Community Reintegration

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Abstract

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

Social Support

- Although rehabilitation programs that focus on transitioning patients into their homes are found to benefit both the caregivers and the stroke survivors, barriers still arise regarding the social aspects of reintegration.

- Admission FIM (motor and cognitive), age, and marital status may predict discharge destination.

- Social support is found to be beneficial at improving mood, social interactions, and even functional outcomes.

- Stroke patients benefit the most from social support that provides a moderate amount of instrumental support, and a high amount of emotional support.

- Large social support networks and having pets have a positive influence on the physical recovery and quality of life of the stroke survivor.

- Social work interventions may not increase independence or social activity.

- Social support interventions that include the stroke patient’s social support network are not associated with improvements in functional recovery or quality, quantity or type of support.

- Day service programs may help to increase participation in leisure activities. Additional studies are needed.

- Although home-based support and care management visits may result in improved knowledge and satisfaction, they are not necessarily associated with improved social activity, quality of life or mood.

- Active case management may help to increase social activity. Additional studies are required.

- Caregiver-oriented, individualised discharge planning may improve caregiver preparedness

- More studies are needed to determine the effect of patient and caregiver education programs.

- More studies are needed to determine the benefit of community walking programs for individuals with stroke.

- Self-management programs may not be more efficient than usual care at improving quality of life after a stroke. This may be due to the various challenges of the programs that outweigh the benefits.

Family Support

- Stroke caregivers may experience financial strain, decreased mental health, decreased social contact and activity and an increased risk for depression.
• Support received from caregiving peers, who share the experience of caring for a stroke survivor, may have a positive effect on caregivers.

• Accessible information made available through a web-based program may reduce healthcare utilization.

• Access to interactive web-based resources may reduce depression in caregivers.

• Stroke patients do better with well-functioning families.

• Information provision and education interventions may have a positive influence on caregiver outcomes; however, more research is needed to clarify the optimal intervention type, dosage, and time post-stroke.

• Although information and education is perceived to be very important, informal carers rarely receive adequate information or training for their needs.

Leisure
• Deterioration in social and leisure activities is common post-stroke. Programs that encourage positive perspectives, acceptance of limitations, and social support may help to reduce psychological distress.

• Leisure therapy may result in improved leisure activity.

• Participation in group exercise and education may result in improved subjective physical outcomes.

Sexuality
• A decrease in sexual activity is very common post stroke and is likely related to a changed body image, reduced self-esteem and lack of communication with one’s partner. Sexual issues need to be addressed as part of community reintegration.

Driving
• Patients for whom there is concern about their ability to drive post-stroke need to be properly assessed.

• Visual attention retraining does not improve driving performance in stroke survivors more than traditional visuoperception retraining.

• Driving-fitness may be improved through the use of a simulator training programs.

Work
• Stroke survivors who were employed prior to the stroke event should be evaluated for their potential to return to work. Vocational rehabilitation strategies to assist the return to work of stroke survivors need to be developed and evaluated.

Factors Influencing Reintegration
Stroke survivors face a number of challenges during the process of reintegration in the community. Negative factors such as lack of accessibility, low emotional state, and lack of support from family and friends, restrict reintegration success. Providing support emotionally and physically prepares patients to face various reintegration challenges with greater ease.
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19.1 Social Support and the Stroke Patient

While the majority of stroke survivors return to live in the community, re-integration based on the resumption of activities of daily living and the adoption of successful psychosocial roles may be an enormous challenge (Palmer & Glass 2003). The ability to return to an acceptable lifestyle, participating in both social and domestic activities has been found to be important in patient satisfaction and in perceived quality of life post stroke (Clark & Smith 1999; Jaracz & Kozubski 2003; Kim et al. 1999; Mayo et al. 2002). Studies which have assessed items in terms of their importance to perceived quality of life in stroke survivors cite items such as the ability to speak, the ability to visit places outside the home, the ability to get around, the ability to do things/pursue leisure activities, independence/control in one’s own life, usefulness to others, stress, sex life and not having a job as receiving high importance but low satisfaction ratings (Kim et al. 1999; King 1996; Robinson-Smith et al. 2000). Additionally, many stroke survivors report poor social integration, loss of social contact, social isolation and loss of previous social roles (Kersten et al. 2002; Knapp & Hewison 1998; Pound et al. 1998).

A study by Boden-Albala et al. (2005) reported that social isolation following first stroke is significantly associated with the risk for recurrent stroke or death where social isolation was defined as “knowing fewer than three people well enough to visit with in their homes” (HR = 1.4, p=0.02). The authors suggested that social isolation may be related to poor outcome via stress, depression, poor treatment compliance and decreased participation in healthy activity. The executive summary of the Public health Service, Agency for Health care policy and research (1995) discuss the transition to the community and noted, “Return to a community residence after an acute hospitalization for stroke, or after an inpatient rehabilitation program, can be difficult for the stroke survivor and family alike. At this time, the person has to assume increased responsibility for independent functioning in the absence of the supportive environment of the inpatient setting, with the family or other caregivers providing needed support. Continuity of services is important during this period, and patient and family counselling may be needed to facilitate family functioning and improved outcomes.” Physical and psychological barriers to participation that keep the individual with stroke isolated need to be addressed in order to promote personal autonomy and social re-integration (Kersten et al. 2002; Pound et al. 1998). Involvement of the community itself in education and rehabilitation may serve to ameliorate attitudes of fear and ignorance that negatively impact the stroke survivor’s ability to participate in paid employment or social activity (Kersten et al. 2002).

According to Glass and Maddox (1992), the stroke experience can be viewed as a psychological transition in that: (1) it takes place in a short period of time and often strikes without warning; (2) it alters the capacity for social role functioning; and (3) the risk of loss of functional independence requires adjustment to a new definition of self and limitation of functional, social and cognitive function which are losses to one’s vital capacities. Thus, the transition of the stroke experience calls for the need to re-establish functional independence while incorporating residual deficits into a new personal identity.

Using this model, Glass and Maddox (1992) asserted that by shifting away from viewing stroke events as inherently stressful to a focus on the effectiveness of coping with loss, adaptation to change and temporal order of coping process, a bridge could be formed for the stroke patient to move from one identity to another. They suggested that social support could help ease the transition of the stroke experience and enhance recovery. Social support has been defined as “the experience or information that one is loved and cared for, valued and esteemed, and able to count on others should the need arise” (Gottlieb et al. 2001).
19.1.1 Social Support and Discharge Destination

According to Meijer et al. (2004), social support is a complex, multidimensional concept that is critical to a stroke patient’s successful return home. As such it should be considered according to specific social domains; homefront (composition of persons in the home and financial means), social situation (availability of care and quality of social network) and residence (adaptability to the needs of the individual).

In an attempt to identify prognostic social support factors for discharge destination within this model, Meijer et al. (2004) identified 6 cohort studies for review and synthesis (Table 19.1.1.1). A meta-analysis was considered impossible given the lack of data, heterogeneity of studies and methodological flaws within the individual studies. All six studies included in the Meijer et al. (2004) review assessed outcomes within the social domain such as social support, marital status, composition of persons in the home, discharge residence and social networks. None of the studies examined social supports within a framework of subdomains.

Overall, the review confirmed the importance of elements of the patient’s social situation in predicting discharge status. Characteristics identified as most important in the prediction of discharge destination were marital status and large social networks with perceived social support such that married patients, as well as those with large social networks who feel that they are well supported, are more likely to be discharged home. Large social networks and perceived social support were also associated with better physical function. The authors identified the small number of studies in the review, the poor methodology associated with all studies, with the exception of a single study (Pedersen et al. 1996), and the limited number of identified prognostic factors as limitations of their review.

More recently, several non-RCT have also investigated the factors that contribute to the discharge destination and some of the challenges of reintegrating in the home and in the community following a stroke.

In two qualitative studies, Gustafsson and colleagues (2013; 2014) conducted semi-structured interviews with the stroke patients and their primary caregiver after taking part in a stroke rehabilitation program (Stroke Rehabilitation Enhancing and Guiding Transition Home program) that focused on enhancing the transitional period into the community. The patients reported that although the rehabilitation program was adequate at preparing them for discharge at home, the experience of being at home was still a struggle. Patients also indicated that the rehabilitation program brought forth the notion that the stroke had changed their ability to partake in certain everyday activities therefore their pre-discharge expectations had changed to accept a new and different way of life with a stroke. The program was valued by many participants which indicated that it better prepared them for their transition and discharge.

Through in-depth interviews, Nanninga (2015) explored some of the challenges and barriers of reintegrating in meaningful places within the community following discharge. Some of the themes that emerged indicated that patients longed for domestic placed during the inpatient clinical phase, and

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<tr>
<th>Table 19.1.1.1 Studies Included in Literature Review and Synthesis (Meijer et al. 2004)</th>
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<tbody>
<tr>
<td>Brosseau et al. 1996</td>
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<tr>
<td>Colantonio et al. 1993</td>
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<td>Geerts et al. 1995</td>
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<td>Glass et al. 1993</td>
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<td>Jehkonen et al. 2001</td>
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many felt the longing of partaking in pre-stroke activities and roles during the post-discharge phase. During the reintegration phase, many stroke survivors longed for recognition and a sense of belonging. Furthermore, participants reported that their own selves have changed due to the stroke however, the spatial and social contexts of their homes remained the same. The spatial score became smaller in both geographical and social sense, and the challenges and complexities encountered in the outside world had a negative effect of repressing patients and family members inwards.

In many cases, discharge destination is not always considered to be the home of the patient. Several authors suggest that a patient’s status can influence discharge destination after hospital care. Some outcomes such as admission FIM, age, and marital status were found to be significantly associated with the likelihood of discharge home or to residential care (Pohl et al. 2013; Stineman et al. 2014; Tanwir et al. 2014). In fact, patients with low admission FIM scores (<60 for cognitive and motor), unmarried or living alone, and above the age of 77 were more likely to be discharged to a residential care facility than at home. Similarly, Obembe et al. (2013) found that age and motor function along with depression scores were significant predictors of community reintegration. Stineman et al. (2014) found that a higher proportion of patients with additional deficits such as visuospatial neglect were found to be discharged to supportive housing compared to those without visual deficits. Stroke etiology, hemispheric location, and admission to the inpatient rehabilitation unit were not found to drive discharge destination (Tanwir et al. 2014).

Conclusions Regarding Discharge Destination

*Rehabilitation programs that focus on the transition from hospital to homes are highly valued by the patients and caregivers; however, many stroke survivors still expressed social barriers that negatively impact the reintegration within the community and in their homes.*

*Factors such as admission FIM (motor and cognitive), age, and marital status were found to be significantly associated with discharge destination.*

Although rehabilitation programs that focus on transitioning patients into their homes are found to benefit both the caregivers and the stroke survivors, barriers still arise regarding the social aspects of reintegration.

Admission FIM (motor and cognitive), age, and marital status may predict discharge destination.

19.1.2 Social Support and Functional Status

As identified in the Meijer et al. (2004) review, the presence of a large social network and the perception of social support can have a positive impact on the physical function of the individual post stroke. A number of studies have focused their examination on the impact of social support on functional status.

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

Glass and Maddox (1992) stressed the need to distinguish between different types of social support and their role in the rehabilitation process. Moderate amounts of instrumental support and high amounts of emotional support appear to be most beneficial to stroke patients. In addition, it was observed that social support impacts patients differently depending on severity of stroke and amount of support received (Glass et al. 1993). Knapp and Hewison (1998) also observed that the availability of a close confiding relationship and social network relationships (i.e., emotional support) served to protect against later depression, which, in turn, resulted in improved functional outcomes. Tsouna-Hadjis et al. (2000) reported different effects associated with different types of family support. Higher levels of instrumental support had a significant and positive effect on both functional and social status in the first 6 months following stroke, but had less impact on depression, whereas emotional support had a different pattern of influence. High levels of emotional support had a significant impact on both depression and social status in the first 3 months post stroke, and on functional status from 3 to 6 months (Tsouna-Hadjis et al. 2000).

In a pre-post study by Jaglal et al. (2013), the telehealth chronic disease self-management program (CDSMP) which focused on providing support pertaining to self-efficacy, health behaviours, and health status, was constructed to allow individuals living in rural and remote communities to access these services. Findings suggest that accessing this program led to significant improvements in all health behaviours, cognitive symptoms, social role function, physical well-being, communication with physicians, and health distress from baseline to 4 months after. Although the findings demonstrate the pivotal need for such programs in remote communities, further investigations of such services through randomized controlled studies are highly encouraged.

**Conclusions Regarding Social Support and Functional Status**

*High levels of social support may facilitate improved functional gains, mood, and social interactions.*

*Moderate amounts of instrumental support and high amounts of emotional support may appear to be most beneficial to stroke patients.*

*Social support is found to be beneficial at improving mood, social interactions, and even functional outcomes.*

*Stroke patients benefit the most from social support that provides a moderate amount of instrumental support, and a high amount of emotional support.*

**19.1.3 Social Support and Quality of Life**

Quality of life is a complex, multidimensional concept that is of increasing interest in stroke rehabilitation research. Bays conducted a literature synthesis and review of 39 articles focusing on the quality of life of stroke survivors during the process of recovery from stroke. In that review, the quality
Quality of life of stroke survivors was found to be consistently lower than that of comparison groups, although among individuals with stroke, quality of life was variable as were the patterns of quality of life over time post stroke (Bays 2001). A number of variables were identified as having a positive influence on the quality of life for the stroke survivor. These included independence in ADLs, functional ability, social support and healthcare resources. Depression, cognitive impairment, stroke severity and aphasia were identified as having a negative impact on quality of life (Bays 2001).

While the quality of life of stroke survivors may be lower than that of comparison groups within the general population, it may be influenced, positively, by the presence of social support. Functional status has been demonstrated to be of considerable importance in the quality of life of stroke survivors; however, the degree of social support an individual receives may moderate the effect of disability and handicap on that individual’s quality of life (Gottlieb et al. 2001; P. Kim et al. 1999). In a large observational study, Shao et al. (2014) found that physical functioning, optimism and social support were significantly related to well-being, and correlated significantly with the meaning of life. In addition, it has been found that the size of social networks and their perceived quality or effectiveness affect the quality of life post stroke (Clarke et al. 2002; Kim et al. 1999; Mackenzie & Chang 2002). Hilari et al. (2010) demonstrated that both the perception of loneliness and satisfaction with one’s social networks influence the development of psychological distress over time. Individuals with larger social networks who also perceive them to be effective in supporting them may have a better quality of life. Haslam et al. (2008) demonstrated that individuals affiliated with a greater number of social groups prior to stroke may be more likely to maintain a larger number of these existing affiliations. Maintenance of group membership, rather than establishing new affiliations, may be important to well-being. However, maintenance of existing memberships may be threatened by cognitive impairment.

In a small study, Kubina et al. (2013) explored the process of re-engagement in personally valued activities and found that having “social connections” and “being in charge” led to activity engagement and risk taking to test one’s ability. These ultimately led to the lowering of current expectations and activity adaptation which supported hope for recovery.

Social interactions are not limited to humans, as animals and pets can be considered as companions especially to those stroke survivors that live alone. Unlike the relationship with family members and primary caregivers which was found to change following a stroke, the relationship with one’s pet was unaffected by the stroke. On the contrary, the presence of the animal companion motivated the stroke survivors to recover both physically and psychologically (Johansson et al. 2014). Furthermore, many patients indicated that the animals were seen as family members that could show them warmer feelings than close friends. Lastly, patients experienced a sense of protection when the family or caregiver(s) were not at home. Given that animals have been shown to provide a variety of benefits to the stroke patients, more RCTs are necessary to investigate other potential benefits of owning a pet.

**Conclusions Regarding Social Support and Quality of Life**

The presence and size of social support networks as well as the perceived effectiveness of social support networks have a positive influence on physical recovery, psychological distress and quality of life post stroke.

Higher levels of support are associated with greater functional gains, less depression and improved mood and social interaction.
The size and perceived effectiveness of social support networks are important predictors of discharge destination.

Having a pet was found to facilitate physical, psychological and social recovery after a stroke.

Large social support networks and having pets have a positive influence on the physical recovery and quality of life of the stroke survivor.

19.1.4 Social Support Interventions
Martin et al. (2002) interviewed 179 stroke survivors 6 to 9 months following the stroke event. Issues raised by survivors included feeling abandoned by the healthcare system, poor access to psychological supports, lack of confidence in resuming social activities, the impact of altered roles within the family and fear of another stroke. The importance of these issues to stroke survivors highlights the need for interventions that will improve patient education and support as well as promote involvement in services and social activities following the stroke patient’s return to the community (Martin et al. 2002).

A Cochrane review by Ellis et al. (2010) pooled mostly unpublished data from 16 studies that examined the impact of interventions which included a healthcare, volunteer or liaison worker (Table 19.1.4.1). Overall, pooled analysis demonstrated no significant difference between those participants with stroke receiving the trial intervention vs. those who did not in terms of either subjective health status (SMD = -0.03, p=0.34) or extended activities of daily living (SMD = 0.04, p=0.22). Similarly, intervention was not associated with improvements in caregiver health status (SMD=0.04, p=0.37). However, caregivers appeared to be more satisfied with the information received about stroke, recovery and rehabilitation. In addition, they tended to feel as though someone had listened to them and were less likely to feel neglected (Ellis et al. 2010).

For the purposes of the present review, we have chosen to present results from randomized controlled trials that have examined the impact of a variety of interventions designed to provide support for the stroke patient and family caregivers within the community. Interventions have been categorized by the nature of the intervention; social work, specialized social support network interventions, day services, home-based support and case management, active case management (including in-home rehabilitation services) and discharge planning programs.

19.1.4.1 Social Work Interventions
Two RCTs examining the effectiveness of social work interventions were identified. These studies are summarized in Table 19.1.4.1.1.

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Clark et al. 2003*</td>
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<tr>
<td>Glass et al. 2004</td>
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<tr>
<td>Forster &amp; Young 1996*</td>
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<tr>
<td>Dennis et al. 1997*</td>
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<td>McManus et al. 2009*</td>
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<tr>
<td>House 2007**</td>
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<tr>
<td>Leathley et al. 2003**</td>
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<tr>
<td>Tilling et al. 2005*</td>
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<tr>
<td>Lincoln et al. 2003*</td>
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<tr>
<td>Christie &amp; Weigall 1984</td>
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<tr>
<td>Frayne 2002**</td>
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<tr>
<td>Mant et al. 2000*</td>
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<tr>
<td>Goldberg et al. 1997</td>
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<tr>
<td>Burton &amp; Gibbon 2005*</td>
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<tr>
<td>Miller et al. 2007**</td>
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<tr>
<td>Boter et al. 2004*</td>
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*published and unpublished data
**unpublished data
**Table 19.1.4.2.1 Summary of Specialized Social Network Interventions**

<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><strong>Glass et al. (2004)</strong>&lt;br&gt;(RCT) 7&lt;br&gt;N=291</td>
<td>E: Psychosocial intervention that included home sessions with a mental health worker&lt;br&gt;C: Conventional care.</td>
<td>• Functional recovery (BI) (-)&lt;br&gt;• Depressive symptoms (+)&lt;br&gt;• Cognitive function (+)</td>
</tr>
<tr>
<td><strong>Friedland and McColl (1992)</strong>&lt;br&gt;(RCT) 5&lt;br&gt;N=88</td>
<td>E: Social support intervention&lt;br&gt;C: Conventional care</td>
<td>• Social Support Inventory for Stroke Survivors (SSISS) (-)&lt;br&gt;• Interpersonal Support Evaluation List (ISEL) (+)&lt;br&gt;• GHQ-28 (-)&lt;br&gt;• SIP (-)</td>
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+ Indicates statistical significance between treatment groups
- Indicates no statistical significance between treatment groups

**Discussion**

Neither study described here reported significant benefit associated with social support interventions that included stroke patients’ social support system. However, only Friedland and McColl (1992)
included direct assessment of perceived social support in addition to other psychosocial variables (psychological distress and health status). The study by Glass et al. (2004) examined the effectiveness of a psychosocial intervention designed to target informational, social, emotional and behavioural challenges encountered by families or entire social support systems (including additional friends and involved professional caregivers) following stroke. Unfortunately, the primary study outcome was functional or physical recovery as measured by the Barthel Index and there were no significant differences between groups following the six-month intervention. As the authors point out, the Barthel Index may not have been an appropriate choice to assess study outcomes in this case. More than 40% of all study participants had achieved maximum scores by the end of the study. This represents a substantial ceiling effect, which would limit the observed variance between the two study conditions (Glass et al. 2004).

In a more recent publication of subgroup analyses of the FIRST trial results, Ertel et al. (2007) demonstrated that, overall, the psychosocial intervention was associated with some positive impact on instrumental ADLs and physical performance and risk for mortality in healthier individuals. For those identified as frail or depressed, the intervention was associated with a possible increase in risk for mortality (Ertel et al. 2007).

**Conclusions Regarding Specialized Social Support Network Interventions**

There is level 1b and limited level 2 evidence that a specialized social support intervention that includes the stroke patient’s social support network may not be effective in improving perceived social support or functional recovery. Subgroup analyses suggest that there may be some benefit in terms of physical performance and instrumental activities of daily living for healthier, non-frail stroke survivors.

**Social support interventions that include the stroke patient’s social support network are not associated with improvements in functional recovery or quality, quantity or type of support.**

**19.1.4.3 Day Services**

A single RCT described the impact of a day program on psychosocial outcomes in a group of individual with stroke aged 18 – 55 (Table 19.1.4.3.1).

**Table 19.1.4.3.1 Summary of Day Services**

<table>
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<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Corr et al. (2004) (RCT) 6 N=26</td>
<td>E1:Cardiff Day Service immediately for 6 months than 6 months without E2:Cardniff Day Service attends for 6 months after 6 months without C:Conventional Care</td>
<td>• (SF36) physical functioning (E2 vs. E1/C (+)) • Extended ADL (-) • Nottingham Leisure Questionnaire (-) • Anxiety and Depression Scale (-)</td>
</tr>
</tbody>
</table>

+ Indicates statistical significance between treatment groups
- Indicates no statistical significance between treatment groups

**Discussion**
Early attendance at this day service was associated with increased ability to carry out occupations, increased satisfaction with performance of activities and regular participation in leisure activities whereas later attendance was associated with participation in a greater number of leisure activities.

In a more recent study, Micklewright et al. (2011) examined participation and vocational outcomes based on time of entry to a comprehensive day program that provided cognitive rehabilitation, traditional core therapies and life skills groups to individuals with brain injury (TBI=54; CVA=29). Overall, participants in the program demonstrated significant gains in participation outcomes assessed by the Mayo-Portland Adaptability Inventory (MPAI). Earlier entry to the program was associated with greater improvements. For instance, participants accessing the program within 6 months of the injury showed a reduction in neurobehavioural sequelae of over 50% during their enrollment, whereas, in individuals entering the program at 6-12 months and 12-24 months experiencing reductions of 24.7% and 27.1%, respectively. Injury etiology had no significant effect on this result. However, it should be noted that individuals with stroke were significantly older and remained in the program significantly longer than participants with TBI.

Community rehabilitation was also examined by Hartman-Maeir et al. (2007) in a prospective controlled study, by comparing patients partaking in a community-based day rehabilitation program to those currently residing at home but not actively participating in the program. Interestingly, findings indicate that the group receiving community-based rehabilitation had significantly lower FIM-motor scores compared to those that did not participate in the rehabilitation program. However, the “life as a whole” and “leisure situation” was found to be higher in the stroke participants compared to those that did not participate.

Conclusions Regarding Day Services

There is level 1b evidence that early attendance (within 6 months of stroke) at a day service is associated with improved participation in leisure activities.

Day service programs may help to increase participation in leisure activities. Additional studies are needed.

### 19.1.4.4 Home-Based Support and Care Management

Twelve RCTs were identified that examined the effectiveness of a home-based support and care management programs. In general, each of these interventions provided a series of contacts between a healthcare professional or trained individual and stroke patient (and their family) in order to identify needs and help to fulfill these by using available resources (Table 19.1.4.4.1).

#### Table 19.1.4.4.1 Summary of Home-Based Support and Care Management Interventions

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| **Allen et al. (2009) RCT (9) N=380** | E: Post discharge intervention + enhanced discharge planning  
C: Enhanced discharge planning |  
• Neuromotor function (-)  
• LOS/ mortality (-)  
• QOL (-)  
• Stroke knowledge and lifestyle modification (+) |
### Community Reintegration

**Dennis et al.** (1997)
RCT (8)
N= 417
- E: Post-stroke visits from a stroke family care worker
- C: Conventional care
  - Oxford Handicap Scale (-)
  - Frenchay Activities Inventory (-)
  - General health/ social adjustment (-)
  - Caregiver mood/ caregiver hassle (+)

**Forster et al.** (2009)
RCT (8)
N= 265
- E: Conventional care + structured patient/carer assessment at 5-6 months
- C: Conventional care + service information package
  - Frenchay Activities Inventory (-)
  - General Health Questionnaire-28 (-)

**Mant et al.** (2000)
RCT (8)
N= 520
- E: Family support care + information package
- C: Conventional care
  - Frenchay Activities Inventory (+)
  - Energy, health, pain and physical function (SF-36) scores (+)

**Mayo et al.** (2008)
RCT (8)
N= 190
- E: Home visits + telephone contacts
- C: Conventional care
  - Physical Component Summary (SF36) score of the SF36 (-)
  - Mental Component Summary, EQ5D, Preference-based Stroke Index, RNLI, BI, Geriatric Depression Scale, Gait speed, Timed Up and Go (-)

**Burton and Gibbon** (2005)
RCT (7)
N= 176
- E: Extended stoke nurse follow-up post discharge
- C: Conventional care
  - Barthel Index (-)
  - Nottingham Health Profile (-)
  - Beck Depression Inventory (-)
  - Frenchay Activities Index (-)
  - Caregiver Strain Index (-)

**Tilling et al.** (2005)
RCT (7)
N= 340
- E: Support from the Family Support Organizer
- C: Conventional care
  - Reintegration (+)
  - Satisfaction with community services (-)
  - Satisfaction with equipment (+)
  - Satisfaction with information (-)

**Boter et al.** (2004)
RCT (6)
N<sub>Start</sub>= 536
N<sub>End</sub>= 486
- E: Home visit+ telephone calls by a nurse following discharge
- C: Conventional care
  - Satisfaction with care (-)
  - Role limitation scale (SF36) (+)
  - Quality of life (-)
  - Perceived burden/ social support for carers (-)

**Drummond et al.** (2013)
RCT (6)
N<sub>Start</sub>=43
N<sub>End</sub>=31
- E: Home visit by an occupational therapist
- C: Conventional care
  - Nottingham Extended Activities of Daily Living Scale (-)
  - Stroke Aphasic Depression Questionnaire(-)
  - Mood (SADQ), readmission to hospital (+)
  - Quality of life/ costs (-)

**Forster and Young** (1996)
RCT (6)
N= 240
- E: Specialized nurse visits
- C: Conventional care
  - Social activities, perceived wellbeing, physical abilities (-)

**Claiborne** (2006)
RCT (5)
N= 28
- E: Care coordination (home visit + telephone appointments) provided by a social worker
- C: Conventional care
  - Physical component scale (SF-36) (-)
  - Mental component scale (SF-36) (+)
  - Geriatric Depression Scale (+)
  - Adherence to prescribed regimens

**Lincoln et al.** (2003)
RCT (5)
N= 250
- E: The Stroke Family Support Organiser (FSO) service
- C: Conventional care
  - Mood (-)
  - Independence (-)
  - Caregivers mood/ strain/ independence (-)

+ Indicates statistical significance between treatment groups
- Indicates no statistical significance between treatment groups

### Discussion
In general, interventions were usually initiated around the time of discharge from either acute care or inpatient rehabilitation and contact was sustained over periods of time ranging from 6 weeks to 12
months. In the majority of studies, the number and content of contacts were not prescribed but were determined by the support worker based on assessment of patient/family needs.

Studies examined the impact of the interventions on a variety of outcomes including patient independence, emotional distress or mood (carer and patient), social activity (carer and patient), health-related quality of life (carer and patient) and caregiver strain (Table 19.1.4.4.1).

Four of the 12 studies summarized above examined the effectiveness of the Family Support Organiser, a service established by the National Stroke Association in the United Kingdom. The main roles of the FSO are to provide both information and advice with regard to performing everyday tasks and contacting other services (Harding & Lincoln 2000). In general, results from these studies were inconsistent. Relatively few significant effects in favour of the intervention were noted. Apart from improved knowledge about stroke and increased satisfaction with services (Lincoln et al. 2003; Tilling et al. 2005), patients receiving FSO services may also be more likely to use resources such as support groups or stroke clubs (Mant et al. 2000). Informal caregivers of individuals with stroke may experience gains in the areas of social activity or quality of life (Mant et al. 2000). In addition, Tilling et al. (2005) demonstrated that carers participating in the FSO program felt that someone had listened to them and were more likely to know how to access appropriate resources within the community. In a qualitative study of participants’ perceptions of the FSO, Lilley et al. (2003) reported that program recipients felt the FSO to be a valuable service, particularly with regard to access to services, claiming appropriate benefits and an ongoing source of information. Although the initial study by Dennis et al. (1997) suggested that use of the FSO service might be associated with adverse effects such as learned helplessness, this has not been confirmed in subsequent studies.

While the stroke patient is admitted to an inpatient rehabilitation service, the stroke nurse acts as a focus for the multidisciplinary care team. Burton and Gibbon (2005) examined the effect of expanding his or her traditional role beyond the usual boundaries of nursing intervention to include the provision of information, education and support to stroke patients and their families throughout their hospital stay and into the community. Overall, the authors suggest that the results of their study demonstrate that an overarching perspective to the organization of stroke services, which promotes continuity of care and relationships through the transition from hospital to community, may improve the perceived health of stroke patients. This approach to continuous care may also serve to reduce caregiver stress during this time period.

A single RCT examined the impact of an intervention featuring frequent, regularly-scheduled contact by a social worker who provided ongoing assessment, counselling and referrals as required (Claiborne 2006). Over the course of the three-month intervention, individuals assigned to the care coordination intervention experienced less depression and better mental health-related quality of life when compared to those participants receiving “usual care”.

One recent RCT investigated the feasibility of occupational therapy pre-discharge home visits for people after stroke (HOVIS program) (Drummond et al. 2013). Adherence to the program after 1 month was 90%. The study shows no significant differences between those receiving visits compared to those not receiving visits on any of the outcome measures except for mood (favouring the visit group), and readmission to hospital after one month (favouring the no-visit group). The average cost of a home visit was £208. Although the program was considered feasible by the authors, there were several issues pertaining to the methodology of the study that were addressed. Some of these issues include a broad inclusion criteria, lack of appropriate assessor blinding, the lack of systematic completion of outcome measures, the need for stricter protocol adherence, lack of investigation of adverse events, and the lack
of knowledge regarding the rehabilitation received by the control group outside of the program. Future RCTs that would investigate the effectiveness of this program are encouraged to take in consideration these issues.

**Conclusions Regarding Home-Based Support and Care Management**

*There is level 1a evidence that home-based support and care management interventions are not associated with improved social activity, mood, quality of life or physical independence. However, there is level 1b evidence that participation in a social worker led program of care coordination featuring frequent, regularly-scheduled contact may result in improved mental health.*

*There is level 1a evidence that involvement with a stroke liaison worker or case manager is associated with increased knowledge about stroke and satisfaction with services.*

*There is level 1a evidence that social support interventions may be associated with a reduction in caregiver burden or strain.*

*There is inconclusive level 1b evidence regarding the efficacy of occupational therapist led home-visits on mental health and hospital readmission.*

**Although home-based support and care management visits may result in improved knowledge and satisfaction, they are not necessarily associated with improved social activity, quality of life or mood.**

**19.1.4.5 Active Case Management**

Two studies examined the impact of a structured active case management programs. All participants received scheduled contacts (telephone calls and home visits) in addition to home-based treatment as required including therapeutic recreation, social work and psychology consults (Goldberg et al. 1997). In a different structured program, participants received mailed letters detailing information regarding stroke, in addition to home visits from nurses and therapists (Ostwald et al. 2014).

**Table 19.1.4.5.1 Summary of Active Case Management**

<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>Goldberg et al. (1997)</td>
<td>RCT (5)</td>
<td>N=55</td>
<td>E: Stroke Transition after Inpatient Rehabilitation (STAIR) intervention. Home based care +therapeutic recreational treatment +social work/ psychology consolations + access to educational resources C:Conventional inpatient follow-up</td>
<td>• Functional independence (FIM)/ IADL ability (+) • Social Activity (FIA) (-) • Quality of life (-) • Psychosocial functioning (-)</td>
</tr>
<tr>
<td>Ostwald et al. (2014)</td>
<td>RCT (5)</td>
<td>N\text{Start}=159 N\text{End}=134</td>
<td>E:Information on stroke, resources, and advice+ home visits form nurses and therapists C: Information on stroke, resources and advice</td>
<td>• Geriatric Depression Scale/Perceived Stress Scale (-) • Short Form Health Survey (SF 36) at 6 months (+) at 1 year (-) • SF 36 for carers (-) • Functional Independence Measure (FIM: Cognitive) (-)</td>
</tr>
</tbody>
</table>

+ Indicates statistical significance between treatment groups
- Indicates no statistical significance between treatment groups
Discussion
The program of active case management described by Goldberg et al. (1997) differs from the previous home-based support interventions in several ways. Contact with patients was regularly scheduled and more frequent. Each case was reviewed bimonthly by a treatment team that included a physiatrist, psychologist, recreational therapist and case manager/social worker to identify potential problems and create specific action plans. Patients were provided with home-based recreational, social work and psychology services as necessary, in addition to educational material and access to additional support. Overall, this program of active case management was associated with an improvement in social activity at 6 months when compared to the control condition, though this did not persist as a significant difference at 1 year. Although the majority of participants (80%) in the active case management program found it to be valuable, participation was not associated with significant improvement in quality of life. Caregiver stress and depression developed over time and were related to differences in patient function rather than social support system (Goldberg et al. 1997).

Ostwald et al. (2014) investigated the effectiveness of a different program of active case management, where both the control group and the intervention group received mailed letters with stroke information and resources, however the intervention groups received additional home visits from nurses and therapists while the control group received advice only. The study did not find any significant differences between the two groups regarding depression and stress scores. Nevertheless, all participants (both intervention and control groups) showed a decrease in depression and stress symptoms after the intervention. Similarly, the memory, social participation, and FIM cognitive scores increased from baseline in all participants, however no difference between the two groups was found. The only significant different found when assessing the health status of caregivers favouring the intervention group.

Conclusions Regarding Active Case Management

There is level 1a evidence that active case management may result in improved social activity and mood however, it may not be more effective than the comparator control treatment. Further study is required.

Active case management may help to increase social activity. Additional studies are required.

19.1.4.6 Discharge Planning Programs
Given the need for ongoing support, patients and their carers should be included in making decisions and setting goals at the time of discharge home from inpatient care. Although patients and their families may be provided with a great deal of information at the time of discharge, patients may experience dissatisfaction around their relative lack of involvement in the process of decision-making in discharge planning (Almborg et al. 2009). Studies that have focussed on discharge planning programs to facilitate transitions home and improve long-term outcomes for both patients and carers are summarized in Table 19.1.4.6.1.

Table 19.1.4.6.1 Summary of 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>
</thead>
<tbody>
<tr>
<td>Shyu et al. (2008)</td>
<td>E: Caregiver-orientated discharge planning program</td>
<td></td>
<td>Caregiver preparedness (-)</td>
<td></td>
</tr>
</tbody>
</table>
Discussion

Individualized education and attention based on careful assessment of the needs of the individual caregiver or caregiving dyad that involves the caregiver in the process of preparation for discharge may improve caregiver preparedness in the short term and quality of care and need for institutionalization in the longer term. Further research is recommended.

Conclusions Regarding Discharge Planning Programs

There is limited level 2 evidence that individualised, caregiver-oriented discharge planning may improve both preparedness and quality of care.

Caregiver-oriented, individualised discharge planning may improve caregiver preparedness.

19.1.5 Patient Education Programs

Despite the advancements in medical treatment, prevention, and care of stroke, part of the progress depends in part on patient and caregiver education. Recently, several studies have attempted to determine the effectiveness of such education programs on the patients’ and caregivers’ physical and mental health status (Table 19.1.5.1).

Table 19.1.5.1 Summary of Patient Education Programs

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forster et al. (2013)</td>
<td>E: London Stroke Carers Training Course (LSCTC) C: Conventional care</td>
<td>• Nottingham Extended Activities of Daily Living (NEADL) scores (-) • Caregiver Burden Scale (CBS) scores (-)</td>
</tr>
<tr>
<td>RCT (5) N\text{Start}=1856 N\text{End}=1247</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wang et al. (2013)</td>
<td>E: 3 3 hour stroke interventions per week for 8 weeks C: General stroke education programme</td>
<td>• Knowledge, behaviour and self-efficacy results from questionnaire (-) • Warning signs, risk factors, dietary, social participation, self-efficacy results from questionnaire (+)</td>
</tr>
<tr>
<td>RCT (4) N\text{Start}=170 N\text{End}=127</td>
<td></td>
<td></td>
</tr>
<tr>
<td>McKellar et al. (2015)</td>
<td>E: Heart and Stroke Foundation booklet, tip sheet, and Cue to Action Trigger Tool (CRCATT) +visits from a research coordinator C:Heart and Stroke Foundation booklet</td>
<td>• Reintegration to Normal Living Index (RNLI) (-) • Experience with health care providers (+)</td>
</tr>
<tr>
<td>RCT (2) N\text{Start}=77 N\text{End}=57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skidmore et al. (2014)</td>
<td>E: Strategy training or attention control sessions + conventional care C:Conventional care</td>
<td>• Reduction in disability (FIM) (+)</td>
</tr>
<tr>
<td>PCT N\text{Start}=10 N\text{End}=10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taricco et al. (2014)</td>
<td>E: 16 adapted physical activity (APA) sessions</td>
<td>• 6 Minute Walk Test (+)</td>
</tr>
</tbody>
</table>
Discussion

Education programs can either be tailored to the patient, the primary caregiver, or both. In a recent study, Forster et al. (2013) investigated the effect of a training program for caregiver (London Stroke Carers Training Course, LSCTC) on the patient’s and the caregiver’s psychological and physical well-being. The study reports no significant differences between the control group which received usual care and the recipients of the LSCTC program on the patient’s activities of daily living, the caregiver’s burden, or the cost of admission for both the caregivers and the patients. The authors suggest that this the lack of significant difference between the two groups may stem from the fact that the education program was delivered in the immediate period of stroke, which may not be the best time to educate caregivers.

In a different study by Wang et al. (2013), patients randomly selected from seven communities received community-based stroke nursing education, while the normal care group selected from medical centres, received general stroke education. Findings show that stroke knowledge (including warning signs, medical treatment, risk factors of stroke, and dietary control), behaviour (i.e. social participation) and self-efficacy did not change after general stroke education but significantly improved after community-based nursing education. Furthermore, the effect was also maintained at the 6-month follow-up. These results suggest that community-based nursing education may have a beneficial effect at improving the patient’s and the caregiver’s knowledge regarding various aspects of stroke. Often, stroke education is provided in hospital-based clinics by nursing staff and the team that is in charge of caring for the patient. The findings from this study has large implications since it validates the benefit of receiving this information outside of the hospital. Therefore, instead of having patients visit the hospital clinics to receive stroke educational material, they can access the educational material in their community.

Other forms of stroke educational material in the form of a guideline to community re-integration (Cue to Action Trigger Tool, CRCATT) have also been recently investigated (McKellar et al. 2015). Patient use of this guide was evaluated along with its impact on the re-integration in activities after a stroke. The intervention group also received a Heart and Stroke Foundation Booklet with tips of how to communicate with health care professionals, while the comparator group only received the booklet and not the re-integration guide. Although no significant difference regarding re-integration to normal living was found between the two groups, those receiving the CRCATT guide felt more able to initiate conversations with family members regarding ‘hidden worries’. Furthermore, the CRCATT guide allowed for access to formal support to help re-integrate in the community, along with facilitating more positive experiences with health care provides. This study also had several limitations that are necessary to consider when interpreting the results. Firstly, the total sample size obtained was not high enough to achieve 80% power to detect a significant difference between the two groups. Secondly, many patients did not meet the inclusion criteria or chose not to participate. Thirdly, there was a general lack of knowledge of the degree of “engagement” in other activities prior to participation, especially activities that were considered “valued” pre-stroke. Lastly, the authors indicate that the results may not necessarily be applicable to the general population since more men than women participated in the study, and inclusion criteria allowed only those that could read English or those that had minor aphasia and cognitive impairments to participate. Nevertheless, this study may provide relevant information with regards to the types of patients that could benefit from this program.
Other programs that focus on strategy training were also shown to improve general disability (FIM) compared to those that received only usual care (Skidmore et al. 2014). A combination of adapted physical activity and therapeutic patient education was also found to improve physical performance, depression, and functional independence relative to those that did not receive this intervention (Taricco et al. 2014). In a pre-post study, Norris et al. (2013) demonstrated that the Action for Rehabilitation in Neurological Injury (ARNI) program which focuses on using both physical and psychological interventions to improve functional independence, was perceived as beneficial for patients. Many also reported that such a program provided outside of the hospital would allow them to adopt a more positive approach to training.

**Conclusions Regarding Education Programs**

*There is limited and inconclusive level 2 evidence regarding the effect of caregiver training programs on the patients’ and caregivers’ well-being.*

*There is limited level 2 evidence that community-based nurse-led education programs for patients may improve stroke knowledge.*

*There is limited and inconclusive level 2 evidence regarding the effect of providing re-integration guidelines to patients.*

*More studies are needed to determine the effect of patient and caregiver education programs.*

### 19.1.6 Community-Based Rehabilitation Programs

A single RCT evaluated the effect of a community walking program on functional rehabilitation (Table 19.1.6.1)

**Table 19.1.6.1 Community-Based Rehabilitation Programs**

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Kim et al. (2014)</strong> RCT (8) N\text{start}=26 N\text{end}=22</td>
<td>E: Community walking training program (CWTP) + Standard rehabilitation C:Standard rehabilitation</td>
<td>• Community Walking Test (+) • Stroke Impact Scale (+) • 10 Meter Walk Test (+) • 6 Minute Walking Test (+).</td>
</tr>
</tbody>
</table>

+ Indicates statistical significance between treatment groups
- Indicates no statistical significance between treatment groups

**Discussion**

In a single RCT by Kim et al. (2014), a community walking program that incorporates the social aspect of participating as a group, was evaluated to determine its effectiveness at improving walking function. Results suggest that when compared to the usual care group that did not receive this intervention, the walking group did significantly better on the ambulation outcomes. Although both groups received standard rehabilitation at the same intensity, the intervention group received additional walking exercises which the control group did not. Therefore, the results must be interpreted with caution as the effect observed may not be due to the social aspect of the program but rather due to the increased intensity of the physical exercise.
Conclusions Regarding Community Based Rehabilitation Programs

There is limited level 1b evidence that community walking programs are more efficient than usual care at improving walking performance and the impact of stroke on the patient.

More studies are needed to determine the benefit of community walking programs for individuals with stroke.

19.1.7 Patient Self-Management Programs

The concept of self-management has existed since its introduction by Bandura in 1977 as part of the Social Learning Theory. It has been defined as “people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives” (Jones & Riazi 2011). Essentially, self-management functions to influence how people behave, motivate themselves, feel, and think which ultimately facilitates ones’ well-being.

For patients affected by chronic conditions like stroke, adopting self-management concepts during rehabilitation facilitates recovery and maintenance of the progress made. Programs that promote self-management thinking help stroke patients to modify their behavior and lifestyle such that when challenges are encountered and difficult to overcome, the individuals can still maintain a sense of resilience despite any negative outcomes that may occur (Dixon et al. 2007; Jones & Riazi 2011). These types of programs have been previously been offered in various forms, whether through family support programs, self-help groups, or community services. It is important to note that self-management programs differ from educational programs (i.e. programs that involve knowledge learning or skills training) since they are designed to encourage patients to actively participate in the management of their own condition (Foster et al. 2007).

Thus far, the evidence for the effectiveness of such programs in stroke literature is limited. One of the earlier studies conducted in a stroke population found that self-efficacy correlated significantly with depression and quality of life at 1 and 6 month post-stroke (Robinson-Smith et al. 2000). Furthermore, depression, sex, comorbidity, age, time post-stroke and motor function were found to predict improvements in self-efficacy (Salbach et al. 2005). Hellstrom et al. (2003) demonstrated that self-efficacy gains during inpatient rehabilitation and were strongly linked with improvements in balance and motor function. As such, patients with low self-efficacy at discharge reported lower gains in balance and motor function after 10 months compared to patient with high self-efficacy (Hellstrom et al. 2003).

In a recent study by Hoffmann et al. (2015), two coping education interventions were assessed to determine their effect on anxiety, depression and quality of life after a stroke. Of the total eight sessions of education provided, the first two sessions were delivered in the hospital and the remaining sessions were provided in the patient’s home. All participants received usual care consisting of multidisciplinary treatment and assessment, and basic education and advice regarding stroke rehabilitation. One of the interventions provided was a coping skills intervention program designed to improve self-awareness and coping skills, which included physio-education, activity participation, cognitive restructuring, and self-management tools. The self-management education program differed from the coping skills program, since it focused largely on assisting patients to learn problem-solving skills, and to help improve communication with health care professionals. Additionally, therapists also worked closely with the patients to develop a goal oriented structured plan in which the patients’ concerns were addressed at
each session. Results indicate that compared to the usual care group, those receiving the coping skills intervention showed greater stroke knowledge and a reduction in their depression scores after the intervention period, however these effects were not maintained at follow-up. Conversely, unlike the improvements observed in the patient receiving the coping skills education program, those participating in the self-management program showed no significant difference in improvement compared to usual care on any of the outcomes measured at post-intervention or at follow-up. These results however, should also be interpreted with caution since the authors acknowledge that the study was underpowered which may have the predisposed the results to type II errors.

Although Hoffmann et al. (2015) investigated the effectiveness of the self-management program, the study did not explore the factors that may influence the effectiveness of the program. This question was addressed in a qualitative study by Boger at al. (2015) through the use of semi-structured interviews from patients that participated in self-management programs. The study found three themes that emerged among all participants: individual capacity, support for self-management, and the self-management environment. Participants suggested that physical impairments, self-confidence, decision making, determination, communication, and finding resources were key elements that were suggested to modulate the effect of self-management programs. Similarly, the role of professionals, the resources and the roles of the carers were found to be crucial factors in the support for self-management. Lastly, participants indicted that neither individual capacity nor support for self-management were sufficient to self-manage if a supportive environment to self-manage was not provided.

Satink et al. (2015) also found similar themes among stroke survivors regarding self-management programs. Participants described the self-management process as a long-term, complex personal learning experience. In most cases, patients were not ready to self-manage at post-discharge. By having professional support in the form of psychological and emotional support, the challenges of adopting self-management skills may have been overcome.

Although several studies suggest some benefits of self-management, more research is needed to determine the ideal format of delivery of self-management programs, the ideal time of delivering this intervention post-stroke, and the structure of such programs (i.e. individual or group-based).

Conclusions Regarding Self-Management Education Programs

There is level 1b evidence that self-management programs are not superior to usual care for improving quality of life of patients with stroke.

Self-management programs may not be more efficient than usual care at improving quality of life after a stroke. This may be due to the various challenges of the programs that outweigh the benefits.

19.2 Family and Stroke

For the individual, a stroke changes the capacity to function, not only as a physical being, but also as a social one. Resuming successful psychosocial roles is a complex and difficult process. This process is reliant upon instrumental and emotional support that comes primarily from the stroke survivor’s family (Palmer & Glass 2003). This transition can be viewed as a process of adaptation as roles, responsibilities and patterns of support within the family change to accommodate the needs of both the stroke survivor and the other members of the family (Palmer & Glass 2003). In viewing the family as a system, it
becomes clear that a stroke has a profound effect not only on the individual stroke survivor but also on the entire family system. At present, research has emphasized the effects of re-integrating the stroke survivor into the family on the caregiver-patient dyad.

19.2.1 Effects of Caregiving on the Caregiver
The brunt of the long-term care of the stroke survivor falls onto family caregivers, and usually, one primary caregiver in particular. Silverstone and Horowitz (1987) in their review of caregiving provided to frail elderly individuals point out that, “... there is no family caregiving system. Rather, one family member occupies the role of primary caregiver and is the primary provider of direct care assistance.”. In most cases, the primary caregiver is the patient’s spouse. If this is not possible, the care of the stroke survivor may fall to a daughter or a son. A study by Sit et al. (2004) reported that of 102 primary caregivers interviewed, 61% were spouses and 31.3% were children of the stroke survivor. In the absence of a spouse or a child, other relatives or even friends and neighbours may serve as primary caregivers, but this is a relatively rare event. Apart from the primary caregiver, other family members tend to play minor roles (Horowitz 1985). Sit et al. (2004) reported that members of the stroke survivor’s immediate family (other than the primary caregiver) function as key providers of emotional support, while friends and neighbours tend to provide tangible or instrumental support and opportunities for social companionship. In the same study, health professionals were identified as providing information and instrumental support including technical support and information about nursing procedures and skills (Sit et al. 2004). Brokulehurst et al. (1981) noted that although friends and relatives provided the primary caregiver with significant support (in the form of assistance with transferring and supervising the stroke patient) shortly after the discharge home, there was little help forthcoming one year after the stroke. If new care demands develop, it is the family (generally the primary caregiver) who must meet those demands (Silverstone & Horowitz 1987).

The ACHPR guidelines for stroke rehabilitation noted that, “Caring for a person with severe disabilities can be a formidable task. Impairments in mobility may tax an elderly spouse’s physical strength and endurance; and cognitive, emotional, and communication problems often have pervasive effects on family and social relationships,” (Post-Stroke Rehabilitation Guideline Panel et al. 1995). As noted by Evans (1987), caregivers cope with physical limitation better than cognitive or emotional limitations. However, even healthy and committed caregivers may “burn out” from the continuous pressure of providing support to a patient 24 hours a day, 7 days a week. At 12 weeks following discharge of the stroke survivor from rehabilitation, Sit et al. (2004) reported that caregivers had experienced a substantial number of physical ailments and 40% had consulted a physician. Placement of elderly individuals in a chronic care facility occurs more often because of deterioration in the caregivers’ health or decompensation in the face of continuous stress than it does because of increased care requirements (Boxall & Mc kercher 1990; Colerick & George 1986). Carers cite the inability to get enough rest or time to fulfill all their obligations created by the need for constancy and vigilance in managing the needs of the stroke survivor as a key impact of caregiving (Stewart et al. 1998). Opportunities for respite may be extremely important (Post-Stroke Rehabilitation Guideline Panel 1995; Stewart et al. 1998).

Family members providing care for stroke survivors are often required to sacrifice their personal needs to meet those of the stroke survivor. Smith et al. interviewed 90 caregivers one year following stroke (L. N. Smith, M. Lawrence, et al. 2004). In that study, carers reported spending 7 days per week in the provision of care and almost half (47.8%) of the 90 caregiver participants reported spending more than 160 hours per week in caregiving activities (range = 4 – 168, mean = 104). It is hardly surprising that reports have suggested that more than 25% of carers under the age of 65 either reduce the number of hours they spend at work or leave their employment entirely in order to juggle the many demands of
providing care for their loved one which may have dire effects on the financial wellbeing of the family (Grant et al. 2004). In a recent study, Ko et al. (2007) reported that a substantial proportion (36%) of working caregivers either reduced the number of hours they worked, or left their jobs entirely to care for their family member.

Caregivers may be faced with a reduction in time for leisure and social activities that, in turn, reduces their own opportunity for much needed social support (Coombs 2007; Palmer & Glass 2003; Smith et al. 2004; Stewart et al. 1998). In their 2004 study, Sit et al. (2004) reported that 65% of the caregivers interviewed reported a feeling of confinement and could not foresee any opportunities for leisure time in the future. Opportunities for interaction are missed and carers may perceive their world to be narrowing while at the same time, their social life and interests may be increasingly limited by their own health concerns (Smith et al. 2004).

Coughlan and Humphreys (1982) in their study of stroke survivors and their spouses 3-8 years after the stroke noted that 41% of patients and 32% of spouses reported “much less enjoyment of life.” For spouses, the chief causes of loss of enjoyment were loss of companionship, increased domestic responsibility and interference with leisure and social activities. Webster & Newhoff (1981) noted that the wives of stroke patients experienced a variety of common problems including having to assume duties formerly assigned to the spouse, lack of people to confide in or talk to, and lack of personal time alone. Spousal carers may experience a profound sense of loss following stroke, including loss of leisure time, of freedom and, perhaps most difficult, a loss of marital partner. Caregivers must not only learn and adapt to new roles and responsibilities in caring for a stroke survivor, they must also create a new normal for themselves and adapt to a new relationship with their spouse (Coombs 2007; Saban & Hogan 2012).

Many studies have examined the effects of caring for the stroke survivor on the primary family caregiver. Most take a cross-sectional approach, providing a snapshot in time of the effects of caregiving on the caregiver along with the identification of factors that moderate the identified effects. Relatively few studies take a longitudinal approach and include examination of the change in effects and influencing factors over time. An examination of changing effects and factors could be useful in determining which interventions might be most helpful at various times in the process of caregiving and family adaptation. For instance, reports suggest that immediately following the discharge of the stroke patient, the experience of burden may be influenced most by stroke severity but as time goes on, other patient characteristics may become more influential (Schulz et al. 1988; Tompkins et al. 1988). In a report of the FINNSTROKE Study, it was determined that the presence of outpatient rehabilitation and support services had no effect on the rate of depression reported among caregivers at 3 months post stroke when comparing districts that offered these services with those that did not (Kotila et al. 1998). By 12 months, however, the absence of such services was associated with a greater number of severely depressed caregivers. A more recent longitudinal study reported that, by 6 months post-stroke, the need for more frequent services from either a GP or district nurse was associated with decreased psychological health on the part of the caregiver (Franzen-Dahlin et al. 2007).

Blake et al. (2003) reported that while the amount of carer strain does not necessarily change from 3 to 6 months post stroke, the items contributing to strain do change. By 6 months post stroke, fewer family changes may be reported, while upsetting behaviours, feelings of confinement and increased financial difficulties may become more frequent. King et al. (2010) reported that, in the first 3-4 months following stroke, caregivers identified “interpersonal disruptions” such as relationship difficulties, conflicts and social involvement as the most stressful problems they faced. In addition, they felt least effective in dealing with these types of problems when they arose (King et al. 2010). Characteristics of the carer,
such as appraisal of caregiving as threatening (vs. benign or beneficial) and associated negative life change, increased anxiety and lower caregiving preparedness, may be associated with greater caregiver distress (King et al. 2010).

Tooth et al. (2005) suggested that not only does the amount of time spent caring change over the period of 6 months to 1 year following discharge from stroke rehabilitation, the type of tasks performed by the caregiver changes, perhaps as a reflection of ongoing improvements in the physical and cognitive function of the individual with stroke. When compared to 6 months, carers spent more time assisting the individual with stroke in travel and leisure activities and less time managing medications and finances (Tooth et al. 2005). These types of tasks may be perceived as considerably less stressful by the caregiver. Of 28 stroke-related patient problems identified by Haley et al., (2009) help with travel and activities such as shopping were ranked 22nd and 28th respectively. The most stressful problems included mood disturbances (such as depression, loneliness, feeling worthless, and anxiety) bowel incontinence and cognitive impairments (i.e. asking the same questions repeatedly and memory impairments) (Haley et al. 2009). Less stressful tasks included assistance with instrumental activities (e.g. shopping or leisure) that may be more within the usual range of adult helping behaviours and are not necessarily associated with the presence of disability (Haley et al. 2009).

In the longer term (up to 2 years post stroke), both quality of life and the experience of depression may become more stable (Berg et al. 2005; Jonsson et al. 2005; Parag et al. 2008; Visser-Meily et al. 2009), although White et al. (2003) reported an increasing burden over time among women. Two studies reported that while burden decreased substantially between one and three years post-stroke, life satisfaction and social support deteriorated (Visser-Meily et al. 2009; Visser-Meily et al. 2008). Depressive symptomatology remained stable over time (Visser-Meily et al. 2009; Visser-Meily et al. 2008). Female gender did not influence the course of depression over time; however, female gender was associated with negative changes in relationship harmony.

Table 19.2.1.1 provides a summary of the identified effects of caregiving and the variables that significantly influence those effects. Despite the variation in variables assessed and measurement tools employed in their assessment, it is clear that the process of caregiving has profound effects on the caregiver.

<p>| Table 19.2.1.1 Summary Of Caregiver Effects And Influencing Factors |</p>
<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Effect</th>
<th>Influencing Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brocklehurst et al. (1981)</td>
<td>(-) Health*</td>
<td>Patient dependence</td>
</tr>
<tr>
<td></td>
<td>(-) Employment</td>
<td></td>
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<tr>
<td>Silliman et al. (1986)</td>
<td>(-) Social activity</td>
<td>Functional status (patient)</td>
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<td></td>
<td>(-) Emotional health</td>
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<tr>
<td>Schulz et al. (1988)</td>
<td>(+) Depression</td>
<td>Stroke severity (patient)</td>
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<tr>
<td></td>
<td>(-) Optimism</td>
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<tr>
<td>Tompkins et al. (1988)</td>
<td>(+) Risk for depression</td>
<td>Initial depression</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lower optimism</td>
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<td></td>
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<td>Married to patient</td>
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<td></td>
<td>Smaller social network</td>
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<td></td>
<td></td>
<td>Younger stroke patient</td>
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<td></td>
<td></td>
<td>Patient impairment</td>
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<tr>
<td>Draper et al. (1992)</td>
<td>(+) Psychological morbidity</td>
<td>Caregiver burden</td>
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<tr>
<td></td>
<td></td>
<td>Behaviour and mood disturbances in patients</td>
</tr>
<tr>
<td>Kotila et al. (1998)</td>
<td>(+) Depression</td>
<td>Stroke severity</td>
</tr>
<tr>
<td>Study</td>
<td>Variables</td>
<td>Outpatient Rehabilitation and Support Services</td>
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<tr>
<td>-------------------------------</td>
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<tr>
<td>Hop et al. (1998)</td>
<td>(-) Quality of life</td>
<td>Functional status of patient</td>
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<tr>
<td></td>
<td>(-) Emotional behaviour</td>
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<td></td>
<td>(-) Social interaction</td>
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<td></td>
<td>(-) Work</td>
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<td>(-) Past-times</td>
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<td></td>
<td>(-) Wellbeing</td>
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<tr>
<td>Bugge et al. (1999)</td>
<td>(+) Strain</td>
<td>Amount of time spent helping</td>
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<td></td>
<td></td>
<td>Amount of time spent with the patient</td>
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<tr>
<td>Blake &amp; Lincoln (2000)</td>
<td>(+) Caregiver strain</td>
<td>Caregiver strain is affected by the following:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Carer mood, Patient EADLs, Negative affectivity</td>
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<tr>
<td>Teel et al. (2001)</td>
<td>(+) Fatigue</td>
<td>3 months</td>
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<td></td>
<td>(-) Vigour</td>
<td>Physical health predicted by: depressive</td>
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<td></td>
<td>(+) Recurrent sorrow</td>
<td>symptoms, fatigue and recurrent sorrow</td>
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<td></td>
<td>(+) Stress</td>
<td>Mental health predicted by: vigour</td>
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<td></td>
<td>(+) Financial difficulties</td>
<td>and perceived stress</td>
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<td></td>
<td>(+) Difficulties with family support</td>
<td>Physical health predicted by: depressive</td>
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<td></td>
<td>(-) Perceived health</td>
<td>symptoms and scheduling difficulties</td>
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<td></td>
<td>(+) Depressive symptoms</td>
<td>Mental health predicted by: perceived stress</td>
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<tr>
<td>Thommessen et al. (2002)</td>
<td>(+) Psychosocial burden</td>
<td>Cognitive function (patient)</td>
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<td></td>
<td>(+) Worry about accidents</td>
<td>ADL function (patient)</td>
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<td></td>
<td></td>
<td>Gender (patient)</td>
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<tr>
<td>Wyller et al. (2003)</td>
<td>(-) Emotional wellbeing</td>
<td>Perceived burden of care</td>
</tr>
<tr>
<td>Adams (2003)</td>
<td>(-) Social function</td>
<td>Not identified</td>
</tr>
<tr>
<td>Morimoto et al. (2003)</td>
<td>(-) Health-related quality of life</td>
<td>Caregiver burden</td>
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<td></td>
<td>(-) Depressive symptoms</td>
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<td></td>
<td>(-) General health</td>
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<td></td>
<td>(-) Vitality</td>
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<td></td>
<td>(-) Mental health</td>
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<tr>
<td>White et al. (2003)</td>
<td>(-) Mental health</td>
<td>Mental health: Gender, burden, age, physical</td>
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<td></td>
<td>(-) Physical health</td>
<td>symptoms</td>
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<td></td>
<td>(-) Quality of life</td>
<td>Physical health: Age, increasing physical</td>
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<td></td>
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<td>symptoms</td>
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<td>Quality of life: Functional status (patient),</td>
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<td>caregiver age, vitality and both mental and</td>
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<td>physical health. By 12 months, however,</td>
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<td>functional status was replaced by aphasia as a</td>
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<td></td>
<td>predictor of QOL</td>
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<tr>
<td>Wyller et al. (2003)</td>
<td>(-) Wellbeing</td>
<td>Caregiver strain</td>
</tr>
<tr>
<td>Blake et al. (2003)</td>
<td>(+) Caregiver strain</td>
<td>Carer mood</td>
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<td></td>
<td></td>
<td>Patient EADL</td>
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<td></td>
<td></td>
<td>Negative affectivity</td>
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<tr>
<td>Grant et al. (2004)</td>
<td>(+) Risk for depression</td>
<td>Negative problem-solving orientation</td>
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<tr>
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<td>Caregiver preparedness</td>
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<td></td>
<td></td>
<td>Social functioning</td>
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<tr>
<td>Forsberg-Warleby et al. (2004)</td>
<td>(-) Life satisfaction</td>
<td>Cognitive impairment</td>
</tr>
<tr>
<td></td>
<td>(-) Satisfaction with leisure activities</td>
<td>Aphasia</td>
</tr>
<tr>
<td>Study</td>
<td>(+) or (-)</td>
<td>Factors</td>
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<td>----------------------------------------------</td>
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<tr>
<td>Grant et al.  (2004)</td>
<td>(+) Risk for depression</td>
<td>Time since stroke event, Social support, Perceived burden, General health, Ethnicity</td>
</tr>
<tr>
<td>Sit et al. (2004)</td>
<td>(+) Increased physical ailments, (-) Psychosocial health</td>
<td>Level of stroke survivor dependence, Amount of tangible support received, Amount of social companionship</td>
</tr>
<tr>
<td>Clark et al. (2004)</td>
<td>(-) Mental health</td>
<td>Family functioning, Patient motor function, Memory and behavioural changes</td>
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<tr>
<td>Smith et al. (2004)</td>
<td>(+) Anxiety, (+) Depression, (+) Carer stress</td>
<td>Number of hours spent caring, Physical function (patient), Social activity (patient), Personal vitality (carer)</td>
</tr>
<tr>
<td>Van Exel et al. (2005)</td>
<td>(+) Carer strain</td>
<td>Carer &amp; patient HRQOL, Patient age, Number of caregiving tasks</td>
</tr>
<tr>
<td>McCullagh et al. (2005)</td>
<td>(+) Carer burden, (-) Carer burden, (+) QOL</td>
<td>Carer &amp; patient anxiety, Social isolation, Skills training, Patient age, male gender, disability (pt. &amp; carer), carer depression, Skills training</td>
</tr>
<tr>
<td>Berg et al. (2005)</td>
<td>(+) Depression, (+) Exhaustion</td>
<td>Age, Stroke severity (acute phase), Caregiver depression during acute phase and, for caregiver-spouses, patient age (at 6 &amp; 18 months), Dependence in ADLs and female sex of caregiver (for caregiver-spouses)</td>
</tr>
<tr>
<td>Tooth et al. (2005)</td>
<td>(+) Caregiver burden, (-) Physical and mental health status</td>
<td>Functional status (patient), Personal supports, Mental health (patient), Employment, Ongoing therapy received, Cognitive status (patient), Mental health (patient)</td>
</tr>
<tr>
<td>Larson et al. (2005b)</td>
<td>(-) QOL</td>
<td>Baseline, Life situation (burden), Well-being, Illness (carer), 6 months, Life situation (burden), General well-being, 12 months, Life situation (burden), Economic situation</td>
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<tr>
<td>Jonsson et al. (2005)</td>
<td>(-) Physical &amp; emotional function, (-) Bodily pain</td>
<td>Increasing carer age</td>
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<tr>
<td>Study</td>
<td>Changes/Outcomes</td>
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<tr>
<td>Bakas et al. (2006)</td>
<td>Decreasing functional status of the stroke patient</td>
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<td></td>
<td>Increasing patient age</td>
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<td></td>
<td>(+) Depression</td>
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<td></td>
<td>(+) Difficulty with caregiving tasks</td>
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<td></td>
<td>(-) Stroke-related caregiver outcomes such as social functioning, subjective well-being and physical health</td>
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<tr>
<td>Grant et al. (2006)</td>
<td>Female gender (carer)</td>
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<td></td>
<td>Severe communication problems/presence of aphasia</td>
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<td></td>
<td>Self-care deficits (patient)</td>
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<tr>
<td>Cameron et al. (2006)</td>
<td>Negative problem-solving orientation</td>
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<td></td>
<td>Social Support</td>
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<tr>
<td>White et al. (2006)</td>
<td>Behavioural and emotional disturbances</td>
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<td></td>
<td>Social participation of stroke survivor</td>
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<td></td>
<td>Quality of relationship between carer and survivor</td>
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<tr>
<td>Larson et al. (2008)</td>
<td>Female gender (caregiving spouse of stroke patient)</td>
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<td>Franzen-Dahlin et al. (2007)</td>
<td>Baseline:</td>
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<td>Self-reported well-being (carer)</td>
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<td>Age (carer)</td>
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<td>Carer illness</td>
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<td>Less knowledge</td>
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<td>6 months:</td>
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<td></td>
<td>Self-reported well-being (carer)</td>
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<td>Need for assistance from GP and/or district nurse (carer and patient)</td>
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<td>12 months:</td>
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<td></td>
<td>Self-reported well-being (carer)</td>
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<td></td>
<td>Carer illness</td>
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<tr>
<td>Rochette et al. (2007)</td>
<td>Caregiver strain</td>
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<tr>
<td></td>
<td>(-) Personal relationships</td>
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<td></td>
<td>(-) Employment</td>
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<td></td>
<td>(-) Recreation</td>
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<td></td>
<td>(+) Participation in nutrition</td>
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<td>(selection of food, meal preparation, eating)</td>
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<td></td>
<td>(+) Responsibilities</td>
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<tr>
<td>Visser-Meily et al. (2008, 2009)</td>
<td>Over time:</td>
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<tr>
<td></td>
<td>(+) Strain</td>
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<tr>
<td></td>
<td>(-) Life satisfaction</td>
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</tr>
<tr>
<td></td>
<td>(-) Relationship harmony</td>
<td></td>
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<tr>
<td></td>
<td>(-) Social support</td>
<td></td>
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<tr>
<td>Simon et al. (2009)</td>
<td>Previous psychological health contributed to psychological impact</td>
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</tr>
<tr>
<td></td>
<td>Coping styles (passive styles had a negative impact)</td>
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<td></td>
<td>Female gender (neg impact on harmony, positive on support)</td>
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<tr>
<td></td>
<td>Physical function of patient (strain)</td>
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<td></td>
<td>Communicative ability of patient (social support)</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Over time:</td>
<td>Predictors of quality of life included caregiver burden, number of reported diseases, and confidence in the support system.</td>
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<tr>
<td>Nir et al. (2009)</td>
<td>Over time:</td>
<td></td>
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<tr>
<td>Carod-Artal et al. (2009)</td>
<td>(+) Caregiver burden</td>
<td>Patient disability (BI), female sex, depression (HADS) Caregiver education, caregiver burden Patient cognitive impairment (MMSE), spousal caregiver, caregiver depression</td>
</tr>
<tr>
<td>Chen et al. (2010)</td>
<td>(-) HRQOL</td>
<td>Caregiver depression</td>
</tr>
<tr>
<td>Cameron et al. (2011)</td>
<td>(+) Caregiver emotional distress</td>
<td>Female gender (carer) Age (younger) Lifestyle interference Lower personal control/mastery Poorer health Patient depression and cognitive impairment</td>
</tr>
<tr>
<td>Baumann et al. (2011)</td>
<td>(+) Social repercussions (e.g. loss of friends, isolation, social roles)</td>
<td>Functional dependence (patient) 2 or more domains of residual impairment (patient)</td>
</tr>
<tr>
<td>Adriaansen et al. (2011)</td>
<td>(+) Life satisfaction</td>
<td>Greater social support Caregiver strain</td>
</tr>
<tr>
<td>Achten et al. (2012)</td>
<td>(-) Life satisfaction</td>
<td>Less social participation (patient) Poorer life satisfaction (patient)</td>
</tr>
<tr>
<td>Kruithof et al. (2012)</td>
<td>(+) Caregiver burden</td>
<td>Cognitive and physical functioning (patient) Caregiver health Age, education, level of burden, self-esteem (caregiver)</td>
</tr>
<tr>
<td>Jaracz et al. (2012)</td>
<td>(+) Caregiver burden</td>
<td>Age (caregiver) Level of social support (caregiver) Presence of illnesses (caregiver) Functional status (patient)</td>
</tr>
<tr>
<td>Peyrovi et al. (2012)</td>
<td>(-) Perceived positive life changes (+) Depression</td>
<td>Functional disability (patient)</td>
</tr>
<tr>
<td>Sreedharan et al. (2013)</td>
<td>(+) Depression</td>
<td>Presence of aphasia (patient) Presence of seizures (patient)</td>
</tr>
<tr>
<td>Godwin et al. (2013)</td>
<td>(-) Quality of life</td>
<td>Age (caregiver) Number of illnesses (caregiver)</td>
</tr>
<tr>
<td>Denno et al. (2013)</td>
<td>(+) Depression</td>
<td>Difficulty of caregiving task Perceived negative life changes from caregiving</td>
</tr>
<tr>
<td>Study</td>
<td>Variables</td>
<td>Health/Well-being</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
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<tr>
<td>Chen &amp; Botticello (2013)</td>
<td>(-) Cognitive functioning (delayed recall)</td>
<td>Male gender</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Age (&gt;65 years vs. 45-64 years)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Race/Ethnicity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Income (lower)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Level of education (lower)</td>
</tr>
<tr>
<td>Clay et al. (2013)</td>
<td>(-) Quality of life (physical and mental)</td>
<td>Number of impairments (patient)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Appraisal of patient impairments (caregiver)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social support received (caregiver)</td>
</tr>
<tr>
<td>Grant et al. (2013)</td>
<td>(+) Depressive symptoms</td>
<td>Occurrence of stroke survivor impairments and problems</td>
</tr>
<tr>
<td></td>
<td>(-) Life satisfaction</td>
<td></td>
</tr>
<tr>
<td>Vincent-Onabajo et al. (2013)</td>
<td>(-) Quality of life</td>
<td>Increase in the age of caregivers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Time post-stroke (&lt;1yr and &gt;2yr)</td>
</tr>
<tr>
<td>McLennon et al. (2014)</td>
<td>(+) Depression</td>
<td>Female caregivers</td>
</tr>
<tr>
<td></td>
<td>(+) Caregiver burden</td>
<td>Caregivers with low mobility and thinking (QOL)</td>
</tr>
<tr>
<td></td>
<td>(-) Self-esteem</td>
<td>Caregivers with depression symptoms</td>
</tr>
<tr>
<td></td>
<td>(-) Ability to cope with stress</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(-) Physical health</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(-) Emotional well-being</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(-) Functional well-being</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(-) Level of energy</td>
<td></td>
</tr>
<tr>
<td>Chow et al. (2014)</td>
<td>(+) Caregiver stress</td>
<td>Physical health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psychological health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of accommodating environment</td>
</tr>
<tr>
<td>Zawadzka &amp; Domanska (2014)</td>
<td>(+) Depression</td>
<td>Time post stroke (shorter)</td>
</tr>
<tr>
<td></td>
<td>(+) Mania</td>
<td></td>
</tr>
<tr>
<td>Oosterveer et al. (2014)</td>
<td>(+) Anxiety</td>
<td>Caregiver strain</td>
</tr>
<tr>
<td></td>
<td>(-) Life satisfaction</td>
<td></td>
</tr>
<tr>
<td>Jessup et al. (2015)</td>
<td>(+) Caregiver burden</td>
<td>Female gender</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Race (African American)</td>
</tr>
</tbody>
</table>

* - and + represent the direction of effect on the stated variable

From the studies summarized above, the most commonly identified effects of caregiving on the caregiver include increased carer stress, strain or burden, decreases in perceived health (both physical and mental), social contact and activity, increased risk for depression, and an overall decrease in quality of life. Many of these, such as caregiver health status, depression and lack of social contact, are also identified as factors influencing other consequences of caregiving. Reports concerning the influence of patient characteristics vary with the effect in question. The presence of stroke-related impairments such as aphasia, are often cited as having a significant impact on caregivers. A systematic review by Grawburg and colleagues (2013) found that caregivers of patients with aphasia are affected at all levels of their health – body functions, activities and participation (based on the ICF framework). Age, severity of stroke, and functional status and cognitive status of the patient are other factors reported as influencing caregiver outcomes.

While much of the research has focused on the effects of caregiving on the caregiver and the associated predictive characteristics, a study by Grant et al. (2013) suggested that there could be a reciprocal effect of caregiving on patient outcomes. The authors performed a mediation analysis to assess how caregiver depression can mediate the effect of the relationship between a stroke survivor’s number of disabilities and level of depression. The findings suggested that caregivers with a higher level of depressive symptoms and a lower level of life satisfaction partially mediate the relationship between a stroke
survivor’s number of disabilities and their depression scores. This partial mediation was demonstrated with a reduction in the direct effect of the number of problems that a stroke survivor experienced and their depressive symptoms from 43.7% to 26.0%.

**Caregiver Burden**

Strain or burden experienced by the caregiver may depend, in part, upon the type of stroke-related challenges faced by the person with stroke. Psychological, behavioural and cognitive changes have been identified as the source of the most stressful caregiving challenges (Draper et al. 1992; Grant et al. 2004; Haley et al. 2009). Carer participants in interviews conducted by Smith et al. (2004) noted that while these types of problems may present the greatest difficulty, health care professionals often choose to ignore them.

Bakas et al. (2004) attempted to clarify which tasks created the most burden for the caregiver and were most influential in determining the mood, social function, subjective wellbeing and physical health of the caregiver. Provision of emotional support, transportation, managing finances, bills and forms related to the stroke and performing household tasks were identified as the most time consuming tasks. Together, these tasks were significantly predictive of caregiver mood, but did not predict any of the other carer outcomes assessed. Tasks identified as the most difficult included managing behavioural problems, providing emotional support, carrying out household tasks and managing finances, bills and forms related to the stroke. Difficult tasks predicted both negative carer mood and outcomes. More difficulty with managing behaviour, providing emotional support and managing finances were significant independent predictors of negative mood while more difficulty in providing emotional support was the only significant predictor of decreased social function, subjective well-being and physical health as a result of caregiving (Bakas et al. 2004). Identification of the specific tasks that contribute most to carer stress may help guide interventions intended to improve the psychosocial outcomes associated with caregiving. Caregiver burned was also significantly higher in caregivers with depressive symptomatology (McLennon et al. 2014), anxiety, and those with low life satisfaction (Oosterveer et al. 2014). Caregiver burden was also significantly higher among female caregivers, spouses, and those of African-American race (Jessup et al. 2015).

**Social Contact and Activity**

Smaller social networks, diminishing social contacts and activities as well as decreased satisfaction with social contact have been identified as both effects of caregiving and as moderators of other effects, most notably the risk of depression or the presence of depressive symptomatology. Decreases in social networking and reciprocal confiding relationships can contribute to a sense of burden and feelings of despair in the caregiver (Schulz et al. 1988).

A decreased sense of belonging once the stroke patient has returned home may contribute to the social isolation of the caregiver making the adjustment to new roles and relationships even more difficult (Grant et al. 2004). In discussion with carers (n=20), Stewart et al. (1998) discovered that many carers feel that, while friends and family may be available for basic or even instrumental support, they do not provide adequate emotional or informational support. Sit et al. (2004) demonstrated that tangible support and social companionship tend to be provided mainly by friends and neighbours while the immediate family were the main providers of emotional support. In that study, tangible support was provided less often than either emotional support or social companionship (Sit et al. 2004). Sit et al. (2004) also reported that the actual caregiver support network tended to be smaller than the perceived network (i.e. the number of persons the caregiver thought would be available). If the carer experiences
dissatisfaction with their current social network, the perceived dissatisfaction can contribute just as much to psychological morbidity of the caregiver as an actual decrease in social networking (Tompkins et al. 1988). On the other hand, if peer support from family or friends is provided, it is considered to be the most effective solution to loneliness or social isolation (Chow & Tiwari 2014).

Age was also found to significantly predict social relationships. Caregivers aged 14-30yr were found to have significantly better social relationships compared to those aged 31-55yr (Vincent-Onabajo et al. 2013).

**Mental Health and Risk for Depression**

The increased risk for depression associated with caregiving is substantial. Many carer’s experience social isolation, depression, loneliness, helplessness, fatigue and burnout in the process of caring for a loved one with a stroke (Chow & Tiwari 2014). Within the literature, the prevalence of caregiver depression has consistently been documented as higher in stroke caregivers (37% to 52%), when compared to non-caregiving populations (12% to 16.5%) (Anderson et al. 1995; Carnwath & Johnson 1987; Draper et al. 1992; Han & Haley 1999; Kotila et al. 1998; Richard Schulz et al. 1995; Silliman et al. 1986; Simon et al. 2009; Wade et al. 1986). However, many of the stroke caregiving studies have relatively small sample sizes and may suffer from weaknesses associated with the use of opportunistic samples with self-selection biases (Han & Haley 1999).

Suh et al. (2005) reported that 41.1% of caregivers, out of a sample of 225, demonstrated depression as determined by the Center for Epidemiological Study Depression Scale (CES-D). In that study, caregiver depression, in addition to perceived caregiver burden and caregiver support, was significantly associated with higher post stroke depression in patients. Berg et al. (2005) reported that 30 – 33% of caregivers in that study were depressed during the follow-up period. In both studies, the rate of depression was higher among caregivers than among patients. Sit et al. (2004) reported level of psychosocial health to be significantly associated with the stroke survivor’s level of dependence, the amount of tangible/instrumental support received and the opportunities for social companionship. Caregivers at the highest risk of depression tend to be more the spouses of younger, more severely impaired patients with lower household incomes, smaller social networks with whom they visit frequently and lower levels of future optimism and expectation (Tompkins et al. 1988). In addition, Grant et al. (2004) found the risk of depression to be associated with a negative orientation to problem solving and caregiver preparedness, in addition to social functioning. Carers who have a negative orientation to problem-solving may be more easily overwhelmed by the stressors and expectations associated with the role of caregiving (Joan S. Grant et al. 2004).

Klinedinst et al. (2009) examined the influence of caregiver characteristics on the health-related quality of life of individuals with stroke based on 132 caregiver/stroke patient dyads. The experience of depressive symptoms in carers at baseline were associated with poor physical function and communication at 4 months and with reduced patient social participation and mood at 12 months. Caregiver depression was the sole modifiable caregiver characteristic that was a significant predictor of health-related quality of life in the individual with stroke (Klinedinst et al. 2009). In essence, when attempting to improve the stroke survivor’s emotional and mental health, the caregiver’s own mental health is neglected and often worsens over the caregiving period (Cecil et al. 2013).

**Financial Outcomes**
In addition to health related challenges, caregivers encounter financial challenges either because of a loss of job due to the increased caregiving demand, or to a loss of income due to the patient’s stroke (Cecil et al. 2013). Many caregivers report having financial concerns which can further deteriorate other aspects of a caregivers’ wellbeing. For instance, McLennon et al. (2014) showed that depression was associated with lower financial wellbeing. Financial hardship largely due to increases in expenditure for the patient and the loss of income, was found to contribute to carers stress (Chow & Tiwari 2014).

Due to these challenges, caregivers often feel restricted to the care they can access in order to maintain a state of general health to be able to continue the caregiving roles. The lack of attention towards these neglected outcomes may further deteriorate the caregivers’ health. Studies show that strain induced by caregiving increases the risk of mortality and cardiovascular diseases by 63% and 23% compared to non-caregivers (Cheng et al. 2014; Haley et al. 2010; Schulz & Beach 1999). These negative outcomes place a significant strain on the efficiency of the health care system which ultimately leads to significant governmental costs. Furthermore, institutionalization of caregivers results in a breakdown in the structure of care, as the patient is then left in the care of other individuals/family members that may not be suitable caregivers.

It is therefore important that health care institutions equip caregivers and family member with the necessary information to make a safe financial adjustment during the caregiving process. Thus far, many support programs dedicated to improving the caregiver’s health have been assessed in research studies, but few have attempted to evaluate programs that deal with the financial challenges that exist amongst caregivers.

Positive Outcomes
Although the emphasis in studies that examine the effects of caregiving is placed upon negative outcomes, positive outcomes associated with caregiving have also been reported. In a recent, systematic review, Mackenzie and Greenwood (2012) identified 9 studies that reported the perceived rewards or benefits associated with the experience of providing informal care for an individual with stroke. Positive aspects of caregiving included improved relationships, feelings of love, devotion, being appreciated by both the patient and the community and being needed. Perceptions of improvement and recovery were associated with positive aspects of care. In addition, carers tended to report more positive aspects over time. New carers found identification of positive aspects associated with caregiving more difficult than more experienced caregivers. Positive consequences of caregiving included finding meaning and purpose and reciprocation for past caring, realising what is important in life, increasing appreciation for life and making the caregiver a better person (Mackenzie & Greenwood 2012).

Haley et al. (2009) administered the Positive Aspects of Caregiving Scale (PACS) to 75 family caregivers 8 – 12 months following the stroke event. On the average, caregivers responded positively to 9 of the 11 PACS items. Approximately 90% of caregivers felt that assuming the caregiving role helped to increase their appreciation of life (90.67%) and made them feel needed (88%). Eight-five percent felt that caregiving enabled them to develop a more positive attitude toward life. Smith et al. (2004) reported that carers try to maintain a positive attitude using such strategies as diversion, humour, letting off steam, or relying on personal belief systems. In that study, most caregivers (>90%) reported satisfaction in seeing that the individual with stroke was well-cared for, was able to enjoy him or herself and had maintained his or her personal dignity.

McPherson et al. (2011) suggested that spousal carers who identify positive aspects (e.g. intrinsic rewards of caring, love and affection, balance in family caregiving) of caring experience a higher degree
of reciprocity in their relationship with the individual with stroke than those who feel that they are giving far more than they are getting. Caregivers who feel as though they are not benefiting from the relationship with the stroke survivor may experience greater negative consequences. Relationship satisfaction, however, may also depend upon the perceived pre-stroke equity within the relationship.

Summary
Many effects and moderating factors associated with caregiving have been identified in the literature. Recent clinical guidelines adopted by the National Heart Foundation in the Netherlands, suggest that early in the rehabilitation process, carers at risk for burden should be identified and ongoing consultation including repeated assessment of strain should be offered following discharge (van Heugten et al. 2006). Caregivers should be involved, closely, in the rehabilitation process. In addition, the authors also recommend routine provision of information, formation of support groups and interventions focussed on counselling (see section 19.2.4). Given the central role played by the informal caregiver on the outcome for stroke survivors, the focus of interventions post-stroke should be expanded to include and/or target caregivers.

Conclusions Regarding Effects of Caregiving Post stroke

Commonly identified effects of caregiving on the caregiver include increasing psychological distress, increased financial burden, decreased social contact and activity, increased risk for depression, increased carer stress, strain or burden and an overall decrease in quality of life.

Decreased social contact and activity in itself may contribute to increased carer strain, increased risk of depression and decreased life satisfaction.

Reports concerning the influence of patient characteristics vary with the effect in question. However, age, severity of stroke and stroke-related impairments, functional status and cognitive status have been reported as influencing caregiver outcomes.

Positive consequences of caregiving include improved appreciation of life, feeling needed or appreciated and development of a more positive outlook. Maintaining a positive attitude has been identified as an important coping strategy.

Stroke caregivers may experience financial strain, decreased mental health, decreased social contact and activity and an increased risk for depression.

19.2.2 The Family Caregiver and Social Support Interventions
Interventions designed to improve the social function and support networks may have beneficial effects on the risk for depression as well as increasing the social activity and improving life satisfaction of the caregiver. In their 1998 review of interventions with families post stroke, Korner-Bitensky et al. (1998) concluded that helping caregivers to maintain social and leisure activity may result in improved caregiver wellbeing.

Table 19.2.2.1 Summary of Support Interventions for Family Caregivers

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
</table>

19. Community Reintegration
### Interventions from Caregiving and Stroke Impact

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>N Start</th>
<th>N End</th>
<th>Treatment A</th>
<th>Treatment B</th>
<th>Outcome Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Wang et al. (2015)</strong></td>
<td>RCT (8)</td>
<td>51</td>
<td>51</td>
<td>E: Weekly personalized caregiver home based (CHI) training</td>
<td>C: Visits from a therapist</td>
<td>Stroke Impact Scale (+), 6 Minute Walking Test (+), Berg Balance Scale (+), Barthel Index (BI) (+), Caregiver Burden Scale (-)</td>
</tr>
<tr>
<td><strong>Franzen-Dahlin et al. (2008)</strong></td>
<td>RCT (6)</td>
<td>100</td>
<td></td>
<td>E: Specialist stroke nurse lead group meetings</td>
<td>C: Conventional resources</td>
<td>Psychological health (-), Stroke knowledge (+)</td>
</tr>
<tr>
<td><strong>Malini (2015)</strong></td>
<td>RCT (6)</td>
<td>240</td>
<td>238</td>
<td>E: Self-help support groups + group meetings</td>
<td>C: No group meetings</td>
<td>Family System Strengths Questionnaire scores (+)</td>
</tr>
<tr>
<td><strong>Smith et al. (2012)</strong></td>
<td>RCT (6)</td>
<td>38</td>
<td></td>
<td>E: Educational videos, online chat sessions, e-mail and message boards, a resource room + professional guide for caregivers</td>
<td>C: Conventional resources</td>
<td>Depression (CES-D) (+), Mastery Scale(-), Self-esteem (10-item Self-Esteem Scale) (-), Social support (MOS Social support survey) (-), Treatment credibility, reported effort and perceived benefit (Credibility/Expectancy Questionnaire) (-)</td>
</tr>
<tr>
<td><strong>Pierce et al. (2009)</strong></td>
<td>RCT (5)</td>
<td>103</td>
<td></td>
<td>E: Use of “Caring Web”</td>
<td>C: Did not use “Caring Web”</td>
<td>Depression (CES-D)/ Satisfaction with Life Scale (-), Healthcare service use (+), Hospital re-admissions (+)</td>
</tr>
<tr>
<td><strong>Steiner et al. (2008)</strong></td>
<td>RCT (4)</td>
<td>73</td>
<td></td>
<td>E: Use of “Caring Web”</td>
<td>C: Did not use caring web</td>
<td>Emotional support (-), Physical help (-), Caregiver health (-)</td>
</tr>
</tbody>
</table>

+ Indicates statistical significance between treatment groups  
- Indicates no statistical significance between treatment groups

### Discussion

Roughly 52.1% or caregivers spend more than 8 hours a day providing caregiving support to the stroke survivor (Yu et al. 2013). In an observational study, Yu et al. (2013) found that 72.7% of caregivers were women and many suffered from hypertension (70.4%), heart disease (33.3%), bone and joint disease (16%) and diabetes (12.3%). Many caregivers indicated to have adopted several coping strategies such as acceptance, active coping, planning, and positive reframing, to manage their role as a caregiver and to cope with the caregiving stress.

Interventions directed toward the family caregiver appear to be positively received and perceived as both useful and necessary. In both the Stewart et al. (2006; 1998) studies, the use of peer helpers or experienced caregivers enhanced the perception of support reported by study participants (Stewart et al. 2006; Stewart et al. 1998). Caregivers reported that the basis of common experience was important in the provision of emotional and affirmation support. This appears to be supported by the review of the internet-based study in which caregivers used the services provided to establish links to other caregivers in similar situations (Pierce et al. 2004). However, no quantitative results were offered with respect to caregiver outcomes in any of these reports.

In a study by Morris and Morris (2012), 12 peer support recipients (9 patients and 3 caregivers) and 10 peer supporters participated in semi-structured interviewed and provided responses to questionnaires examining the experience of involvement in hospital- (ward-) based peer support groups. Overall, participation in peer support groups was viewed favourably. Overall, benefits included receiving helpful
information and advice, making connections with others, improved confidence and energy and increased awareness of difficulties following stroke. The opportunity to discover similarities with others was considered valuable. Inclusion of staff in peer groups was perceived as important and helpful.

Two studies examined the effectiveness of group-based education and support interventions. In a single-group study, Won et al. (2008) demonstrated that participation in a psycho-educational program was associated with improvements in health risk-taking behaviours and well-being, particularly for participants under the age of 65. However, a more recent RCT demonstrated no benefit to psychological health or well-being associated with participation in a group education and support program. It should be noted that the intervention described by Won et al. (2008) was provided as 6 sessions over 6 weeks rather than over 6 months and the topics presented were distinctly different than those in the later RCT (taking care of you, reducing personal stress, communicating feelings, needs and concerns, communicating in challenging situations, learning from our emotions and mastering caregiving decisions rather than symptoms of stroke, risk factors, treatment, prevention, personality changes, and social aspects of living with stroke) (Won et al. 2008).

Malini et al. (2015) explored the effect of group support, provided over a period of 3 months for a total of 6 meetings. The results suggest that the scores from the Family System Strengths Questionnaire were significantly higher in the caregivers that participated in self-help support group meetings compared to those that were did not partake in the support group meetings. Wang et al. (2015) showed that patients also benefited more from weekly personalized caregiver-mediated home-based training compared to the caregivers that received visits from the therapist but were not provided the home-based training.

Three identified studies were part of a single project examining the effectiveness of an internet-based intervention called “Caring Web” (Pierce et al. 2004; Pierce et al. 2009; Steiner et al. 2008). The most complete information for all participants is provided in the 2009 publication in which 73 participants completed the year-long intervention. Participants appeared willing to use the web-based application and found it accessible. A follow-up study evaluating the accessibility and design of the website found that caregivers accessed the site 10-15 times per month, using it for approximately 1-2 hours per week on average. Over 92% of caregivers stated that the site was easy to use, clear, and were satisfied with the services (Pierce & Steiner 2013). The use of the website was not associated with improvements in depression or life satisfaction; however Caring Web users had significantly fewer visits to the emergency room and re-admissions to hospital. The authors suggest that use of the web-based service helped carers to make more informed decisions and improved problem-solving resulting reduced healthcare utilization.

**Conclusions Regarding Social Support Interventions for the Caregiver**

*Support provided by caregiving peers may have a positive effect on the caregiver.*

*There is level 1b evidence that participation in an online program providing information and support through contact with both a nurse and other caregivers has no impact on depression or life satisfaction. However, access to web-based information may be associated with reductions in healthcare utilization.*

*There is level 1a evidence that group-based programs and support may improve stroke-related knowledge and family structure however, it may not have an impact on psychological health.*
There is level 1b evidence that interactive educational resources and professional support accessed via online chat sessions, message boards and educational videos may reduce depression in caregivers but has no impact on mastery or self-esteem.

There is level 1b evidence that a caregiver-mediated home-based program may improve the physical impairments of stroke patients.

Support received from caregiving peers, who share the experience of caring for a stroke survivor, may have a positive effect on caregivers.

Accessible information made available through a web-based program may reduce healthcare utilization.

Access to interactive web-based resources may reduce depression in caregivers.

19.2.3 Family Interactions and Stroke

While it may seem obvious that families play an important role in the rehabilitation and community reintegration of stroke patients, few studies have examined the relationship between family interactions and/or function and the rehabilitation of stroke patients. Close family members, not necessarily caregivers, may experience deterioration in physical, social and emotional function in the first year following the stroke event (Schlote et al. 2006). In a sample of 64 close relatives of stroke patients, Schote et al. reported the greatest perceived decline in health-related quality of life while the patient was still involved in inpatient rehabilitation (Schlote et al. 2006). By 6 months, improvements were made; however, by 12 months post stroke, close relatives experienced a decline in both mental and physical health.

In addition, when faced with the sudden disability of a family member, as is the case post stroke, family function changes, especially when the family becomes responsible for the long-term care and support of the stroke survivor (Clark & Smith 1999). The availability of a close family member, provision of emotional support, family communication, family problem solving and the attitude of the family toward the family member who has experienced the stroke all affect the recovery process (Bleiberg 1986; Palmer & Glass 2003). Bleiberg (1986) cited an earlier study by Adler et al. (1969) in which the relationship between the stroke patients’ activities of daily living status and family attitudes was studied in 120 stroke patients and their families. Family attitudes that were found to be related positively to the patients’ ADL scores included family perception of the patient as not nervous, the family desire for the patient to be more active, family desire that the patients should perform much independent ADL as possible, family perception that patient was not a burden and the family’s desire to avoid re-hospitalization (Adler et al. 1969; Bleiberg 1986).

When looking at a family interaction after stroke, one study found that there was little difference in terms of morale, couple functioning and health status between stroke families and normal healthy families (Bishop et al. 1986). However, problems encountered as a consequence of the stroke such as work, transportation, socialization and role changes can strain normal family functioning (Bishop et al. 1986; Silliman et al. 1986). Clark and Smith (1999) reported that more than one-half of patients and 40% of spouses assessed rated their families as generally dysfunctional 12 months after the stroke event. Over a 12-month period, change in family function was observed in the following domains; ability to solve problems both inside and outside of the family, decline in family communication, increasing
problems in adapting to new roles and responsibilities, adoption of a more flexible style of behavioural control, and improvement in affective involvement (Clark & Smith 1999).

Clark and Smith (1999) noted that while spouses and carers were generally in agreement regarding the state of family dysfunction, there were differences in longitudinal trends over time that may signal differences in perceived family function between family members. Problems such as diffuse expectations about family responsibility, which may be problematic, should be addressed during the rehabilitation stage and again when the patient re-integrates with the family. Furthermore, differences in perception that can be a source of conflict and long-lasting problems for patients and carers need to be identified since differences in the perceptions of ability of the stroke patient contribute to carer strain and family dysfunction (Kinsella & Duffy 1980; Knapp & Hewison 1999).

Family functioning appears to have a direct impact on treatment and rehabilitation adherence. As noted by Evans et al. (1987), poor family functioning contributes to poor treatment adherence and results in deterioration in functioning capacity and/or further interference in family functioning. In addition, family variables tend to contribute to re-hospitalization of the patients accounting for over 28% of the variance at the time of re-hospitalization (Evans et al. 1987). Characteristics of families that adhered to treatment principles could be summarized as follows: (1) they communicate and exchange information clearly and directly; (2) they solve problems effectively; and (3) they report strong, emotional interest in one another (Evans et al. 1987). These were the attributes of a well-functioning family that in turn facilitated the rehabilitation process and prevented re-hospitalization.

Given the association between family functioning and treatment adherence (Evans et al. 1987), increased ADL function and increased social function (Clark & Smith 1999), post-stroke interventions should be designed to identify and address the concerns of the family. While the development of family focussed interventions is important, the difficulty in conducting an assessment of family function or attempting to intervene in family functioning should be acknowledged. Attempts to assess or intervene may be seen as intrusive and outside the sphere of rehabilitation (Clark & Smith 1999). Inclusion of information regarding the effects of stroke on family function and access to family counselling may assist families in adapting to the reintegration process (Clark & Smith 1999).

Conclusions Regarding Family Interactions and Stroke:

Perceived family dysfunction is common post stroke. However, family function affects treatment adherence, performance of ADLs and social activity. Stroke patients do better with well-functioning families. Effective communication, good problem solving or adaptive coping, and strong emotional interest in each other characterize well-functioning families.

Stroke patients do better with well-functioning families.

19.2.4 Information Provision and Family Education

Given the impact of stroke on family adjustment, the efficacy of family education as an intervention is gaining considerable importance. Casas (1989) sought to determine if a relationship between family education prior to discharge and family adjustment existed. A survey instrument, “Experience in Coping with Stroke,” was developed and mailed to a sample of 166 stroke families. Casas was unable to detect a significant correlation between education provided to the family of a stroke patient and family adjustment (Casas 1989). However, the majority of respondents did indicate the need for more information, feeling that it would have helped them to cope better with their situation. More recently,
Bakas et al. (2002) identified the following 5 central themes of needs and concerns of importance to family caregivers: information, emotions and behaviours, physical care, instrumental care and personal responses to caregiving.

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

Stein et al. (2003) surveyed 50 family members of stroke patients undergoing inpatient rehabilitation. The authors observed that of those who participated, the knowledge of family members with regard to stroke etiology and functional outcome was limited. Family members’ ability to predict functional outcome on discharge was worse than their knowledge of current functional status. Stein et al. proposed that further efforts must be made to enhance the knowledge level of family members of patients undergoing rehabilitation (Stein et al. 2003).

Two reviews focused on the provision of information and/or education to individuals and families following stroke. Korner-Bitensky et al. (1998) reviewed 10 studies describing family interventions post stroke and noted that most interventions focused on the provision of information. Education interventions did improve caregiver knowledge about stroke. However, studies including social aspects of support provided less conclusive results, perhaps due to poorer design or the use of more subjective outcomes (Korner-Bitensky et al. 1998).

A more recent Cochrane review identified 17 completed trials focusing on the effects of provision of information and/or education on the primary outcomes of knowledge about stroke and stroke services, and the impact on health and mood (Smith et al. 2008). Table 19.2.4.1 lists the studies selected for inclusion in that review. Based on data from identified studies, Smith et al. (2008) concluded that, overall, participation in the information provision or education condition was associated with improvement in knowledge about stroke and increased satisfaction with some of the information received. In addition, there was some evidence that active interventions (i.e. those providing information in a more interactive fashion, offering greater opportunity for involvement on the part of patients and caregivers) were more effective than passive interventions in terms of impact on patient depression and anxiety. Analyses were limited by the absence of a consistently used method to assess study outcome. Pooled analyses were possible for the outcomes of knowledge, mood, mortality and some specific questions regarding satisfaction. Remaining outcomes were assessed qualitatively.

<table>
<thead>
<tr>
<th>Table 19.2.4.1 Studies Included in the Cochrane Systematic Review (Smith et al. 2008)</th>
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</thead>
<tbody>
<tr>
<td>Banet and Felchlia 1997</td>
</tr>
<tr>
<td>Downes et al. 1993 (unpublished data)</td>
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<tr>
<td>Draper et al. 2007</td>
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<td>Ellis et al. 2005</td>
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</tbody>
</table>
A number of RCTs have examined information provision and/or family education and training as a means to improve outcomes for patients and their families. These studies are summarized in Table 19.2.4.2.

<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>Evans et al. 1988</td>
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<td>Frank et al. 2000</td>
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<tr>
<td>Hoffmann et al. 2007 (published &amp; unpublished data)</td>
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<td>Johnson et al. 2000 (published &amp; unpublished data)</td>
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<td>Kalra et al. 2004 (published &amp; unpublished data)</td>
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<tr>
<td>Larson et al. 2005</td>
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<tr>
<td>Lomer and McLellen 1987</td>
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<tr>
<td>Lowe et al. 2007 (published &amp; unpublished data)</td>
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<tr>
<td>Maasland et al. 2007</td>
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<tr>
<td>Mant et al. 1998 (published &amp; unpublished data)</td>
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<tr>
<td>Pain and McLellan 1990</td>
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<tr>
<td>Rodgers et al. 1999 (published &amp; unpublished data)</td>
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<tr>
<td>Smith et al. 2004 (published &amp; unpublished data)</td>
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</tbody>
</table>

Table 19.2.4.2 Summary of Family Education/Information Provision Interventions Post-Stroke

- **Green et al. (2007)**
  - RCT (8)
  - N= 400
  - E: A single, one-on-one educational-counselling interview + an appointment at a “lifestyle class”
  - C: Conventional care + access to pamphlets
  - Outcomes: Stroke knowledge (+), State of change (-)

- **Hoffmann et al. (2007)**
  - RCT (8)
  - N= 138
  - E: Computer-generated tailored written information
  - C: Generic written information
  - Outcomes: Knowledge, self-efficacy, depression, perceived health status (-), Satisfaction of content (+)

- **Mant et al. (1998)**
  - RCT (8)
  - N= 120
  - E: Information packages about stroke, its effects, and local contact names and support groups
  - C: No information package
  - Outcomes: Knowledge, access to community services, health status, quality of life (-), Caregiver mental health (+)

- **Mant et al. (2000)**
  - RCT (8)
  - N= 520
  - E: Family support care + information package
  - C: Conventional care
  - Outcomes: Carers Frenchay activity index (+), Carers energy, health, pain and physical function (SF-36) (+), Benefit to stroke patients (-)

- **Rodgers et al. (1999)**
  - RCT (8)
  - N= 260
  - E: Attend the Stroke Education Program
  - C: Conventional care + access to pamphlets
  - Outcomes: SF-26 scores (-) excluding social function (+), Stroke knowledge (+), Satisfaction with information (+), Hospital Anxiety and Depression Scale, Nottingham E-ADL, Oxford Handicap Scale (-)

- **Smith et al. (2004)**
  - RCT (8)
  - N= 170
  - E: Stroke Recovery Programme Manual + bi-weekly meetings with the multi-disciplinary care team
  - C: Conventional care
  - Outcomes: Stroke knowledge (-), Hospital Anxiety and Depression Scale (+), Patient and carer satisfaction (-), Physical functioning (-)

- **Cadhilac et al. (2011)**
  - RCT (7)
  - N= 143
  - E1: Attend a stroke specific self-management program
  - E2: Attend a generic self-management program
  - C: No management program
  - Outcomes: Positive life engagement, quality of life, mood (-)

- **Eames et al. (2013)**
  - RCT (7)
  - E: Education and support package, which included an information booklet + telephone contact with a
  - Outcomes: Self-efficacy, satisfaction with information (+), Stroke knowledge, level of anxiety,
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>N</th>
<th>Intervention (T)</th>
<th>Control (C)</th>
<th>Outcomes/Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Johnston et al. (2007)</td>
<td>RCT (7)</td>
<td>203</td>
<td>E: Information and exercises + regular home visits and telephone calls</td>
<td>C: Conventional care</td>
<td>• Observer Assessed Disability Scale (+)</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>• Barthel Index (-)</td>
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<td></td>
<td></td>
<td>• Hospital Anxiety and Depression Scale, patient satisfaction with care (-)</td>
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<td></td>
<td></td>
<td></td>
<td>• Carer distress (-)</td>
</tr>
<tr>
<td>Kalra et al. (2004)</td>
<td>RCT (7)</td>
<td>300</td>
<td>E: Training in basic nursing + techniques for personal care</td>
<td>C: Conventional care</td>
<td>• Health care / social care cost (+)</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td>• Functional status (BI and FAI) (-)</td>
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<td>• Psychological state, quality of life (-)</td>
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<td></td>
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<td></td>
<td>• Patient mortality (-)</td>
</tr>
<tr>
<td>King et al. (2012)</td>
<td>USA</td>
<td>225</td>
<td>E: Caregiver problem solving intervention + sessions with a clinical psychology student</td>
<td>C: Conventional care</td>
<td>• Caregivers depression, health and perceived caregiver outcomes(+)</td>
</tr>
<tr>
<td></td>
<td>RCT (7)</td>
<td></td>
<td></td>
<td></td>
<td>• Anxiety (-)</td>
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<td></td>
<td>• Family functioning, preparedness (-)</td>
</tr>
<tr>
<td>Bakas et al. (2009b)</td>
<td>RCT (6)</td>
<td>50</td>
<td>E: TASK notebooks + weekly calls from a nurse offering advice</td>
<td>C: Brochure on family caregiving + weekly calls from a nurse who did not offer advice</td>
<td>• Optimism, perceived task difficulty (-)</td>
</tr>
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<td>• Threat appraisal (+)</td>
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<td></td>
<td>• Depression, life changes, perceived general health (-)</td>
</tr>
<tr>
<td>Clark et al. (2003)</td>
<td>RCT (6)</td>
<td>62</td>
<td>E: Stroke information package + counselling visits</td>
<td>C: Conventional care</td>
<td>• Functional recovery (Barthel Index), social recovery (Adelaide Activities Index) (+)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Health status, depression, anxiety, mastery (-)</td>
</tr>
<tr>
<td>Lowe et al. (2007)</td>
<td>RCT (6)</td>
<td>100</td>
<td>E: Conventional care + “Carefile” book</td>
<td>C: Conventional care</td>
<td>• Stroke knowledge (+)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Satisfaction with information received (-)</td>
</tr>
<tr>
<td>Evans et al. (1988)</td>
<td>RCT (5)</td>
<td>213</td>
<td>E1: Educational classes</td>
<td>C: Conventional care</td>
<td>• Problem solving, communication, global family function (E1/E2 vs. C (+))</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>E2: Counselling sessions</td>
<td></td>
<td>• Patient adjustment (E2 vs. E1/C (+))</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>• Stroke knowledge, affective involvement (E1/E2 vs. C (+))</td>
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<td></td>
<td></td>
<td>• Role Skills Scale (-)</td>
</tr>
<tr>
<td>Hartke and King (2003)</td>
<td>RCT (5)</td>
<td>88</td>
<td>E: Conference call education sessions + an information manual</td>
<td>C: Conventional care + information manual</td>
<td>• Stress (-)</td>
</tr>
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<td></td>
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<td></td>
<td>• Burden (+)</td>
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<td></td>
<td>• Competence (+)</td>
</tr>
<tr>
<td>Johnson &amp; Pearson (2000)</td>
<td>RCT (5)</td>
<td>41</td>
<td>E: Educational classes</td>
<td>C: Conventional care</td>
<td>• Depression, hope (+)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Coping (-)</td>
</tr>
<tr>
<td>Larson et al. (2005a)</td>
<td>RCT (5)</td>
<td>100</td>
<td>E: Education and support program</td>
<td>C: Single session with a stroke specialist</td>
<td>• Quality of life, well-being, life situation, health (-)</td>
</tr>
<tr>
<td>Schure et al. (2006)</td>
<td>RCT (5)</td>
<td>257</td>
<td>E1: Group education/ counselling</td>
<td>C: Conventional care</td>
<td>• Informational and emotional support (E1 vs. E2 (+))</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>E2: Home based education/ counselling</td>
<td></td>
<td>• Advisory support, self-knowledge, burden (-)</td>
</tr>
<tr>
<td>Van den Heuvel et al. (2002)</td>
<td>RCT (5)</td>
<td>212</td>
<td>E: Group based education</td>
<td>C: Conventional care</td>
<td>• Knowledge (E1/E2 vs. C (+))</td>
</tr>
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<td></td>
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<tr>
<td>Grant et al. (2002)</td>
<td>RCT (5)</td>
<td>212</td>
<td>E1: Social problem solving telephone partnerships</td>
<td></td>
<td>• Problem solving skills, caregiver</td>
</tr>
<tr>
<td>Intervention Details</td>
<td>Effects</td>
<td></td>
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</table>
| **RCT (4)**<br>N= 74<br>E2: Sham telephone intervention | preparedness, depression (E1 vs E2/C (+))
| C: Conventional care | Caregiver burden (-) |
| **Grant (2001)**<br>RCT (4)<br>N= 30 | Depression at 2 and 5 weeks (+) at 13 weeks (-)
| E: Home visit or telephone contact form a nurse | Problem Solving Inventory (-)
| C: Sham telephone contact | Caregiver preparedness at 2 and 5 weeks (+) at 13 weeks (-)
| **Lorenc et al. (1992)**<br>RCT (3)<br>N= 30 | Knowledge (E2 vs E1/C (+))
| E1: Information package about stroke | Consumer satisfaction (-) |
| E2: Information package + asked to question themselves on the material | |
| C: Conventional care | |
| **Perrin et al. (2010)**<br>RCT (3)<br>N= 61 | Depression (-)
| E: Transition Assistance Program including interview with clinical interventionalist + videophone contacts | Carer strain (+)
| C: Conventional care | |
| **Aguirrezabal et al. (2013)**<br>PCT<br>NStart=271<br>NExc=150 | Patient satisfaction after discharge (HomeSat) (+)
| E: Educational session + clinical patient guidebook | Caregiver satisfaction (+)
| C: Information and support upon request | |

+ Indicates statistical significance between treatment groups
- Indicates no statistical significance between treatment groups

**Discussion**

The interventions summarized above demonstrate considerable variation both in types of interventions used and outcomes assessed. At first glance, evidence with regard to the usefulness of providing information and education to stroke patients and their families appears confusing. However, it may be easier to provide an overview of effectiveness by summarizing effects according to the basic type of intervention employed; i.e. the provision of information packages or materials, interactive education sessions or the provision of specific training of relevant skills (Table 19.2.4.2). As determined previously (Smith et al. 2008; Visser-Meily et al. 2005), a quantitative or pooled overview of effectiveness is difficult given the marked heterogeneity of outcome assessment across studies.

When the evidence is viewed according to the type of intervention used, it would appear that all of the tested forms of information provision or education have a generally positive effect on a variety of the assessed outcomes. Information provision alone appears to have the most limited effect. However, the addition of either a family support worker or counselling may increase the positive effects associated with the provision of information materials (Clark et al. 2003; Mant et al. 2000). Tailoring the provision of information to the specific needs of the stroke survivor and the primary caregiver might also enhance the effectiveness of this strategy (Bakas et al. 2009a; Hoffmann et al. 2007). Providing caregivers with online resources and email access to a rehabilitation nurse has also been suggested to improve caregiver preparedness (Stone 2014).

Group education sessions, like information materials, may increase the level of stroke-related knowledge (Evans et al. 1988; Green et al. 2007; Rodgers et al. 1999; Schure et al. 2006; van den Heuvel et al. 2002). In addition, group education sessions may be associated with additional positive effects such as reduced depression (Cadilhac et al. 2011; Johnson & Pearson 2000) improved self-efficacy (van den Heuvel et al. 2002), increased perceived emotional support (Schure et al. 2006), increased competence and lower caregiver burden (Hartke & King 2003).
Two studies (Bakas et al. 2009b; Johnston et al. 2007) examined the use of workbook based strategies supplemented by regular contact and advice. While neither study was able to demonstrate a significant impact on either the experience of depression nor perceived health of the carer, both interventions seemed have an effect on outcomes related to caregiver confidence. In Bakas et al. (2009b) carers involved in the intervention displayed more optimism and found tasks less difficult.

In a study both caregivers and patients received educational materials (Aguirrezabal et al. 2013). The caregivers received educational information in addition to training classes led by a multi-disciplinary team, while the patients received a clinical patient guidebook. Results show that satisfaction after discharge was significantly higher regarding the amount of information received, community support, hospital contact, and preparation for returning home, compared to participant groups that did not receive training or a patient guidebook. Caregiver satisfaction was also significantly higher in those receiving the educational materials. Similarly, education geared towards both patients and their families regarding patient positioning and position-changing techniques resulted in significant benefits for the patients in their activities of daily living (Hebel et al. 2014).

With the rising incidence of young strokes, the need for education and support programs tailored to this demographic group is evident. In 2014, a hospital-based program (The Young Empowerment Stroke Support (YESS)) based on occupational therapy principles was developed to provide education and support to young individuals with stroke (Muller et al. 2014). One of the goals of the program was to encourage social and community participation outside of the program context. Half of the participants reported to have engaged in interactions with individuals outside of the groups, and over half of the participants indicated engagement in leisure opportunities outside of the program. Participants valued the educational component of the program and also the information provided that pertained to community resources.

Specific skills training also appeared to have a positive influence on both caregiver (Grant 1999; Grant et al. 2001; Kalra et al. 2004; King et al. 2007; Oupra et al. 2010) and patient outcomes (Kalra et al. 2004), and was consistently associated with a reduction in depression.

Training in problem-solving skills may result in improved caregiver preparedness as well as reductions in anxiety and depression (Grant 1999; Grant et al. 2001; King et al. 2007). Lui et al. (2012) assessed perceived problem-solving abilities, social support, anxiety, depression and physical well-being in a group of 103 informal stroke caregivers. Perceived problem-solving ability was a significant predictor of perceived social support at 3 months. In addition, confidence in problem solving and perceived personal control of emotion and behaviour while problem-solving were associated with later assessments of physical well-being and the perception of difficulty associated with various elements of caregiving.

In addition, providing caregivers with hands-on, practical training in basic nursing and personal care assistance resulted in improved outcomes for both the caregiver and patient on a range of outcomes including depression, anxiety and quality of life (Kalra et al. 2004; McCullagh et al. 2005). Carer skills training was also associated with shorter lengths of stay and reductions in resource use resulting in significantly lower health and social care costs (Patel et al. 2004).

In a recent systematic review and meta-analysis, the effect of psychological interventions (i.e. interventions that involved counselling, social support groups, psychoeducation) aimed at improving the well-being of caregivers was evaluated (Cheng et al. 2014). The studies included in the meta-analysis are found in Table 19.2.4.2.
The study revealed that psychoeducation had no significant effect on caregiver burden, competence and depression at post-intervention. However, a small significant effect (-0.12 [-0.23,-0.01]; p=0.03) was found regarding family functioning after psychoeducation. The authors acknowledge that several limitations of the study may have biased the results. The study included only Chinese and English literature, and several relevant studies were excluded due to insufficient information regarding the intervention, primary outcome, and the identity of the caregivers. The studies included in the analysis were also of poor methodological quality and varied in the type and intensity of the intervention.

**Conclusions Regarding Information Provision and Education Interventions:**

*There is level 1a evidence from a meta-analysis that psychoeducational interventions have no significant effect on the burden or health of caregivers but may benefit family functioning.*

*There is level 1a evidence of a positive benefit, associated with the provision of information and education through a variety of intervention types. Education sessions may have a greater effect on outcome than the provision of information materials alone.*

*There is level 1a evidence that skills training is associated with a reduction in depression.*

*There is level 1b evidence that a problem-solving intervention for caregivers is associated with a reduction in depression, life changes, and health. These benefits may not be maintained beyond 6 months.*

*There is level 1b evidence that training in basic nursing skills improves outcomes of depression, anxiety and quality of life for both the caregiver and the stroke patient.*

*Information provision and education interventions may have a positive influence on caregiver outcomes; however, more research is needed to clarify the optimal intervention type, dosage, and time post-stroke.*

19.2.4.1 Perceived Needs for Information, Education and Training
Caregivers may find themselves in the position of having to provide skilled nursing assistance to the stroke survivor while having little or no experience in delivering appropriate care and support. They often receive no training or instruction and, therefore, have no choice but to learn what is required of them in their new role by trial and error (Silverstone & Horowitz 1987). The role of caregiver may be perceived simply as an accepted obligation (Hare et al. 2006; Sit et al. 2004). The demands associated
with learning how to appropriately care for and support the stroke survivor may be perceived as overwhelming by the carer (Grant et al. 2004).

Family or informal caregivers often feel unprepared for the role. Caregivers may find themselves in the position of having to provide skilled nursing assistance to the stroke survivor while having little or no experience in delivering appropriate care and support. They often receive little information that is suited to their needs and no training or instruction. Carers, therefore, may have no choice but to learn what is required of them in their new role by trial and error. Carers with little education tend to receive the least informational support, perhaps due to the prevalent use of written information (Sit et al. 2004). Hoffmann et al. suggested that the majority of written information provided to stroke patients and their caregivers is written in language that may exceed the average reading of the recipients and is, therefore, of limited use (Hoffmann et al. 2004).

Although the provision of information and education is an important need identified by stroke patients and their caregivers, it is often unfulfilled. Patients and families/caregivers most often identify information needs in the areas of stroke risk, recurrence and secondary prevention, patient safety, cognitive and emotional problems, specific and individual consequences of stroke, medication management, communication difficulties, and access to further information, community resources and stroke support groups. Health care professionals, particularly general practitioners, neurologist and physiotherapists are regarded as primary information providers by both patients and their caregivers (Sit et al. 2004; Wachters-Kaufmann et al. 2005). The type of support received and who provides support, as discussed above, were two of three themes identified in a qualitative study by Cameron and colleagues (2013). A patient and their caregiver progress through stages of recovery, each requiring unique support needs. These needs vary according to the type and intensity of support, by whom and how the support is provided, and what the primary focuses are (Cameron et al. 2013).

To determine what information is provided routinely to stroke patients and whether this information is perceived as adequate and/or effective from the point of view of the healthcare professional, Hoffman et al. (2007) surveyed 20 members of multidisciplinary stroke teams. Most participants provided information to 25% or fewer of their patients, while approximately one-half provided information to caregivers. Information was most often provided in the written form (created by the individual team, from community-based organizations or pro forma handouts such as exercise sheets), though frequently, written information was used to supplement information provided verbally. While provision of information was perceived to have a positive impact on recovery and health outcomes, most participating professionals (90%) believed that patients and carers rarely received adequate educational materials. Stroke team participants believed that important topics during acute care included information regarding the stroke itself (what a stroke is and its causes) and what to expect during rehabilitation. Following discharge, professionals felt patients should receive information regarding stroke support groups and community resources, effects of stroke on family/marriage and where to obtain further support/information. This is in contrast to the information needs identified in patient-centred studies. In a survey of community services in an Australian city, Eames et al. (2008) noted that fewer than 40% considered caregiver or patient feedback in designing written materials.

**Conclusions Regarding Perceived Need for Information, Education and Training**

*Although the receipt of information is of great importance to stroke patients and their families/caregivers, relatively few receive adequate information about topics they perceive to be important. Caregivers rarely receive adequate training in skills they require to care for the stroke survivor.*
Healthcare professionals involved in stroke care may acknowledge the importance of education for patients and carers; however, relatively few provide adequate information based upon the information needs of the recipients. In addition, written materials should be suited to the educational/reading level of the intended recipient.

Although information and education is perceived to be very important, informal carers rarely receive adequate information or training for their needs.

19.3 Leisure

19.3.1 Social and Leisure Activities Post Stroke
Interviews with stroke survivors have revealed a decrease in participation in leisure activities along with reports of social isolation, both of which can create problems for both the survivor and his/her informal caregiver (Pound et al. 1998).

A reduction of social and leisure activity is common post stroke. Niemi et al. (1988) noted that stroke patients in their survey reported 80% deterioration in leisure domains. Belanger et al. (1988) reported that, 6 months after returning home, fewer than 50% of the 129 stroke patients included in their sample participated in regular physical activities, and more than 50% did not participate in leisure activities outside of the home. When compared to control groups (though these are not defined), individual leisure activities such as participating in crafts or performing odd jobs, were undertaken less frequently while television watching was undertaken much more frequently by stroke survivors than in the control group (Belanger et al. 1988). Eriksson et al. (2012) reported gaps between what one wants to do and what one does do at one year post stroke. Most reported gaps were in the leisure domain and included such activities as travelling for pleasure, participating in sports or outdoor life. No gaps were reported for watching TV or videos or listening to the radio. Of course, number of occupations gaps was associated with independence in ADLs and extended ADLs.

Interestingly, O'Connell et al. found that the decline in participation in leisurely events was a consequence largely attributed to other non-stroke related factors such as transport difficulties, health issues unrelated to stroke, losing interest in the activities previously undertaken, fatigue, and physical limitations (O'Connell et al. 2013; White et al. 2014). Activities such as listening to music and reading for pleasure were often declined due to poor eyesight, headaches and lack of concentration (O'Connell et al. 2013). Patients also had a decreased interest in artistic events such as attending the cinema, musical performances, concerts, dancing, and singing, although, Jean et al. indicates that listening to music may decrease depression scores (Jean et al. 2013).

Often deterioration in leisure activity and social participation is marked by an uncertain and gloomy view of the future (Lawrence & Christie 1979) and may result in a decreased sense of well-being (Sveen et al. 2004). Most often women and those with high educational backgrounds are least likely to engage in post-stroke social and leisure activities (Labi et al. 1980). Labi et al. (1980) suggest that the great value placed on body image and social status (both of which are compromised after stroke) by women and higher educated individuals contributed to their subsequent lack of involvement in social activities. Davidson and Young (1985) also noted that younger stroke patients were more likely to experience greater losses to their interpersonal and leisure life.
Lawrence and Christie (1979) observed that physical disability in itself was less important to the stroke patient than others response to their disability. Furthermore, those patients who had a spouse or a caregiver that lived with them and attended to their needs were not as inclined to engage in frequent socialization. Patients were noted to be unoccupied throughout much of the day and were not involved in household activities (Putterill et al. 1984). Interestingly, even after patients had re-gained their physical dependence, they did not return to their normal social life (Labi et al. 1980). Putterill et al. (1984) noted that this lack of involvement was not due to an inability to perform such tasks, but that patients did not know how to manage such tasks in the presence of their physical disabilities. Taking on new social activities that required leaving the home was considered risky for most patients eliciting fears such as toileting in strange and oftentimes difficult facilities (Davidson & Young 1985). Consequently, patients tended to stay at home which in turn may lead to isolation and loneliness for many stroke survivors (Davidson & Young 1985; J. White et al. 2014). Furthermore, loss of activity is often directly associated with depression (Feibel & Springer 1982) and reduced well-being (Sveen et al. 2004).

Although patients commonly expressed feelings of regret and guilt about being dependent on others, many reported that the support received from their spouses was important for maintaining and improving their psychological wellbeing (White et al. 2014). Oftentimes, psychological distress decreased in patients over time due to the adoption of various coping strategies that focused on positive perspectives, social support, and acceptance of limitations (White et al. 2014).

Given that depression itself is a major concern post-stroke, the deterioration of interpersonal and leisure life needs to be addressed in order to avoid further risk of developing post-stroke depression (see discussion of depression in Chapter 18). As the stroke patient begins to re-integrate into the community, they must acquire the skills needed to either resume or adapt to prior social and leisure activities or to engage in new interests. Such acquisition and adaptation requires not only developing functional independence in activities of daily living, but also dealing with the perceived changes in body image and social status.

In order to promote the early identification of stroke survivors at risk for social inactivity, researchers attempted to create a simple rule to be used in the prediction of social inactivity as assessed on the Frenchay Activities Index (Schepers et al. 2005). Using information obtained on admission to rehabilitation and a cut-off score of 19 (see Table 19.3.1.1), the proposed instrument had a sensitivity of 82% and specificity of 76% (AUC = 0.85) for the prediction of social inactivity/activity at one-year post stroke. It should be noted that interpretation of FAI scores should be undertaken with caution (Salter et al. 2005; Schepers et al. 2005). Many of the items on the scale are related to housework activities, which are undertaken by women in a traditional household model. This may result in an inflation of FAI scores among women and a corresponding depression of FAI scores among men (who may never have engaged in these activities). Further evaluation of this predictive aid is required.

Conclusions Regarding Leisure Activities Post-Stroke

Deterioration in social and leisure activities is common post-stroke and is greatest in women, the young and those who are better educated. Perceptions about how others view their disabilities and perceptions about how they will be able to cope post-stroke may influence the degree of social isolation experienced.

Deterioration in social and leisure activities is common post-stroke. Programs that encourage positive perspectives, acceptance of limitations, and social support may help to reduce psychological distress.
19.3.2 Leisure Interventions and Social Participation

A 2003 analysis of the effect of comprehensive occupational therapy (OT) interventions identified a small but significant favourable effect of OT intervention on ADL, extended ADL and social participation (Steultjens et al. 2003). While leisure therapy may often be part of a comprehensive occupational therapy intervention, no specific effect associated with leisure therapy was determined. In addition, studies included in the 2003 analysis were very heterogeneous; interventions were dissimilar in terms of approach, duration, intensity and assessment of outcome (Landi et al. 2004). In addition, the assessment of social participation was not well defined. A more recent meta-analysis was undertaken by Walker et al., in which the effect of leisure-based, community, occupational therapy on activities of daily living, extended activities of daily living and on leisure activity in patients with stroke was assessed (Walker et al. 2004).

Walker et al. (2004) identified 9 completed randomised controlled trials assessing occupational therapy interventions, which included the provision of ADL and/or leisure therapy. Data was obtained and included from 8 studies (Table 19.3.2.1).

The primary identified outcome was extended activities of daily living (EADL) scores on the Nottingham Extended Activities of Daily Living Scale. Other outcomes included scores on the Barthel Index (personal ADL or PADL), General Health Questionnaire, Nottingham Leisure Questionnaire and death at the end of intervention and the end of the trial. Using pooled analysis, data for 655 patients who received community occupational therapy was considered. Of these, 174 patients received leisure therapy interventions and 481 received ADL-specific interventions. Overall, community occupational therapy (OT) was associated with an increase in extended activities of daily living scores (weighted mean difference = 1.30) and with leisure activity scores (weighted mean difference = 1.51). When type of intervention was considered, leisure therapy was associated with improved leisure activity scores (weighted mean difference = 1.96), but not with extended-ADL or personal ADL scores. Participation in ADL interventions were associated with increased extended-ADL scores (weighted mean difference = 1.61) but not with increased leisure activity. A significant interaction between mode of assessment and leisure activity scores on the Nottingham Leisure Questionnaire was identified as a potential source of bias.

Table 19.3.2.1. Summary of Exercise and Education Group Interventions

<table>
<thead>
<tr>
<th>Factor Type</th>
<th>Factors Facilitating Participation</th>
<th>Factors Impeding Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity-based</td>
<td>• Determination</td>
<td>• Sense of pride</td>
</tr>
<tr>
<td></td>
<td>• Disclosing aphasia</td>
<td>• Inability to speak well</td>
</tr>
<tr>
<td></td>
<td>• Finding solutions</td>
<td>• Fear of family member’s reaction</td>
</tr>
<tr>
<td></td>
<td>• Being motivated and positive</td>
<td>• Fear of asking for help</td>
</tr>
<tr>
<td></td>
<td>• Composing with limits</td>
<td>• Fear of being judged</td>
</tr>
<tr>
<td></td>
<td>• Persevering in trying to communicate</td>
<td>• Preference of being alone</td>
</tr>
<tr>
<td></td>
<td>• Being sociable</td>
<td></td>
</tr>
<tr>
<td>Capability-based</td>
<td>• Energy</td>
<td>• Communication limitations</td>
</tr>
<tr>
<td></td>
<td>• Communication recovery</td>
<td>• Physical limitations</td>
</tr>
<tr>
<td></td>
<td>• Physical recovery from hemiparesis</td>
<td>• Cognitive limitations</td>
</tr>
<tr>
<td></td>
<td>• Emotional control</td>
<td>• Lack of emotional control</td>
</tr>
<tr>
<td></td>
<td>• Cognitive improvements</td>
<td>• General factors (i.e. fatigue)</td>
</tr>
<tr>
<td>Family and social circle</td>
<td>• Family members providing support</td>
<td>• Poorly adjusted speakers</td>
</tr>
<tr>
<td></td>
<td>• Available speaking partners</td>
<td>• Poor spousal relationship</td>
</tr>
<tr>
<td></td>
<td>• Encouragement from family</td>
<td>• Lack of support</td>
</tr>
</tbody>
</table>
Six studies examining participation outcomes following exercise-based interventions were identified (Table 19.3.2.2).

**Table 19.3.2.2 Participation Outcomes Following Exercise-Based Interventions**

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>PEDro Score</th>
<th>Interventions*</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mead et al. (2007)</strong></td>
<td>RCT (8)</td>
<td>N= 66</td>
<td>E: Exercise + tea &amp; chat (3X/wk for 12wk) C: Relaxation training</td>
</tr>
<tr>
<td><strong>Van de Port et al. (2012)</strong></td>
<td>RCT (8)</td>
<td>N= 250</td>
<td>E: Task-oriented, group-based circuit training (2X/wk for 12wk) C: Conventional care</td>
</tr>
<tr>
<td><strong>Harrington et al. (2010)</strong></td>
<td>RCT (7)</td>
<td>N= 24</td>
<td>E: Group exercise &amp; education (2X/wk for 8wk) C: Conventional care</td>
</tr>
<tr>
<td><strong>Marsden et al. (2010)</strong></td>
<td>RCT (5)</td>
<td>N= 42</td>
<td>E: Group exercise &amp; education (1X/wk for 7wk) C: Conventional care</td>
</tr>
<tr>
<td><strong>Huijbregts et al. (2008)</strong></td>
<td>PCT</td>
<td>N= 30</td>
<td>E: Exercise + information/ goal-setting (2X/wk for 8wk) C: Standard education program</td>
</tr>
<tr>
<td><strong>Patterson et al. (2010)</strong></td>
<td>PCT</td>
<td>N= 43</td>
<td>E: Group exercise + peer support C: Peer support</td>
</tr>
</tbody>
</table>

+ Indicates statistical significance between treatment groups
- Indicates no statistical significance between treatment groups

**Discussion**

Only one of the three RCTs investigating leisure therapy was able to demonstrate beneficial and lasting effects of leisure therapy compared to conventional or control therapies (Drummond & Walker 1995). Both the Jongbloed and Morgan (1991) and Parker et al. (2001) studies were carried out over a limited
number of treatment sessions; 5 and 10, respectively. Furthermore, therapists from both studies reported difficulty in maintaining a clear distinction between ADL or leisure-based therapies. With only Drummond and Walker’s (1995) study demonstrating significant results in favour of leisure therapy, no clear conclusions can be made regarding the impact of leisure therapy on the resumption of former social activities and stroke rehabilitation.

The results of a pooled data meta-analysis incorporating data from these three RCTs suggested that there is, in fact, a modest benefit associated with leisure therapy in terms of reported leisure activity (Walker et al. 2004). However, the number of patients included in this pooled analysis was still quite small (n=174). In addition, moderate levels of heterogeneity were associated with the outcome measures at the end of the intervention and a possible source of measurement bias was identified. It is interesting to note that specific therapy aimed at improving leisure activity, improved only leisure activity. The benefits of leisure therapy did not extend to extended or personal activities of daily living (Walker et al. 2004).

A single RCT examined the impact of an in-home leisure education program designed to enhance leisure activity and experience through personal empowerment (Desrosiers et al. 2007). The program focuses on development of awareness and of specific competencies to promote personal autonomy in leisure. By the end of the program, participants experienced improved activity in terms of both duration and number. However, this is not necessarily surprising as one of the conditions for ending the intervention was integration of “significant leisure activities in her/his life” (p.1096). Although participation in the intervention was not associated with improved well-being or health-related quality of life, when compared to the control group, it was associated with the presence of fewer symptoms of depression.

Community-based, group exercise has also been examined for its possible social benefit. While effective in improving physical function as well as satisfaction with physical performance, evidence regarding the impact of group exercise on participation outcomes is less clear. On the other hand, factors such as perceived recovery, the amount of retained activities, and community reintegration have been found to predict perceived participation (Eriksson et al. 2013). Marital status however, was not a significant predictor of perceived participation (Eriksson et al. 2013). The severity of a patient’s depression was also significantly associated with limited community participation and low social support (White et al. 2014). In an observational study, Le Dorze et al. (2014) identified several factors that facilitated or impeded participation in patient with aphasia, outlined below in Table 19.3.2.1.

Two non-RCTs reported significant benefits in terms of social functioning associated with participation in group-based exercise and education programs (Huijbregts et al. 2008; Lai et al. 2004). However, two RCTs demonstrated benefits associated with group exercise and education in terms of perceived physical function only (Harrington et al. 2010; Mead et al. 2007), gait speed, walking distance and performance on the modified stairs test (van de Port et al. 2012) It should be noted that individuals included in the Mead et al. (2007) trial demonstrated a high level of function. Variability in social function could not be evaluated due to large ceiling effects on assessments at baseline. Neither van de Port et al. (2012) nor Harrington et al. (2010) reported significant between group differences in terms of subjective social outcomes.

While the quantitative impact of group-based exercise on social participation has not been established, qualitative study has suggested that this type of intervention may be of psychosocial value to the participants. Overall, participants appeared to enjoy the opportunity to gather with other individuals with stroke and welcomed the opportunity to engage with others in a social situation (Carin-Levy et al. 2009; Huijbregts et al. 2008; Reed et al. 2010). In addition, regularly scheduled activities such as exercise
or relaxation therapy helped participants to find the motivation they needed to engage in other activities outside of the home (Carin-Levy et al. 2009).

Further research is required to establish the role of leisure therapy and related interventions, such as programs of group exercise, in helping the community-dwelling individual with stroke engage in social and leisure activities. The role of intensity and duration of leisure therapy as it is related to the effectiveness of the leisure therapy intervention should also be examined.

Conclusions Regarding Leisure Therapy Intervention Post-Stroke

*When considered individually, there appears to be conflicting evidence as to the benefit of leisure therapy post-stroke and following discharge. However, based on the information from a meta-analysis using pooled data from the same RCTs, there is level 1a evidence that leisure therapy is associated with modest improvement in leisure activity.*

*There is level 1b evidence that participation in a leisure education program focused on awareness and competency development is associated with improvement in number and duration of activities and reduction in depressive symptoms.*

*There is level 1a evidence that participation in group education and exercise programs result in improved physical outcomes, but not social/leisure participation outcomes.*

Leisure therapy may result in improved leisure activity.

Participation in group exercise and education may result in improved subjective physical outcomes.

19.4 Sexuality

In 1975, the World Health Organization acknowledged the importance of sexual health, which it defined as “the integration of the somatic, emotional, intellectual and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love.” In a study of individuals aged 50 – 92, Gott et al. (2003) reported that among this group of older individuals, sex remained an important element of a close emotional relationship. However, sex may be assigned a lower priority, not due to aging per se, but rather due to an increasing prevalence of disability or health problems that create a barrier to sexual activity (Gott & Hinchliff 2003). Sexual dysfunction after stroke has been reported to be a problem that has a significant impact on the wellbeing of stroke patients. However, it is an issue that is often underestimated or simply ignored during rehabilitation despite its importance to stroke survivors (Buzzelli et al. 1997; Murray & Harrison 2004).

19.4.1 Decreased Sexuality Following Stroke

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

It appears that decreased sexual activity or abstinence is common following a stroke. In some studies, more than 80% of the participants have reported a decline in sexual frequency (Akinpelu et al. 2013; Buzzelli et al. 1997). Fugl-Meyer et al. (1975) reported that approximately one-third of the stroke survivors assessed in that study had stopped having sexual intercourse entirely. Leshner et al. (1974) noted a significant decrease in the frequency of sexual intercourse with 45% of patients having ceased intercourse completely. Kinsella and Duffy (1980) reported 83% of aphasic patients ceased having sexual relations after a stroke. While some studies reported no change in libido (Bray et al. 1981), others reported a decline in a substantial number of stroke patients (Carod et al. 1999; Cheung 2002; Choi-Kwon & Kim 2002).

As one might anticipate, the prevalence of sexual dissatisfaction post-stroke is very high. In the recent study by Carlsson et al. (2007), 50% of stroke patients and their partners were both dissatisfied with their sex life. Both partners reported feeling satisfied in only 25% of couples. The reasons for sexual dissatisfaction are complex and not necessarily related to a decline in arousal function. Social and psychological factors have an important role in decreased sexual frequency and satisfaction with sex (Carod et al. 1999; Cheung 2002; Korpelainen et al. 1999). Cheung (2002) identified increasing age and functional disability, a belief that the stroke affected sex, lack of communication with one’s partner and an unwillingness to participate as related to declining sexual satisfaction. Sexual dysfunction after stroke such as reduced penile erection, vaginal lubrication and orgasmic dysfunction are commonly reported after stroke. Monga et al. (1986) found that prior to the stroke none of the male patients in their study reported sexual problems and almost all had erections. After the stroke only 38% of male patients had erections and 58% reported having sexual problems. 43% of female patients experienced orgasms and only 7% reported sexual problems prior to suffering the stroke. After the stroke only 11% experienced orgasms and almost one half reported having sexual problems (Monga et al. 1986). In a more recently study however, 100% of male patients and 58% of female patients were classified as having sexual dysfunction (Stein et al. 2013). Although, few studies have linked arousal dysfunction directly to dissatisfaction (Sjogren & Fugl-Meyer 1981), sexual dysfunction led to minimal depression in 3%, mild depression in 54.4%, moderate depression in 36.4%, and severe depression in 6.0% of patients (Stein et al. 2013).

A decrease in sexual activity between partners may be attributed, in part, to their inability to discuss sexuality with their spouse, general attitudes toward sexuality and an unwillingness to participate in sexual activity (Cheung 2002; Giaquinto et al. 2003; Korpelainen et al. 1999). Although 94% of patients reported physical limitations prevented them for engaging in sexual activities, 58.8% reported feeling less sexually desirable (Stein et al. 2013). Often, this is a result of reduced body image and self-esteem in the patient and difficulties in accommodating the patient’s disabilities and body changes by the spouse. Individuals with aphasia may experience added difficulties around a reduced ability to initiate sexual activities or engage in intimate sexual conversation with their partner (Lemieux et al. 2001). Giaquinto et al. (2003) observed that it is psychological factors, rather than medical ones, that account for the discontinuity of sexual activity. As noted by Giaquinto et al. (2003) and Buzzelli et al. (1997), patients’ partners contributed to the decline of sexual activity. Many expressed a fear of relapse, anguish, lack of excitement, and even horror that prevented them from encouraging sexual activities. However, resumption of a sexual relationship with their partners is important to many stroke survivors (Bray et al. 1981; Buzzelli et al. 1997; Cheung 2002; Murray & Harrison 2004; Stein et al. 2013).
Maintaining a healthy sexually active lifestyle after a stroke is an important aspect of wellbeing. Many patients reported that sexual issues encountered due to the stroke accounted for 71% of one’s overall recovery, with no significant difference between females and males (J. Stein et al. 2013). Worsening of sexual functioning was found in 42% of patients, while 42% found no change and only 5% found an improvement following a stroke (Seymour & Wolf 2014; J. Stein et al. 2013).

Currently, there is no data on the impact of therapeutic interventions on post-stroke sexuality, and therefore, we can make no conclusions with regard to treatment based on evidence. Nevertheless, some treatments make empirical sense. Open discussion about sexuality should be initiated during rehabilitation and re-addressed again after transition into the community. Edmans reported that information and advice provided prior to discharge was perceived as useful by stroke patients and their partners and that, in general, couples felt that the subject of sexual activity should be included in rehabilitation (Edmans 1998). Open discussion is the basis of recommendations made as part of recently published Dutch clinical guidelines (van Heugten et al. 2006). In the absence of intervention studies, these recommendations are based on limited and consensus level evidence (van Heugten et al. 2006).

Table 19.4.1.1 Recommendations Regarding Sexuality and Intimacy, Dutch Clinical Guidelines for Carers of Stroke Patients (van Heugten et al. 2006).

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

Recent AHA/ASA-endorsed practice guidelines also recommend the discussion of sexual issues both during rehabilitation and again upon return to the community (Duncan et al. 2005). Patients and spouses should be reassured that sexual activity is permissible, that they can achieve satisfaction and intimacy and that sexual activity will not result in another stroke. However, dependencies in primary activities of living such as self-care and impaired exteroception for touch contribute to the reduction of sexual activities noted in stroke patients (Sjogren & Fugl-Meyer 1982). Accordingly, both patient and partner are required to recognize and adjust for effects of motor, sensory and attentional deficits, easy fatigability and most importantly, changes in body image and self-esteem. Interventions that address the importance of effective communication, sharing of concerns and the development of adaptive approaches in positioning, foreplay and timing to avoid fatigue have been suggested (McCormick et al. 1986; Sjogren & Fugl-Meyer 1982). A study by McLaughlin and Cregan (2005) surveyed healthcare professionals (n=13) within the area of stroke rehabilitation and reported that despite receiving inquiries from patients regarding sexuality and sexual activity, most had difficulty addressing these issues primarily due to lack of appropriate training. A more recent study shows that about 75% of patients reported waiting to have received information regarding sexual dysfunction after stroke and only 15.2% were offered or sought out this information (J. Stein et al. 2013). The most common sources of educational information was provided through the internet and brochures (35%), and through a physician (30%), although 60% of patients preferred to receive counselling regarding sexual dysfunction through their physician. Nursing staff and physical therapists were considered second and third choices for providing counselling (45%, 36.3%). The authors suggest that sexual rehabilitation needs to be recognized as an important issue for individuals following stroke and members of the multi-disciplinary stroke rehabilitation team should receive appropriate and comprehensive training in sexual health care. A recent cross sectional study of stroke survivors found that 71% of individuals considered sexual
recovery to be an important part of their rehabilitation. The majority of individuals indicated that not enough information about sexual dysfunction following stroke had been provided to them. Additionally, 30% indicated they would like printed materials, and 27% discussion, as their preferred source of educational material (Hamam et al. 2013).

### 19.4.2 Inappropriate Sexual Behaviour

Inappropriate sexual behaviour is most commonly defined as i) overt acts associated with increased libido or ii) persistent, uninhibited, sexual behaviours directed either at oneself or others (Bardell et al. 2011). The presence of ISB may have a significant, negative, impact on the individual, and her/his course in rehabilitation, in addition to her/his family and healthcare providers (Bardell et al. 2011; Monga & Ostermann 1995).

In individuals with progressive cognitive impairment, reported prevalence of inappropriate sexual behaviour (ISB) ranges from 2% to 17% (Stubbs 2011). However, estimated prevalence specific to the population of individuals with stroke is not known. Although the cause of hyper sexuality is not known, individuals with right frontal lobe stroke, cognitive impairment and/or a diagnosis of dementia may be at greater risk for ISB. The use of pharmacologic agents, such as citalopram, to treat ISB may be common; however, the effectiveness of these treatments may not be particularly effective (Bardell et al. 2011).

**Conclusions Regarding Sexual Activity Post-Stroke**

*A decrease in sexual activity is very common post-stroke. There is general agreement that sexual drive is still present and the main barriers to sexual activity are physical impairments and psychological factors, in particular a changed body image and lack of communication.*

*Inappropriate sexual behaviour following stroke is not well studied. There may be an association between inappropriate sexual behaviour and the presence of right frontal lobe stroke and cognitive impairment.*

*There is level 3 evidence that sexual issues should be discussed during rehabilitation and addressed again after transition to the community when the stroke survivor and significant other are ready.*

A decrease in sexual activity is very common post-stroke and is likely related to a changed body image, reduced self-esteem and lack of communication with one’s partner. Sexual issues need to be addressed as part of community reintegration.

### 19.5 Driving

The ability to drive is a significant marker of independence. As noted by Churchill (1998), “resumption of driving often represents the final step toward independence and reintegration into the community,”. Inability to drive may be associated with disruption in lifestyle, an inability to participate in the community, resume pre-stroke roles or maintain independence and autonomy (White et al. 2012). Resumption of driving, although perceived as a relief, may be accompanied by a lack of confidence (J.H. White et al. 2012). Stroke patients who do not resume driving report that this decision negatively impacted social activities and wellbeing (Mackenzie & Paton 2003). Similarly, Finestone et al. (2010) reported that driving is significantly associated with community reintegration one year following stroke.
According to Section 9 of the Canadian Medical Association’s Determining Fitness to Drive, 6th edition, “cerebrovascular insufficiency can cause disabling symptoms that are difficult to detect. If there is reason to suspect a problem, a careful history and evaluation of the degree of disability present is probably the best method for determining fitness to drive. Where resources are available, assessment by a trained occupational therapist would be optimal. A road test may also be helpful but cannot always be relied on to reveal that true extent of the disability because of the fluctuating nature of the symptoms,” (Canadian Medical Association 2000).

The same document added, “patients who have had a stroke should not drive for at least one month. During this time they require assessment by their regular physician. They may resume driving if functionally able and if a neurologic assessment discloses no obvious risk of sudden recurrence and any underlying cause have been addressed with appropriate treatment. Where there is a residual loss of motor power, a road test may be required. This assessment may be carried out at assessment centre or by motor vehicle licensing authorities. It may be necessary to restrict the person to driving a car equipped with an automatic transmission or modified controls. The physician should take particular care to note any changes in personality, alertness, or decision-making ability in stroke patients, however subtle and inconsistent, that could significantly affect driving ability. These patients may drive well one day, but incompetently the next,” (Canadian Medical Association 2000).

Stroke patients demonstrate greater driving deficiencies than healthy individuals (Heikkila et al. 1999) and, among individuals with medical conditions, stroke patients are at greater risk of being involved in at-fault accidents (McGwin et al. 2000). In a study originating in NSW, Australia, Pearce et al. (2012) reported crash rates for all licensed drivers of 91/100,000 (proportion: 0.0091, 95% CI 0.0090-0.0092) and an at-fault accident rate of 222/100,000 (proportion: 0.022, 95% CI 0.0039-0.11) for individuals resuming driving following stroke (and completion of a driving assessment). MacKenzie and Paton (2003) reported that 14 of 18 aphasic patients included in their study resumed driving despite scoring lower than an age, education and years of driving-matched control group on measures of road sign recognition and comprehension. It should be noted that within the group of stroke patients with aphasia participating in this study (Mackenzie & Paton 2003), there were no significant differences in road sign recognition and comprehension between patients who resumed driving and those who did not.

Tasks that are frequently repeated and are closely associated to personal autonomy, like driving, may be incorporated as an aspect of self-concept (Scott et al. 2009). Most normal, driving, adults believe that they are much better drivers than they are, despite evidence to the contrary. The same may be true of individuals with stroke; however, self-assessment of driving ability following stroke may also be affected by impaired cognition and self-awareness (Scott et al. 2009). Patomella et al. (2008) assessed the driving ability of 38 individuals approximately 1 year following stroke using a driving simulator, an assessment of awareness of driving disability and a stroke driver screening assessment (Patomella et al. 2008). The majority of patients (75%) demonstrated at least one major discrepancy between performance and awareness indicating that there had been at least one major mistake made of which the patient was entirely unaware. Scott et al. (2009) reported that stroke survivors demonstrated significant bias in estimating their driving ability when compared to the “average driver”. This bias in favour of their own ability was less noticeable when they were asked to compare themselves to their significant other, although they tended to compensate by elevating the ability of their companion. In addition, when
asked to identify important factors in making a decision about driving, stroke survivors identified only one domain, convenience, while significant others felt that cognitive abilities, physical function and professional advice were important. Conversely, a recent study by Stapleton et al. (2012) found that self and proxy ratings of driving ability were significantly correlated with each other and both ratings correlated well with on road driving assessments completed by a professional (Spearman’s correlation coefficient = 0.497 (stroke survivor) p= 0.005; Spearman’s correlation coefficient = 0.614 (proxy) p= 0.005). Despite demonstrable deficits, many stroke survivors make decisions regarding their driving without professional advice and/or evaluation (Fisk et al. 1997). A recent study (Finestone et al. 2009) reported that 41.7% of individuals with a valid license, who drove prior to their assessment, failed their first evaluation.

Although individuals with stroke may choose to drive, there is considerable evidence that they also choose to self-regulate their driving and reduce their “driving exposure” (Finestone et al. 2009; Fisk et al. 2002; C. Mackenzie & Paton 2003). Commonly identified self-imposed driving restrictions include increased carefulness, driving shorter distances, reduced frequency, not driving at night, in busy times such as rush hour or in winter (Finestone et al. 2009; Fisk et al. 2002; Mackenzie & Paton 2003; Pearce et al. 2012; White et al. 2012).

19.5.1 Driving Assessment
While physicians in Canada are legally responsible for identifying patients who are unsafe to drive, there are few guidelines or specific tools upon which to base such evaluations. Furthermore, guidelines often fail to address the effects of changes in visual perception, problem solving, memory and visual inattention on driving (Korner-Bitensky et al. 1990).

The means by which driving and driving-related abilities are assessed and the predictive value of assessment have been examined in a number of studies.

Nouri & Lincoln (1993) demonstrated that, given the results of cognitive testing, GP’s were able to predict the results of an on-road test in only 56% of patients, while Heikkila et al. (1999) observed that a multidisciplinary neurological team was able to evaluate driving ability reliably. Akinwuntan et al. (2002) observed that, while the predictive accuracy of their study team’s decision regarding a patient’s suitability for driving was limited (R² = 0.53), the road test’s predictive abilities were even lower (R² = 0.28). Although the road-driving test may appear to be a valid measure, the test was relatively subjective as there were no standardized methods to evaluate the test. In a follow-up study, it was demonstrated that an on-road assessment for stroke patients based on a 13-item checklist is a reliable tool with acceptable inter-rater reliability and good agreement with the results of a test conducted by a state-registered evaluator (Akinwuntan et al. 2005). In addition, the results of the off-road, Stroke Driver Screening Assessment corresponded with the outcome of the on-road evaluation in 78.9% of individuals tested (Akinwuntan et al. 2005).

Driving represents both independence and a return to life within the community. However, an evaluation of driving fitness or ability needs to be accomplished before the stroke survivor resumes driving. In a recent examination of driver assessment, Tan et al. (2011) reported that approximately half of study participants received a driving assessment (54%) while 68% of individuals returned to driving. More individuals who were assessed resumed driving than those who were not, but this difference was not statistically significant (p=0.31).
It is suggested that some combination of off road (neuropsychological assessment) and on road testing would provide the most accurate prediction of driving ability (Akinwuntan et al. 2007; Akinwuntan et al. 2002; Chua et al. 2012). Ideally, off road assessments would be used to predict readiness for on road evaluation. A number of screening procedures have been evaluated for their ability to predict driving ability in stroke survivors prior to on-road testing.

Mazer et. al. (1998) noted that a screening process is useful in identifying those stroke patients who are not ready for an on-road evaluation. In doing so, expenses and risks associated with an on-road assessment in stroke survivors can be reduced. In a recent literature review, Marshall et al. (2007) attempted to identify the most consistent predictors of driving ability following a stroke event. The authors identified a total of 11 studies for which the primary outcome was on-road assessment and an additional 6 studies examining driving cessation. Of 111 identified possible predictors, cognitive screening tests, such as the Trail Making Tests (A and B) and the Rey-Osterreith Complex figure design in particular, have been used most frequently and have been consistently predictive of driving assessment outcomes. Additional tests identified that may be of use include the Motor Free Visual Perceptions Test, the Useful Field of View test as well as tests of road knowledge (road sign and hazard recognition tests) and reaction time. The authors point out that few studies have reported the development of cut-off points with appropriate sensitivity and specificity suitable for use within a stroke population for the majority of these tests.

Akinwuntan et al. (2002) reported the results of a systematic review and meta-analysis undertaken to identify determinants of fitness to drive following stroke. Based on the data provided in 30 studies (27 of which could be included in the pooled analysis), the authors demonstrated that the Road Sign Recognition Test, Compass and Trail Making Test –B were most predictive of success in an on-road evaluation. Reported sensitivity of each test was 84% (cut-off 8.5), 85% (cut-off 25) and 80% (cut-off 90 seconds) for identification of potentially unsafe drivers using the Road Sign, Compass and Trail-Making Test, respectively. Both the Road Sign Recognition Test and the Compass Test are components of the Stroke Drivers Screening Assessment (SDSA). This study was paralleled by a recent observational study which demonstrated that those passing the Modified-Washington-University Road Test had significantly greater scores on the Trail Making Test – A and B, and did significantly better on the Snellgrove Maze Task compared to those that failed the road test (Barco et al. 2014). Similarly, those that had better useful field of view were more likely to pass the road test compared to those with poorer scores. The Trail Making Test – A and the Snellgrove Maze Task combined were found to provide the best model for predicting failure on the road test (Barco et al. 2014).

Akinwuntan et al. (2002) provided a note of caution in relying too heavily upon neuropsychological or cognitive testing alone in the prediction of driving fitness. In an additional study, completion of an on-road evaluation was associated with the completion of driving therapy prior to on-road assessment (Akinwuntan et al. 2006). In addition, type of therapy may influence the result of on-road testing. In general, provision of contextual therapy such as on-road or simulator training may be more effective than off-road, non-contextual therapy. Based on the results of 6 studies, it was found that 76% of individuals who received contextual therapy passed on-road evaluation vs. 42% who received only non-contextual therapy (Akinwuntan et al. 2002).

Conclusions Regarding Assessment of Driving Ability

Patients for whom there is concern about their ability to drive need to be identified and proper assessment and treatment initiated. Determination of ability to drive should not rely solely on neuropsychologic testing or road test evaluation. Rather, a 2-step process is recommended in which
the patient is first screened for readiness to participate in an on-road evaluation. In addition, provision of contextual driving therapy may be associated successful on-road evaluation.

Patients for whom there is concern about their ability to drive post-stroke need to be properly assessed.

19.5.2 Interventions and Driving Performance
Despite the effort applied to determining how to evaluate the driving ability of stroke survivors, relatively little attention has been paid to how one might intervene to improve the driving ability of stroke survivors. Studies examining the effectiveness of a treatment intervention on driving performance post stroke were identified below.

Table 19.5.2.1 Summary of Interventions and Driving Performance

<table>
<thead>
<tr>
<th>Author, Year Country PEDro Score</th>
<th>Methods</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| Akinwuntan et al. (2005) RCT (8) N=83 | E: Simulator based training C: Driving related cognitive tasks | • Stroke Driver Screening Assessment (-)  
• Useful Field of View (-)       |
| Akinwuntan et al. (2010) RCT (8) N=69 | E: Simulator based training C: Driving related cognitive tasks | • Useful Field of View (-)                                       |
| Devos et al. (2009) RCT (8) N=83     | E: Simulator based training C: Driving related cognitive tasks | • On-road test performance (+)     
• Anticipation and perception of road signs (+)  
• Visual behavior and communication/quality of traffic participation and turning left (+)  
• In-opperational skills (-)    
• Individual tactical items (-)               |
| Mazer et al. (2003) RCT (7) N=97     | E: Visual information processing training C: Visuoperceptual retraining with commercially available computer software | • Useful Field of View(-)  
• On-road driving test (-)  
• Visuoperception tests (-)  
• Everyday attention (-)       |
| Crotty et al. (2009) RCT (6) N=26     | E: Dynavision training intervention C: No training | • On-road assessment (-)  
• Response time (-)       
• Visual scanning (Visual Scanning Analyzer) (-)  
• Driving self-efficacy (Adelaide Driving Self-Efficacy Scale) (-) |

+ Indicates statistical significance between treatment groups  
- Indicates no statistical significance between treatment groups

Discussion
Multiple RCTs investigated the effect of different training interventions on driving performance. Three studies investigated simulator based programs versus basic driving related cognitive tasks. Results indicated that among both experimental and control groups, participants significantly improved on the
majority of study endpoints, including the on-road test. The proportion of subjects deemed “unfit to drive” pre-training who transitioned to “fit to drive” post-training was significantly greater for the experimental group. Follow-up analyses at six months post-stroke showed maintenance of these beneficial effects with 73% of study subjects allocated to the experimental group eligible to legally resume driving compared to only 42% of the control group. Beneficial effects were greatest for patients with a more diverse educational background and lower disability following stroke. These findings suggest that simulator training may enhance driving recovery post-stroke however, the authors state that an overlap of treatment with the period of spontaneous neurological recovery post-stroke and the large number of dropouts may have affected the findings of the study (Akinwuntan et al. 2005). Additionally, a control group participating in non-driving related tasks would be telling as to the true effects of simulator based training. Further analyses of this study by Devos et al. (2009) supported these positive outcomes with improved on-road test performance for the experimental group. Implementation of simulator based driving therapy into the rehabilitative program of subacute post-stroke patients with mild deficits may be beneficial for the restoration of driving performance (Devos et al. 2009).

In the largest study included in this section, patients with hemispheric stroke were assigned to a visual attention retraining program or usual visuoperception retraining. No differences were found for outcomes pertaining to on-road driving, visuoperception or attention however, a significant improvement of on-road driving ability was observed for subjects with right-sided lesions. This finding suggests the importance of targeted interventions for rehabilitation of post-stroke impairments (Mazer et al. 2003). One, small RCT found Dynavision training to ineffectively recover driving skills in post-stroke patients (Crotty & George 2009). Further research with greater power is required, specifically focussing on simulator based training as it may be most beneficial in the recuperation of skills associated with driving. While alternative interventions may not have been as effective, special attention should be given to variable treatment effects for post-stroke patients with specific lesion locations.

Conclusions Regarding Driving Ability Treatment Interventions Post-Stroke

There is level 1b evidence that a visual attention-retraining program is no more effective than traditional visuoperception retraining in improving the driving performance of patients with stroke.

There is level 1b evidence that a simulator training program involving use of appropriate adaptations and driving through complex scenarios similar to real life is associated with improvement in driving fitness and successful on road evaluation.

There is level 1b evidence that Dynavision training is not effective in improving the results of on-road assessments in individuals with stroke.

Visual attention retraining does not improve driving performance in stroke survivors more than traditional visuoperception retraining.

Driving-fitness may be improved through the use of a simulator training programs.

19.6 Returning to Work Post Stroke

A recent review identified 70 studies (N=8810) that included reports of employment status following stroke (Daniel et al. 2009). The proportion of patients returning to work ranged from 0 – 100% (mean =
44% across studies). However, only 14 of the 70 identified studies included return to work as the primary study outcome. Furthermore, only 3 of these studies examined return to work in groups of individuals who were employed pre-stroke and also used appropriate strategies for data analyses given the influence of time on the probability of return to work (Daniel et al. 2009). The reviewers suggest that the interpretation of all other studies may be difficult given variable follow-up periods and definitions of work as well as problems with possible selection biases.

In a 2002 review of studies reporting on the return to work, Wozniak and Kittner (2002) also noted that there was considerable variation in the definitions applied to “work” and “return to work” ranging from resumption of meaningful activity to the return to gainful employment on either a full or part-time basis. Given the range of “work” defined within the studies reviewed, it was not surprising that reported percentages of patients who do return to work ranged from 9 – 91%. Additionally, 23% - 92% of patients who return to work reported that adjustments, such as reduction in working hours, change in employment or restructuring of the work environment had been made to facilitate their return (Wozniak & Kittner 2002). Despite the heterogeneity of studies included in their review, Wozniak and Kittner (2002) identified neurological and functional disability as the major determinants of resumption of work post stroke.

Observational studies suggest that while many stroke survivors may be capable of working, a substantial proportion do not return to work or must alter their hours of work or place of employment to do so (Coughlan & Humphrey 1982; Vestling et al. 2003). In a large, prospective, population-based study, Busch et al. (2009) reported that a significant proportion of independent (53%) and active (39%) individuals who had been employed prior to stroke did not return to work one year following the stroke event. However, resuming employment may have a positive impact on quality of life and well-being for both the individual with well-being and his/her spouse (Gabriele & Renate 2009; Vestling et al. 2003).

A stroke patients’ return to work is dependent on factors such as age (Busch et al. 2009; Fugl-Meyer et al. 1975; Gabriele & Renate 2009; Howard et al. 1985; Maaijwee et al. 2014; Naess et al. 2004; Tanaka et al. 2014), functional ability (Black-Schaffer & Osberg 1990; Busch et al. 2009; Fugl-Meyer et al. 1975; Gabriele & Renate 2009; Glozier et al. 2008; Howard et al. 1985; Naess et al. 2004; Peters et al. 2013; Saeki & Toyonaga 2010; Hirotaka Tanaka et al. 2011; Tanaka et al. 2014; Wozniak et al. 1999), motor weakness or muscle strength (Saeki et al. 1995; Sreedharan et al. 2013; Tanaka et al. 2014; Wozniak et al. 1999), type of employment (e.g. white vs. blue collar) (Hackett et al. 2012; Howard et al. 1985; Lindstrom et al. 2009; Saeki et al. 1995; Hirotaka Tanaka et al. 2011; Vestling et al. 2003) level of education and income (Gabriele & Renate 2009; Trygged et al. 2011; Wozniak et al. 1999), and post-stroke duration (Maaijwee et al. 2014; Peters et al. 2013) such that younger, more independent individuals with better muscle strength and motor control with more education who were employed in high-paying, white-collar professions are more likely to return to work in the months and years following a stroke event. Other identified factors influencing return to work include the presence of aphasia (Black-Schaffer & Osberg 1990; Doucet et al. 2012; Tanaka et al. 2014; Wozniak et al. 1999), apraxia or other cognitive impairments (Kauranen et al. 2012; Saeki et al. 1995; H. Tanaka et al. 2014; Vestling et al. 2003), diabetes (Busch et al. 2009), fatigue (Andersen et al. 2012), or psychiatric morbidity (Glozier et al. 2008), length of stay in hospital or rehabilitation (Black-Schaffer & Osberg 1990; Glozier et al. 2008; Trygged et al. 2011) and size of employing business enterprise (Hannerz et al. 2012). Although identified as influential in several studies, the role of gender in return to work remains unclear (Busch et al. 2009; Coughlan & Humphrey 1982; Gabriele & Renate 2009; Saeki & Toyonaga 2010; Smolkin & Cohen 1974; Sreedharan et al. 2013; Trygged et al. 2011; Weisbroth et al. 1971).
In-patient stroke rehabilitation is perceived, by stroke survivors of working age as being aimed at restoring bodily function and promoting function in activities of daily living rather than supporting a return to the workplace (Medin et al. 2006). Chan (2008) reported that the majority (55%) of individuals receiving employment services from a community-based agency were successful in returning to paid employment (Chan 2008). However, these individuals tended to change type of employment from blue to white collar jobs. Reasons for poor outcome included need for further rehabilitation, failure to return for assessment and being unfit for work.

A review of the vocational rehabilitation and return to work following stroke included 6 retrospective, single cohort studies (Baldwin & Brusco 2011). Overall, reported rates of employment post vocational rehabilitation ranged from 12% and 49%. Although, in general, vocational rehabilitation appeared to be associated with increased rates of return to employment, the process of synthesis and review was complicated by the use of varying definitions of employment and of vocational rehabilitation. At present, no clinical research examining the effectiveness of post-stroke vocational rehabilitation programs to comparison or control conditions could be identified.

Clinical practice guidelines (Duncan et al. 2005) provide the following suggestions with regard to return to work post stroke, based on poor evidence derived from “opinion of respected authorities, case reports, and expert committees”:

1. Recommend that all patients, if their condition permits, be encouraged to be evaluated for the potential of returning to work.
2. Recommend that all patients who were previously employed be referred to vocational counselling for assistance in returning to work.
3. Recommend that all patients who are considering a return to work but who may have psychosocial barriers (eg. Motivation, emotional and psychological concerns) be referred for supportive services, such as vocational counselling or psychological services.

Conclusions Regarding Return to Work Post-Stroke

A substantial proportion of stroke survivors who were employed prior to the stroke event do not return to work. Factors influencing return to work include the severity of functional limitations, age and type of pre-stroke employment.

There is level 3 evidence that stroke survivors who worked prior to their stroke should, if their condition permits, be encouraged to be evaluated for their potential to return to work.

Stroke survivors who were employed prior to the stroke event should be evaluated for their potential to return to work. Vocational rehabilitation strategies to assist the return to work of stroke survivors need to be developed and evaluated.

19.7 Factors Influencing Community Reintegration

Stroke patients discharged from hospital care can face numerous challenges upon their return to the community. Oftentimes, the discharge goals of health care professionals do not align with those of the patients. Current evidence suggests that patients prioritize returning to “normality” and resuming previous roles while health care providers focus on the effects of specific interventions once discharged into the community (Wood et al. 2010). This misalignment can curtail rehabilitation outcomes and

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impede reintegration within the community. It is therefore crucial that rehabilitation specialists also target potential barriers to community reintegration prior to discharge such that patients can be better prepared to confront potential barriers within the reintegration process.

A recent qualitative meta-analysis by Walsh et al. (2015) reviewed 18 studies (Table 19.7.1), of good methodological quality to determine factors influencing community reintegration. The review identified four factors/themes that were similar across all studies: 1) primary effects of stroke, 2) personal factors, 3) social factors and 4) environmental factors.

Table 19.7.1 Studies Included in the Meta-Analysis by Walsh et al. 2015

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
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<tbody>
<tr>
<td>Wood et al. (2010)</td>
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<tr>
<td>Carlsson et al. (2009)</td>
<td>White et al. (2012a)</td>
</tr>
<tr>
<td>Alaszewski et al. (2007)</td>
<td>White et al. (2012b)</td>
</tr>
<tr>
<td>Robison et al. (2009)</td>
<td>Rittman et al. (2007)</td>
</tr>
<tr>
<td>Jones et al. (2008)</td>
<td>Dickson et al. (2008)</td>
</tr>
<tr>
<td>Ellis-Hill et al. (2009)</td>
<td>Kubina et al. (2013)</td>
</tr>
<tr>
<td>Erikson et al. (2010b)</td>
<td>Barnsley et al. (2012)</td>
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</table>

Primary effects of stroke pertain to the barriers encountered resulting from the direct physical and cognitive impairments associated with stroke (Walsh et al. 2015). Many of the studies revealed overall physical limitations such as communication deficits (Alaszewski et al. 2007), fatigue (O’Sullivan & Chard 2010; White et al. 2012b), cognitive and memory impairments (Alaszewski et al. 2007), loss of mobility and motor function, and limited capacity to perform fundamental functions (Alaszewski et al. 2007; Burton 2000; Gustafsson & Bootle 2013; O’Sullivan & Chard 2010; Rittman et al. 2007; Robison et al. 2009; Burton 2000; Carlsson et al. 2009; Dickson et al. 2008; Jones et al. 2008; Robison et al. 2009; White et al. 2012b). Completing meaningful tasks and goals such as returning to work, home, or driving where described as powerful motivators in the first year post stroke (Alaszewski et al. 2007; Burton 2000; Jones et al. 2008; Rittman et al. 2007; Robison et al. 2009; Wood et al. 2010). Stroke survivors that accept the change in their abilities and adapt to their post-stroke selves are found to better integrate within the community (Burton 2000; Carlsson et al. 2009; Dickson et al. 2008; Kubina et al. 2013; O’Sullivan & Chard 2010; Rittman et al. 2007; Robison et al. 2009; White et al. 2012b; White et al. 2012a; Wood et al. 2010). On the other hand, negative emotional factors such as loss of control, self-consciousness, reduced self-esteem and confidence (Burton 2000; Carlsson et al. 2009; Dickson et al. 2008; Gustafsson & Bootle 2013; Jones et al. 2008; Rittman et al. 2007; Robison et al. 2009; White et al. 2012b; White et al. 2012a; Wood et al. 2010), as well as overwhelming feelings of fear, anxiety, anger and frustration (Barnsley et al. 2012; Burton 2000; Carlsson et al. 2009; Jones et al. 2008; O’Sullivan & Chard 2010; Robison et al. 2009; Wood et al. 2010) were found to have the opposite effect, thus negatively impacting one’s ability to return in the community.

Social environments that foster a sense of support and belonging allow stroke patients to increase their motivation of participating in group activities (Alaszewski et al. 2007; Dickson et al. 2008; Erikson et al. 2010b; Kubina et al. 2013). Important sources of social support are family members and close friends which can provide substantial practical and emotional support (Barnsley et al. 2012; Burton 2000; Erikson et al. 2010b; Gustafsson & Bootle 2013; Kubina et al. 2013; O’Sullivan & Chard 2010; Rittman et
al. 2007; Robison et al. 2009). However, stroke patients can also experience feelings of dependency from family members which have a negative effect on the patients’ wellbeing and can cause stress (Wood et al. 2010) and tension in relationships (Dickson et al. 2008).

Other factors that can negatively impact community reintegration relate to a lack of accessibility and limited access to various community centres due to environmental constraints (Gustafsson & Bootle 2013; Rittman et al. 2007). Patients have reported environmental barriers from unsafe sidewalks to a lack of accessible entrances that prevent them from leaving their homes. Such constraints become even more apparent for individuals living in rural communities where the nearest accessible centres are located at a significant distance. Transportation challenges can also isolate stroke survivors and thus impede the process of reintegration. Not surprisingly, driving was reported to be the most important facilitator of community reintegration and accessibility (Barnsley et al. 2012; O'Sullivan & Chard 2010; Rittman et al. 2007; Robison et al. 2009; Rochette et al. 2007; White et al. 2012a; Wood et al. 2010).

Lastly, it is important for health care professionals to provide a positive and supportive rehabilitation experience early during the process in order for patients to obtain or sustain a sense of confidence in their rehabilitation progress and to be motivated to achieve various personal goals (Carlsson et al. 2009; Ellis-Hill et al. 2009; Jones et al. 2008; Robison et al. 2009). White et al. (2012a) found that participants who were provided with clear information regarding the tasks needed to achieve a certain goal were “empowered” to follow the necessary steps to resume their previous activities and to adapt to their post-stroke abilities (White et al. 2012a).

Conclusions Regarding Factors Influencing Community Reintegration

The physical limitations of stroke have a direct impact on the patient’s ability to reintegrated back into the community. Accepting and adapting to a post-stroke status can mitigate the negative effects that come as a result of stroke.

The individual characteristics of stroke patients such as optimism, determination, competitiveness, resilience and initiative can facilitate community reintegration.

Emotional and social support from family, friends and professionals plays a crucial role in reintegration success.

Physical barriers and the lack of environmental accessibility limit one’s ability to return in the community.

Stroke survivors face a number of challenges during the process of reintegration in the community. Negative factors such as lack of accessibility, low emotional state, and lack of support from family and friends, restrict reintegration success. Providing support emotionally and physically prepares patients to face various reintegration challenges with greater ease.

19.8 Cochrane Reviews of Community Reintegration Strategies Post Stroke

There are two current Cochrane reviews pertaining to strategies for reintegration back into the community following a stroke. These two reviews both examine the role of the informal caregiver in this stage of the stroke recovery process. The caregiver has a large role in this aspect of recovery and, as such, an emphasis is placed on both their ability to continue assisting the stroke survivor to further
improve and return to their previous life and social role, as well as to maintain the overall health and well-being of the caregivers themselves. These two reviews are summarized in Table 19.8.1.

Table 19.8.1 Summary of Cochrane Reviews Community Reintegration strategies following stroke

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Country</th>
<th>Description</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legg et al. (2011) UK</td>
<td>Randomized controlled trials examining non-pharmacological interventions for informal caregivers of stroke patients (compared with no or routine care) were included in the review. Only studies for which caregivers were the primary target of the intervention were included.</td>
<td>8 studies met the inclusion criteria and were included in the review.</td>
<td>Only one study demonstrated reduced caregiver stress and strain (MD=-8.67, 95% CI: -11.3 to -6.04, p&lt;0.001), depression (MD=-0.61, 95% CI: -0.85 to -0.37, p&lt;0.001), and health related quality of life (MD=-11.97, 95% CI: -15.59 to -8.35, p&lt;0.001) in participants undergoing a ‘Teaching Procedural Knowledge’ intervention (MD=-8.67, 95% CI: -11.3 to -6.04, p&lt;0.001).</td>
</tr>
<tr>
<td>Forster et al. (2012) UK</td>
<td>RCTs comparing an information or education intervention (with or without additional therapy) with standard care (or therapy alone) were included in this review. Studies included interventions aimed at stroke patients, their caregivers, or both.</td>
<td>21 trials met the criteria for inclusion.</td>
<td>Intervention groups demonstrated a significant increase in patient and carer knowledge (SMD 0.29, 95% CI: 0.12 to 0.46, p&lt;0.001 and SMD 0.74, 95% CI: 0.06 to 1.43, p=0.03). No significant differences between intervention and control groups were noted in measures of anxiety, hope, or hopelessness. Decreased depressive symptoms were observed in favour of patient intervention groups when measured on a continuous scale (MD -0.52, 95% CI: -0.93 to -0.1, p=0.01). Significant differences in depressive symptoms were also noted in subgroup analysis when examining differences between active and passive information delivery methods. No significant differences were observed between intervention and control groups on measures of ADL, participation, social activities, service use, or satisfaction</td>
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</table>

The results of these two reviews have demonstrated that there may be some value in providing interventions for carers of stroke survivors both to help ensure their continued health and well-being, as well as to encourage and facilitate re-integration of the stroke patients themselves back into the community. In particular, knowledge and education interventions appear to have some effect in reducing stress and increasing knowledge in these individuals.
Summary

1. Rehabilitation programs that focus on the transition from hospital to homes are highly valued by the patients and caregivers; however, many stroke survivors still expressed social barriers that negatively impact the reintegration within the community and in their homes.

2. Factors such as admission FIM (motor and cognitive), age, and marital status were found to be significantly associated with discharge destination.

3. High levels of social support may facilitate improved functional gains, mood, and social interactions.

4. Moderate amounts of instrumental support and high amounts of emotional support may appear to be most beneficial to stroke patients.

5. The presence and size of social support networks as well as the perceived effectiveness of social support networks have a positive influence on physical recovery, psychological distress and quality of life post stroke.

6. Higher levels of support are associated with greater functional gains, less depression and improved mood and social interaction.

7. The size and perceived effectiveness of social support networks are important predictors of discharge destination.

8. Having a pet was found to facilitate physical, psychological and social recovery after a stroke.

9. There is level 1a evidence that social work interventions providing counselling along with information and education for stroke patients and their families may not be associated with improvements on measures of independence or social activity.

10. There is level 1b and limited level 2 evidence that a specialized social support intervention that includes the stroke patient’s social support network may not be effective in improving perceived social support or functional recovery. Subgroup analyses suggest that there may be some benefit in terms of physical performance and instrumental activities of daily living for healthier, non-frail stroke survivors.

11. There is level 1b evidence that early attendance (within 6 months of stroke) at a day service is associated with improved participation in leisure activities.

12. There is level 1a evidence that home-based support and care management interventions are not associated with improved social activity, mood, quality of life or physical independence. However, there is level 1b evidence that participation in a social worker led program of care coordination featuring frequent, regularly-scheduled contact may result in improved mental health.

13. There is level 1a evidence that involvement with a stroke liaison worker or case manager is associated with increased knowledge about stroke and satisfaction with services.

14. There is level 1a evidence that social support interventions may be associated with a reduction in caregiver burden or strain.
15. There is inconclusive level 1b evidence regarding the efficacy of occupational therapist led home-visits on mental health and hospital readmission.

16. There is level 1a evidence that active case management may result in improved social activity and mood however, it may not be more effective than the comparator control treatment. Further study is required.

17. There is limited level 2 evidence that individualised, caregiver-oriented discharge planning may improve both preparedness and quality of care.

18. There is limited and inconclusive level 2 evidence regarding the effect of caregiver training programs on the patients’ and caregivers’ well-being.

19. There is limited level 2 evidence that community-based nurse-led education programs for patients may improve stroke knowledge.

20. There is limited and inconclusive level 2 evidence regarding the effect of providing re-integration guidelines to patients.

21. There is limited level 1b evidence that community walking programs are more efficient than usual care at improving walking performance and the impact of stroke on the patient.

22. There is level 1b evidence that self-management programs are not superior to usual care for improving quality of life of patients with stroke.

23. Commonly identified effects of caregiving on the caregiver include increasing psychological distress, increased financial burden, decreased social contact and activity, increased risk for depression, increased carer stress, strain or burden and an overall decrease in quality of life.

24. Decreased social contact and activity in itself may contribute to increased carer strain, increased risk of depression and decreased life satisfaction.

25. Reports concerning the influence of patient characteristics vary with the effect in question. However, age, severity of stroke and stroke-related impairments, functional status and cognitive status have been reported as influencing caregiver outcomes.

26. Positive consequences of caregiving include improved appreciation of life, feeling needed or appreciated and development of a more positive outlook. Maintaining a positive attitude has been identified as an important coping strategy.

27. Support provided by caregiving peers may have a positive effect on the caregiver.

28. There is level 1b evidence that participation in an online program providing information and support through contact with both a nurse and other caregivers has no impact on depression or life satisfaction. However, access to web-based information may be associated with reductions in healthcare utilization.

29. There is level 1a evidence that group-based programs and support may improve stroke-related knowledge and family structure however, it may not have an impact on psychological health.
30. There is level 1b evidence that interactive educational resources and professional support accessed via online chat sessions, message boards and educational videos may reduce depression in caregivers but has no impact on mastery or self-esteem.

31. There is level 1b evidence that a caregiver-mediated home-based program may improve the physical impairments of stroke patients.

32. Perceived family dysfunction is common post stroke. However, family function affects treatment adherence, performance of ADLs and social activity. Stroke patients do better with well-functioning families. Effective communication, good problem solving or adaptive coping, and strong emotional interest in each other characterize well-functioning families.

33. There is level 1a evidence from a meta-analysis that psychoeducational interventions have no significant effect on the burden or health of caregivers but may benefit family functioning.

34. There is level 1a evidence of a positive benefit, associated with the provision of information and education through a variety of intervention types. Education sessions may have a greater effect on outcome than the provision of information materials alone.

35. There is level 1a evidence that skills training is associated with a reduction in depression.

36. There is level 1b evidence that a problem-solving intervention for caregivers is associated with a reduction in depression, life changes, and health. These benefits may not be maintained beyond 6 months.

37. There is level 1b evidence that training in basic nursing skills improves outcomes of depression, anxiety and quality of life for both the caregiver and the stroke patient.

38. Although the receipt of information is of great importance to stroke patients and their families/caregivers, relatively few receive adequate information about topics they perceive to be important. Caregivers rarely receive adequate training in skills they require to care for the stroke survivor.

39. Healthcare professionals involved in stroke care may acknowledge the importance of education for patients and carers; however, relatively few provide adequate information based upon the information needs of the recipients. In addition, written materials should be suited to the educational/reading level of the intended recipient.

40. Deterioration in social and leisure activities is common post-stroke and is greatest in women, the young and those who are better educated. Perceptions about how others view their disabilities and perceptions about how they will be able to cope post-stroke may influence the degree of social isolation experienced.

41. When considered individually, there appears to be conflicting evidence as to the benefit of leisure therapy post-stroke and following discharge. However, based on the information from a meta-analysis using pooled data from the same RCTs, there is level 1a evidence that leisure therapy is associated with modest improvement in leisure activity.
42. There is level 1b evidence that participation in a leisure education program focused on awareness and competency development is associated with improvement in number and duration of activities and reduction in depressive symptoms.

43. There is level 1a evidence that participation in group education and exercise programs result in improved physical outcomes, but not social/leisure participation outcomes.

44. A decrease in sexual activity is very common post-stroke. There is general agreement that sexual drive is still present and the main barriers to sexual activity are physical impairments and psychological factors, in particular a changed body image and lack of communication.

45. Inappropriate sexual behaviour following stroke is not well studied. There may be an association between inappropriate sexual behaviour and the presence of right frontal lobe stroke and cognitive impairment.

46. There is level 3 evidence that sexual issues should be discussed during rehabilitation and addressed again after transition to the community when the stroke survivor and significant other are ready.

47. Patients for whom there is concern about their ability to drive need to be identified and proper assessment and treatment initiated. Determination of ability to drive should not rely solely on neuropsychologic testing or road test evaluation. Rather, a 2-step process is recommended in which the patient is first screened for readiness to participate in an on-road evaluation. In addition, provision of contextual driving therapy may be associated successful on-road evaluation.

48. There is level 1b evidence that a visual attention-retraining program is no more effective than traditional visuoperception retraining in improving the driving performance of patients with stroke.

49. There is level 1b evidence that a simulator training program involving use of appropriate adaptations and driving through complex scenarios similar to real life is associated with improvement in driving fitness and successful on-road evaluation.

50. There is level 1b evidence that Dynavision training is not effective in improving the results of on-road assessments in individuals with stroke.

51. A substantial proportion of stroke survivors who were employed prior to the stroke event do not return to work. Factors influencing return to work include the severity of functional limitations, age and type of pre-stroke employment.

52. There is level 3 evidence that stroke survivors who worked prior to their stroke should, if their condition permits, be encouraged to be evaluated for their potential to return to work.

53. The physical limitations of stroke have a direct impact on the patient’s ability to reintegrated back into the community. Accepting and adapting to a post-stroke status can mitigate the negative effects that come as a result of stroke.

54. The individual characteristics of stroke patients such as optimism, determination, competitiveness, resilience and initiative can facilitate community reintegration.
55. *Emotional and social support from family, friends and professionals plays a crucial role in reintegration success.*

56. *Physical barriers and the lack of environmental accessibility limit one’s ability to return in the community.*
References


Appendix

Acute Stroke
1. There is level 1b evidence that psychological interventions with a mental health worker improve depressive symptoms and cognitive function, but may not improve functional recovery.

2. There is level 1a and level 2 evidence that post-discharge homes visits do not improve motor functioning, quality of life, activities of daily living or caregiver burden, but may improve caregiver mood.

3. There is level 2 evidence that home based active care management improves activities of daily living, but not social activity, quality of life or psychosocial functioning.

4. There is level 1a evidence that stroke information programs do not improve stroke knowledge, depression, anxiety, quality of life or activities of daily living, however; they may improve caregiver mental health.

5. There is level 1a evidence that stroke patients are satisfied with the information encompassed within stroke programs; however, the evidence on self-efficacy is conflicting.

Subacute Stroke
1. There is level 1a evidence that structured home visits do not improve social activities, activities of daily living or perceived well-being.

2. There is level 2 evidence that stroke education programs do not improve quality of life, or overall health.

3. There is conflicting level 1a evidence regarding the effectiveness of simulator training program on driving fitness and driving evaluations.

4. There is level 1b evidence that a visual attention-retraining program is not more effective than traditional visuoperception retraining in improving the driving performance of patients with stroke.

5. There is level 1b evidence that Dynavision training does not improve on-road assessments in individuals with stroke.

Chronic Stroke
1. There is level 1b and level 2 evidence that social work interventions providing counselling along with information and education for stroke patients and their families do not improve functional independence or social activity.

2. There is level 2 evidence that a specialized social support intervention does not improve depression, anxiety or social impairment.

3. There is level 2 evidence that home based active care management does not improve activities of daily living or depression symptoms.

4. There is level 2 evidence that stroke education programs improve knowledge of warning signs, risk factors, diet, and social participation, but not self-efficacy.

5. There is level 1b evidence that caregiver home-based training improves gait, balance and activities of daily living, but not caregiver burden.

6. There is level 1b evidence that self-help support groups improve family relationships.
7. There is level 1b and level 2 evidence that stroke education programs do not improve quality of life, mood or stress, but may improve depression. The evidence on caregiver burden is conflicting.

8. There is level 1b evidence that group exercise and education improves physical function, but not activities of daily living or patient and caregiver quality of life.