th>
<th>TPS</th>
<th>Sample Size</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Post TPS</td>
<td>Mean=NA NStart =29 NEnd=25</td>
<td>Intervention: All patients received the primary healthcare-based physiotherapy intervention (PHCPI) for 60hr/d, 2d/wk for 10wks. The PHCPI involved performing exercises that strengthen the extremities, improve balance, improve walking ability and encourage functional use of the hand and arm. <strong>Outcomes:</strong> Modified Motor Assessment Scale (MMAS); Short-Form-Postural Assessment Scale for Stroke (SFPASS); Reintegration to Normal Living Index (RNLI); 6 Minute Walk Test (6MWT); Health Related Quality of Life Scale (HRQOL).</td>
<td>and walking speed (p=0.01) from baseline to post intervention were found. 2. Significant increases in community reintegration (p=0.01) and total health related quality of life (p&lt;0.01) from baseline to post intervention were found.</td>
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<tr>
<td>Galvin et al. (2014)</td>
<td>Ireland</td>
<td>Observational No Score TPS Mean=2wks NStart=20 NEnd=15</td>
<td>Population: Intervention Group (N=20): Mean age=63.15±13.3yr; Gender: Male=13, Female=7. <strong>Intervention:</strong> Patients and relatives who had participated in the Family-Mediated Exercise therapy (FAME) trial were interviewed separately to examine perceptions of the therapy and outcomes. The FAME intervention consisted of standard therapy plus 35mins of family-mediated exercise therapy for 8wks. The assessment was conducted once and lasted 45mins. <strong>Outcomes:</strong> Evaluation of the FAME trial.</td>
<td>1. Patients reported that the personalised nature of the trial motivated them to complete their exercises, and added structure to their daily routine. 2. Therapeutic gains were reported with patients stating they had made gains in strength, balance, mobility and confidence; relatives added psychological gains had been observed including motivation, enthusiasm, and empowerment. 3. Patients reported that family participation motivated them to complete their exercises and relatives noted a sense of involvement in the recovery process. 4. Caregiver burden was reported in only two relatives but both stated that time-consumption was the only drawback of the FAME trial.</td>
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<tr>
<td>Malini (2015)</td>
<td>India</td>
<td>RCT PEDro=6 TPS≥1yr TPS≥1yr NStart=240 NEnd=238</td>
<td>Population: Experimental Group (EG, N=118): Mean age=Unspecified; Gender: Male=0, Female=118. Control Group (CG, N=120): Mean age=Unspecified; Gender: Male=0, Female=120. <strong>Intervention:</strong> The EG attended self-help support groups and participated in group meetings. The CG did not attend any group meetings. The intervention was provided 1/15d over a period of 3m for a total of 6 meetings. Assessments were conducted at baseline at post-treatment. <strong>Outcomes:</strong> Family System Strengths Questionnaire (FSS).</td>
<td>1. FSS scores were significantly higher in the EG compared to the CG at post-treatment (p=0.001). 2. FSS scores within groups improved significantly for the EG from a mean score of 21.06 to 44.73 from baseline to post-treatment (p=0.001) but the CG did not demonstrate any significant improvements (p=0.15). 3. FSS ratings at baseline for the EG revealed that 58 caregivers rated the strength of their family system as “poor”, 60 gave a “moderate” rating, and no caregivers gave a “good” rating but at post-treatment this had improved to 85 providing a “good” rating, 33 gave a “moderate” rating, and no caregivers gave a “poor” rating.</td>
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<tr>
<td>Bastawrous et al. (2015)</td>
<td>Canada</td>
<td>Qualitative No Score</td>
<td>Population: Median age (age range)=47yr (38-45yr); Gender: Males=0, Females=23. <strong>Intervention:</strong> Caregiving daughters were interviewed based upon their role as a caregiver, experiences with their parent’s stroke, and their caregiving-related role overload effect on valued relationships ▪ Relationships as a partner and mother suffered when involvement was hindered</td>
<td>1. Caregiving-related role overload effect on valued relationships ▪ Relationships as a partner and mother suffered when involvement was hindered</td>
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</table>
health and everyday life in order to analyze the impact of role overload on daily life. **Outcomes:** Thematic analysis.

- Older children were more understanding of the caregiving role, while younger children required more attention and were less understanding
- In some cases, partners felt they were a secondary priority, resulting in the daughters feeling more stressed and compelled to choose between their spouse and mother
- Other partners were supportive and facilitated the daughter’s caregiving role

2. Caregiving-related role overload effect on participation in valued activities
- Daughters were forced to take fewer hours, delay their return to work after the stroke, or quit
- Unemployed daughters felt fortunate in that they realized employment would make caregiving more difficult and foster resentment
- Rearrangement of living situation in order to co-reside with their parent, regardless of relationship status
- Reduction of leisure activities (eg., travelling, exercise)
- Respite was seen as an important need to not feel overwhelmed by the caregiving role

Wang et al. (2015a)  
Taiwan  
RCT  
Pedro=8  
TPS$_{exp}$=18mo  
TPS$_{control}$=18.5mo  
N$_{start}$=51  
N$_{end}$=51

**Population:** Experimental group (EG; N=25): Mean age=62.0±9.5yr; Gender: Males=13, Females=12.  
Control group (CG; N=26): Mean age=65.4±10.6yr; Gender: Males=17, Females=9.  
**Intervention:** Patients and their caregivers were randomly allocated either to the experimental group or to the control group. The experimental group were given weekly personalized caregiver-mediated home-based (CHI) training, and the control group received visits from the therapist without intervention. The intervention period lasted 12 weeks. Assessments were conducted at baseline and at the end of the intervention.  
**Outcomes:** Stroke Impact Scale (SIS); Berg Balance Scale (BBS); 10 Meter Walk Test (10MWT); 6 Minute Walk Test (6MWT); Barthel Index (BI); Caregiver Burden Scale (CBS).

1. A significant difference between the two groups in the improvement on the SIS was found (composite physical subscale: $p<0.001$; communication subscale: $p=0.03$; social participation subscale: $p=0.019$; general recovery subscales: $p<0.001$).
2. A significant difference between the two groups was found regarding the free-walking velocity ($p=0.006$), 6MWT ($p=0.003$), BBS ($p=0.006$), and on the BI ($p=0.008$).
3. No significant difference between groups on the CBS was found.

Chang et al. (2015)  
South Korea  
Pre-Post  
No Score  
TPS$_{mean}$=NA

**Population:** Stroke Survivors (N=19): Mean Age=74.47±4.64yr; Gender: Males=10, Females=9; Family Caregivers (N=19): Mean Age=61.5±14.3yr; Gender: Males=4, Females=15.  
**Intervention:** Family caregivers were provided with

1. The perceived health of the patients and caregivers significantly improved ($p<0.001$).
2. The functional difficulty as measured by K-ADL ($p<0.001$) and K-IADL ($p=0.001$) displayed significant improvements.
1 hr didactic education on the importance of family involvement within care, 1 hr per wk they received patient-specific caring skills and met with the RN to revise a monthly health management plan. The stroke survivors met with the RN each wk to receive the results of their health education plan, they participated in exercise sessions twice a wk with the physical therapist and they participated in ADL and IADL training sessions each day for 30 min. Data was analyzed at baseline and after 12 wk.

**Outcomes:** Korean Activities of Daily Living (K-ADL); Korean Instrumental Activities of Daily Living (K-IADL); Visual Analog Scale (VAS); Caregiving Satisfaction Scale (CSS); Modified Caregiver Satisfaction Scale (MCSS);

3. The scores of caregiver satisfaction (p<0.001) and satisfaction of adult day care service of the family caregivers (p<0.001) increased significantly.

4. The cost of health services decreased from $99.40 during the month before the intervention to $52.35 during the last month of the intervention; however, this decrease was not statistically significant.

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**Cameron et al. (2015)**  
Canada  
RCT  
PEDro=6  
TPSmean=NA  
NStart=31  
NEnd=19

**Population:** Standard Care (SC, N=10) Caregivers: Mean Age=55±10.9; Gender: Males=2, Females=8; Self-Directed Intervention (SD, N=10) Caregivers: Mean Age=57±14.9yr; Gender: Males=2, Females=8; Social Support Person-Directed Intervention (SSP, N=11) Caregivers: Mean Age=57±19.4yr; Gender: Males=3, Females=8.

**Intervention:** SSP received the Timing it Right Stroke Family Support Program, consisting of a meeting during acute care following by six monthly telephone support calls where they discussed caregivers current needs and strategies to have them met. SD received the guidebook from the SSP intervention along with one in-person orientation session. From three Canadian cities, assessments were at baseline, 1mo, 3mo, and 6mo with an optional qualitative interview.

**Outcomes:** Medical Outcomes Study Social Support Scale (MOSSSS); Positive Affect Scale (PAS); Centre for Epidemiological Studies Depression Scale (CESD); Pearlin’s Mastery Scale (Mastery).

1. No significant between-group differences were found in terms of PAS and CESD changes over time.

2. SSP significantly improved in MOSSSS (p=0.04) compared to SC and SD significantly improved in Mastery (p=0.02) compared to SC.

3. Qualitative caregiver interviews (n=19) reflected the complex interaction between caregiver needs, preferences and available options when reporting on level of satisfaction.

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**Bakas et al. (2015)**  
United States  
RCT  
PEDro=8  
TPSmean=NA  
NStart=254  
NEnd=176

**Population:** Experimental Group (EG=123): Mean Age=54.0±12.5yr; Gender: Males=27, Females=96; Control Group (CG, N=131): Mean Age=54.7±11.4yr; Gender: Males=28, Females=103.

**Intervention:** Stroke caregivers recruited from 2 rehabilitation hospitals and 6 acute care hospitals were assessed at baseline (within 8 wk after stroke survivor discharge), post-intervention (8wk), 24wk, and 52wk. Both groups received the American Heart Association pamphlet and 8 weekly calls from a nurse with a booster call at 12 wks. In addition, EG received the Telephone Assessment and Skill-Building Kit (TASK) II Resource Guide with calls focussed on training caregivers.

**Outcomes:** Patient Health Questionnaire Depressive Symptom Scale (PHQ-9); Bakas Caregiving

1. There were no significant differences between EG and CG in terms of changes in PHQ-9 and BCOS from baseline to 8wk, 12 wk, 24wk, or 52wk.

2. At 8wk, EG reported a significantly greater reduction in UD from baseline than CG (Mean difference=−2.9, p=0.025) but no significant differences at other timepoints.

3. At 8wk for the subgroup with PHQ-9≥5, EG reported a significantly greater reduction in PHQ-9 from baseline than CG (Mean difference=−2.6, p=0.013).
<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malini (2015)</td>
<td>Experimental Group (N=118); Gender: Male=0, Female=188; Control Group (N=120) Males=0, Females=120.</td>
<td>The members of the experimental group attended support groups within their villages every 15 days, while the control group did not attend any of the meetings. After 3 mo the family systems strengths were assessed.</td>
<td>Family Strength Questionnaire</td>
<td>There was a significant and positive increase in the family system strengths of caregivers who participated in the self-help group meetings (p=0.001).</td>
</tr>
<tr>
<td>Wang et al. (2015b)</td>
<td>Experimental Group (EG; N=25): Mean age=62.0±9.5 yr; Gender: Males=13, Females=12. Control Group (CG; N=26): Mean age=65.4±10.6 yr; Gender: Males=17, Females=9.</td>
<td>Participants were randomly allocated to the experimental group and received caregiver-mediated training or to the control group and were maintained on routine care. The intervention lasted 12 weeks, conducted weekly for approximately 90 minutes.</td>
<td>Berg Balance Scale (BBS); 10 Meter Walk Test (10MWT); Stroke Impact Scale (SIS); Barthel Index (BI); Caregiver Burden Scale (CBS).</td>
<td>A significant between-group difference was found on the following SIS subscales: composite physical (p&lt;0.001), communication (p=0.03), social participation (p=0.019) and general recovery (p&lt;0.001), favoring the EG. 2. The EG performed significantly better than the CG on the free-walking velocity (p=0.006), 6MWT (p=0.003), BBS (p=0.006), and BI (p=0.008). 3. No significant between-group difference was found regarding the CBS.</td>
</tr>
<tr>
<td>Van den Berg et al. (2016)</td>
<td>Experimental Group (EG; N=31): Mean age=64.5±18.5 yr; Gender: Males=19, Females=12. Control Group (CG; N=32): Mean age=70.1±12.4 yr; Gender: Males=21, Females=11.</td>
<td>Caregiver of stroke patients were randomly allocated either to the experimental group or to the control group. The experimental group received an 8-week caregiver-mediated training program with support using a customized exercise app loaded onto a tablet. The patient and their caregiver were asked to perform a selective set of exercises for 8 weeks, at least 5 times a week for 30 minutes, and had a weekly evaluation session with the physiotherapist. Additionally, participants in the intervention group wore an activity monitor the Fitbit Zip (Fitbit, Inc, San Francisco, CA) for the 8-week intervention period. Participants allocated to usual rehabilitation care received interdisciplinary rehabilitation following the standards outlined by the Australian clinical guidelines for stroke management. Outcomes were assessed at baseline, week 8, and at week 12.</td>
<td>Stroke Impact Scale (SIS); Rivermead Mobility Index (RMI); Barthel Index (BI); Nottingham Extended ADL (NE-ADL); Timed Up and Go Test (TUG); modified Rankin Scale (mRS); Fugl Meyer Assessment-Lower extremity (FMA-LE); Motricity Index (MI); Berg Balance Scale (BBS); Length of Stay</td>
<td>Intention to treat analysis: 1. There was no between-group difference on the SIS mobility, (P=0.6) at 8 weeks. 2. A difference between groups in the memory domain of the SIS at 12 weeks, which favored the EG (−11.2, 95% confidence interval [CI], −18.2 to −4.3; P=0.0018) was found. 3. However, the CG performed significantly better on the strength domain of the SIS (8.2, 95% CI 0.8–15.5; P=0.0299) and the TUG (−8.0, 95% CI −15.3 to −0.8; P=0.0307) at week 12. 4. There were no between-group differences in LOS. 5. Carers in the EG reported higher self-efficacy assessed with the GSES (−3.3, CI 95% −5.7 to −0.9; P=0.0078) and less fatigue on the FSS (4.6, CI 95% 0.3–8.8; P=0.0369) at week 12. Per protocol analysis: 1. Those who had received the intervention program at home demonstrated a trend toward improved mobility in the SIS mobility domain (−9.8, CI 95% −20.1 to 0.4; P=0.06) at week 8. The SIS communication domain showed significant better outcomes at week 8 (−7.7, CI 95% −14.0 to −0.3).</td>
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</table>
19. Community Reintegration

Ali et al. (2016)  
Pakistan  
Observational  
No Score  
TPS\text{mean}=NA  
N_{\text{Start}}=90  
N_{\text{End}}=90

**Population:** Mean Age=34.9±8.3yr; Gender: Males=14, Females=59.  
**Intervention:** Family caregivers of stroke patients were surveyed to examine the effect of social support and coping on psychological stress.  
**Outcomes:** Incapacity Status Scale (ISS0; Multidimensional Scale of Perceived Social Support (MSPSS); Coping Strategies Questionnaire (CSQ); Depression Anxiety Stress Scale-42 (DASS-42).  

1. Caregivers perceived significantly more social support from family (p=0.00) or significant others (p=0.00) compared to friends.  
2. Increased monthly income is significantly associated with lower DASS-42.  
3. Social support from family is significantly associated with lower DASS-42 depression subscale.

Bertilsson et al. (2016)  
Sweden  
RCT  
PEDro=4  
TPS\text{mean}=NA  
N_{\text{Start}}=183  
N_{\text{End}}=183

**Population:** Experimental Group (EG, N=88) Caregivers: Mean Age=60±14.6yr; Gender: Males=32, Females=56; Control Group (CG, N=95) Caregivers: Mean Age=64±13.1yr; Gender: Males=23, Females=72.  
**Intervention:** Cluster randomized. EG received client-centred Activities of Daily Living (ADL) training, with stroke participants actively involved in their rehabilitation enabling ADL and guided by their needs and expressed desires. CG received usual ADL care; caregivers of enrolled stroke survivors were assessed at 3mo and 12mo post-intervention.  
**Outcomes:** Caregiver Burden Scale (CBS; subdomains of general strain, isolation, disappointment, emotional involvement, and environment); Informal care; Occupational Gaps Questionnaire (OGQ); Life Satisfaction (LiSat-11).  

1. At 12mo, no significant differences comparing caregivers from EG to caregivers from CG in terms of CBS. OGQ, LiSat-11, or Informal Care.
## 19.2.3 Family Interactions and Stroke

### Table 19.2.3 Family Interactions and Stroke

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Kinsella and Duffy</strong> (1980) UK</td>
<td>No Score</td>
<td>79 patient-spouse pairs were assessed on attitude.</td>
<td>Overprotection and unrealistic attitudes were a more common response than rejection or retributive guilt feelings.</td>
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<tr>
<td><strong>Bishop et al.</strong> (1986) USA</td>
<td>No Score</td>
<td>24 stroke patients and their spouses were studied. All patients were at home and had suffered a stroke at least 1-year previously. Couples were assessed on variables of morale (Philadelphia Geriatric Morale Scale), family functioning (McMaster Family Assessment Device), health status and patient functional capacity and were match-paired to healthy normal couples.</td>
<td>Stroke patients and their spouses were healthy on all variables, including family function. Members of the couple did not differ on most variables whether compared as husband-wife of patient-spouses. Wives did not differ on any variables. Husbands from the stroke sample differed from the matched husbands on the number of doctor visits made in the previous six months.</td>
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<tr>
<td><strong>Evans et al.</strong> (1987b) USA</td>
<td>No Score</td>
<td>Caregivers of 60 stroke patients were assessed five months after patient discharge from a stroke care unit using the McMaster Family Assessment Device (FAD) to determine the relationship between family and post-stroke treatment adherence. Also patients' functioning capacity was measured using the Barthel Index and cognitive impairment with The Mental Status Exam (MSE).</td>
<td>Better functioning families were consistently high on signs of treatment adherence. Families with specific dysfunction may not be as capable of helping patients to comply with rehabilitation efforts as families who function more effectively.</td>
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<tr>
<td><strong>Evans et al.</strong> (1987a) USA</td>
<td>No Score</td>
<td>The Family Assessment Device and clinical data for 60 stroke patients were used to predict outcomes at 6-months and one year post-stroke.</td>
<td>Problem solving scores, family communication skills and patient self-care ability predicted family-rated patients adjustment.</td>
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<tr>
<td><strong>Clark and Smith</strong> (1999a) Australia</td>
<td>No Score</td>
<td>60 stroke survivors, 46 spouses and 25 other family members were assessed for family function (McMaster Family Assessment Device) on admission to and discharge from rehabilitation and at 6 and 12 months post discharge.</td>
<td>Patient ratings reflected deterioration of family communication, role definition and general family function. Spouse ratings reflected deterioration of communication and role functioning while behavioural control improved (indicating the adoption of a more flexible style of behavioural control). Ratings of other family members demonstrated deterioration of family role definition, gradual improvement in affective responsiveness and involvement and improvement in behavioural control. Overall, a greater degree of family dysfunction existed 12 months post stroke than on admission – more than ½ of patients and 40% of spouses rated families as dysfunctional at 12 months.</td>
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<tr>
<td><strong>Clark and Smith</strong> (1999b) Australia</td>
<td>No Score</td>
<td>60 stroke survivors living in a home environment were assessed on admission to from discharge and then again at 6 and 12 months post discharge. Assessments included the abnormal illness behaviour, ADL ability, social activity, depression, family functioning, and knowledge of stroke care</td>
<td>Multivariate regression analysis determined that global family function was a significant predictor (p&lt;0.05) of improved ADL function at both 6 and 12 months post rehabilitation discharge along. Global family functioning was also a significant predictor of social activity as measured on the</td>
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and expectations of rehabilitation. Frenchay Activity Index at 6 and 12 months (p<0.05).

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Design Type</th>
<th>Score</th>
<th>TPS</th>
<th>Mean</th>
<th>N Start</th>
<th>N End</th>
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<tbody>
<tr>
<td>Dietz et al. (2013)</td>
<td>USA</td>
<td>Qualitative</td>
<td>No Score</td>
<td>TPS</td>
<td>Mean=88±81.68mo</td>
<td>9 (3 groups)</td>
<td>9 (3 groups)</td>
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<tr>
<td><strong>Population:</strong></td>
<td>Persons with Aphasia (PWA; N=3): Mean age=56.33±24.85yr; Gender: Males=2, Females=1. Primary Caregiver (N=3) and Member of Social Network (N=3).**</td>
<td><strong>Intervention:</strong></td>
<td>Data from personal interviews conducted on a triad of people (person with aphasia (PWA), primary caregiver, and another member of their social network) were assessed to determine the social role changes experienced by PWA, to understand the use of communication strategies when attempting to reclaim previous social roles, and to determine whether discrepancies exist between PWA and their potential proxies regarding social role changes/adaptations. <strong>Outcomes:</strong></td>
<td>Emerging themes regarding the renegotiation of social roles of PWA.</td>
<td>1. Three major themes were generated: (1) interpersonal life changes, (2) community interactions and hobbies, and (3) augmentative and alternative communication (AAC) strategies. 2. (1) This reintegration process affects the nature and quality of personal relationships not only for the PWA but also to their caregivers and loved ones. However, other members of the PWAs social network did not experience life changes of the same magnitude as primary caregivers but instead, they focused less on the negative impacts of aphasia and more on the residual skills of the PWA. 3. (2) Caregivers sometimes report information that conflicts with the perception of the PWA regarding post-stroke interpersonal life changes and community interaction/hobbies. PWA tend to focus on the strategies that they developed to overcome communication barriers. Caregivers focused heavily on their own experiences rather than the experiences of the PWA. 4. (3) All three members of each triad agreed that AAC was vital to the ability of the PWA to return to prior social roles and to renegotiate new roles.</td>
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<tr>
<td>Epstein-Lubow et al. (2014)</td>
<td>USA</td>
<td>Retrospective</td>
<td>No Score</td>
<td>TPS</td>
<td>Mean=NA</td>
<td>N Start=2747</td>
<td>N End=2747</td>
</tr>
<tr>
<td><strong>Population:</strong></td>
<td>Fee-for-service Medicare patients. Patients With Caregiver: Age Range: &lt;65 to &gt;84yr; Gender: Males=224, Females=258. Patients Without Caregiver: Age Range: &lt;65 to &gt;84yr; Gender: Males=848, Females=1420. <strong>Intervention:</strong></td>
<td>To evaluate the association between family caregiver presence and patient completion of the Care Transitions Intervention (CTI) for 30 days following discharge. <strong>Outcomes:</strong></td>
<td>Completion of the intervention after discharge: defined by participation in, at minimum, the post hospital home visit.</td>
<td>1. Compared to patients without a family caregiver for the in-hospital discussion, patients with a family caregiver had higher consent rates to the intervention (68.9% of patient-caregiver dyads compared with 53.5% of patients alone; p&lt;0.0001) and completion of the intervention (44.84% of patient-caregiver dyads compared with 15.8% of patients alone; p&lt;0.001). 2. There were no between group differences regarding 30-day admissions. 3. Patients with a caregiver present at enrollment were twice as likely to consent to participate compared with those without one, after adjusting for potential confounders (stats not shown).</td>
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<tr>
<td>Grigorovich et al. (2015)</td>
<td>Canada</td>
<td>Cohort</td>
<td>No Score</td>
<td>TPS</td>
<td>Mean=NA</td>
<td>N Start=399</td>
<td>N End=399</td>
</tr>
<tr>
<td><strong>Population:</strong></td>
<td>Phase 1: Survivors: (N=399); Age=66.44±10.73yr; Gender: Males=235, Females=164; Caregivers: (N=399); Age=58.44±0.77yr; Gender: unspecified; Phase 2: Survivors: (N=80); Age=61.96±16.15yr; Gender: Males=42, Females=38;</td>
<td>1. In phase 1, caregiver’s participation restriction was significantly associated (p&lt;0.05) with caregivers’ younger age, being employed, more depression symptoms, and lower mastery.</td>
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</table>
19. Community Reintegration

**Phase 1**

- **N Start**: 399
- **N End**: 399

**Intervention**: Data were collected by 1-hour long phone interviews with caregivers at 1, 3, 6, 12 mo post-stroke. A second phase containing a subset of the participants completed the same questionnaires at 18 and 24mo post-stroke.

**Outcomes**: Caregiver Impact Scale (CIS); Center for Epidemiologic Studies (CES-D); Caregiver Assistance Scale (CAS); 36-Item Short-Form Health Survey (SF-36); Brain Impairment Behaviour Scale (BIBS); Mini-Mental State Examination (MMSE); Stroke Impact Scale (SIS).

**Phase 2**

- **N Start**: 80
- **N End**: 80

**Caregivers**: (N=399); Age= 57.06±14.51yr; Gender: unspecified.

**Intervention**: The aims of this study were: (1) to determine the effect of caregiver availability on rehabilitation outcomes in patients with subacute stroke; and (2) to ascertain whether additional factors, such as the size of potential care support network (ie, number of potential caregivers) and caregiver type (ie, primary caregiver identity), make a difference to outcomes among those with caregivers.

**Outcomes**: Rehabilitation effectiveness (based on the difference between discharge and admission Barthel Index (BI) score).

2. In phase 2, caregiver’s participation restriction was only significantly associated with caregivers’ younger age, high levels of depression, providing high level of assistance to survivors and lower levels of survivors’ community participation.

**Table 19.2.4 Information Provision and Family Education Post-Stroke**

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evans et al. (1988)</td>
<td>USA</td>
<td>5 (RCT)</td>
<td>213 patients &amp; family caregivers were randomized to one of three groups: Group 1 was assigned to an education group (two 1-hour classes); Group 2 was assigned to a counselling group (2 hours of education as group 1 with an additional 7 individual 1 hour counselling sessions); Control patients were assessed but caregivers were not scheduled for education or counselling.</td>
<td>Six months after stroke, all groups showed worsening family function, but the education and counselling group demonstrated significantly less deterioration than controls on problem solving, communication and global family function. Only the counselling group significantly improved patient adjustment relative to control. One year after stroke, the education and counselling groups were significantly better than the control group on</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Outcome Measures</td>
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<tr>
<td>Lorenc et al. (1992)</td>
<td>UK</td>
<td>3 (RCT)</td>
<td>30 stroke patients were randomly assigned to either a no treatment control group (Group C), to receive a information package about stroke (Group A) or to receive an information package and asked to question themselves about their comprehension of the material in the information pack (Group B).</td>
<td>Group B scored significantly higher than the other two groups on knowledge scores. Subjects receiving information and meta-cognitive strategy recalled significantly more information than the other two groups. No differences between groups on consumer satisfaction.</td>
</tr>
<tr>
<td>Mant et al. (1998)</td>
<td>UK</td>
<td>8 (RCT)</td>
<td>71 patients and 49 caregivers were randomly placed into an intervention group that received information packages about stroke, its effects, and local contact names and support groups or were placed into a control group that received no information package. Patients and caregivers were followed 6-months later and interviewed on knowledge about stroke, satisfaction on information received, access to community services, health status and quality of life.</td>
<td>No significant differences were observed between the intervention and the control groups on any of the outcome measures. However, caregivers in the intervention group reported significantly better mental health than caregivers of the control group patients.</td>
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<tr>
<td>Grant (2001)</td>
<td>USA</td>
<td>4 (RCT)</td>
<td>This study involved 30 primary family caregivers who had primary unpaid responsibility for the patient an average of at least 6 hours day. Caregivers were randomly assigned to receive either a home visit or telephone contact from a registered nurse to develop the use of social problem solving skills in managing caregiving problems or to a control group that received a sham brief telephone contact. Intervention participants (home visit or telephone contact) received an initial 3-hour training session, prior to the discharge of the stroke survivor from rehabilitation, to learn how to use positive problem orientation in managing caregiving responses and were given a concrete list of problem-solving steps to follow. Subsequent home visits/telephone contact lasted approximately 45 minutes. Contacts followed a diminishing schedule (weekly for month 1, bi-weekly for month 2 and then once during the 3rd month post discharge).</td>
<td>At 2 and 5 weeks, the telephone support group demonstrated significantly reduced levels of depression (p&lt;0.01 and p=0.05, respectively). While both intervention groups demonstrated less depression at 13-weeks, differences between intervention and control groups were non-significant. At 2 and 5 weeks, the telephone group demonstrated higher problem-solving scores on the Problem Solving Inventory (p=0.01 and p=0.05, respectively). This difference was not significant at the post intervention assessment. Level of caregiver education was significantly associated with the presence of positive problem solving skills (p&lt;0.05). As for depression and problem-solving, significant differences in caregiver preparedness were demonstrated between the telephone group and the other groups at both 2 and 5 weeks, but not at 13 weeks. There were no between group differences in general health status, caregiver burden or satisfaction with services. Lower levels of caregiver burden were demonstrated to be significantly associated with positive perceptions of preparedness at the 2 and 5-week assessments (p&lt;0.05).</td>
</tr>
<tr>
<td>Rodgers et al. (1999)</td>
<td>UK</td>
<td>8 (RCT)</td>
<td>260 stroke patients and their carers were randomized to receive either an invitation to attend the Stroke Education Program (SEP) or conventional stroke unit care (control). The SEP involved one 1-hour small group education sessions for inpatients</td>
<td>47% of patients and 22% of carers randomized to SEP completed the program. SF-36 scores were similar for SEP patients and the controls. Informal carers in the control group scored significantly better on social functioning of SF-36</td>
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</table>
and their carers, followed by six 1-hour educational sessions after discharge. The control group had access to information leaflets about stroke. 6 months post stroke, study participants were assessed on the Short Form 36 healthy survey questionnaire (SF-36), Hospital Anxiety and Depression Scale (patients), General Health Questionnaire (carers), Nottingham E-ADL and the Oxford Handicap Scale. then SEP group. Patients and informal carers in SEP groups scored significantly higher on stroke knowledge than controls. SEP patients were significantly more satisfied with information they had received about stroke. No significant differences were noted between groups on emotional or functional outcomes.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Duration</th>
<th>Intervention</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mant et al. (2000)</td>
<td>UK</td>
<td>8 weeks</td>
<td>Single blind trial of 520 patients and their carers (n=323) randomized to receive either family-support care with the use of an information package or usual post-stroke care.</td>
<td>Patients and informal carers in SEP groups scored significantly higher on stroke knowledge than controls. SEP patients were significantly more satisfied with information they had received about stroke. No significant differences were noted between groups on emotional or functional outcomes.</td>
</tr>
<tr>
<td>Johnson &amp; Pearson (2000)</td>
<td>USA</td>
<td>5 weeks</td>
<td>41 community dwelling stroke survivors were randomly assigned to either a treatment or control group. Treatment consisted of attending a series of 8 – 2-hour educational classes over a period of 4 weeks. Study participants were assessed for depression, hope and ways of coping before and after the intervention.</td>
<td>Results favoured the intervention. Participation in the educational intervention was associated with significantly less depression and more hope when compared to the control group. There was a trend toward improved coping associated with participation in the intervention.</td>
</tr>
<tr>
<td>Grant et al. (2002)</td>
<td>USA</td>
<td>4 weeks</td>
<td>74 primary family caregivers to a stroke patient, related by blood or marriage, with non-remunerative responsibility for stroke survivor for an average of at least 6 hours a day after discharge were randomized to one of 3 groups. Group 1 participated in social problem-solving telephone partnerships (SPTP) along with usual discharge planning services. Group 2 received a sham telephone intervention in addition to usual discharge planning services and group 3 received only the usual discharge planning services.</td>
<td>Stroke survivors had suffered an ischemic stroke caused by either thrombi or emboli, were 35 years of age or older, with FIM score 36 - 96 and discharged home from rehab facility. The SPTP group had better problem solving skills, greater caregiver preparedness, and, less depression compared to the other 2 groups. However, there was no significant difference in caregiver burden between the groups.</td>
</tr>
<tr>
<td>Van den Heuvel et al. (2002)</td>
<td>Netherlands</td>
<td>5 weeks</td>
<td>212 participants (main caregivers of non-institutionalized stroke patients) were randomly assigned to either a 8-week group program consisting of 8 meetings, 16 hours of education or to 8 to 10 weeks of home visit programs consisting of 4 visits, 8 hours of education or to a control group. The Group and Home programs dealt with topics such as expressing emotions, receiving information and learning how to use active coping strategies. Fewer topics were dealt with during each home visit than during each group visit. Health education nurses supervised the Group program and specialized</td>
<td>The intervention groups demonstrated a significant increase in knowledge about patient care and about self-efficacy. The amount of social support remained stable in intervention groups, but decreased in control groups. There was no significant difference between the home visit group and the group support program. However, younger female caregivers benefited the most from the interventions.</td>
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<tr>
<td>Authors</td>
<td>Year</td>
<td>Country</td>
<td>Design</td>
<td>Description</td>
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<tr>
<td>Clark et al.</td>
<td>2003</td>
<td>Australia</td>
<td>6 (RCT)</td>
<td>62 patients with stroke and their spouses were randomized to either the intervention group, receiving a stroke information package and 3 counselling visits or the control group, receiving no information or counselling. Patients and their spouses were assessed at admission, discharge and 6 moths after discharge.</td>
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<tr>
<td>Hartke and King</td>
<td>2003</td>
<td>USA</td>
<td>5 (RCT)</td>
<td>88 spouses or spousal equivalents of stroke survivors, who also acted as the primary caregiver to the stroke patients, were randomized to either the telephone support group intervention or to receive usual care. The telephone group received 8, 1-hour conference call education sessions. This group received manual outlining the eight topics of discussion. The manual also included an audiotape of a relaxation procedure and a publication on stress management. The Usual care group also received the same stress management publication and a brief written description of caregiver stress and stroke. The usual care group did not receive any regular support sessions.</td>
</tr>
<tr>
<td>Kalra et al.</td>
<td>2004</td>
<td>300 carers of stroke patients were randomised to intervention or control conditions. Participants in the control group received training in basic nursing and techniques to facilitate basic personal care. Outcomes assessed included cost to health and social services systems, caregiving burden, functional status of both patient and carer (BI and FAI), psychological state, quality of life, and patient’s institutionalization or mortality at one year post stroke.</td>
<td>Care costs for patients whose caregivers received training were lower than for those whose carers were untrained (p=0.001). Training was associated with less caregiver burden (p=0.0001), anxiety (p=0.0001), depression (p=0.0001) as well as improved quality of life (p=0.001). Mortality, institutionalization and functional status of the patient were not associated with caregiver training. Training was associated with lower levels of patient anxiety (p&lt;0.0001) and depression (p&lt;0.0001). Patients of trained carers also reported higher quality of life than those whose caregivers had not been part of the training intervention (p=0.009). A subsequent study examining cost effectiveness (Patel et al. 2004) reported that patients involved in the training condition had shorter lengths of stay and received less physiotherapy and occupational therapy than patients in the control condition. Total healthcare and social care costs were significantly less for patients whose caregivers received training. This difference was attributed to the shorter lengths of stay experienced by patients whose caregivers received training. While not difference in caregiver QALY’s were found, this</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
<td>Intervention Details</td>
<td>Results</td>
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<tr>
<td>Smith et al. (2004) UK</td>
<td>8 (RCT)</td>
<td>170 patients admitted to a stroke rehabilitation unit and their carers were randomly assigned to receive either usual care or an education intervention consisting of a Stroke Recovery Programme Manual and bi-weekly meetings with the multi-disciplinary care team to receive information, discuss progress and develop goals. The primary study outcome was stroke knowledge (both carer and patient). Secondary outcomes included physical and social function, handicap, patient and carer mood and patient and carer satisfaction. Assessment of outcome was undertaken at 3 &amp; 6 months post-discharge by home visit.</td>
<td>There were no significant differences in stroke knowledge between treatment groups at 3 &amp; 6-month assessment. There was no significant change in knowledge between baseline and 6 months in either group (p=0.24). At 3 months and at 6 months, participation in the education program was associated with reductions in patient anxiety as measured on the Hospital Anxiety and Depression Scale’s anxiety subscale (p=0.034 and p=0.021 respectively). There were no other significant differences reported between treatment groups.</td>
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<tr>
<td>Larson et al. (2005) Sweden</td>
<td>5 (RCT)</td>
<td>100 spouses of stroke patients were randomly assigned to either a control groups (n=50) or intervention group (n=50). Intervention consisted of a small group (10 participants in each group) education and support program conducted once per month for 6 months. Sessions consisted of a lecture on a given topic (nature of stroke, treatment and recovery, psychological and social effects of stroke, secondary prevention) followed by group discussions. The control group received regular information during hospitalization and at discharge with the option to attend a single open session with a stroke specialist. Outcomes were assessed via self-report questionnaires.</td>
<td>Attendance in the intervention programme was 71%. There were no significant differences between groups on measures of quality of life, well-being, life situation or health state. Within group analysis demonstrated that, during the intervention, participants attending the education programme reduced their negative well-being. Unfortunately, this was a temporary effect, ending after the intervention did. Participants described the education programme as a positive experience and appreciated meeting others in similar situations and the opportunity to talk about their own situation.</td>
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<tr>
<td>Grasel et al. (2005) Germany</td>
<td>No Score</td>
<td>71 patients/carers received either standard transition intervention (prior to hospital discharge) or the intensified transition intervention. Standard transition included advice/practical help (insurance/forms), mediation with self-help groups, observing therapy sessions, one brief care advice, application for nursing aids &amp; forwarding a report to outpatient service. Intensive transition added the following: psycho-educational seminar for carers, a 3-session training course (nursing), therapeutic weekend care at home prior to discharge, telephone counselling for 3 months post-discharge (initiated by the clinic). Follow-up assessment was at 6 months following discharge.</td>
<td>62 patient/carers completed follow-up assessments. For patients, there were no significant differences between groups in terms of patient function on either the BI or FIM; however, both groups experienced significant increases in function over time. Evaluations of Timed up &amp; go demonstrated more successful completions associated with membership in the intervention group. There were no significant between group differences for change in carer physical health or depressive symptoms over the 6-month period. For healthcare/resource use, participation in the intervention was associated with significantly fewer physician visits between baseline and follow-up (p=0.018). More intervention participants made use of outpatient services (50%) than control group (33%).</td>
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<td>Schure et al. (2006) Netherlands</td>
<td>5 (RCT)</td>
<td>257 family caregivers of stroke patients were randomly allocated to group education/counselling (n=130), home visiting education/counselling (n=78) or control group (n=49). Group intervention took place over 10 weeks. Groups of 10 – 12 met 8 times</td>
<td>In general, caregivers reported involvement in the intervention as a positive experience, however, the program was criticised for lack of follow-up. Some caregivers participating in the home visit condition complained about the lack</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Intervention Details</td>
<td>Evaluation Details</td>
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<tr>
<td>Howe et al. (2007)</td>
<td>UK</td>
<td>Community Reintegration</td>
<td>Outcome assessment included evaluation of the program on a visual analogue scale, preferences for type of intervention, and the mechanisms of change questionnaire.</td>
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<td>Lowe et al. (2007)</td>
<td>UK</td>
<td>Home visiting</td>
<td>Caregivers in the group condition experienced significantly greater informational support and emotional support than caregivers in the home visiting condition (p&lt;0.005). There was no difference between groups in advisory support, normative support or gaining self-knowledge. More caregivers preferred group intervention, but caregivers with this preference tended to experience greater burden than those who preferred home visits (p&lt;0.05). No comparisons with the control group were reported.</td>
<td></td>
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<tr>
<td>King et al. (2007)</td>
<td>USA</td>
<td>Caregiver problem-solving intervention</td>
<td>Caregiver outcomes included depression, anxiety, perception of life changes and health caregiving. Caregivers also provided a rating on the FIM to assess survivor function.</td>
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<tr>
<td>Johnston et al. (2007)</td>
<td>No Score</td>
<td>203 stroke patients and their carers were randomly assigned at discharge from hospital to receive either</td>
<td>At 6 months, patients in the intervention group demonstrated significantly better disability.</td>
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For 2 hours. Home visiting consisted of 4 visits of 4 hours long also over 10 weeks. The content and use of counselling and educational strategies was the same for both group and home settings. Sessions were conducted by experienced home care nurses. At baseline, both groups demonstrated similar levels of stroke knowledge (p=0.91). By 3 months post stroke, patients in the carefile group demonstrated significantly greater stroke knowledge than the control group (p<0.05). This difference was maintained at 6 months (p<0.005). At six months, most (98%) patients in the intervention group reported that the carefile provided useful information and more than ½ (53%) said that they used it as reference material regarding their stroke. 98% reported that they would recommend its use to other stroke patients. However, at 3 & 6 months less than 30% of patients in both groups reported receiving sufficient information about stroke causes and prevention. There were no significant between group differences regarding satisfaction with information received. |
<table>
<thead>
<tr>
<th>Country</th>
<th>Study Title</th>
<th>Study Year</th>
<th>Study Design</th>
<th>Intervention Description</th>
<th>Control Description</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK 7 (RCT)</td>
<td>A pilot study of the intervention on carer outcomes</td>
<td>2009</td>
<td>Randomized Controlled Trial</td>
<td>A workbook-based intervention or control (normal care) conditions. The intervention was administered over 5 weeks &amp; consisted of information and exercise accompanied by regular contact (home visits &amp; telephone) to monitor goals &amp; achievements and provide support. A pilot study of the intervention (Frank et al. 2000) demonstrated to significant between group differences for functional limitations or mood.</td>
<td>recovery than those in the control group (p=0.019) as assessed on the Observer Assessed Disability scale. There were no significant between group differences on the Barthel Index. Similarly, there were no significant between group differences in either patient or carer scores on the HADS, or for patient satisfaction with care. There was a significant group X time interaction for “confidence in recovery”; however, this did not modify the intervention effect on recovery from disability. There were no significant effects on carer outcomes (distress or satisfaction with care) associated with the intervention.</td>
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<tr>
<td>Hoffmann et al. (2007) Australia 8 (RCT)</td>
<td>138 stroke patients were randomly assigned</td>
<td>2007</td>
<td>Randomized Controlled Trial</td>
<td>To receive either computer-generated tailored written information or generic written information. The intervention material was customized for each patient based on collaboration between the nurse and the patient to determine individual informational needs and optimal format for layout and presentation. Primary outcomes included stroke knowledge, self-efficacy, anxiety &amp; depression and perceived health status at 3 months post-discharge.</td>
<td>There were no significant between group differences for change in knowledge, self-efficacy, depression or perceived health status from baseline through follow-up. Patients receiving the intervention were significantly more satisfied than patients in the control group with the content (p=0.003) and presentation (p&lt;0.001) of the written information they received. Significantly more patients in the control group than the intervention group expressed a desire for additional information (p&lt;0.001).</td>
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<tr>
<td>Green et al. (2007) Canada 8 (RCT)</td>
<td>400 patients with TIA or mild stroke seen in a stroke prevention clinic were randomly assigned</td>
<td>2007</td>
<td>Randomized Controlled Trial</td>
<td>To receive either a single, one-on-one educational-counselling interview and an appointment at a “lifestyle class” or usual care (brief discussion of stroke and access to pamphlets). The primary outcome was knowledge acquisition and retention at 3 months. Stage of change was also assessed.</td>
<td>There was a significant between group difference for stroke knowledge (symptoms, risk factors and actions) at three-months (p&lt;0.001) adjusting for baseline knowledge scores. There was shift from passive to active change for the whole sample, but there was no significant between-group difference noted for this variable.</td>
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<tr>
<td>Oupra et al. (2010) Australia &amp; Thailand No Score</td>
<td>140 patients with stroke &amp; their family caregivers were recruited and assigned to receive either the Supportive Educative Learning Program (SELF – n=70 patient/caregiver pairs) or usual care (n=70 patient/caregiver pairs). Intervention &amp; control conditions were conducted at separate facilities. Caregivers enrolled in the SELF program participated in 3 group sessions containing a combination of didactic teaching, demonstration and hands-on learning as well as written materials. After discharge, intervention caregivers were contacted via telephone once per month for three months. Outcomes included patient psychological health (GHQ-28) and the Caregiver Strain Index (CSI). Assessments were administered at discharge and 3-month follow-up.</td>
<td>Both groups demonstrated significant improvement in psychological health (GHQ-28 scores) from discharge to follow-up (p&lt;0.001); however, caregivers in the intervention group had better GHQ scores at both discharge and follow-up than caregivers assigned to the control condition (p=0.006 &amp; p&lt;0.001, respectively). Caregivers in both groups demonstrated a significant reduction in strain over time (p&lt;0.001, both groups). Assignment to the control group was associated with greater strain than intervention at both assessment points (p&lt;0.001 at discharge and follow-up).</td>
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<tr>
<td>Bakas et al. (2009) USA 6 (RCT)</td>
<td>Within one month of discharge home, 50 patients and their carers were randomly assigned to either the TASK intervention group or an attentional control</td>
<td>2009</td>
<td>Randomized Controlled Trial</td>
<td>Outcomes were not assessed over time, rather 3 separate analyses were conducted at each of the 3 assessment points. Relative to the control</td>
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At baseline, a TASK notebook (tip sheets for skill-building, stress management workbook, brochure on family caregiving) was sent to TASK participants. Caregivers received 8 weekly calls from a trained TASK nurse who facilitated weekly assessments of skill needs and gave individualized assistance based on skills identified as important by the carer. Participants assigned to the attention control group received only the brochure on family caregiving and 8 weekly calls from a nurse who engaged in active listening, but offered no advice or information. 6 study outcomes (optimism, task difficulty, threat appraisal, depressive symptoms, life changes and perceived general health) were assessed at 4, 8 and 12 weeks.

| **Perrin et al. (2010)** | 61 carer/patient dyads from either Puerto Rico or Texas were randomly assigned to either the Transition Assistance Program (TAP) or usual care. The TAP is described as a brief intervention with 3 elements: skill development, education, supportive problem-solving (via videophone). Just prior to discharge, participants received one face-to-face interview with a clinical interventionalist, followed by 4 videophone contacts with carers (one call in each of weeks 1, 2, 4 and 6). The principle educational tool used was “A Guidebook for Caregivers of Veterans Post Stroke”. Outcomes included caregiver strain (Caregiver Strain Index), depression (CES-D), satisfaction with the use of telehealth technology and veteran functional status (FIM and FONE-FIM). Assessments were conducted at baseline, 1 and 3 months post-discharge. |
| **Cadilhac et al. (2011)** | Individuals with stroke (n=143) were recruited from 7 hospitals and were randomly assigned to attend either a stroke specific self-management program (SSMP) (n=48), a generic self-management program (n=47), or be given access to information and education provided by the hospital team or GP (n=48). The SSMP was an 8-week program facilitated by health professionals and peer leaders. Participants (and informal carers if they elected to attend) engage in skill development through practical problem-solving, identification and use of available resources and behavioural change. Topics/information is specific to the experience of stroke. The 6-week generic program covered a range of topics, but was not stroke specific. In addition to feasibility outcomes, assessment of positive/active life engagement, quality of life and mood (Irritability, depression and anxiety) was conducted at baseline, 2-4 weeks and 6 months. |

There were no significant treatment effects on depression associated with the TAP program, although participation in the program may have had some minor positive effect on individuals who scored above the threshold for possible depression on the CES-D administered at baseline. There was a significant between-group difference in change in carer strain between 1 and 3 months, such that individuals assigned to the TAP program experienced a decrease in reported strain while individuals in the control group reported increased strain (p=0.01). Within the treatment group, satisfaction with the TAP program was inversely correlated with strain and depression in caregivers (r = -0.44 and 0.53, p<0.01). Patient function was similarly correlated with carer satisfaction with the TAP program.

<p>| <strong>Cadilhac et al. (2011)</strong> | 52% of participants with stroke were able to complete the SSMP vs. 38% for the generic intervention (p=0.18). Attendance by informal carers was not reported. Improvements in all health domains were noted for participants in all 3 conditions. There were no significant differences between groups in terms of positive life engagement, quality of life or mood. Examination of effect sizes revealed larger positive effects (indicative of benefit) associated with treatment for individuals in the SSMP and generic programs than those in the control condition. In terms of positive/active engagement, effect sizes were 1.47 and 0.66 for the SSMP and generic programs, respectively. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Design</th>
<th>N (Exp)</th>
<th>N (Cont)</th>
<th>Age (Mean ± SD)</th>
<th>Gender</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>King et al. (2012)</td>
<td>USA</td>
<td>RCT</td>
<td>255</td>
<td>255</td>
<td>67.0 ± 12.2</td>
<td>Male=126, Female=129</td>
<td>Intervention (n=136) or control (n=119) group. The intervention was a caregiver problem solving intervention (CPSI) that involved 10 sessions with a clinical psychology student (advanced) and focused on skills for problem solving and coping with stressors of caregiving. The control group was a wait-list group that received usual care. Outcomes were assessed at baseline, 3-4 months after discharge, 6 months, and 12 months after discharge. Caregivers were assessed for depression (CES-D), perception of Life Change (BCOS), preparedness (Preparedness for caregiving scale), and family functioning (General functioning scale of the McMaster Family Assessment Device). The mediator and moderator variables of these outcomes included caregiver perceived health, resources and stressors, appraisal of caregiving and coping with problem solving.</td>
<td>There were no significant differences in outcomes between the intervention and control group. The mediator variable, caregiving appraisal (threat appraisal domain) was significantly associated with greater depression and anxiety, less preparedness and more negative perceived life change. (p&lt;0.0001). At 3-4 months after discharge (time 2), caregivers in the intervention group experienced significant lower levels of depression and improved health and perceived caregiver outcomes compared to wait-list controls. These differences were not maintained at 6 or 12 months.</td>
<td></td>
</tr>
<tr>
<td>Eames et al. (2013)</td>
<td>Australia</td>
<td>RCT</td>
<td>138</td>
<td>138</td>
<td>67.4 ± 12.1</td>
<td>Male=106, Female=32</td>
<td>Intervention</td>
<td>Stroke knowledge as measured by the 25-item Knowledge of Stroke questionnaire was the primary outcome of the study. Secondary outcomes included self-efficacy (using the Self-efficacy to Perform Self-Management Behaviour), anxiety and depression (Hospital Anxiety and Depression Scale - HADS), patient quality of life (using the Stroke and Aphasia specific quality of life scale – SAQOL-39g), and caregiver burden (Caregiver Strain Index). Outcomes were assessed pre-discharge and at 3 month follow-up.</td>
<td>Data were combined for stroke survivors and their caregivers. Participants in the intervention group experienced statistically significant increases in self-efficacy for accessing stroke information, had greater feelings of being informed and had more satisfaction with information received on all levels. The primary outcome, stroke knowledge, was not significantly different between the groups, nor was level of anxiety, depression, quality of life or caregiver burden.</td>
</tr>
<tr>
<td>Aguirrezabal et al. (2013)</td>
<td>Spain</td>
<td>RCT</td>
<td>76</td>
<td>74</td>
<td>68.0 ± 12.6</td>
<td>Male=53, Female=23</td>
<td>Population: Experimental Group (EG, N=76): Mean age=68.05±12.2yr; Gender: Male=53, Female=23. Control Group (CG, N=74): Mean age=65.4±12.14yr; Gender: Male=52, Female=22. Intervention: The EG attended an educational session consisting of information and a caregiver training class provided by a multi-disciplinary team along with a clinical patient guidebook given to all patients. The CG received information and support upon request without coordination from physicians and therapists. The intervention lasted 2hrs and was provided once only. Assessments were conducted at baseline and at 6m follow-up.</td>
<td>1. HomeSat ratings of satisfaction after discharge were significantly higher for the EG in regards to amount of information received, community support, hospital contact (all p&lt;0.001) and preparation for returning home (p=0.03) compared to the EG at 6m follow-up. 2. HomeSat total ratings were significantly higher in the EG compared to the CG at 6m follow-up (p=0.001). 3. Caregiver satisfaction was significantly higher for the EG on all three satisfaction questions compared to the CG caregivers at</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Language</td>
<td>Design</td>
<td>Scores</td>
<td>Participant Data</td>
<td>Intervention</td>
<td>Outcomes</td>
<td>6m follow-up (all p&lt;0.001).</td>
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<tr>
<td>Godwin et al. (2013b) USA</td>
<td>Pre-Post</td>
<td>No Score</td>
<td>TPS_{mean} = NA</td>
<td>N_{start} = 159</td>
<td>Population: Intervention Group (N=159): Mean age=66.4±9.14yr; Gender: Male=119, Female=60.</td>
<td>Intervention: The intervention group received an educational program focusing on recovery, skill training, counseling, and community resources. The length and frequency of the intervention was not noted. Assessments were conducted at baseline, 6m and 12m follow-ups. Outcomes: Mutuality Scale (MS); Perceived Stress Scale (PSS-10).</td>
<td>1. MS scores were significantly higher among patients compared to their caregivers (p&lt;0.0001) over all time-points. 2. PSS-10 scores were significantly lower among patients compared to their caregivers (p=0.0001) over all time-points. 3. PSS-10 scores for caregivers who completed the 12m follow-up were significantly higher at baseline compared to caregivers who withdrew from the study at baseline and 6m follow-up (p=0.02). 4. MS scores among caregivers was significantly associated with caregivers’ PSS-10 scores (p&lt;0.0001). 5. PSS-10 scores for patients was significantly associated with caregivers’ PSS-10 scores (p=0.047).</td>
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<td></td>
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<tr>
<td>Mores et al. (2013) Canada</td>
<td>Observational</td>
<td>No Score</td>
<td>TPS_{mean} = NA</td>
<td>N_{start} = 11</td>
<td>Population: Mean age=58yr; Gender: Males=1, Females=10.</td>
<td>Intervention: A semi-structured focus group was conducted 1m after the end of the Family Informal Caregiver Stroke Self-Management (FICSS) program. Program facilitators evaluated each module at the end of each session and a completed a summative review at the end of the program. Outcomes: Oberst Caregiving Burden Scale (OCBS: time subscale), Perceived program impact, timing of the program, overall program evaluation.</td>
<td>1. Average OCBS score was high (44/75), indicating that caregivers were providing an extensive amount of care to the stroke survivors. 2. Program helped to improve caregiver and stroke survivor quality of life. 3. Caregivers were satisfied with the length of each FICSS session and duration of the program. Suggestions included; the utilization of afternoon or evening sessions, the use of various times throughout the day, and the need for the program to be offered as soon as possible. 4. The focus group recommended the following changes to the program: removing homework, offering community resources earlier in the program, removal of sexuality component and its replacement with more important topics, and a less structured format. Evaluation by program facilitators agreed and went further regarding the program content, resources and exercises, participant and facilitator manuals, and overall program facilitation.</td>
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<tr>
<td>Danzl et al. (2013) USA</td>
<td>Qualitative Descriptive Study</td>
<td>No Score</td>
<td>TPS_{mean} = 3.6yr</td>
<td>N_{start} = 25</td>
<td>Population: Stroke Survivor Group (SS, N=13): Mean age=63.4yr; Gender: Males=4, Females=9. Caregiver Group (CG, N=12): Mean age=55.9, Gender: Males=5, Females=7.</td>
<td>Intervention: In order to describe the experience of stroke for survivors and their caregivers in the rural Appalachian Kentucky region, semi-structured, open-ended interviews were conducted with the stroke</td>
<td>1. Stroke onset  • There was a lack of knowledge of stroke prevention and warning symptoms  • Lack of access to emergency services  • Distrust in local health care services 2. Transition through the health care continuum  • Acute care</td>
<td></td>
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</tbody>
</table>
Community Reintegration

Outcomes: Summary of participants’ experiences of stroke through the following structure: stroke onset, transition through the health care continuum (acute care, inpatient rehabilitation, and community-based rehabilitation), and reintegration into life and their rural community.

- Those that could remember described the value of emotional support from social networks and from health care providers
- There should be careful consideration of the language used when describing the stroke
- Inpatient rehabilitation
  - Some participants were released home directly from acute care and found they were unprepared to deal with their condition
  - Interaction with other people with stroke and the health care providers who were knowledgeable about stroke helped SSs avoid feelings of isolation from their usual social circles
- Community-based rehabilitation
  - Sharp decline in support from health care system
  - Challenges in accessing emergency care extended to rehabilitation services in rural areas
  - Patients were often unaware of local or online resources and access to the proper services usually came from knowing the right people
  - Most important need in local community-based rehabilitation was psychological support
  - Some participants had difficulty adapting and felt a loss of freedom/independence while living in a skilled nursing facility
  - Nursing facilities led to feelings of guilt and distrust of care providers by the SS’s caregivers

3. Reintegration into life and rural communities

- Slow physical recovery and challenges resuming previous roles lead to loss of personal identity
- Hobbies/activities were difficult due to residual physical/cognitive deficits and lack of support from the community
- Nonexistent respite services for caregivers
- Coping mechanisms included: prayer, having a positive outlook, goal setting, and embracing/modifying past roles
- Positive community support facilitated
**Pringle et al.** (2013)  
UK  
Qualitative  
No Score  
TPS$_{meas}$=NA  
N$_{start}$=12  
N$_{end}$=12  

**Population:** Stroke Survivor Group (SSG, N=12): Age range=47-82yr; Gender: Males=7, Females=5. Carer Group (CG, N=12): Age range=25-81yr; Gender: Males=2 (1 survivor nominated 2 carers), Females=11.  
**Intervention:** Data was collected through participant diaries for up to 1mo after discharge as well as interviews 1mo after discharge to raise awareness of the support healthcare workers can provide stroke survivor (SS)/carer dyads during this time.  
**Outcomes:** Thematic analysis.  

1. Revisioning  
   - Altered concept of Image and identity  
   - Alternating focus and a new reality  
2. Reconnecting  
   - With the past/past self  
   - With choice and control  
3. Revisiting-helped participants to make sense of their situation  
   - The stroke event  
   - Previous life  

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**Cobley et al.** (2013)  
UK  
Qualitative  
No Score  
TPS$_{meas}$=NA  
N$_{start}$=19  
N$_{end}$=19  

**Population:** Mean age=69.85±13.42yr; Gender: Males=13%, Females=87%.  
**Intervention:** To determine patients’ and carer’s experiences of Early Supported Discharge services and inform future Early Supported Discharge service development and provision.  
**Outcomes:** Themes that were common to participants receiving Early Supported Discharge Services.  

1. Themes specific to participants receiving Early Supported Discharge services were:  
   - the home-based form of rehabilitation; speed of response; intensity and duration of therapy; respite time for the carer; rehabilitation exercises and provision of technical equipment; disjointed transition between Early Supported Discharge and ongoing rehabilitation services.  
2. Participants receiving Early Supported Discharge or conventional community services experienced difficulties related to:  
   - limited support in dealing with carer strain;  
   - lack of education and training of carers;  
   - inadequate provision and delivery of stroke-related information;  
   - disjointed transition between Early Supported Discharge and ongoing rehabilitation services.  

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**Hebel et al.** (2014)  
Poland  
Cohort  
No Score  
TPS$_{exp}$=NA  
TPS$_{con}$=NA  
N$_{start}$=243  
N$_{end}$=157  

**Population:** Experimental Group (EG, N=Unspecified): Median age=72yr; Gender: Unspecified. Control Group (CG, N=Unspecified): Median age=72.5yr; Gender: Unspecified.  
**Intervention:** The EG and their families received an educational program that consisted of a presentation and training in patient positioning and position-changing techniques. The CG did not receive any educational material. The intervention was provided two times with each session lasting 2hrs. Assessments were conducted at baseline, 3m and 12m follow-ups.  
**Outcomes:** Barthel Index (BI); Modified Rankin Scale (MRS); Nottingham Extended Activity of Daily Living Index (NEADL).  

1. BI median scores were significantly different between the two groups at baseline (p=0.02).  
2. MRS median scores did not differ significantly between the EG and CG at 3m follow-up (p=0.18) but both groups improved from baseline to 3m follow-up (p<0.002 and p<0.005 respectively).  
3. BI median scores did not differ significantly between the EG and CG at 3mo follow-up (p=0.07) but both groups demonstrated a significant increase from baseline to 3m follow-up (both p<0.001).  
4. NEADL median scores differed significantly between the EG and CG (p=0.004) at 3m follow-up.  
5. MRS median scores did not differ significantly between the EG and CG at 12m follow-up (p=0.53) but both groups
**Stone et al.** (2014)  
**USA**  
Pre-Post  
No Score  
TPS\_mean=NA  
N\_start=70  
N\_end=30  

**Population:** Stroke Group (N=36/70): Age range=18-34yr; Gender: Males=25/70, Females=45/70.  
**Intervention:** A website was provided to caregivers (CGs) with resources and e-mail access to a rehabilitation nurse practitioner. CGs were assessed before and after the utilization of the website.  
**Outcomes:** Preparedness for Caregiver Scale (PCS); Client Satisfaction Questionnaires (CSQ).  

1. No significant relationships were found for the following: CG and patient age or gender, CG and patient experience with computer, amount of assistance patients needed, or the number of times accessed internet.  
2. The use of the website was found to improve scores on questions 1-3, 7-8, and the summary scale (Q1: How well prepared do you think you are to take care of your family member’s physical needs?; Q2: How well prepared do you think you re to take care of his or her emotional needs?; Q3: How well prepared to you think you are to find out about and set up services for him or her?; Q7: How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?; Q8: How well prepared do you think you are to respond to and handle emergencies that involve him or her?).

**Muller et al.** (2014)  
**USA**  
Pre-Post  
No Score  
TPS\_range <1yr to 8yr  
N\_start=23  
N\_end=13  

**Population:** Mean age=32yr; Gender: Males=10, Females=3.  
**Intervention:** The Young Empowerment Stroke Support (YESS) Program is a hospital-based program that is based on occupational therapy principles, designed to provide support and education for younger individuals with stroke. The YESS group met 9x over 18 weeks for 6 months.  
**Outcomes:** Socialization, healthy coping, and role attainment: Stroke Impact Scale (SIS); Community Integration Questionnaire (CIQ); and a member satisfaction questionnaire.  

1. Changes in the SIS handicap domain reached statistical significance (p=0.034), and also the CIQ total score (p=0.028) and the home integration domain (p=0.002).  
2. The post group survey collected descriptive data about social and communication activity outside of the group context and its results showed that half of individuals reported interaction with another member outside of the group context via text, Facebook, phone, in-person, or email. These findings were important since one of the goals of establishing the group was for encouragement of social and community participation inside and outside the group context.  
3. Over half of the group members reported they engaged in various leisure and ADL
opportunities outside of the group context, and also reported socialization as a favorite aspect of the group process.

4. Participants indicated that the most useful aspects of the group process was learning about new information, education, and information on community resources.

19.3 Leisure

19.3.1 Social and Leisure Activities Post Stroke

<table>
<thead>
<tr>
<th>Author, Year Country</th>
<th>PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lawrence and Christie</strong> (1979) Australia No Score</td>
<td>45 people who had suffered a stroke 3 years previously and their close relatives and friends were interviewed about life changes attributed to the stroke.</td>
<td>Deterioration of interpersonal relationships was reported; 70% viewed their future with uncertainty or gloom; physical disability in itself was less important than people’s response to their disability. Inappropriate and dysfunctional responses were present in over half the group.</td>
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<tr>
<td><strong>Labi et al.</strong> (1980) USA No Score</td>
<td>121 stroke survivors and 141 controls with minimum score of 20.0 on the Kenny self-care evaluation were tested on three parameters of social function – socialization in the home, socialization outside the home and hobbies and interest – to determine social reintegration of long-term survivors of a completed stroke.</td>
<td>A significant proportion of survivors manifested social disability, despite complete physical recovery. Age, physical impairment or specific neurological deficits could not account for most of the disability. The greatest social functioning impairments were seen in women and those of higher educational background.</td>
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<tr>
<td><strong>Belcher et al.</strong> (1982) USA No Score</td>
<td>An exploratory study of the social-leisure levels of 42 married and 31 single individuals after stroke. Patients were studied using the Activity Pattern Indicator.</td>
<td>Single patients demonstrated greater levels of participation in performing personal care, home management and social interaction activities.</td>
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<tr>
<td><strong>Feibel and Springer</strong> (1982) USA No Score</td>
<td>91 stroke patients were assessed for physical independence in activities of daily living and mobility via the Katz Index, and, depression by nurses’ observation, patient’s mood, behaviour, somatic complaints and number of social activities.</td>
<td>Incidence of depression was 26% 6 months after stroke. Depression was significantly correlated with failure to resume premorbid social activities. Depressed patients lost a mean of 67% of their previous activities. Depression status was not significantly correlated to age, sex, marital status or side of brain involvement.</td>
<td></td>
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<tr>
<td><strong>Putterill et al.</strong> (1984) Australia No Score</td>
<td>41 patients were assessed via a standard questionnaire to evaluate problems experienced after stroke.</td>
<td>Most patients were found to be unoccupied during the day, even in mobile patients.</td>
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<tr>
<td><strong>Davidson and Young</strong> (1985) USA No Score</td>
<td>29 stroke patients living in private homes for 1 to 7 or 12 to 18 months were interviewed in their homes with a 16 question interview form to determine the patient’s evaluation of his/her ability to function since discharged to home.</td>
<td>Inability to resume former social activities was reported by 38% of the patients. None of the patients had become involved in any new activities and 58% of patients reported feeling lonely. Life after stroke was rated to be of poorer quality than before by 86% of the</td>
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<tr>
<td>Study</td>
<td>Country</td>
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<td>Belanger et al. (1988)</td>
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<td>Young et al. (2001)</td>
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<td>Sveen et al. (2004)</td>
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<td>Schepers et al. (2005)</td>
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<td>Boosman et al. (2011)</td>
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<tr>
<td>No Score</td>
<td>satisfaction) the social Support List – interaction (level of social support), the Barthel index (ADL-dependency), the MMSE (cognitive impairment) and the Frenchay Activities Inventory (participation in social activities).</td>
<td>Overall, individuals in the socially inactive group were significantly less satisfied with their sexual lives, self-care ability and leisure situation. On logistic regression, social activity (assessed by the FAI) was a significant predictor of life satisfaction (OR = 1.07, 95% CI 1.01-1.12)</td>
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<tr>
<td>Kwok et al. (2011) Hong Kong No Score</td>
<td>Individuals with stroke were interviewed at 3 and 12 months post stroke to examine the association between HRQOL and participation domains (as specified in the London Handicap Scale – LHS). At each assessment, the BI, LHS, WHO-QOL (4 domains: physical health, psychological health, social interaction and environment), GDS and MMSE were administered.</td>
<td>The independence and social integration domains of the LHS were significantly associated with the physical and social domains of the WHO-QOL, respectively, at both 3 and 12 month assessments. LHS occupation was not significantly associated with QOL domains at 3 months; however, at 12 months there were significant associations demonstrated between LHS occupation and both the physical and environmental domains of QOL. It is of note that scores on the Geriatric Depression Scales were significantly associated with all QOL domains at both 3 and 12 month assessments.</td>
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<tr>
<td>Eriksson et al. (2012) Sweden No Score</td>
<td>161 individuals with stroke were assessed at baseline (in hospital) and 12 months post stroke (at home) using the BI, Katz ADL index, Occupational Gaps Questionnaire (OGQ), the SIS and the Life Satisfaction Scale (LiSat-11). For the OCQ, a gap was identified for each activity in which there was a discrepancy between the 2 questions; 1) Do you perform the activity now? and 2) Do you want to perform the activity now? 28 activities were included on the OGQ (8 IADLs, 6 social activities, 10 leisure activities and 4 work-related activities).</td>
<td>At 1-year post stroke, 87% of respondents reported occupational gaps. There was a median of 3 gaps per person (range 0-22). 39% of all reported gaps were in the leisure domain. Most frequent gaps identified were for sports, outdoor life and travelling for pleasure. The number of gaps was associated with global life satisfaction (r=0.41) and with satisfaction with leisure specifically (r=0.46). However, there was no significant difference in number of identified occupational gaps between those who reported high life satisfaction and those with low global life satisfaction. Individuals who were independent in ADLs had significantly fewer gaps than those who were not independent (p&lt;0.001 – BI; p&lt;0.001 – Katz ADL).</td>
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<tr>
<td>Berges et al. (2012) US No Score</td>
<td>605 stroke survivors (age &gt;50 years) participated in this prospective cohort study. Data was collected within 72 hours of discharge from inpatient rehabilitation and at 3 months post discharge. Affect was measured using the CES-D and social participation was measured using 4 items taken from the PAR-PRO Measure of Home and Community Participation.</td>
<td>For each one point increase in positive affect, a significant association of 21% increased odds of being in a higher social participation category (OR=1.21, 95%CI: 1.15-1.27). A fully adjusted model remained significant and showed a 17% increase in the odds of being in a higher social participation category (OR=1.17, 95%CI: 1.10-1.25)</td>
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<tr>
<td>Jansen et al. (2012) Netherlands No Score</td>
<td>This prospective cohort study included information from 308 participants with first ever stroke, 190 of whom had complete data and were included in the final analysis. Participants all lived at home, and were assessed at 1 and 3 years post stroke using the Frenchay Activities Index (FAI) as a measure of social activity.</td>
<td>No significant change in FAI score was found between 1 and 3 year follow up. 76.3% of participants maintained their level of activity between 1 and 3 years, 11.6% declined in activity, and 12.1% had an increase in activity level between time points. Predictors of FAI decline were impaired MI leg (OR=0.39, 95%CI: 0.15-0.97) and being socially inactive at 1 year (OR=0.19, 95%CI: 0.04-0.84)</td>
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<tr>
<td>Wolf et al. (2012) US No Score</td>
<td>A cross sectional design was implemented to examine differences in activity participation between younger (&lt;65 years) and older (≥65 years) stroke survivors. 177 individuals were included in the study. Participants completed</td>
<td>There was a significant difference in both the quantity and nature of activities between groups (high demand, low demand, instrumental activity, and social activity) both prior to stroke and currently, with the younger cohort reporting increased frequency of activities in</td>
<td></td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Study Design</td>
<td>Score</td>
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<td><strong>van der Zee et al. (2013)</strong>&lt;br&gt;Netherlands</td>
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<td><strong>O’Connell et al. (2013)</strong>&lt;br&gt;Ireland</td>
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<td><strong>Jean et al. (2013)</strong>&lt;br&gt;France</td>
<td>Observational</td>
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<tr>
<td><strong>White et al. (2014)</strong>&lt;br&gt;Australia</td>
<td>Observational</td>
<td>No Score</td>
<td>TPS</td>
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### Walsh et al. (2015)

**Ireland**
**Observational**
**No Score**

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<th>TPS</th>
<th>Mean = 28 (IQR = 38) mo</th>
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<tr>
<td>N(_{\text{Start}})</td>
<td>196</td>
</tr>
<tr>
<td>N(_{\text{End}})</td>
<td>196</td>
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</tbody>
</table>

**Population:** Mean Age = 61.9 ± 13.9; Gender: Males = 115, Females = 77, Not Specified = 4.

**Intervention:** Adult stroke survivors living in their own home within the community were surveyed to assess self-reported need in relation to stroke recovery and community re-integration.

**Outcomes:** Irish-adapted questionnaire (information about stroke; health after stroke; everyday living; work and leisure; family; friends and use of supports groups; personal and household finances).

1. Emotions (53%). Fatigue (52%), and Concentration (48%) were reported as having the highest levels of need.
2. No significant difference was found for time since stroke between those who reported multiple unmet needs and those who reported one or no unmet needs.
3. Individuals who returned to driving were significantly more likely to live in a rural area (p = 0.03) and be independent with personal care post-stroke (p = 0.001).

### Zhang et al. (2015)

**China**
**Observational**
**No Score**

<table>
<thead>
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<th>TPS</th>
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<tr>
<td>N(_{\text{End}})</td>
<td>639</td>
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</tbody>
</table>

**Population:** Mean Age = 69 ± 11 yr; Gender: Males = 442, Females = 197.

**Intervention:** Community-dwelling stroke survivors in rural areas were interviewed to investigate the impact of environmental barriers on activity and participation.

**Outcomes:** World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0); 12-item Craig Hospital Inventory of Environmental Factors (CHIEF); Canadian Neurological Scale (CNS); Abbreviated Mental Test (AMT); Hamilton Rating Scale for Depression (HRSD).

1. Physical/structure barriers were significantly associated with decreased activity (OR = 1.86, p = 0.004) and participation (OR = 1.99, p = 0.001).
2. Attitudinal/support barriers and policy barriers were not significantly associated with changes in activity or participation.
3. Service/assistance barriers was significantly associated with decreased participation (OR = 1.58, p = 0.12) but not activity.
4. CNS, AMT, HRSD, and Living alone were significantly correlated with activity and participation (p < 0.05).

### Rozon et al. (2015)

**Canada**
**Observational**
**No Score**

<table>
<thead>
<tr>
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</thead>
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<tr>
<td>N(_{\text{Start}})</td>
<td>186</td>
</tr>
<tr>
<td>N(_{\text{End}})</td>
<td>138</td>
</tr>
</tbody>
</table>

**Population:** Mean Age = 63.3 ± 12.5 yr; Gender: Males = 105, Females = 81.

**Intervention:** Patients from 11 hospitals in Canada with a first mild stroke were interviewed at 1 mo, 6 mo, and 1 yr post-stroke to explore changes in sleep, driving, employment relationships, and leisure.

**Outcomes:** Assessment of Life Habits 3.1 (LIFE-H 3.1) items: Sleep, Driving a vehicle, Interpersonal relationships category, Having a sexual

1. Adjusting for age and gender, driving a vehicle, having interpersonal relationships, holding a paid job, and participating in recreational activities demonstrated a significant probability of obtaining a perfect score on the LIFE-H from 1mo to 6mo.
2. From 1mo to 1yr after adjusting for age and gender, driving a vehicle, having interpersonal relationships, having a sexual relationship, holding a paid job, and participating in sports and recreation showed a significant probability of
relationship, Holding a paid job, Participating in sports/recreational activities, Beck Depression Inventory-II (BDI-II).

obtaining a perfect score on the LIFE-H.

3. Male gender was shown to be significant in obtaining a perfect score regarding sleep, driving, and holding interpersonal relationships.

4. Age was shown to be significant in the probability of obtaining a perfect score regarding having a sexual relationship.

5. The presence of depressive symptoms were significant predictors of obtaining a perfect score on the LIFE-H regarding driving, holding an interpersonal relationship, holding a paid job and participating in sports.

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**Zhang et al. (2016)**
China Observational No Score

<table>
<thead>
<tr>
<th>TPStart=NA</th>
<th>NEnd=818</th>
</tr>
</thead>
</table>

**Population:** Mean Age=69yr; Gender: Males=541, Females=277.

**Intervention:** Community-dwelling stroke survivors in rural China were interviewed and observed to explore which home barriers are associated with social isolation.

**Outcomes:** Social isolation indicators; Home fall hazards assessment; World Health Organization Disability Assessment Schedule 2.0 (WHODAS)

1. After adjusting for confounders, distant toilet (OR=2.36, p<0.001), unsuitable seat (1.57, p=0.038), and inaccessible light switches (1.57, p=0.02) were found to be significantly associated with social isolation.

2. Other factors in the home fall hazards assessment were not found to be significant predictors.

3. Severely impaired cognition (OR=2.23, p=0.001), severely impaired mobility (OR=10.97, p<0.001), and severely reduced self-care ability (p=5.64, p<0.001) were significantly associated with social isolation.

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**Akosile et al. (2016)**
Nigeria Observational No Score

<table>
<thead>
<tr>
<th>TPStart=NA</th>
<th>NEnd=71</th>
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</thead>
</table>

**Population:** Mean Age=64.14±10.26yr; Gender: Male=35, Female=36.

**Intervention:** Community dwelling stroke survivors were surveyed to determine associations of the level of satisfaction with community reintegration (measured using the Reintegration to Normal Living Index (RNLI)) with related factors.

**Outcomes:** Age; Post-stroke duration; Level of support from community; Level of support from family; Gender; Hypertension; Diabetes Mellitus; Assess to physiotherapy; Pre-stroke employment status (Employed, Self-employed, Unemployed); post-stroke employment status (Employed, Self-employed, Unemployed); Usage of assistive mobility devices (Cane, Wheelchair, Zimmer’s frame, Nil); Marital status (Married, Divorced, Separated); Support from family (High, Moderate, Low); Support from family (High, Moderate, Low).

1. Factors significantly correlated with RNLI: Age (p=0.003); Diabetes Mellitus (p=0.005); Pre-stroke employment status (p=0.047); Post-stroke employment status (p=0.000) Usage of assistive mobility devices (p=0.000); Support from community (p=0.028).

2. Factors not significantly correlated with RNLI: Post-stroke duration; Level of support from community; level of support from family; Hypertension; Access to physiotherapy, Marital status, Support from family.

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**Norlander et al. (2016)**
Sweden Observational No Score

<table>
<thead>
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<th>TPStart=NA</th>
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</thead>
</table>

**Population:** 10-year follow-up: Mean Age=76yr; Gender: Males=86, Females=59.

**Intervention:** Patients with first-ever stroke were enrolled and surveyed at baseline, 16 months and 10 years to identify predictors of frequency of social and leisure activities.

**Outcomes:** Frenchay Activities Index (FAI)-community subscale, FAI-social and civic life subscale (FAI-CSC); Body functions: Mini-Mental

1. After 10 years, cognitive impairment (MMSE; p=0.025), depressed mood (GDS-20; p=0.005), impaired motor function related to stroke (p=0.002), urinary incontinence (Bl item; p=0.004), driving a car (p=0.001), frequency of exercise (p=0.002), mobility (p=0.001), carrying out pre-stroke interests (p<0.001), health condition limiting mobility (SF36; p<0.001), age (p<0.001), social anchorage outside of the household contact.
19. Community Reintegration

State Exam (MMSE), Geriatric Depression Scale (GDS-20), impaired motor function related to stroke, difficulty speaking, getting angry, pain, feeling of being tired, Barthel Index (BI) urinary incontinence item; Activities and participation: driving, using public transit, frequency of exercise, mobility, carrying out pre-stroke interests, Short Form Health Survey-36 (SF36); Personal factors: living situation, main occupation, support, rehabilitation, social anchorage outside of household.

frequency and extent of network (p=0.002, p<0.001) were significantly correlated with FAI-CSC.

19.3.2 Leisure Interventions and Social Participation

Table 19.3.2 Leisure Therapy Interventions

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jongbloed and Morgan (1991) Canada 6 (RCT)</td>
<td>40 stroke patients were randomized to receive either an occupational therapy intervention (aimed at resuming former leisure therapy, engaging in new activities or both), or to receive OT visits (asked questions about leisure activity involvement throughout the life span). Patients visited by the OT for 5 hour long sessions at the patients’ home over 5 consecutive weeks.</td>
<td>No significant difference was reported between the intervention and control groups in activity involvement or satisfaction with involvement.</td>
</tr>
<tr>
<td>Drummond &amp; Walker (1995) UK 6 (RCT)</td>
<td>65 patients were randomized to receive either leisure therapy or conventional occupational therapy by a therapist for a minimum of 30 minutes a week for the first 3 months following discharge and then 30 minutes a fortnight for the next three months or to receive no additional input over that which they were receiving from hospital and social services.</td>
<td>Those receiving leisure therapy showed greater leisure scores than those in the conventional therapy group at 6 months and also when compared to the controls at 6 months. No differences were found between groups on motor performance and functional performances at discharge</td>
</tr>
<tr>
<td>Parker et al. (2001) UK 6 (RCT)</td>
<td>This is a multi-centre trial with 466 patients randomized to three groups. Two treatment groups received occupational therapy (OT) interventions at home for up to 6 months with a minimum of 10 sessions lasting not less than 30min. The ADL group treatment goals were set in terms of improved independence in self-care task. Leisure group goals were to improve leisure activity and intervention included practising the leisure activity and the ADL</td>
<td>No significant differences were found between groups on any of the outcome measures.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Score</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------</td>
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</tr>
<tr>
<td>Parker et al. (2004)</td>
<td>UK</td>
<td>6 (RCT)</td>
</tr>
<tr>
<td>Eng et al. (2004)</td>
<td>Canada</td>
<td>No Score</td>
</tr>
<tr>
<td>Lai et al. (2004)</td>
<td>China</td>
<td>No Score</td>
</tr>
</tbody>
</table>
**Community Reintegration**

Home visits. The leisure intervention consisted of 12 steps (roughly equivalent to sessions) to address 3 components (leisure awareness, self-awareness & competency development) in the promotion of personal empowerment to improve leisure experiences. Primary study outcome was HRQOL and general well-being. Leisure related outcomes included participation (duration & number) in passive & active leisure activities and satisfaction with leisure.

Leisure Satisfaction Scale were significantly greater among individuals in the intervention group vs. controls (p=0.003); however, there was no between group difference in satisfaction with use of spare time. Although there were increases in well-being and HRQOL over time, there was no significant between group differences noted. In the intervention group, depressive symptomatology decreased over time (p<0.01), and at the end of the program, less symptomatology was associated with treatment (p=0.01).

**Mead et al. (2007)**

UK 8 (RCT)

66 individuals with stroke who had been discharged from inpatient rehabilitation and had no significant dysphasia or cognitive impairment and were able to participate in exercise were randomly assigned to intervention (group exercise, n=32) or control (relaxation, n=34) groups. All sessions were conducted 3 times per week for 12 weeks; each session lasted approximately 1 ¼ hours including a “tea & chat” time. Exercise training included both endurance and resistance training that was graded in difficulty from baseline to completion. Relaxation included deep breathing and progressive relaxation techniques. Contraindications were omitted to avoid possible confounding with exercise. Outcomes were assessed at baseline, program completion and at 7-month follow-up. Assessments included evaluations of physical function in addition to Extended Activities of Daily Living (Nottingham EADL) and HRQOL (SF36).

There were no significant between group differences in participation as assessed on the NEADL at either 3 months or 7 months. The only significant differences between groups identified on the SF36 were for the “Role Physical” subscale which suggested significant improvements in favour of the intervention at both assessment points (p=0.002 & p=0.04, respectively). Unfortunately, analysis of SF-36 social functioning was not possible given 54% ceiling effect noted on baseline assessment. Given the inclusion criteria, study participants were experiencing relatively mild functional impairments (mean FIM at 3 months = 118.2, 95% CI 116.9-199.3 in the exercise group and 118.3, 95% CI 117.1-199.4 in the relaxation group).

**Huijbregts et al. (2008)**

Canada No Score

30 individuals with stroke chose to participate in either the MOST program (Moving On after Stroke) or the Living with Stroke (LWS) program (a standard, community-based, group education program). The group-based MOST program consisted of 17 2-hour sessions conducted 2 times/week for 8 weeks + 1 booster session conducted 6 weeks after the end of the main intervention. Each session consisted of 1 hour of weekly information presentations & goal setting while hour 2 was devoted to exercise – either land-based (3 sessions) or water-based (14 sessions). Assessments of On within-groups analysis, participants in the MOST program demonstrated significant change from baseline to follow-up in terms of ABC scores (p<0.005), RNL scores (p<0.05) and FIM scores (p<0.05). Participants in the LWS program demonstrated significant change over time on FIM scores only (p<0.05); however, on between group comparisons for change, there were no significant differences noted. Participants in the MOST program were more frequently enrolled in formal exercise programs than the LWS participants at baseline and at follow-up. When controlling for baseline participation, this difference remained significant at the 12-week follow-up (p=0.05). In qualitative exit interviews, participants in both programs expressed enthusiasm about the opportunity to meet and socialize with other individuals with stroke. In both groups,
participation, depression, balance and function were conducted at baseline, the end of the program, and 12 weeks post intervention.

**Marsden et al. (2010)**

Australia 5 (RCT)

In a randomized crossover trial, 25 individuals with stroke and 17 carers were assigned to either the Community Living After Stroke For Survivors and Carers (CLASSiC) program or to a delayed intervention control group. The program was conducted in a rural setting by a stroke-specific multidisciplinary team and consisted of 7 weekly 2.5 hour group sessions. Each session included a 1-hour physical activity component followed by a “healthy options morning tea” and another 1-hour group education session (presentations, discussion & group activities on a variety of topics). One week after the intervention group completed the program, the control group began it. All participants were assessed at baseline, at 8 weeks, and 12 weeks after study entry. Primary study outcome was health-related quality of life assessed using the Stroke Impact Scale and the Health Impact Scale.

The authors do not report the results of their statistical between-group comparisons, although they state that they did not reach significance. Qualitatively, a trend in favour of the intervention group over the control group is reported for perceived overall recovery, the 6 minute walk test and all self-reported health-related quality of life domains except memory and mobility (Stroke Impact Scale). Similarly, carers displayed trends in favour of the intervention for the 6 minute walk test, timed up and go and all self-reported health related quality of life domains except the community, ADL/IADL and memory (Health Impact Scale).

**Harrington et al. (2010)**

UK 7 (RCT)

243 individuals with stroke were randomly assigned to receive either standard care or a peer-volunteer-facilitated exercise and education intervention. Intervention sessions were conducted twice per week for 8 weeks. Each session consisted of one hour exercise (with qualified instructors) followed by a short break and 1 hour of interactive education. Sessions were intended to be fun and non-didactic, encouraging group participation – these also included some goal-setting sessions, social sessions and unstructured group discussion times. Home exercise manuals and directories of local resources were also provided to participants. Family members and carers were encouraged to attend and help in the exercise sessions. One session was dedicated to family members. Control participants received standard care + an information sheet about local groups. Three primary study outcomes measures were the SIPSO (Subjective Index of Physical and Social Participation, Depression, Balance and Function) and the Health Impact Scale.

The total SIPSO scores were significantly lower in the intervention group than the control group at baseline. There was significant improvement associated with the intervention vs. control in terms of change in perceived physical outcome (SIPSO-physical) at both 9 weeks (p=0.02) and 1 year (p=0.02) evaluations. There were no significant between group differences noted on either the FAI or RMI. In addition, there was a significantly greater improvement in the psychological domain of the WHOQol-Bref at 6 month in the intervention vs. control group (p=0.01).
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Score</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patterson et al. (2010)</td>
<td>Australia</td>
<td>No Score</td>
<td>22 individuals with stroke participating in a community-based stroke maintenance exercise group were compared with 21 individuals with stroke participating in a peer support group. The exercise intervention consisted of a 60-minutes class providing both exercise and peer support was conducted once/week led by a physiotherapist. The peer support group also met once/week for 60 minutes and provided a program of personal sharing, planning leisure activities &amp; community-based participation. Peer support was provided via active participation and facilitation from a key group member. Assessments were conducted at baseline and three months and included the home-functioning questionnaire (HFQ) and the EQ-5D.</td>
<td>Participants in both groups experienced significant improvements over time on the HFQ (p=0.001). However, there were no significant group X time interactions suggesting that both interventions were effective in helping participants to improve their ability to complete daily tasks. There were no significant between or within group improvements reported for either quality of life or health status (EQ-5D).</td>
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</tr>
<tr>
<td>Van de Port et al. (2012)</td>
<td>Netherlands</td>
<td>8 (RCT)</td>
<td>A multi-centred study in which individuals with stroke discharged home from inpatient rehabilitation (&amp; able to walk 10 m unassisted) were randomly assigned to participate in either a group-based, task-oriented circuit training programme (n=126) or usual care (n=124). The circuit training programme was a 90-minutes in length (warm-up, circuit training, evaluation, short break and group game) and offered 2X/week for 24 weeks. Usual care consisted of one-to-one physiotherapy treatments over the same period of time. Primary study outcome was mobility as assessed on the mobility domain of the SIS. Secondary outcomes included the remainder of the SIS, RMI, falls efficacy (FES), Nottingham EADL, HADS and fatigue severity (FSS). All secondary assessments were performed at baseline, 12 and 24 weeks.</td>
<td>Individuals in the circuit training received a mean of 72 minutes (±39) per session comared with 34 minutes (±10) in the control group (p&lt;0.05). However, there was no significant between group difference on the primary outcome between groups. In terms of leisure outcomes, there were no significant group X time interactions for social participation (SIS) or leisure ADLs (Nottingham EADL). For both of these outcomes, however, there were significant improvements noted over time, regardless of group membership (p=0.007 and p&lt;0.001, for the SIS and N-EADL, respectively).</td>
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</tr>
<tr>
<td>Robinson et al. (2013)</td>
<td>USA</td>
<td>Pre-Post</td>
<td>Population: Mean Age=68.0±8.5y; Gender: Male=16, Female=14. Intervention: The participation in community activities of stroke patients was assessed through in-person and telephone interviews.</td>
<td>1. The total number of community trips over a 3wk period was significantly lower in stroke patients compared to healthy controls (12.3±7.8 vs 21.1±10.4 respectively) (p&lt;0.001). 2. The total number of community activities over a 3wk period was significantly lower in stroke patients</td>
<td></td>
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<tr>
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<td>Study Design</td>
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<tr>
<td>Kubina et al. (2013)</td>
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<td>Qualitative</td>
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<td>Eriksson et al. (2013)</td>
<td>Sweden</td>
<td>Cross-Sectional</td>
<td>No Score</td>
<td>Mean=NA</td>
<td>N Start=116</td>
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<td>Brown et al. (2013)</td>
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<td>Qualitative</td>
<td>No Score</td>
<td>Mean=71.5±62.3mo</td>
<td>N Start=25</td>
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<tr>
<td>Outcomes: Emerging themes regarding (1) living with changes in friendships, (2) good times together and support from friends, and (3) the importance of stroke and aphasia friends.</td>
<td>experienced by participants: increased appreciation for friends, new friendships and being proactive. 2. (2) Good times together and support from friends encompassed the sub-themes: spending time with friends and doing things together, laughter and engaging in positive interactions with friends and emotional support from friends, which were all positive interactions experienced. 3. (3) The importance of stroke and aphasia friends was found as an over-arching theme identified by the participants. Some of the features of participant’s friendship with fellow stroke and aphasia survivors were the same as those discussed more generally: spending time with friends and doing things together, laughter and engaging in positive interactions with friends, and emotional support from friends. What distinguished the two themes are the subthemes of mutual understanding and ease of communication and supporting each other.</td>
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<tr>
<td><strong>Le Dorze et al.</strong> (2014) Canada Observational No Score TPS&lt;sub&gt;Mean&lt;/sub&gt;=5.7yr N&lt;sub&gt;Start&lt;/sub&gt;=17 N&lt;sub&gt;End&lt;/sub&gt;=17</td>
<td><strong>Population:</strong> Mean Age=65.7yr; Gender: Male=12, Female=5. 1. Identity-based personal factors that were mentioned as facilitating participation included determination (n=25), disclosing aphasia (n=17), finding solutions (n=13), being motivated and positive (n=9), composing with limits (n=6), persevering in trying to communicate (n=6) and being sociable (n=4). 2. Identity-based personal factors that were mentioned as barriers to participation included a sense of pride (n=13), an inability to speak well (n=7), fear of a family member’s reaction (n=6), preferring being alone (n=5), a fear of asking for help (n=3) and a fear of being judged (n=3). 3. Capability-based personal factors that were mentioned as facilitating participation included energy (n=10), communication recovery (n=8), physical recovery from hemiparesis (n=5), emotional control (n=3) and cognitive improvement (n=2). 4. Capability-based personal factors that were mentioned as barriers to participation included communication limitations (n=39), physical limitations (n=24), cognitive limitations (n=14), lack of emotional control (n=6) and general factors including fatigue (n=4). 5. Family and social circle factors that were mentioned as facilitating participation included family members providing support (n=45), available speaking partners (n=9), encouragement from family (n=8), opportunities to practice with their social circle (n=5) and family obligations (n=3). 6. Family and social circle factors that were mentioned as barriers to participation included poorly adjusted speakers (n=26), a poor spousal relationship (n=13), lack of support (n=10), a restricted social circle (n=10)</td>
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</table>
Health and social service factors that were mentioned as facilitating participation included being referred to community organizations (n=5), being offered help (n=1), the ability to access new services through a rehabilitation center (n=1), satisfying speech language therapy (n=17) and satisfaction with rehabilitation administrators (n=14).

Health and social service factors that were mentioned as barriers to participation included not being offered community rehabilitation (n=7), a short rehabilitation duration (n=4), no knowledge of other services (n=4), a belief that their aphasia was too severe or mild for treatment (n=5), dissatisfaction with medical and acute care services (n=7), abrupt discharge (n=6), insufficient support (n=3) and a dissatisfaction with speech language therapy.

Aspects of community organizations that were mentioned as facilitating participation included the opportunity to practice talking with others (n=9), a feeling of being welcomed (n=7), the opportunity to share personal experiences (n=6) and a sense of belonging (n=5).

An aspects of community organizations that was mentioned as a barriers to participation was a limited budget (n=2).

An economic factor that was mentioned as a barrier to participation was a precariousness financial situation (n=3).

Societal attitudes that were mentioned as facilitating participation included tolerance of their limitations (n=15) and positivity (n=6).

Societal attitudes that were mentioned as barriers to participation included ignorance about aphasia (n=14) and high societal expectations (n=6).

White et al. (2014) Australia Longitudinal Observational No Score TPSmean=NA NStart=134 NEnd=110

Population: Mean Age=75±12yr; Gender: Males=60, Females=74. Intervention: Consecutively recruited stroke patients participated in face-to-face interviews at baseline, 3mo, 6mo, 9mo and 12mo. Outcomes: Hospital Anxiety and Depression Scale (HADS Anxiety, Depression); Modified Rankin Scale (mRS); Assessment of Quality of Life (QOL); Multi-dimensional Scale Perceived Social Support; Adelaide Activities Profile (AAP).

At each time-point the proportion of participants meeting depression thresholds remained relatively consistent (22%, 29%, 22%, 28%, 20%) while those meeting anxiety thresholds significantly reduced (p=0.00001) at each respective time-point (47%, 34%, 29%, 25%, 14%).

The proportion of comorbid depression and anxiety at baseline was 69% and at 12mo was 34%.

Anxiety at any time point during the 12mo study period was associated with baseline anxiety (p<0.0001), baseline depression (p<0.0001) and having less disability (p=0.04).

There was no independent association with having a past history of depression and anxiety (p=0.05).

The severity of depression at any time during the 12mo study period was significantly associated with baseline anxiety (p<0.0001), low social support
19. Community Reintegration

Egan et al. (2014)  
Canada  
Prospective cohort  
No Score  
TPSmean=NA  
NStart=67  
NEnd=55  

**Population:** Mean age=64.8±13.3yr; Gender: Males=39, Females=28.  
**Intervention:** Stroke patients who had been discharged from an acute stroke unit or stroke rehabilitation unit after a stroke were assessed to explore the effects between participation and emotional and physical well-being during the first 2 years post-stroke. Participants were interviewed on 5 occasions within the first 24 months post-stroke: at 6m, at 9m, at 12m, at 18m, and at 24m.  
**Outcomes:** Reintegration to Normal Living Index (RNLI: participation); General Well-being Schedule (GWB); General Self-rating of Health Question (GHQ); Functional Independence Measure (FIM).

1. Time since stroke was a significant predictor of general wellbeing (p<0.01), health (p=0.001), and participation (p<0.01).  
2. FIM (p<0.05), income (p<0.001), and time since stroke (p<0.05) were significantly associated with physical well-being (GHQ).

Vincent-Onabajo et al. (2016)  
Nigeria  
Observational  
No Score  
TPSmean=15.07±21.02mo  
NStart=55  
NEnd=55  

**Population:** Mean Age=53.55±14.3yr; Gender: Males=35, Females=20.  
**Intervention:** Community-residing stroke survivors receiving outpatient physiotherapy were surveyed to examine leisure participation.  
**Outcomes:** Developed questionnaire regarding participation in 34 leisure activities before and after stroke (4 domains: recreational, social, productive/cognitive, cognitive).

1. No significant associations between global leisure participation and the social-demographic or clinical attributes were observed.  
2. Participants that were employed (p<0.01) or with moderate disability (p<0.05) had significantly more recreational participation.  
3. There was a significant association between Educational qualification and the productive/creative domain (p<0.01).  
4. Employment (p<0.05), Education (p<0.0001), Type of stroke (p<0.05), and Post-stroke duration (p<0.05) were significantly associated with cognitive domain participation.

19.4 Sexuality

19.4.1 Decreased Sexuality Following Stroke

**Table 19.4.1 Sexuality Post Stroke**

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kalliomaki et al. (1961) Finland</td>
<td>Information was collected on libido and coitus frequency using personal interviews in 105 patients who had suffered a cerebral vascular accident.</td>
<td>A decrease in libido was observed in both males and female patients and was more common in those suffering with right-sided paralysis than left-sided paralysis. There was a decrease in coitus frequency as well in all men and in half the women.</td>
</tr>
<tr>
<td>Bray et al. (1981) USA</td>
<td>Investigation of sexual interest, function and attitudes of 35 stroke patients using a structured interview.</td>
<td>No changes in sexual interest or desire for both men and women after stroke. Men experienced</td>
</tr>
</tbody>
</table>
a decrease in the ability to achieve erection and to ejaculate and only one woman reported experiencing orgasm after stroke. 79% of men and 73% of women reported sexual functioning was important.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sjogren and Fugl-Meyer (1981)</td>
<td>Sweden</td>
<td>41 patients were investigated after prior discharge to their home for quality and quantity of sexual problems via structured interview.</td>
<td>Sexual dysfunction was common after stroke with 2 out of 3 males dissatisfied with intercourse frequency, more than 1 out of 3 dissatisfied with duration of foreplay and more than 1 out of 2 dissatisfied with total sex-play time. Much less females reported post-stroke dissatisfaction. Men reported erectile dysfunction as main pleasure-reducing factor and women reported general fatigue as main reason for decreased sexual enjoyment.</td>
</tr>
<tr>
<td>Sjogren and Fugl-Meyer (1982)</td>
<td>Sweden</td>
<td>110 stroke patients were evaluated in change in frequency of sexual intercourse as related to degree of physical impairment and levels of dependence in activities of daily living.</td>
<td>75% of patients reduced their frequency or ceased having intercourse. Primary ADL-dependence and impaired cutaneous sensibility were the main negative determinants.</td>
</tr>
<tr>
<td>Coslett and Heilman (1986)</td>
<td>USA</td>
<td>26 males were sexually active until their stroke and were married or in long-standing sexual relationships at the time of interview and had suffered a stroke at least 6 months previously.</td>
<td>Prevalence of major sexual dysfunction was significantly greater after right than after left hemispheric strokes.</td>
</tr>
<tr>
<td>McCormick et al. (1986)</td>
<td>USA</td>
<td>37 female spouses of male stroke patients participated in discussions around sexuality after stroke within a Spouse Support Group at a stroke rehabilitation unit.</td>
<td>Participants reported that no healthcare professional had discussed sexual activity with them. They, therefore, had assumed that sexual activities were to be avoided and could cause another stroke. Wives were hesitant to engage in sexual activities and felt that their husbands were also afraid. Couples were hesitant to change their sexual roles and try new things to accommodate disability. Coital positioning was a difficulty experienced by most couples due to the presence of hemiplegia and hemiparesis. The authors note that participants viewed open discussion of sexual health positively.</td>
</tr>
<tr>
<td>Boldrini et al. (1991)</td>
<td>Italy</td>
<td>86 patients with hemiparesis secondary to stroke were examined for changes in sexual life using a structured interview.</td>
<td>Marked decline in sexual activity after stroke was noted in both men and women patients. Clinical factors did not appear to play a role in determining decreased sexual activity between couples.</td>
</tr>
<tr>
<td>Buzzelli et al. (1997)</td>
<td>Italy</td>
<td>57 male and 15 female stroke survivors along with their significant others were interviewed at 1 month and again at 1 year following the stroke event.</td>
<td>60 patients reported a decline in sexual activity (83.3%). Eight patients and their partners reported an increase in activity. Mean decline in frequency was 34%. Sexual activity most often recommenced between 3 and 6 months post stroke. No association was found between gender or side of lesion and decline in sexual activity. Duration of marriage was the only variable significantly predictive of weekly sexual activity.</td>
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</table>
Performance. Age, education, disability and depression were not significant predictors. High levels of activity prior to the stroke event did not predict maintenance of sexual activity. Patients stressed the importance of the sexual role/relationship, however, male patients felt it to be more important than female. Female caregivers were more concerned with other aspects of disability. Variables associated with disruption of sexual activity were: fear of relapse, belief that one must be healthy to have a sex life and partner who is “turned off” or horrified at the prospect of sexual activity with a “sick person”.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Score</th>
<th>Participants and Design</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Edmans (1998)</td>
<td>UK</td>
<td>No Score</td>
<td>Of 33 pairs of questionnaires, 12 patients and 9 partners returned completed questionnaires regarding sexual activity following stroke, usefulness of information received and further information required. All couples had received information sheets regarding sex post stroke and sexual activity was discussed with staff while stroke survivor was admitted to the stroke unit. Questionnaires were sent out approximately 1 month following discharge.</td>
<td>Approximately 50% of stroke patients and 1/3 of partners felt that the frequency of sexual activity had decreased following stroke. Problems reported were: lack of interest from one or both partners, lack of motivation from one or both partners, physical incapacity of the stroke patient, difficulty in finding a comfortable position, difficulty in arousing partner, difficulties due to sensory deficits on patients affected side. While all received information prior to discharge, no further information had been received. Respondents felt that additional information regarding problems with sexual activity and the duration of such problems would be useful. In general, couples felt that resuming sexual activity should be included as a routine part of stroke rehabilitation.</td>
</tr>
<tr>
<td>Korpelainen et al. (1999)</td>
<td>Finland</td>
<td>No Score</td>
<td>192 stroke patients and 94 spouses participating in stroke adjustment courses sponsored by the Finnish Stroke and Aphasia Federation completed a self-administered questionnaire about their pre-stroke and post-stroke sexual functions and habit measuring libido, coital frequency and sexual arousal including erectile and orgasmic ability and vaginal lubrication and sexual satisfaction.</td>
<td>Sexual dysfunction and dissatisfaction with sexual life were common in both male and female stroke patients and in their spouses. Psychological and social factors such as general attitudes about sexuality, fear of impotence, inability to discuss sexuality, unwillingness to participate in sexual activity and the degree of functional disability, exert a strong impact on sexual functioning and quality of sexual life after stroke.</td>
</tr>
<tr>
<td>Carod et al. (1999)</td>
<td>Spain</td>
<td>No Score</td>
<td>41 female and 49 male stroke survivors who had been sexually active prior to stroke were assessed one year after stroke. Main outcomes were libido, impotence, sexual satisfaction, disability, depression, psychosocial status, vitality and mental health.</td>
<td>71.5% of participants reported a marked decline in sexual function. Disability was not related to reported sexual decline. Approximately ½ reported diminished libido. Decline in libido was correlated with depression, the psychosocial dimension of the SIP, vitality and mental health. Stroke etiology, laterality, disability and age were not associated with reduced libido. A diagnosis of impotence was made in 48% of men. Men who were diagnosed as impotent had significantly worse physical functioning scores.</td>
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on the physical dimension of the Sickness Impact Profile (SIP) than those who did not \((p=0.001)\).

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Score</th>
<th>Participants</th>
<th>Methodology</th>
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<tbody>
<tr>
<td>Lemieux et al. (2001)</td>
<td>Canada</td>
<td>No Score</td>
<td>6 couples consisting of an individual with post stroke aphasia (1 to 3 years following the stroke event) and his/her partner participated in semi-structured interviews. Couples were interviewed together (8 questions) then, each partner completed a 35-item questionnaire while the aphasic partner was interviewed (25 questions).</td>
<td>Couples reported reduced frequency of intercourse though the frequency of other sexual activities (hugging, kissing, genital touching) increased for several of the couples. For those couples who could remember, sexual activity had not changed in importance. For ¼ of the aphasic subjects, sex had been important prior to the stroke and maintained its importance following the stroke event. Half of the aphasic participants reported reduced desire. 2/3 of spouses of aphasic participants reported reduced desire. Only 2 partners reported satisfaction with sexual activity. Aphasic participants reported increased difficulty in initiating and communicating about sex with their partners. They reported feeling as though improvement in communication skills would improve their sex life. No couples reported being asked about issues of sexuality by any healthcare professionals. All couples expressed interest in knowing more about sexual health issues.</td>
</tr>
<tr>
<td>Choi-Kwon and Kim (2002)</td>
<td>Korea</td>
<td>No Score</td>
<td>70 sexually active stroke survivors were interviewed 3 months post stroke. 55 of the 70 were interviewed again at 2 years post stroke. Mean age = 56.</td>
<td>At 3 months, 49% reported decreased libido and 65% reported decreased coital frequency. 26% reported difficulties with arousal function. At 2 years, decreased libido was reported in 44% of patients, decreased frequency in 49% and decreased arousal in 20%. Decreased frequency was significantly related to emotional incontinence at both 3 months and 2 years post stroke. Low frequency prior to stroke was related to low frequency post stroke. Reductions in sexual activity were not related to gender, age, education, functional disability, nature and laterality of lesion or the presence of risk factors such as diabetes mellitus or hypertension. The percentage of patients who recovered sexual activity was greater among patients who were emotionally stable than those who had emotional incontinence.</td>
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<tr>
<td>Cheung (2002)</td>
<td>China</td>
<td>No Score</td>
<td>Self-administered questionnaire was given to 63 men and 43 women post stroke. All patients had little or no residual disability. Mean time from stroke event = 20.8 months.</td>
<td>39% of patients reported sexuality as important, however, most worried more about recurrence of stroke (78.3%) than they did about impotence/lack of sexual activity (18.9%). Men felt sex to be more important and worried about impotence more than women. Approximately ½ believed that stroke affected sexual function however, approximately ½ of patients felt willing to engage in sexual activity. Few patients</td>
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</table>
discussed sex with their partner (16.9%). Decline in libido was associated with increasing age, increasing disability, no communication with one’s partner and unwillingness to engage in sexual activity. Decline in sexual satisfaction was associated with increasing age and disability, belief that stroke affected sex, lack of communication and unwillingness to participate. Regression analysis revealed that psychosocial factors were important in libido, frequency and satisfaction. Disability was significantly associated with sexual functioning in males, but not in female stroke patients.

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants/Setting</th>
<th>Methodology</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Giaquinto et al. (2003)</td>
<td>68 stroke patients admitted to rehabilitation unit were followed and assessed on a questionnaire and structured interview concerning patients’ private lives including data on sexual performance from both patient and their partner. In a second interview, patients were assessed from depression by the Centre for Epidemiologic Studies-Depression scale (CES-D) and the Structured Clinical Interview for DSM-IV S=(SCID). Disability was evaluated via the Functional Independence Measures.</td>
<td>Sexual decline was common in the post-stroke period with age and disability acting as significant variables. There was no correlation between sexual decline and gender, lesion location, marriage duration, education duration or education. Patient’s partners played a substantial role in the decline of sexual activity. Many partners experienced fear of relapse, anguish, lack of excitement or horror which withheld them from encouraging sexual activities.</td>
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<tr>
<td>Carlsson et al. (2007)</td>
<td>56 stroke patients and their partners were included upon admission to a stroke unit. Patients were assessed at baseline and one year. Life satisfaction was rated by both patients and spouses on the LiSat-9. Scores were compared with an age-matched “norm group”. Most patients had experienced mild stroke and couples were relatively young (patient, median age = 60 &amp; partner median age = 59).</td>
<td>Score for general life satisfaction (patients p=0.001, partners p=0.05), leisure (patients p=0.001, partners p=0.01) and sex life (patients p=0.01, partners p=0.025) were significantly lower than norm values at one year. Spouses were significantly less satisfied with their relationships than the norm (p=0.001), but patients were almost as satisfied. In general, patients were less satisfied with life than their partners (p=0.007), while partners were significantly less satisfied with their relationship (p=0.035). In 25% of couples, both partners were satisfied with their sex life. In 50% of couples, both partners were not satisfied.</td>
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<tr>
<td>Thompson and Ryan (2009)</td>
<td>18 individuals with stroke (aged 33-78 years) participated in in-depth interviews regarding the impact of stroke on spousal relationships over a period of 3 months.</td>
<td>Participants felt that the nature of the spousal relationship had changed. Participants tended to view their partners as friends or carers. All, but one, respondent described a loss of or reduction in sexual desire. Intimacy was avoided, partly out of fear that this would lead to intercourse. Participants cited prescribed medications and fear of recurrent stroke as reasons for loss of desire.</td>
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<tr>
<td>Akinpelu et al. (2013)</td>
<td>77 stroke survivors attending outpatient physiotherapy were included. Participants completed outcome measures pertaining to motor ability, quality of life, depression, and sexual dysfunction.</td>
<td>94.8% reported difficulties in one or more of the 7 areas of sexual dysfunction. Depression, overall quality of life, willingness to have sex, general attitude, and ability to express feelings of a sexual nature were all associated with</td>
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</table>
Population: Mean Age=55.1±14.2yr; Gender: Male=23, Female=14.

Intervention: Patients completed a battery of questionnaires concerning sexual dysfunction following stroke.

Outcomes: Changes in Sexual Functioning Questionnaire Short Form (CSFQ-14); Fatigue Assessment Scale (FAS); Barthel Index (BI); Beck Depression Inventory (BDI);
Patient experiences and preferences relating to information about sexual dysfunction following stroke.

1. According to the CSFQ-14, all male patients and 58% of female patients were classified as having sexual dysfunction.
2. According to the BDI, 3% of patients had minimal depression, 54.4% had mild depression, 36.4% had moderate depression and 6.0% had severe depression.
3. According to the BI, 78.8% of patients were fully independent, 18.2% required minimal assistance and 3% were very dependent.
4. According to the FAS, 50% of women and 39% of men were classified as having significant fatigue.
5. Sexual issues were rated as moderately to very important to overall recovery in 71% of patients with no significant difference observed between males and females (p=0.391).
6. Sexual functioning following stroke was reported to have worsened in 42% of patients, not having changed in 42% and improved in 5% with no significant difference observed between males and females (p=0.844).
7. Sexual issues due to the physical limitations of stroke were reported by 94% of patients and 58.8% reported feeling less sexually desirable.
8. Concerns about sex and safety were reported by a minority of patients with 2.8% having concerns about sex causing another stroke and 8.8% indicating that their partner was worried about causing them harm.
9. Information about sexual dysfunction following stroke was only offered to or sought out by 15.2% of patients while 75% reported wanting to have received information.
10. No significant difference between males and females was observed in regards to wanting or receiving information about sexual dysfunction (p=0.21).
11. Information about sexual dysfunction was provided through a brochure, book or the internet in 35% of cases or through a physician in 30%.
12. The information delivered to patients concerning sexual dysfunction post stroke was regarded as not enough in 77.8% of...
cases, the right amount in 18.5% and too much in 3.7%.
13. The first choice for the preferred method of counselling concerning sexual dysfunction was physician in 60%.
14. A physician was reported as being the first choice for counselling concerning sexual dysfunction in 60% of patients, a nurse as the second choice in 45% and a physical therapist as the third choice in 36.3%.
15. Patients reported their preferred method of receiving information concerning sexual dysfunction was a printed material (30%) while 27.1% preferred a discussion with a healthcare provider.
16. Patients reported preferring to receive information about sexual issues following stroke before discharge from the hospital or rehabilitation facility in 26.5% of cases, 1yr post stroke in 17.6%, 6mo post stroke in 14.7%, 3mo post stroke in 11.8% and never in 5.9%.

Seymour et al. (2014) USA Observational No Score TPS mean=6-18mo NStart=13 NEnd=13

Population: Mean Age=62.08±15.10yr; Gender: Male=9, Female=4.
Intervention: Patients completed an over the phone assessment.
Outcomes: Quality of Sexual Function scale (QSF); Stroke Impact Scale; Patient Health Questionnaire 9-item (PHQ-9); Incidence of sexual function conversations with healthcare professionals; Self-reported sexual function.
1. SIS scores were interpreted as normal across all domains except for emotion which was interpreted as low (mean=59.40±9.11).
2. The PHQ-9 total score across the sample showed mild depressive symptoms (mean=4.92±7.24).
3. QSF scores were interpreted as mildly problematic for the psychosomatic quality of life domain (mean=20.85±8.60), the sexual dysfunction self-reflection domain (mean=10.77±4.09) and for the total score (mean=55.00±17.92).
4. QSF scores were interpreted as having no to little problem on the sexual activity domain (mean=14.77±7.17) and the sexual dysfunction partner reflection domain (mean=6.62±3.12).
5. A changed sexual functioning following stroke was reported in 5 (38.5%) patients.
6. Patients reported having conversations with health care professionals about sexual functioning post stroke in 4 (30.8%) cases.

Sansom et al. (2015) Australia RCT PEDro=6 TPS<72hr NStart=10

Population: Sexual Rehabilitation group (EG; n=4): Mean age=64.8±20.6yr; Gender: Males=2, Females=2. Control group (CG; n=6): Mean age=64.8±20.6yr; Gender: Males=3, Females=3.
Intervention: Participants were randomly to receive a structure sexual rehabilitation program for a single 30min session (EG) or no additional treatment (CG).
1. There was no significant difference between the EG and CG groups post treatment in CSFQ-14 (p=0.255), DASS (p=0.868), or SAQOL (p=0.57).
Outcomes were assessed at baseline and post treatment.  
**Outcomes:** Short Form Changes in Sexual Functioning Questionnaire (CSFQ-14); Depression Anxiety and Stress Scale (DASS); Stroke Assessment Quality of Life (SAQOL).

### 19.4.2 Inappropriate Sexual Behaviour

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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</thead>
<tbody>
<tr>
<td>Monga et al. (1986) Canada No Score</td>
<td>Case study of 3 stroke patients who demonstrated hypersexuality and deviant sexual behaviour after stroke.</td>
<td>All 3 patients had temporal lobe lesions on computerized tomography scan and a history of post-stroke seizure activity.</td>
</tr>
<tr>
<td>Korpelainen et al. (1998) Finland No Score</td>
<td>Described 2 cases of hypersexuality in stroke patients.</td>
<td>Appeared that hypersexuality in patients studied were associated with moclobemide treatment.</td>
</tr>
<tr>
<td>Bardell et al. (2011) Canada No Score</td>
<td>Retrospective chart review of 10 inpatients with identified inappropriate sexual behaviour (ISB). Included an age-, sex- and marital status-controlled comparison group. Examined potential contributing factors and effectiveness of interventions used in treatment of ISB.</td>
<td>8 of 10 individuals with ISB had a history of stroke vs. 4 in the control group. Although this difference was not statistically significant ((p=0.17)), there was a significant association between the presence of right frontal lobe stroke and ISB (6/10 in the ISB group, 0/10 in the control group; (p&lt;0.05)). MMSE scores for individuals with ISB were significantly lower than those without and more individuals with ISB had been diagnosed with dementia than individuals in the comparison group ((p=0.037)). Citalopram was the most frequently recorded treatment for ISB; however, it was not particularly effective. 7 individuals were treated with citalopram for ISB—no effect was noted for 4/7 cases and “some reduction” in behaviour for the remaining 3.</td>
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### 19.5 Driving

### 19.5.1 Driving Assessment

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Nouri &amp; Lincoln</td>
<td>79 stroke patients in two investigations were</td>
<td>Analysis of data from 45 randomly selected</td>
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<tr>
<td>Year</td>
<td>Country</td>
<td>Score</td>
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<tr>
<td>1992</td>
<td>UK</td>
<td>No Score</td>
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<td>1993</td>
<td>UK</td>
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<td>1998</td>
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<td>1999</td>
<td>Finland</td>
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<td>2000</td>
<td>Canada</td>
<td>No Score</td>
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Community Reintegration

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<tr>
<th>Study Reference</th>
<th>Location</th>
<th>Subject Description</th>
<th>Outcome Summary</th>
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<tbody>
<tr>
<td>Akinwuntan et al. (2002) Belgium No Score</td>
<td>Retrospective study of a 2-year predriving evaluation of 104 patients with sequelae of first stroke. Patients underwent predriving assessments and a road test. Their suitability to drive was based on a team decision and performance on an on-road test.</td>
<td>ranged from 52% to 82%. For the group as whole, the positive predictive value of the MVPT was 60.9% and the negative predictive value was 64.2%. Univariate logistic regression showed that those who were older and had lower MVPT scores were more likely to fail the on-road test. Those with right-hemisphere lesions were more likely to fail than those with left hemisphere lesions.</td>
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<tr>
<td>Akinwuntan et al. (2003) Belgium No Score</td>
<td>36 patients with stroke participated in determining road test reliability in assessing patients’ ability to drive. Two assessors judged results of driving performance from the Center for Determination of Fitness to Drive and Car Adaptation (CARA) in a car fitted with a video camera. A third assessor evaluated all the video recordings.</td>
<td>39.4% were judged suitable to drive, 43.3% as not immediately suitable and 17.3% as not suitable. Side of lesion, kinetic vision, visual scanning &amp; a road test were the best predictors of the team decisions. Combination of acuity (left &amp; right eyes) &amp; the figure Rey test was the best subset to predict road test ($R^2 = .28$).</td>
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<td>Radford et al. (2004) UK No Score</td>
<td>93 stroke patients referred for assessment of fitness to drive or who had been driving before their stroke were used to determine concurrent validity of the Stroke Drivers Screening Assessment (SDSA) which was compared with criterion standards. Patients were assessed on the SDSA, Visual Object and Space Perception (VOSP) Battery, Stroop Neuropsychological Screen Test, the Trail-Making Test (TMT), and the Cognitive Estimates Test for executive abilities and the Recognition Memory Tests (RMT) and the Verbal Description of Road Signs (VDRS) for visual memory.</td>
<td>The SDSA subtests significantly correlated with the Stroop test, and the TMT suggesting that they measure executive abilities and attention. The SDSA Dot Cancellation (DC) significantly correlated with the VDRS and the SDSA Square Matrices (SM) test significantly correlated with the VOSP cube analysis and the RMT face subtest suggesting that the SM test also measures visuospatial abilities and visual memory. The SDSA Road Sign Recognition (RSR) significantly correlated with the VOSP cute analysis.</td>
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<tr>
<td>Akinwuntan et al. (2005a) Belgium No Score</td>
<td>38 individuals with first-ever stroke were assessed using a battery of off-road tests and an on-road driving test. The off road tests included a dot cancellation test, square matrix test and road sign recognition test (Stroke Driver’s Screening Assessment - SDSA). Experienced traffic &amp; safety experts conducted the on-road test using a TRIP checklist (13 road test items). Following the test, subjects were judged fit to drive, temporarily unfit or unfit to drive.</td>
<td>Interrater reliability of the road test items was reported to be high (ICC=0.83). At the item level, interrater reliability ranged from moderate to high (ICC = 0.63 – 0.87). The outcome of the SDSA correlated with the judgement of the driving evaluator in 78.9% of the subjects. Correlations between evaluations performed by the principal test evaluator and the state evaluator were high ($r=0.80$, $p&lt;0.001$).</td>
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<tr>
<td>Akinwuntan et al. (2006) Belgium No Score</td>
<td>68 stroke patients were assessed prospectively. Each patient underwent a mandatory pre-driving assessment within 18 months of the stroke event. Each pre-driving assessment included visual tests (monocular and binocular visual acuity, kinetic vision), neuropsychological tests (Rey figure copying, logistic regression analysis demonstrated that the best model to predict on-road performance consisted of binocular visual acuity, dot cancellation, square matrix (compass) and incompatibility (attention) tests. However, this model explained only 35% of variance in on road performance.</td>
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www.ebrsr.com
useful field of view, test for attentional performance – divided attention, visual scanning incompatibility, visual field and visual neglect), SDSA component tests (dot cancellation test, square matrix tests, road sign recognition) and an on-road driving evaluation. Each evaluation lasted approximately 2 – 3 hours and was administered by certified psychologists and driving assessment experts. Based on the results of the assessment, a group comprised of a physician, psychologist and a driving safety expert, classified each patient as “fit to drive”, “temporarily unfit to drive” or “unfit to drive”.

<p>| Smith-Arena et al. (2006) USA No Score | 39 patients admitted to an acute stroke rehabilitation facility completed driving evaluations post discharge. This study attempted to identify impairments during hospital admission that could predict the likelihood of successful in-clinic driving evaluation. Data recorded included cognitive impairment (MMSE), motor weakness (motricity index), visual field defects (hemianopsia or visual neglect evaluated via “confrontation testing”), proprioceptive loss (limb placement task), and functional status (FIM). Driving evaluation is comprised of a 1 hour, in-clinic session for the assessment of 4 functional domains (perception, vision, cognition, motor function) as well as reaction time to simple and complex stimuli. In-vehicle assessments are made based on the results of in-clinic testing. Patients who passed the in-clinic evaluation had fewer cognitive (MMSE scores -- p=0.004), but more physical impairments (upper limb motricity index p=0.05; lower limb motricity index p=0.01) on admission to stroke rehabilitation than individuals who failed the driving evaluation. Though normal visual field was present in more individuals who passed the driving evaluation than those who failed, this difference was not significant (p=0.24). |
| Bouillon et al. (2006) Canada No Score | Historical cohort study of 172 individuals with neurological conditions (left &amp; right CVA, TBI, Cognitive Decline, “other”). Results from the Cognitive Behavioural Driver’s Inventory (CBDI), the MVPT, Bells Test and on-road driving evaluation were abstracted from patient files. Among individuals with stroke, only the CBDI was able to differentiate between individuals who passed vs. those who failed their on-road evaluations, but only among those individuals with right CVA (p=0.003). Among individuals with left CVA, using a cut-off score of 45, the CBDI demonstrated sensitivity = 100% and specificity of 53%. For individuals with right CVA, using a cut-off score of 47, the CBDI demonstrated sensitivity = 73% and specificity of 89%. The CBDI was reported to be a significant predictor of on-road performance for individuals with right CVA or TBI only. For individuals with left CVA or cognitive decline, none of the tests evaluated were suitable predictors of on-road performance. |
| Soderstrom et al. (2006) | The relationship between the results of neuropsychological testing and on-road testing was determined. Patients and controls were matched for age and gender. No significant differences between |</p>
<table>
<thead>
<tr>
<th>Country</th>
<th>Study Details</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Sweden</td>
<td>Sweden No Score examined in 34 stroke patients and 20 healthy controls. The neuropsychological battery of tests consisted of 6 tests: Trail Making Test part B, Reaction Time Test, Finger Tapping Test, Wisconsin Card Sorting test, Rey Complex Figure Test, Digit-Symbol test. On road testing was completed within one month of the neuropsychological testing.</td>
<td>Patients and controls were reported on the Rey-Complex Figure Tests and the Wisconsin sorting test. Patients demonstrated significantly worse performance on all other tests. The difference was greatest for tests involving speed of information processing and divided attention. 50% of controls failed the on-road evaluation – a few more control subjects than patients failed. There were no significant correlations between neuropsychological tests, or the Traffic Theory Knowledge Test, and driving performance. The authors report no predictive value associated with the neuropsychological test battery. Fifteen stroke subjects who failed the on-road test were offered behind-the-wheel training (either 12 or 6 hours depending on their driving performance). All 15 also received 2 hours of instruction on traffic theory. 13/15 patients passed the on-road test following the training period. Neuropsychological retesting at the termination of training revealed no significant changes. The only significant improvement noted was on the Traffic Theory Knowledge Test.</td>
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<tr>
<td>New Zealand</td>
<td>Innes et al. (2007) New Zealand No Score 36 men &amp;14 women, 35 with previous stroke, underwent SMC Tests (a battery of computerized sensory-motor and cognitive tests) and an independent on-road driving assessment to determine whether such a test battery could predict driving performance in individuals with brain disorders. The SMC Tests program utilizes a modified car body interfaced with a computer. Patients use the steering wheel, indicator, accelerator, clutch and brake pedals/hand controls to respond to computer generated test stimuli. Sensory-motor tests include 3 visuoperceptual tests (visual resolution, static perception and dynamic perception), 4 visuomotor tests (ballistic movement, footbrake reaction, clutch reaction and hand control reaction) and 3 eye-arm tracking tests (sine tracking, random tracking and step tracking). Cognitive tests included divided attention, complex attention, visual search, decision-making, planning and impulse control. All 50 patients and 12 control subjects were assessed off road using the SMC tests and then on road. On-road assessment was conducted by a physical therapist and a driving instructor blinded to performance on off-road testing.</td>
<td>64% of patients failed the on-road driving assessments due to near-misses with other vehicles or hazards or due to definite safety concerns during assessment. Analysis demonstrated that there were significant differences between those who passed and those who did not on all SMC tests with the exception of the three visuoperceptual tests. Logistic regression was used to produce a predictive model comprised of 5 SMC test measures: planning, complex attention, tracking, ballistic movement, divided attention. The sensitivity and specificity of this model was 97% and 89% respectively. The correlation between the estimated probability of failing the on-road assessment using this model and observed on-road Driving Scale scores was $r=0.77$.</td>
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<tr>
<td>Belgium</td>
<td>Akinwuntan et al. (2007) Belgium No Score 43 stroke patients completed a pre-driving assessment. This study attempted to determine if a short battery of tests (Figure of Rey, visual neglect, on-road test) were sufficient to predict the results of a standard battery of neuropsychological tests.</td>
<td>86% of all participants were correctly classified as “pass” or “fail” using the shortened test battery. The sensitivity and specificity for the shortened examination were 77% and 92%,</td>
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<tr>
<td>Study</td>
<td>Population</td>
<td>Outcomes</td>
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<tr>
<td><strong>Ponsford et al. (2008)</strong></td>
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<tr>
<td>UK</td>
<td>N=10</td>
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<tr>
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<td>Using retrospective data from 200 patients with stroke, the authors examined the assessment process in determining fitness to drive. Over the course of a day, assessments were conducted by an orthoptist (visual function), a physiotherapist, and an occupational therapist. In-car tests (track test and road test) were conducted by an approved driving instructor. Assessor meetings were conducted twice during the day-long testing (following clinical examinations and again following in-car testing).</td>
<td>Overall, 54% were considered fit to drive &amp; 9% could drive following modification to the vehicle (&amp; training). Important factors associated with the outcome were vision (acuity &amp; filed), neuropsychological function (divided attention) and in-car testing results – specifically, reaction time, anticipation, speed and positioning. For individuals who failed the assessment, cognitive impairment was the main problem.</td>
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<td><strong>Pauley et al. (2013)</strong></td>
<td>Canada</td>
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<tr>
<td>Cohort</td>
<td>G1, N=10</td>
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<tr>
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<td></td>
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<tr>
<td>TPS&lt;sub&gt;E2&lt;/sub&gt;=54d</td>
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<td>TPS&lt;sub&gt;CG&lt;/sub&gt;=NA</td>
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<td>N&lt;sub&gt;End&lt;/sub&gt;=30</td>
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<td>Population: Experimental Group 1 (EG1, N=10): Median age=61yr; Gender: Male=6, Female=4. Experimental Group 2 (EG2, N=10): Median age=55.5yr; Gender: Male=8, Female=2. Control Group (CG, N=10): Median age=59yr; Gender: Male=5, Female=5. Intervention: EG1 (right hemispheric stroke), EG2 (left hemispheric stroke) and the CG (healthy controls) sat at a simulated pedal configuration with signals given to release the accelerator pedal and press the brake pedal. Three techniques were tested; a right-sided accelerator with right leg operating the accelerator and brake, a right-sided accelerator with left leg operating the accelerator and brake, and a left-sided accelerator with left leg operating the accelerator and brake. All patients performed 60 trials, 20 for each technique, in a random order with each 15-30secs apart. Assessments were conducted during each trial. Outcomes: Foot Pedal Reaction Time (RT); Foot Pedal Movement Time (MT); Foot Pedal Total Response Time (TRT).</td>
<td>1. RT was significantly faster for the CG compared to EG1 (p&lt;0.001) and EG2 (p=0.008) but no significant difference was found between EG1 and EG2 (p=0.09). 2. RT revealed a significant main effect of Group (p&lt;0.001) but no effects were found for pedal technique (p=0.88) or Group x pedal technique (p=0.19). 3. MT was significantly faster for the CG compared to EG1 (p=0.007) but not compared to EG2 (p=0.08). No significant difference was found between EG1 and EG2 (p=0.27). 4. MT revealed significant main effects for Group (p=0.02), pedal technique (p=0.002) and Group x pedal technique (p=0.001). 5. TRT was significantly faster for the CG compared to EG1 (p&lt;0.001) and EG2 (p=0.008). No significant difference was found between EG1 and EG2 (p=0.09). 6. TRT revealed significant main effects for Group (p&lt;0.001) and Group x pedal technique (p=0.007), but no effect of pedal technique (p=0.06) was found.</td>
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<td><strong>Barco et al. (2014)</strong></td>
<td>USA</td>
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<tr>
<td>Observational</td>
<td>N=72</td>
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<td>TPS&lt;sub&gt;Mean&lt;/sub&gt;=8.6±10.7mo</td>
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<tr>
<td>N&lt;sub&gt;Start&lt;/sub&gt;=121</td>
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<tr>
<td>N&lt;sub&gt;End&lt;/sub&gt;=72</td>
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<td>Population: Intervention Group (N=72): Mean age=59.3±13.0yr; Gender: Male=39, Female=33. Intervention: Patients completed a driving test at an outpatient driving assessment clinic and a set of questionnaires testing psychometric, vision, and motor abilities. Assessment on the driving test lasted 50-60mins and the questionnaires took 90mins to complete. Outcomes: Modified Washington University Road Test (mWURT); Clock Drawing Task (CDT); Snellgrove Maze Task (SMT); Trail Making Test Part A (TMT-A), Trail Making Test Part B (TMT-B); National Institutes of Health Stroke Scale (NIHSS); Useful Field of View (UFOV: Subtest 2); Short Blessed Test (SBT); Nine Hole Peg Test (9HPT: Left, Right); Rapid Pace Walk Test (RPW); Grip Strength: Left, Right; Visual Acuity; Pelli–Robson Contrast Sensitivity Chart (PRSC).</td>
<td>1. A total of 45 patients passed the mWURT and 27 patients failed. 2. Performance on the TMT-A, TMT-B (both p=0.0001), SMT (p=0.001), UFOV Subtest 2 (p=0.005), NIHSS (p=0.008), CDT (p=0.027) and SBT (p=0.043) were significantly greater for those who passed the mWURT compared to those who failed. 3. 9HPT Left and Right (p=0.027 and p=0.038 respectively), and Grip Strength Right (p=0.018) were significantly greater among those who passed the mWURT compared to those who failed but other measures of motor ability did not differ significantly between groups; Grip Strength Left (p=0.334) and RPW (p=0.200). 4. Visual Acuity was significantly greater in</td>
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19.5.2 Interventions and Driving Performance

Table 19.5.2 Interventions and Driving Performance

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<thead>
<tr>
<th>Author, Year Country</th>
<th>Methods</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Klavora et al.</td>
<td>10 patients with stroke (6 – 17 months prior to study)</td>
<td>On the on-road evaluation, 6/10 patients were those who passed the mWURT compared to those who did not (p=0.029) but no difference was reported for PRCSC between those who passed and those who did not (p=0.355). 5. TMT-A and SMT combined were found to provide the best model for predicting failure on the mWURT with a receiver operating characteristic area under the curve of 0.87.</td>
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<tr>
<td>Devos et al. (2015) USA Case Series No Score TPS=307d (210-530) NStart=73 NEnd=73</td>
<td>Population: Mean age=73±11yr; Gender: Males=66, Females=7. Intervention: Participants driving skills were retrospectively analyzed by lesion location. Outcomes: Driving Deficits.</td>
<td>1. Lesions in the parietal lobe showed correlations to vehicle control and speed adaptations (r Range=0.23-0.25). 2. Lesions in the occipital lobes correlated strongly with visual field (r=0.53) and moderately with visual neglect (r=0.28).</td>
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<tr>
<td>Hird et al. (2015) USA PCT No Score TPS: 48hr-7d NStart=20 NEnd=20</td>
<td>Population: Acute Stroke group (EG; n=10): Mean age=55.1±17.32yr; Gender: Males=7, Females=3. Healthy Control group (CG; n=10): Mean age=55.4±16.7yr; Gender: Males=4, Females=6. Intervention: Participants consisting of acute stroke patients (EG) and healthy controls (CG) performed in a driving simulator. Outcomes: Errors.</td>
<td>1. EG group committed over twice as many errors as the CG group in the City Driving (p&lt;0.01) and Bus Driving (p&lt;0.05) tasks. 2. There was no significant difference between groups in simple right hand turns (p&gt;0.05); however, the EG group made significantly more errors in left hand turns (p&lt;0.05).</td>
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<tr>
<td>McNamara et al. (2015a) Australia Observational No Score TPS&lt;16wk NStart=21 NEnd=21</td>
<td>Population: Mean age=74.5yr (47-92); Gender: Males=10, Females=11. Intervention: Participants underwent semi-structured interviews were conducted in the first 16 weeks post-stroke, while inpatients in either acute or rehabilitation stroke wards. Outcomes: Qualitative Responses.</td>
<td>1. Participants viewed driving as an indicator of independence. 2. Participants reported that they felt the need to focus on their physical recovery and return home before addressing the issue of driving. 3. Previous driving limits influenced current perception of driving.</td>
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<tr>
<td>McNamara et al. (2015b) Australia Observational No Score TPS&lt;3yr NStart=40 NEnd=40</td>
<td>Population: Mean age=65±17yr; Gender: Males=25, Females=15. Intervention: Participants who returned to driving following stroke underwent semi-structured interviews. Outcomes: Driving Distance; Driving Confidence; Demographics.</td>
<td>1. Male stroke survivors were more likely to return to driving, drive further and more often. 2. Stroke survivors under 65 years were likely to drive further. 3. Driving confidence was significantly associated with kilometres driven (p&lt;0.006), distance driven (p&lt;0.027) and self-limiting driving (p&lt;0.001).</td>
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<tr>
<td>Year</td>
<td>Location</td>
<td>Study Type</td>
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<tr>
<td>(1995)</td>
<td>Canada</td>
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<tr>
<td>Mazer et al.</td>
<td>Canada</td>
<td>7 (RCT)</td>
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<tr>
<td>Akinwuntan et al.</td>
<td>Belgium</td>
<td>8 (RCT)</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Study Design</td>
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<td>Devos et al. (2009) Belgium 8 (RCT)</td>
<td>This study represents further analysis of data derived from the Akinwuntan et al. (2005) study examining a driver training program. The authors examined the impact of the two modes of training (task specific simulator training vs. cognitive training) on the 13 specific items of the on road test.</td>
<td>Overall, performance on the on-road test (overall) and 4 items (anticipation &amp; perception of road signs, visual behaviour &amp; communication, quality of traffic participation and turning left) improved significantly more for patients who received similar training than for those in the cognitive group. There was a non-significant trend toward greater improvement in operational skills (road position &amp; mechanical operations) associated with simulator training. Performance on individual tactical items (speed, distance from car ahead, lane position changes) did not differ between groups. In addition, simulator training had a greater impact on visuointegrative items (anticipation &amp; perception of signs, visual behaviour and communication, quality of traffic participation) than cognitive training.</td>
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<td>Crotty et al. (2009) Australia (RCT) N/A</td>
<td>26 stroke patients were randomly assigned either to receive the Dynavision training intervention or be placed on a wait list. Participants assigned to the intervention group received 3 Dynavision training sessions (as per the Dynavision manual) per week for 6 weeks. The primary study outcome was on-road driving ability assessed at 6 weeks using a standardized on-road driving assessment. Secondary outcomes included abilities in response time measures, visual field scanning (visual scanning analyzer) and driving self-efficacy (Adelaide Driving Self-Efficacy Scale).</td>
<td>There were significant differences at baseline on visual scanning scores for neglect and abilities in response time (2-choice inspection, response and reaction). There were no significant between group differences in terms of on-road assessment results (p=0.22). Although the difference did not reach statistical significance, a greater proportion of individuals in the intervention group passed the assessment than in the control group (76.9% vs. 46.2%). There were no significant improvements demonstrated for response times, visual scanning or driving self-efficacy associated with Dynavision training vs. control group.</td>
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<tr>
<td>Akinwuntan et al. (2010) Belgium 8 (RCT)</td>
<td>5-year follow-up study of Akinwuntan et al. 2005. 61 participants were re-assessed. Blinded follow-up assessments were the same as those conducted at 6 months. In addition, BI, HADS, number of km/year driven and number of self-reported accidents and tickets were reported. Driving status at 5 years was the primary outcome.</td>
<td>60% (18/30) of patients who had received simulator training were considered fit to drive at 5-year follow-up vs. 48% (15/31) from the cognitive training group (p=0.36). 44 patients completed all assessments. 85% of those driving at 6 months continued to drive at 5 years. Among drivers, there was no increased risk of accident vs. pre-stroke; however, there was an increased risk of self-reported traffic tickets (RR=2.88). Cessation of driving was associated with older age, lower BI scores and higher depression scores.</td>
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<tr>
<td>Akinwuntan et al. (2010) Belgium 8 (RCT)</td>
<td>Additional report/analyses from Akinwuntan et al. 2005.</td>
<td>There were no significant between group differences reported on the UFOV. However, there were significant within group improvements on the UFOV test for both groups. Improvements were sustained at follow-up (3 months).</td>
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</table>
24 individuals with stroke and 20 healthy control participants were provided a training session in a realistic driving simulator first driving on a simulated seaside road (low traffic density) at a speed of up to 30 km/h. Then participants were provided with a straight road in which they had to avoid a collision with a truck at 40Km/h. Participants were provided with 3 attempts at the braking task. Braking speed/reaction time was the primary outcome.

On the first attempt, significantly fewer patients than healthy controls were able to avoid a collision. Rates of avoidance in both groups increased with each trial. Similarly, mean reaction time (0.8, rang 0.5-1.2) in the patients was significantly longer than in health controls (0.7 sec. 0.5-1.3) (p=0.02). Reaction times decreased on the second and third attempts for individuals with stroke (p<0.001).

### 19.6 Returning to Work Post Stroke

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Weisbroth et al.</strong> (1971) USA No Score</td>
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<tr>
<td>623 hemiplegic stroke patients under the age of 65 who were seen for extended vocational counselling at the Institute of Rehabilitation Medicine were followed.</td>
<td>37% of patients returned to work. Women were more likely to return to work than men. Those with left hemiplegia who returned to work differed from those who did not return to work on variables of ambulation, use of affected upper extremity and non-verbal abstract reasoning. Those with right-sided hemiplegia who returned to work differed from those who did not return to work on the variables of verbal cognitive and communicative deficits.</td>
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<td><strong>Smolkin and Cohen</strong> (1974) USA No Score</td>
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<td>74 hemiplegic stroke patients were evaluated for vocational outcomes after a vocational rehabilitation project.</td>
<td>32% of patients returned to work. More men than women returned to work, 38% vs. 10%.</td>
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<td><strong>Fugl-Meyer et al.</strong> (1975) Sweden No Score</td>
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<td>A descriptive analysis of the incidence and survival of patients with first stroke with hemiplegia before the age of 66 with special regard to employment.</td>
<td>32% of all 6-year survivors and 41% of those who had only one stroke returned to work. Return to work was correlated with degree of motor handicap and age.</td>
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<td><strong>Mackay and Nias</strong> (1979) Scotland No Score</td>
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<td>100 stroke patients aged 65 years or less were studied. Patients and relatives were interviewed 72-hours post-stroke and again 6-months post-stroke. 90 of the stroke patients were matched with healthy controls from the community.</td>
<td>Of the 45 patients employed before stroke onset, 9 had died and 17 had returned to work by 6-months post-stroke. Of the 28 patients who returned home, 16 relatives were not working prior to stroke, 8 had to abandon their jobs to look after the patient, 2 had to reduce their work hours and only 2 were able to work their normal hours.</td>
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<td><strong>Coughlan and Humphery</strong> (1982) UK No Score</td>
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<td>Postal questionnaire completed by the spouses of 170 surviving stroke patients who had attended medical rehabilitation up to eight years earlier with focus on both the physical and psychosocial aspects of outcome for stroke.</td>
<td>101 men were in paid employment at time of stroke. Of the 71 under the age of 65 at follow up, 30% were in paid employment and 5 patients had worked at some time during follow-up. Of the 21 currently working, only 10 were employed full-time in their previous occupation and the remainder reduced their hours and/or changed the nature of their work.</td>
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<td>Study</td>
<td>Country</td>
<td>Score</td>
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<tr>
<td>Kotila et al. (1984)</td>
<td>Finland</td>
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<td>Howard et al. (1985)</td>
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<td>Bogousslavsky and Regili (1987)</td>
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<tr>
<td>Heinemann et al. (1987)</td>
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<td>Black-Shaffer and Osberg (1990)</td>
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<td>Adunksy et al. (1992)</td>
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<td>Saeki et al. (1995)</td>
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<td>Wozniak et al. (1999)</td>
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<td>Vestling et al. (2003)</td>
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<td>Glozier et al. (2008)</td>
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<tr>
<td>Busch et al. (2009)</td>
<td>UK</td>
<td>No Score</td>
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Social activity was categorized as inactive, moderately active or very active at one year. Mean patient age = 53.8 (SD=12.9).

2/3 were working full-time. On regression, the final model demonstrated that older age, female sex, black ethnicity, diabetes and dependence at 1 week were independently associated with lower odds of returning to work at one year. On cross-sectional analysis, return to work was associated with higher BI and FAI score categories. However, of 161 people who were independent on follow-up (BI >19), 53% had not returned to work. Similarly, 39% of individuals who were very active (FAI.30/45) were not employed at 1 year.

Gabriele & Renate (2009)
Germany
No Score

70 couples (individuals with first-ever stroke and his/her spouse) were interviewed at baseline (mean 4.3 months post stroke) and one year later. Assessments via interview included the BI, the Patient Competency Rating Scale (PCRS) and the WHOQOL Bref. All patients had been employed or seeking employment at the time of his/her stroke. Mean age of patients was 52.4, and of spouses was 50.3 years. 80% of spouses were female.

26.7% of patients employed prior to stroke returned to work by 1 year; 87.5% were white collar workers. Mean age of patients not returning to work was 5 years greater than those who did return to work (p=ns). Sex and household income were significantly associated with return to work such that females were more likely than men to be employed (p=0.002) as were individuals with an income of more than 2000 euros/month prior to the stroke (p=0.041). Individuals who did not return to work had significantly poorer BI scores at admission, as well as PCRS ADLs and PCRS-cognition scores than individuals who did return to work (p<0.01 in all cases). Quality of life was stable over time in both groups, but individuals who returned to work had significantly lower quality of life at each assessment point. In addition, spouses of patients who returned to work demonstrated significantly greater QOL (physical, psychological & environmental subscales) than those with unemployed partners. Scores on the social subscale of the WHOQOL were not significantly different between groups.

Lindstrom et al. (2009)
Sweden
No Score

855 individuals with stroke who had been employed prior to the event responded to a questionnaire intended to investigate important factors in returning to work. Univariate analysis and multiple logistic regression were employed to identify significant factors associated with return to gainful employment.

The majority of study participants were aged 45-55 and there were more men than women included (n=517 vs. 301). 65% of participants returned to work. On multiple logistic regression, individuals who considered it important to work (OR = 5.10, 95% CI 3.35-7.74), could still run 100 m (OR=2.77, 95% CI1.5-5.12), and had support to return to work (OR = 3.66, 95% CI 2.27-5.9) were most likely to do so. In addition, higher SES (OR = 2.12, 95% CI 1.39-3.24) and not feeling like a burden to others (OR=3.33, 95% CI 1.94-5.7) were also associated with increased likelihood of return to work. Gender, independence in activities of daily living and cognitive abilities were not associated with return to work.
<table>
<thead>
<tr>
<th>Study &amp; Year</th>
<th>Country</th>
<th>Score</th>
<th>Individuals</th>
<th>Follow-up</th>
<th>Outcomes</th>
<th>Predictors of Return to Work</th>
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<tbody>
<tr>
<td><strong>Saeki et al. (2010)</strong>&lt;br&gt;Japan No Score</td>
<td>325 individuals with stroke were registered in the study. All participants were less than 65 years of age and had been employed prior to the stroke event. Patients were grouped by time to return to work – early return was &lt;100 days post stroke and late return ≥100 days.</td>
<td>253 patients were available for follow-up. 55% returned to work. On stepwise regression, male gender (OR=3.24, 95% CI 1.11-10.96), having a functional hand on the hemiplegic side (OR=4.66, 95% CI 1.4-19.53), and being independent (Barthel Index score of 80 – 100) (OR=2.71, 95% CI 1.08-7.03) were all significantly associated with early return to work (n=127).</td>
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<td><strong>Andersen et al. (2012)</strong>&lt;br&gt;Denmark No Score</td>
<td>83 individuals with first stroke who were &lt;60 years of age and employed either full-time or part-time at the time of the stroke event. Patients were recruited during acute care stay; follow-up occurred at 10 days, 3 months, 1 year and 2 years post event. Outcomes included fatigue (assessed using the Multi-dimensional Fatigue Inventory (MFI-20) and return to work (defined as working or studying at least 10 hours/week).</td>
<td>53% of patients had returned to work at 1 year – 58% by 2 years. Presence of post-stroke fatigue (General Fatigue score &gt;12) appeared to be associated with lower chance of return to paid work (OR=0.51, 95% CI 0.18-1.39 and 0.39 95% CI 0.16-1.08 at 1 and 2 years respectively).</td>
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<td><strong>Tanaka et al. (2011)</strong>&lt;br&gt;Japan No Score</td>
<td>Based on the same cohort as Saeki et al. 2010. Reported regression analysis to examine predictors for early return to work.</td>
<td>The sample was 80% male. Successful early return to work was recorded for 30% of participants. White collar employment (vs. blue collar), Barthel Index score at baseline and employment status (yes vs. no) at discharge were identified as significant predictors of early return to work. In individuals with mild physical impairments, the presence of cognitive dysfunction (aphasia, visuospatial neglect, attention dysfunction, memory impairment and intellectual impairments) was associated with inability to return to work.</td>
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<td><strong>Trygged et al. (2011)</strong>&lt;br&gt;Sweden No Score</td>
<td>Individuals with first-ever stroke discharged from hospital from 1996-2000 (n=7,081). The association between return to work (1-4 years post discharge) and income and education variables was examined controlling for age, sex, stroke subtype and length of stay.</td>
<td>Individuals with higher levels of education (university-level, RR=1.33), and higher income (upper quartile vs. lower, RR=2.02) returned to work more often than those with lower levels of education and/or lower income. Men and women had about the same probability for return to work once adjustment had been made for gender differences in level of education and income. Length of stay was also associated with return to work such that individuals with shorter lengths of stay were more likely to return to work.</td>
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<tr>
<td><strong>Hannerz et al. (2012)</strong>&lt;br&gt;Denmark No Score</td>
<td>Previously employed stroke patients from the years 2000-2006 (n=13, 178) identified from 2 large population databases. Length of follow-up = 2 years. The study population was considered according to pre-stroke employment in enterprises defined by 4 size categories: micro (1-9 employees), small (10-49 employees), medium (50-249 employees) and large (≥250 employees).</td>
<td>Size of enterprise was significantly associated with return to work post stroke (=0.034). Compared to the largest institutions, each increase in size of enterprise was associated with a small increase in the odds of returning to work post stroke.</td>
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<td><strong>Doucet et al. (2012)</strong>&lt;br&gt;France No Score</td>
<td>Participants included stroke survivors who had been working at the time of their stroke were at least 3 Individuals who returned to work were more likely to be married or have a partner, were less</td>
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<tr>
<td>Authors</td>
<td>Year</td>
<td>Country</td>
<td>Study Type</td>
<td>Population</td>
<td>Interventions</td>
<td>Outcomes</td>
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<tr>
<td>Hackett et al.</td>
<td>2012</td>
<td>Australia</td>
<td>No score</td>
<td>A population of young stroke survivors (age 17-65) with recent stroke were</td>
<td>Return to work was also facilitated through professional support (p&lt;0.004), having contact</td>
<td>75% of participants in this study returned to part or full time paid employment during the first</td>
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<td>studied to determine rates of return to work following stroke, as well as</td>
<td>between an occupational physician and the Centre for Rehabilitation and Physical Medicine</td>
<td>year following stroke. Univariate analysis showed that number of variables associated with return to paid</td>
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<td>variables associated with return to paid employment.</td>
<td>staff (p&lt;0.007), and having been returned to driving (p&lt;0.001).</td>
<td>employment.</td>
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<tr>
<td>Sreedharan et al.</td>
<td>2013</td>
<td>India</td>
<td>No Score</td>
<td>150 stroke survivors and their caregivers were studied to explore the</td>
<td>Employment loss in stroke survivors had a statistically significant association with</td>
<td>Employment loss in stroke survivors had a statistically significant association with functional</td>
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<td>relationship between return to work and social functioning.</td>
<td>return to work (p=0.037), male gender (p=0.001), and limb weakness (p=0.043).</td>
<td>disability (p=0.037), male gender (p=0.001), and limb weakness (p=0.043).</td>
</tr>
<tr>
<td>Kauranen et al.</td>
<td>2013</td>
<td>Finland</td>
<td>No Score</td>
<td>Stroke survivors who had been employed prior to stroke were prospectively</td>
<td>The number of cognitive deficits post stroke onset (mean = 8 days post onset) was the</td>
<td>The number of cognitive deficits post stroke onset (mean = 8 days post onset) was the only</td>
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<td>studied to determine if the initial cognitive severity of the stroke</td>
<td>only factor significantly associated with an inability to return to work (OR=2.23, 95%CI:</td>
<td>factor significantly associated with an inability to return to work (OR=2.23, 95%CI: 1.29 to 3.92).</td>
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<td>predicts the return to work.</td>
<td>1.29 to 3.92). Age, education, type of work, NIHSS score, lesion characteristics, and</td>
<td>Age, education, type of work, NIHSS score, lesion characteristics, and Barthel index scores were</td>
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<td>Barthel index scores were not found to be associated with return to work in this</td>
<td>not found to be associated with return to work in this population.</td>
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<tr>
<td>Peters et al.</td>
<td>2013</td>
<td>Nigeria</td>
<td>Retrospective</td>
<td>Population: Mean age=47.2±12.3yr; Gender: Males=57, Females=44.</td>
<td>1. More than half of study participants (55%) returned to work after the stroke event.</td>
<td>1. More than half of study participants (55%) returned to work after the stroke event.</td>
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<td>No Score</td>
<td>Intervention: To explore the frequency and determinants of return to work</td>
<td>2. Multivariable logistic regression results revealed that the only statistically</td>
<td>2. Multivariable logistic regression results revealed that the only statistically significant</td>
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<td>TPS=19.5±22.0mo</td>
<td>(RTW) among Nigerian stroke survivors.</td>
<td>significant predictors of RTW after stroke were functional status (p&lt;0.001) and post-</td>
<td>significant predictors of RTW after stroke were functional status (p&lt;0.001) and post-</td>
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<td>NStart=101</td>
<td>Outcomes: Functional ability: modified Rankin Scale (mRS).</td>
<td>stroke duration (p&lt;0.05). However, absence of disability (OR=57.7, 95%CI: 12.0 –</td>
<td>stroke duration (p&lt;0.05). However, absence of disability (OR=57.7, 95%CI: 12.0 – 276.8) or</td>
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<td>NEnd=101</td>
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<td>276.8) or slight disability (OR=15.1, 95%CI: 3.9-58.3) were associated with a higher</td>
<td>slight disability (OR=15.1, 95%CI: 3.9-58.3) were associated with a higher chance of returning</td>
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<td>chance of returning to work.</td>
<td>to work.</td>
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<td>Maaijwee et al.</td>
<td>2014</td>
<td>Netherlands</td>
<td>Prospective</td>
<td>Population: TIA Group (TIA, N=215): Mean age=39.7±8.0yr; Gender: Males=</td>
<td>1. 202 (29.1%) of participants were unemployed at follow-up.</td>
<td>1. 202 (29.1%) of participants were unemployed at follow-up.</td>
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<td>Cohort</td>
<td>Ischemic Stroke Group (IS, N=425): Mean age=47.2±12.3yr; Gender: Males=</td>
<td>2. A greater proportion of unemployment was</td>
<td>2. A greater proportion of unemployment was</td>
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<td>88, Females=127.</td>
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<td>Study</td>
<td>No Score</td>
<td>TPS</td>
<td>Mean</td>
<td>N&lt;sub&gt;Start&lt;/sub&gt;</td>
<td>N&lt;sub&gt;End&lt;/sub&gt;</td>
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Population: Mean age=39.1±8.1 yr; Gender: Males=182, Females=243. Intracerebral Hemorrhage Group (ICH, N=54): Mean age=36.2±8.7 yr; Gender: Males=26, Females=28. **Intervention**: The incidence of unemployment after first time TIA, IS, or ICH was prospectively analysed. Participants were drawn from the Follow-Up of TIA and stroke patients and Un-elucidated Risk factor Evaluation (FUTURE) study. **Outcomes**: Unemployment after stroke.

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<tr>
<th>Study</th>
<th>No Score</th>
<th>TPS</th>
<th>Mean</th>
<th>N&lt;sub&gt;Start&lt;/sub&gt;</th>
<th>N&lt;sub&gt;End&lt;/sub&gt;</th>
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<tr>
<td>Tanaka et al. (2014)</td>
<td>Japan</td>
<td>Prospective</td>
<td>No Score</td>
<td>TPS&lt;sub&gt;Overall&lt;/sub&gt;=574d</td>
<td>N&lt;sub&gt;Start&lt;/sub&gt;=250</td>
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</table>

Population: Mean age=55.3±7.2 yr; Gender: Males=280, Females=71. **Intervention**: To examine clinical, functional, and occupational factors associated with return to work within 18 months after stroke (with a focus on higher cortical dysfunction on return to work) in the chronic phase. **Outcomes**: Return to work.

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<tr>
<th>Study</th>
<th>No Score</th>
<th>TPS</th>
<th>Mean</th>
<th>N&lt;sub&gt;Start&lt;/sub&gt;</th>
<th>N&lt;sub&gt;End&lt;/sub&gt;</th>
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<tr>
<td>Brey and Wolf (2015)</td>
<td>USA</td>
<td>Prospective Cohort</td>
<td>No Score</td>
<td>TPS&lt;sub&gt;Overall&lt;/sub&gt;=3mo</td>
<td>N&lt;sub&gt;Start&lt;/sub&gt;=24</td>
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Population: Skilled workers (N=12): Mean age=51.17±7.33 yr; Gender: Males=42%, Females=58%. Unskilled workers (N=9): Mean age=49.67±7.75 yr; Gender: Males=33%, Females=67%. **Intervention**: Participants with stroke completed an assessment battery of questionnaires approximately 3 weeks and 7 months post stroke. Data was used found in the young patient population compared with the Dutch control population in all age groups for both men (OR 3.2 [95% CI 2.5-4.0]) and women (2.3 [1.8-2.9]), besides women between 55-65 yr and men<35 yr.

3. Female and male patients between the ages of 35-44 yr had the highest risk of unemployment (women: 4.7 [3.0-7.0]; men: 9.4 [5.6-15.3]).

4. Longer duration of follow-up (2<sup>nd</sup> tertile: 2.8 [1.7-4.7], p<0.0001; 3<sup>rd</sup> tertile: 3.4 [1.9-6.1], p<0.0001) and higher NIH Stroke Scale score (1.1 [1.0-1.1], p<0.0001) at admission were both factors associated with significantly higher risk of unemployment.

5. There was no difference in unemployment rates between IS (1.4 [0.9-2.3]) and TIA patients (OR 1). However, there was a higher risk of post-stroke unemployment in patients with ICH (2.2 [0.9-4.9]).
to investigate the relationship among the factors that influence return to work for young adults with mild stroke from different socioeconomic backgrounds. Individuals were placed in “skilled” and “unskilled” worker category based on the Hollingshead Index.

**Outcomes:**
- Wechsler Memory Scale The Digit Span Forward/Backward (WMS-DSF/WMS-DSB)
- Wechsler Memory Scale Spatial Span Forward/Backward (WMS-SSF/WMS-SSB)
- Delis-Kaplan Executive Function System (DKEFS)
- California Verbal Learning Test (CVLT-II)
- Wechsler Test of Adult Reading (WTAR)
- Stanford Presenteeism Scale (SPS)
- Work Ability Index Questionnaire (WAI)
- Environmental work conditions.

WAI was not significantly different between the two groups (p=0.164).

3. Individuals in the unskilled worker group reported significantly less favorable work environments than individuals in the skilled group specifically regarding supervisor support and work autonomy following a mild stroke (p=0.017, p=0.049).

**Wang et al. (2015b)**
Taiwan RCT PEDro=6 TPS=51

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<tr>
<th>Population: Experimental Group (EG; N=25): Mean age=62.0±9.5yr; Gender: Males=13, Females=12. Control Group (CG; N=26): Mean age=65.4±10.6yr; Gender: Males=17, Females=9.</th>
<th>1. A significant between-group difference was found on the following SIS subscales: composite physical (p&lt;0.001), communication (p=0.03), social participation (p=0.019) and general recovery (p&lt;0.001), favoring the EG.</th>
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<td>Intervention: Participants were randomly allocated to the experimental group and received caregiver-mediated training or to the control group and were maintained on routine care. The intervention lasted 12 weeks, conducted weekly for approximately 90 minutes. Outcomes: Berg Balance Scale (BBS); 10 Meter Walk Test (10MWT); free-walking velocity; 6 Minute Walk Test (6MWT); Stroke Impact Scale (SIS); Barthel Index (BI); Caregiver Burden Scale (CBS).</td>
<td>2. The EG performed significantly better than the CG on the free-walking velocity (p=0.006), 6MWT (p=0.003), BBS (p=0.006), and BI (p=0.008).</td>
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<td>3. No significant between-group difference was found regarding the CBS.</td>
<td>3.</td>
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References


study... including commentary by Jones TM and Dean CM. International Journal of Therapy & Rehabilitation, 20(12), 597-605.


Olaleye, O. A., Hamzat, T. K., & Owolabi, M. O. (2014). Stroke rehabilitation: should physiotherapy intervention be provided at a primary health care centre or the patients’ place of domicile? Disabil Rehabil, 36(1), 49-54.


