

# F. Psychosocial Issues Educational Supplement

Andrew McClure, Robert Teasell MD FRCPC, Katherine Salter

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**F1. Post-Stroke Depression**

## **F1.1 Depression: General Information**

## F1.1 Depression: General Information

### F1.1.1 Depression: General Information

**Q1. Give three possible explanations why post-stroke depression is common.**

**Answer**

1. *Coincidental*: The risk factors for stroke are similar to the risk factors for depression.
2. *Reactive*: Due to the physical losses incurred following a stroke.
3. *Neurological*: Neurotransmitter imbalance caused by the stroke itself.

**Discussion**

A variety of emotional and behavioural disorders may develop following cerebrovascular lesions. The DSM-IV categorizes post-stroke depression as a “*mood disorder due to general medical conditions*” with the specifiers of: (a) depressive features; (b) major depressive-like episodes; (c) manic features; or (d) mixed features. The two types of depressive disorders most associated with stroke are major depression and minor depression, the latter of which has been defined for research purposes by the DSM-IV criteria as a “*depressed mood or loss of interest and at least 2 but fewer than 4 symptoms of major depression.*”

Depression is often observed in patients with severe physical illnesses. While the endogenous features of depression are present in these patients, the interpretations of vegetative signs are not clear. There appears to be less emphasis on feelings of low self-esteem, guilt and self-blame when depression accompanies physical illness while hypochondrial concerns, lethargy, and behaviour disturbances are most characteristic (Morris et al. 1987). Three possible explanations for the association between physical illness and depression have been sought. First, and least likely is a coincidental or even a causal relationship. It is possible that those risk factors which lead to the development of a stroke (i.e., hypertension, smoking, poor dietary habits, etc.) are also associated with development of a stroke. The second is a negative mood reaction to the physical consequences of the stroke. The impact of the physical illness may wield its effect through the losses it causes to the individual as a major negative life event (losses to self-esteem, independence, employment, etc.). This has elements of a grief reaction. The third possible explanation is a neurotransmitter imbalance as a result of cerebral damage caused by the stroke. Although this latter theory gained some popularity two decades ago with the reporting of increased incidence of depression in left frontal strokes, more recent research has not been able to substantiate this finding (see section F1.3)

### F1.1.2 Prevalence and Natural History of Post-Stroke Depression

**Q2. How common is depression following a stroke?**

**Answer**

1. Depression is common following stroke.

2. Incidence is about 20% of acute and subacute strokes and prevalence ranges from 30-40% of stroke patients, with a greater number having minor depression.

### **Discussion**

Depression is a well-documented sequela of stroke. Based on pooled data from published prevalence studies (Robinson 2003 -- Table 18.1), the mean prevalence of depression among in-patients in acute or rehabilitation settings was 19.3% and 18.5% for major and minor depression respectively while, among individuals in community settings, mean prevalence for major and minor depression was reported to be 14.1% and 9.1%. Among patients included in outpatient studies, mean reported prevalence was 23.3% for major depression and 15% for minor depression (Robinson 2003). Overall mean prevalence ranged from 31.8% in the community studies to 35.5% in the acute and rehabilitation hospital studies. A recent systematic review of prospective, observational studies of post-stroke depression (Hackett et al. 2005) reported that 33% of stroke survivors exhibit depressive symptoms at some time following stroke (acute, medium-term or long-term follow-up). This pooled estimate was based on data collected from 51 studies in population, hospital and rehabilitation based settings. The authors stated that this is likely to be an underestimation of the frequency with which post-stroke depression occurs. Errors in estimation may be attributed to under-reporting of unusual mood, difficulties in the assessment of depression in neurologically impaired individuals and variability in the methods used to assess and define depression or "caseness" within the literature (Hackett et al. 2005).

In a recent, large, case-control study, Linden et al. (2007) reportedly identified depression in 34% of patients (n=149) one year post stroke compared to 13% of sex and age-matched controls (n=745). All types of depressive disorders, both major and minor, were more frequent among individuals with stroke. Major depressive disorders were most frequent among individuals with stroke who were more than 80 years of age (Linden et al. 2007). Whyte et al. (2004) reported that the risk for depression among individuals aged 65 or over, living in the community and who have experienced a stroke 2 years previously, is 6 times greater than for their stroke-free counterparts.

Estimates of prevalence may be affected by the time from stroke onset until assessment. Patients who are assessed during the subacute phase may be in a period of transition during which they are attempting to adjust to the consequences of stroke. Depression at this time may simply be a reflection of the difficulties associated with this transition. In fact, the highest rates of incident depression have been reported in the first month following stroke (Andersen et al. 1995, Aben et al. 2003, Bhogal et al. 2004, Morrison et al. 2005, Aben et al. 2006). Aben et al. (2003) found that 21.6% of patients were depressed when assessed within the first month of stroke. The proportion of incident cases decreased to 5.1%, 6.0%, 5.6% and 7.1% at 3, 6, 9 and 12 month assessments, respectively. Paolucci et al. (2005) reported that, of 1064 patients included in the DESTRO study, 36% developed depression. Eighty percent of these became depressed within the first three months of the stroke event (Paolucci et al. 2005). In that study, dysthymia (mild depression) was the most common form of depression, occurring in 80.7% of the cases. Major depression was diagnosed in only 2.9% of the cases.

While the incidence of major depression post-stroke may decrease over the first 24 months following stroke (Astrom et al. 1993, Verdelho et al. 2004), minor depression tends to persist or increase over the same time period (Burvill et al. 1995; Berg et al. 2003, Verdelho et al. 2004).

In a recent study, approximately one-half of individuals identified as experiencing depression during the acute phase post stroke, continued to experience depression at 18 months; however, more women than men were identified in the acute phase while more men than women were identified as depressed at 18 months post stroke (Berg et al. 2003).

### **F1.1.3 Stroke Location and Depression**

**Q3. Describe the relationship between post-stroke depression and the location of the stroke in the brain.**

#### **Answers**

1. Initially it was thought that left hemispheric stroke patients, particularly those with more frontal lesions, were more susceptible to depression.
2. There was speculation that this may have been related to loss of catecholamine pathways more prominent in the frontal left hemisphere.
3. More recently it has been recognized that left hemispheric stroke patients are more likely to become depressed early after a stroke (i.e. during the rehabilitation phase) while right hemispheric stroke patients are more likely to become depressed later on in the course of the stroke.
4. At present there is significant doubt that depression is more predominant in left versus right hemispheric stroke patients. There remains a wide diversity of finding in studies looking at the relationships between stroke location and depression. Not all studies have confirmed this relationship and recent meta-analyses have failed to establish a definitive relationship between the site of the brain lesion and depression.

#### **Discussion**

The association between the brain lesion as a result of stroke and post-stroke depression has been the topic of much research. While it has been suggested that lesion location may account for up to 50% of the variance in the development of PSD (Robinson 1986), the complex association between lesion location and the susceptibility to post-stroke depression is not well understood (Ghika-Schmid and Bogousslavsky 1997). There have been 2 meta-analyses examining this relationship (Singh et al. 1998, Carson et al. 2000)

**Singh et al. (1998)** conducted a critical appraisal on the importance of lesion location in post-stroke depression. The authors systematically selected 26 original articles that examined lesion location and post-stroke depression. Thirteen of the 26 articles satisfied inclusion criterion. Six of those studies found no significant difference in depression between right and left hemisphere lesions. Two studies found that right-sided lesions were more likely to be associated with depression and 4 studies found that left-sided lesions were more likely to be associated with post-stroke depression. Only one study matched patients with and without depression for lesion location and size to identify non-lesion risk factors. The authors noted that all of the studies reviewed were methodologically flawed. None of the studies were comparable with respect to sample, timing and analysis of CT scan and psychiatric evaluation. Consequently, Singh et al. (1998) were unable to make any definitive conclusions concerning stroke lesion location and the risk for depression.

**Carson et al. (2000)** undertook a systematic review examining the association between post-stroke depression and lesion location. All reports on the association of post-stroke depression with location of brain lesions were included in the review. In total 48 reports were included for review. The authors of the review identified 38 reports that found no significant difference in risk of depression between lesion sites; 2 reported an increased risk of post-stroke depression with left-sided lesions; 7 reported increased risk with right-sided lesions; and one report demonstrated an association between depression and lesions in the right parietal region or the left frontal region. However, 4 studies were observed to be from the same samples of patients and were treated as one report. Thus 35 reports were analyzed.

When data from all reports were pooled, lesion location was not associated with depression. The null effect remained regardless of whether a fixed-effect model (0.95, 95% CI 0.83-1.03) or a random-effect model (0.95, 95% CI 0.83-1.10) had been used. Based on the results generated by their systematic review, the authors concluded that the risk of post-stroke depression was not affected by location of the brain lesion.

Carson et al. (2000) identified several sources of bias that may have led to the different results of the individual studies. The main source of bias appears to be the heterogeneity of study patients. There was evidence to suggest that patients selected from the community, but not those selected from hospitals or rehabilitation units, experience an increased risk of depression with right-sided lesions. The exclusion of aphasic patients that usually occurs in reports that follow patients from hospitals and rehabilitation units may have accounted for this finding. Furthermore, differences among individual studies were most apparent when carried out in the first 28 days of stroke; these were studies most often conducted in inpatient units.

Based on the results of a meta-analysis conducted by Bhogal et al. (2004), there appears to be some evidence that depression following stroke may be related to the anatomical site of brain damage, although the nature of this anatomic relationship is not completely clear (Bhogal et al. 2004; Figure 18.1). The John Hopkins Group (Robinson & Szetela 1981, Robinson & Price 1982, Robinson et al. 1983, 1984, 1986, 1987) carried out a series of studies exploring the relationship of post-stroke depression to the location of the lesion within the brain itself. They found that in a selected group of stroke patients, similar to those admitted to a stroke rehabilitation unit, depression appeared to be more frequent in patients with left hemispheric lesions (Robinson & Szetela 1981, Robinson & Price 1982, Robinson 1986, Robinson et al 1987).

Among these patients, the severity of depression correlated inversely with the distance of the lesion from the frontal poles (Robinson & Szetela 1981, Robinson & Price 1982, Robinson et al. 1983, 1984, 1986, 1987, Starkstein et al. 1987). Patients with subcortical, cerebellar or brainstem lesions had much shorter-lasting depressions than patients with cortical lesions (Starkstein et al. 1987, 1988).

The correlation of major depression to the proximity of the lesion to the frontal pole has been confirmed by Sinyor et al. (1986) and Eastwood (1989). Right hemispheric lesions failed to demonstrate a similar relationship with depression. Interestingly, in one study, patients who had both an anxiety disorder and a major depression showed a significantly higher frequency of cortical lesions, while patients with major depression only had a significantly higher frequency of subcortical (basal ganglia) stroke (Starkstein et al. 1987).

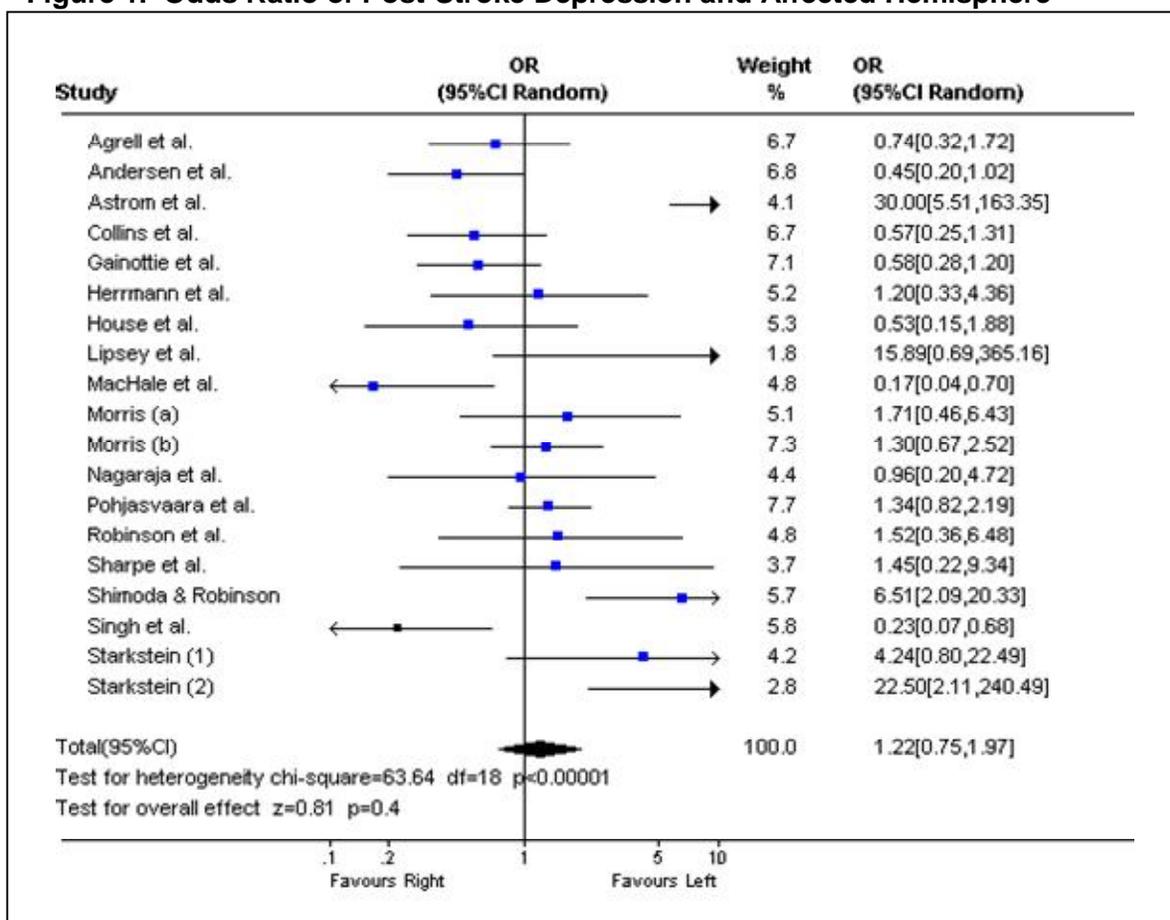
It has been speculated that the role of the brain lesion in the development of post-stroke depression is mediated by the depletion of catecholamines believed to play a major role in the

etiology of depression (Robinson et al. 1986). It has been suggested that when cerebral catecholaminergic neurons are injured, they markedly reduce neurotransmitter production during the regenerative process causing a decline in neurotransmitter availability, not only in the injured area, but also throughout the cerebrum.

The region close to the frontal pole has been reported to have the greatest concentration of catecholaminergic fibres. This was thought to correspond to the observation that injuries to the frontal region of the cortex produce the greatest vulnerability to post-stroke mood disorder. Sinyor et al. (1986), Eastwood et al. (1989) and Ebrahim et al. (1987) were unable to replicate the interhemispheric differences found by the John Hopkins' group. Robinson et al. (1983) failed to confirm their previously established interhemispheric differences when looking at a larger number of patients. Folstein et al. (1977) found that patients with right-sided lesions were more likely to suffer psychological symptoms of irritability, loss of interest, difficulty in concentrating, subjective memory loss and depressed mood when compared to controls or patients with left hemispheric lesions. Most recently, Aben et al. 2006, attempted to replicate the finding that left-sided strokes and/or anterior strokes are associated with an increased risk for PSD. The findings could support neither this hypothesis nor the hypothesis that post-stroke depression results from generalized vascular damage (Aben et al. 2006). Finally, the two large systematic reviews by Singh et al. (1998) and Carson et al. (2000) referred to previously, failed to find a relationship between the stroke lesion site and depression. As important as the contribution of Robinson and his group is to our understanding of post-stroke depression, there are potential weaknesses in their research in part related to selection biases in the patient population, which might account for why their findings have not been consistently replicated. These weaknesses were outlined by Malec et al. (1990) and Ebrahim (1990).

The site and size of the brain lesion in stroke does not appear to be strongly correlated with depression although the data is not consistent and it continues to be difficult to determine whether positive findings can be accounted for by the clinical consequences of the stroke or the neurophysiological changes that may lead to depression. Recent reports have suggested that psychosocial risk factors including age, sex and functional impairment or previous history of psychiatric disturbance are greater contributors to the development of PSD than lesion location (Singh et al. 2000, Berg et al. 2003, Carota et al. 2005, Aben et al. 2006).

Figure 1. Odds Ratio of Post-Stroke Depression and Affected Hemisphere



#### F1.4 Assessment of Post-Stroke Depression

##### **Q4. How well is depression diagnosed after a stroke?**

##### **Answer**

1. Detection and diagnosis of post-stroke depression is often inconsistent.
2. Compliance with guidelines for screening of depression is poor.
3. Identified barriers to routine screening include time pressures and concerns about screening tools.

##### **Discussion**

The detection of depression is not always consistent. Given the fluctuation in the incidence of depression post stroke, timing of assessment may be an important factor in screening and diagnosis, particularly during the initial post-stroke transition phase. Apart from timing, the standards against which depression is assessed are also important. At present, the criteria provided by the DSM-IV are the gold standard against which diagnosis is made and form the basis for the evaluation of assessment tools.

According to the DSM-IV-TR, both major and minor depression may be distinguished from a “Mood Disorder due to a General Medical Condition” when the mood disturbance is judged to be a direct consequence of a medical condition such as stroke. Major and minor depression following stroke, or PSD, may be classified as Mood Disorder due to Stroke with major-depressive-like episode or with depressive features, respectively (Salter et al. 2007). The primary concern with the use of the DSM in the diagnosis and assessment of post-stroke depression is that the diagnostic criteria provided includes vegetative symptoms of depression such as psychomotor retardation, fatigue, sleep and appetite disturbances, which, in themselves, may be a consequence of the stroke event. Gainotti et al. (1997) reported distinct differences between functional depression and post-stroke depression and demonstrated that the motivated or reactive aspects of depression are more prevalent in PSD. However, it has also been suggested that the DSM criteria for depression are equally valid among psychiatric and stroke patients. For example, Spalletta et al. (2005) reported that vegetative symptoms appearing in the DSM-IV were as discriminative of the presence of major and minor depression in a group of stroke patients as the psychological and cognitive criteria. The authors recommended, therefore, that all symptoms be considered regardless of source.

Schubert et al. (1992) carried out a chart review of 15 stroke patients on a medical ward. Charts were examined for detection of depression by the rehabilitation team. Chart evaluation revealed no notation of depression or mention of possible depressed mood by the rehabilitation team. However, when psychiatric charts were reviewed, 68% of patients were diagnosed with some psychiatric diagnosis: 26% with major depression and 42% with adjustment disorder with depressed mood. Assessment by the Beck Depression Inventory identified 50% of the patients as mildly depressed; again, this was a higher rate than that detected by the rehabilitation team. However, Lincoln et al. (2003) noted that there was poor agreement between psychiatric diagnosis and self-report questionnaires. It has been reported that, in terms of screening or classifying patients on the basis of depressive symptomatology, rating scales are quite sensitive, but lack specificity (Lincoln et al. 2003, Schramke et al. 1998, Aben et al. 2002), perhaps due to the inclusion of somatic symptoms.

Dam et al. (1989) suggested that discrepancies in diagnosis between psychiatric interviews and self-report scales could be explained by an indifference to symptoms, typical in patients with right-hemisphere stroke, which would be more pronounced when relying on self-report to assess depression. However, Schramke et al. (1998) reported that patients with left hemisphere lesions were assessed as experiencing greater levels of distress than patients with right hemisphere lesions on the Center for Epidemiologic Studies Depression Scale (CES-D) and the Hamilton Rating Scale for Depression (HRSD). However, this difference between groups reached significance only on assessments made with the CES-D, a self-report measure (Schramke et al. 1998). Self-report measures rely on the assumption that the individuals being evaluated are sufficiently self-aware to provide an accurate self-assessment and report. As Lincoln et al. (2003) pointed out, this is not necessarily true of individuals who have experienced a stroke, who may either minimize or exaggerate changes.

Although, screening for post-stroke depression is included among the recommendations appearing in current guidelines, reported compliance is low. The UK National Clinical Guidelines for Stroke recommend screening for depression within the first month of a stroke event; however, the National Sentinel Audit (Bowen et al. 2005) for the years 2001 – 2002 revealed a compliance rate of only 50%. When hospitals with psychologist input were examined separately, the rate of compliance was 60%. A recent study examined reasons for non-compliance (Hart and Morris 2008). Based on survey responses received from 75 healthcare

professionals affiliated with 16 stroke units in the UK, the authors found that while compliance for screening was low, attitudes toward the practice were positive. While nurses most often performed the screening, neither the profession of the individual responsible for this task nor the availability of psychologist input had an effect on compliance. Identified barriers to screening included time pressures and concerns about screening tests, while being knowledgeable about screening, having screening in the job role and belief in the value of screening were identified as facilitators (Hart and Morris 2008).

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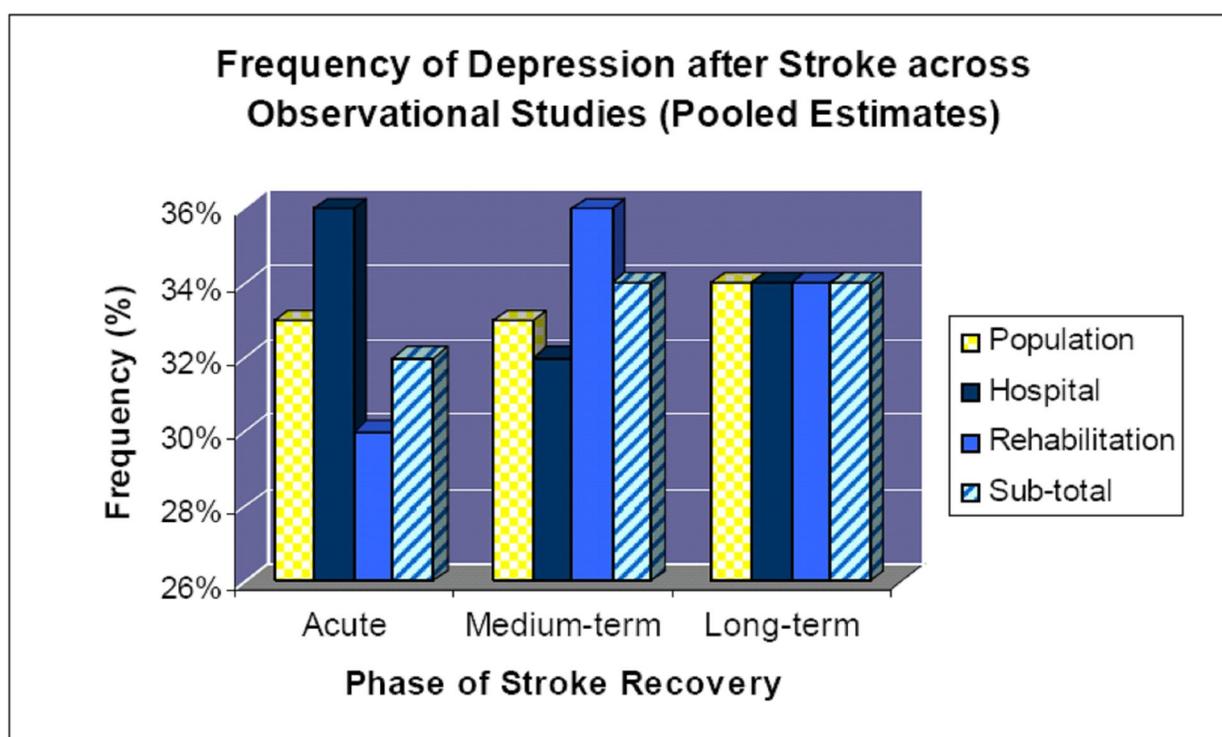
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## Key Studies: Prevalence of Post-Stroke Depression

Hackett ML, Yapa C, Parag V, Anderson CS. Frequency of depression after stroke: a systematic review of observational studies. *Stroke* 2005;36:1330-1340.

Author / Year Country PEDro score	Methods	Outcome
Hackett et al. 2005 Worldwide No Score	A systematic review of observational studies to determine estimates of the frequency of depressive symptoms after stroke. Searched for candidate articles published between 1977 and 2002.	Fifty-one studies met the eligibility criteria and yielded a pooled estimate of 33% for depression among stroke survivors.



**Importance:** Based on data collected from 51 observational studies in community, hospital and rehabilitation-based settings, the authors reported an estimated 33% of stroke survivors exhibit depressive symptoms at some time following stroke (i.e. acute, medium term or long-term follow-up). Post-stroke depression may have a negative impact on functional recovery and social activity and has also been associated with cognitive impairment and increased mortality.

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**F1.2 Impairment and Depression Post-Stroke**

## F1.2 Impairment and Depression Post-Stroke

### F1.2.1 Functional Impairment and Depression Post-Stroke

**Q1. Describe the relationship between functional ability and depression.**

**Answer**

1. Depression is associated with lower functional ability and in turn can have a negative impact on functional recovery.
2. The co-occurrence of stroke and depression is associated with greater physical limitations than either condition on its own.
3. Physical impairment and post-stroke depression appear to act upon each other, and each influences the recovery of the other.
4. Identification and treatment of depression in the early phases may serve to enhance further functional recovery.

**Discussion**

Depression post stroke is associated with functional ability and may have a negative impact on recovery. Although patients with post-stroke depression may experience significant recovery, functional ability will remain at a lower level than non-depressed patients, despite rehabilitation interventions. Goodwin and Devanand (2008) demonstrated that co-occurrence of stroke and depression is associated with greater physical limitations than either condition on its own. Physical impairment and post-stroke depression appear to act upon each other, and each influences the recovery of the other.

Van de Port et al. (2006) recently published the results of a prospective cohort study (n=205), which demonstrated that mobility decline was experienced by 21% of participants between 1 and 3 years post stroke. Significant predictors of this decline in mobility status were level of activity, cognitive problems, fatigue and depression. Given that the relationship between depression and physical impairment may be reciprocal, depression may contribute to a progressive deterioration in mobility, which may in turn contribute to increased feelings of depression.

Since depression is a treatable condition, which impacts both function and functional recovery, it should be taken into account in the evaluation and treatment of all stroke patients (Ramasubbu et al. 1998). As Ramasubbu et al. (1998) pointed out, early recognition and treatment of depression may “optimize rehabilitation potential” and reduce “significant human and financial costs associated with post-stroke functional impairment”.

### F1.2.2 Cognitive Impairment and Depression Post-Stroke

**Q2. What is the impact of post-stroke depression on cognitive impairment?**

**Answer**

1. Post-stroke depression appears to have a negative impact on cognition; however, the relationship between post-stroke depression and cognition appears to be poorly understood.

### **Discussion**

Overall, there appears to be a relationship between cognitive impairment and the presence of depression, although the reported results vary and the relationship appears complex. Spalletta et al. (2002) reported a strong relationship between cognitive impairment and post-stroke depression, but only for patients with left-sided lesions. Among that subgroup of patients, the presence of depression was found to be a significant predictor of cognitive impairment and vice versa. Verdelho et al. (2004) reported a transient relationship with varying time courses associated with specific depressive symptoms. More recently, both Barnes et al. (2006) and Saxena et al. (2008) reported an association between the presence of depression and the development of mild cognitive impairment. However, Barnes et al. (2006) reported that this association was independent of the presence of vascular disease on MRI (including large or small infarcts).

As is the case for many of the factors with which PSD has been associated, it is difficult to determine whether cognitive impairment results from depression, is a risk factor for depression, or both (Andersen et al. 1995, Saxena et al. 2008). However, Murata and colleagues (2000) demonstrated that, in 41 stroke patients with major depression diagnosed in an acute hospital setting, improvement in depression over 3 – 6 months was associated with significantly greater increases in cognitive function when compared to depressed individuals with no mood improvements. The authors suggest that, since patients with major depression whose mood improved experienced greater cognitive improvement than any other group of study participants, depression leads to cognitive impairment and produces a “dementia of depression”. Further study is required to clarify the association between cognitive impairment and depression following stroke.

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**F1.3 Prevention of Post-Stroke Depression**

## F1.3 Prevention of Post-Stroke Depression

### Q1. What evidence is there for preventative treatment of post-stroke depression?

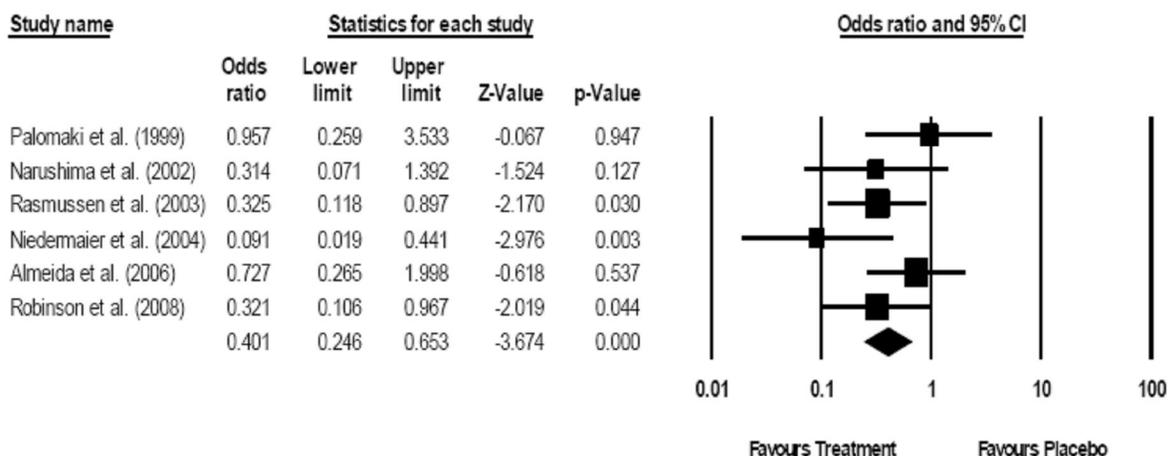
#### Answers

1. Early initiation of antidepressant therapy in non-depressed stroke patients has been associated with a reduced risk of development of post-stroke depression.
2. While treatment over a period of one year was associated with a significant reduction in risk, further study is needed to assess both the duration of treatment and optimal timing for initiation of therapy.

#### Discussion

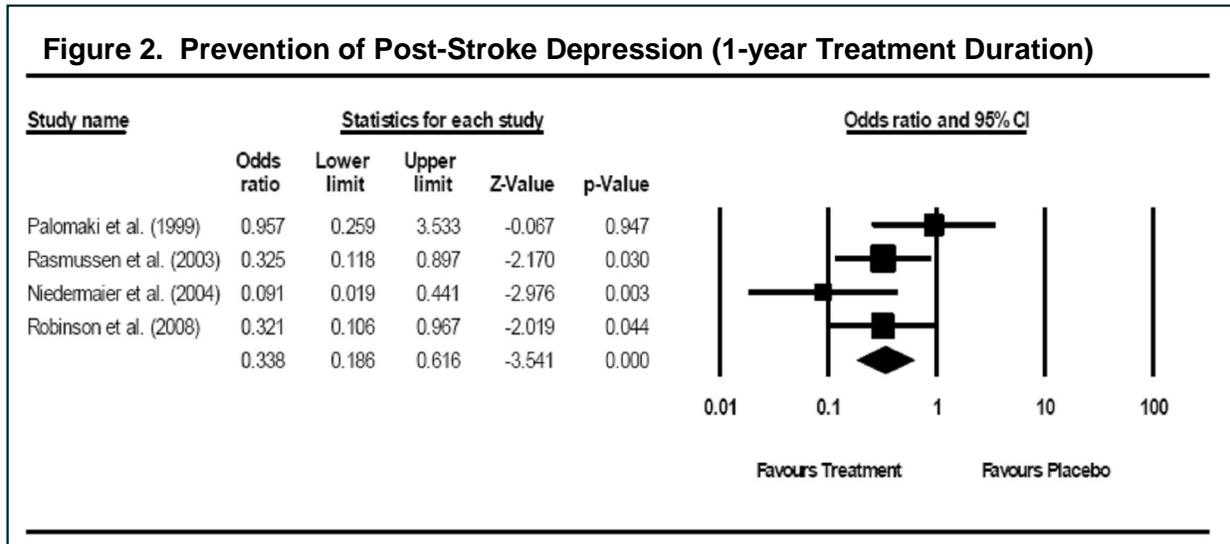
Given the negative impact of post-stroke depression on stroke recovery, early initiation of antidepressant treatment in stroke patients to prevent the development of post-stroke depression has been studied. (Palomäki et al. 1999, Narushima et al. 2002). Overall, individual studies offer conflicting evidence with regard to prevention of PSD through pharmacological intervention. However, a positive trend toward protection against depression appears to be present. Given that all of the studies included only patients with no depression at baseline and used the appearance of depression as a primary study outcome, a pooled analysis of data was conducted to evaluate the effectiveness of pharmacological intervention in the prevention of depression following stroke (Figure 1). It should be noted that all but one study (Almeida et al. 2006) used an interview-based assessment to determine the presence of depression.

**Figure 1. Prevention of Post-Stroke Depression**

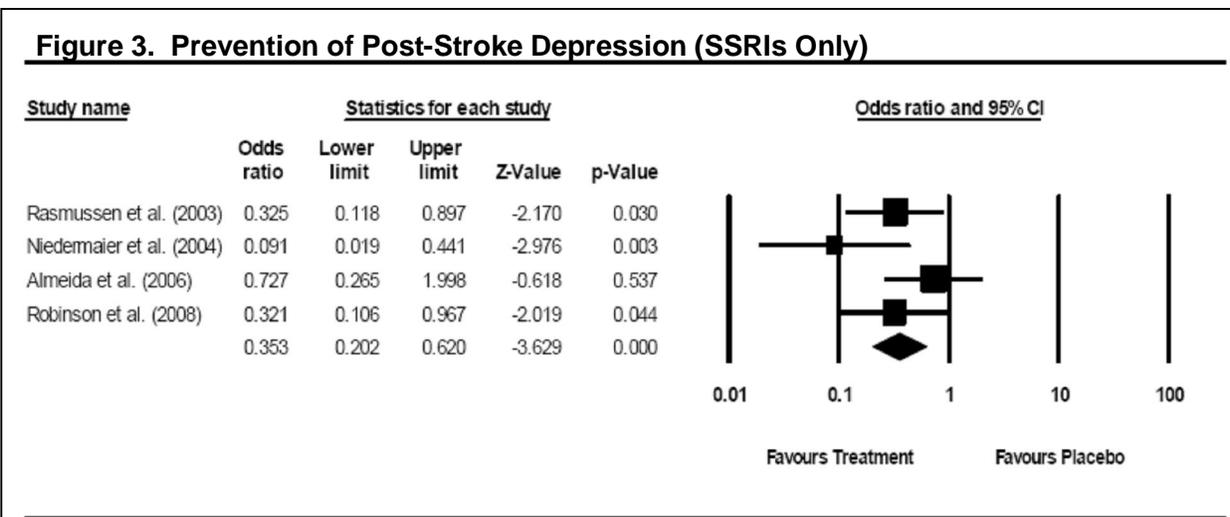


Pooled analysis of data from observations from a total of 583 patients demonstrated a significantly reduced risk for depression associated with pharmacological treatment (OR=0.40). Although there was no significant heterogeneity identified between studies, there are some notable differences such as variations in pharmacologic agents used, and length of treatment,

that should be noted. Duration of treatment ranged from 3 months (Narushima et al. 2002) to one year (Paolmaki et al. 1999, Rasmussen et al. 2003, Niedermaier et al. 2004, Robinson et al. 2008). Cases of depression presented in figure 18.2 were those recorded at the end of treatment in each study. Two of the three studies that did not demonstrate a significant effect in favour of treatment reported a shorter duration of intervention (3 months – Narushima et al. 2002 and 24 weeks - Almeida et al. 2006). When evaluated in a pooled analysis (Figure 2), treatment lasting one year was associated with a significant reduction in risk (OR = 0.34).



According to current guidelines for treatment of post-stroke depression, SSRIs are currently the preferred pharmacologic intervention. Four of the six identified studies examined the use of SSRIs for the prevention of PSD. Pooled analysis of these four studies (Figure 3) demonstrated results similar to the overall analysis such that treatment is associated with a significant reduction in the risk for PSD (OR = 0.35).



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## **F1.4 Treatment of Post-Stroke Depression**

## F1.4 Treatment of Post-Stroke Depression

### **AHA/ASA Endorsed Guidelines for the Management of Adult Stroke Rehabilitation Care: Recommendations for Mood Disturbance: Depression and Emotionalism (Duncan et al. 2005)**

#### **Assessment**

- The Working Group makes no recommendation for the use of any specific diagnostic tool over another.
- Recommend using a structured inventory to assess specific psychiatric symptoms and monitor symptom change over time.
- Recommend assessing poststroke patients for other psychiatric illnesses, including anxiety, bipolar illness and pathological affect.

#### **Treatment**

- Strongly recommend that patients with a diagnosed depressive disorder be given a trial of antidepressant medication, if no contraindication exists.
- The Working group makes no recommendation for the use of one class of antidepressants over another; however, side effect profiles suggest that SSRIs may be favoured in this patient population.
- Recommend SSRIs as the antidepressant of choice in patients with severe, persistent, or troublesome tearfulness.
- There is insufficient evidence to recommend for or against the use of individual psychotherapy alone in the treatment of PSD.
- Recommend patients be given information, advice, and the opportunity to talk about the impact of the illness on their lives.
- Routine use of prophylactic antidepressants is not recommended in post- stroke rehabilitation.
- Recommend that mood disorders causing persistent distress or worsening disability be managed by, or with the advice of, an experienced clinical psychologist or psychiatrist.

### **F1.4.1 Pharmacologic Treatment of Post-Stroke Depression**

#### ***Q1. What pharmacological options are available for treatment of post-stroke depression?***

#### ***Answers***

1. Tricyclic antidepressants
2. SSRIs
3. Methylphenidate

#### ***Discussion***

Treatment of post-stroke depression may involve the use of medications, the rare use of electroconvulsive treatments, and psychosocial therapies. Drug therapy for depression is based on the notion that depression is associated with an imbalance and under-activity of the cerebral noradrenergic and serotonergic systems.

A meta-analysis of 7 trials examining the effectiveness of pharmacologic interventions (Hackett et al. 2005) demonstrated no clear benefit associated with the use of these agents in the treatment of post-stroke depression (OR=0.76, CI 0.51 to 1.12). The authors urge caution in the interpretation of these results citing small sample sizes, small number of studies reporting the same endpoint, and differences in defining and assessing post-stroke depression. It should also be noted that the analysis included trials using a variety of pharmacologic agents and did not distinguish between trials of heterocyclic and SSRIs, for example.

In a more recent meta-analysis of 16 studies (including 6 studies from the Chinese literature) examining the use of antidepressants in individuals with post-stroke depression, Chen et al. (2006) reported a significant treatment response regardless of the definition of response used by individual study authors. In addition, treatment was associated with a significant reduction in depressive symptomatology on all scales used to assess outcome. Chen et al. (2006) also identified a relationship between duration and benefit of treatment. Pooled analysis of studies with treatment durations of 1 and 2 weeks revealed no significant treatment effects. However, from 3 weeks onward, demonstrated effects were, generally, of increasing significance. Like the Hackett et al. (2005) analysis, Chen et al. (2006) included trials examining the use of a variety of agents.

**Q2. What evidence is there for tricyclic antidepressants as treatment for PSD?**

**Answer**

1. There is strong evidence that heterocyclic antidepressants improve depression post stroke.
2. Side effects in elderly patients mean that these medications should be used with caution in this population.

**Discussion**

Cyclic antidepressants may block the reuptake of both serotonin and norepinephrine to different degrees within the cerebrum, thereby increasing the levels of these neurotransmitters in the brain. Finklestein et al. (1987) conducted a retrospective review study of 60 stroke patients with depression who were treated with one of several cyclic antidepressant drugs including doxepine, maprotiline, trazadone, desipramine, amitriptyline, imipramine or who received no treatments. It was found that only 17% of the untreated patients attained an improvement in depression scores compared to 40% of the drug responders. Furthermore, drug responders showed a greater improvement in depression change scores than non-drug responders or untreated patients. Although this was a comparative retrospective study it demonstrates the potential value of anti-depressants post stroke.

There are several RCTs that have investigated the efficacy of heterocyclic drugs in the treatment of post-stroke depression. All 3 studies investigating the efficacy of heterocyclic antidepressants in post-stroke depression were of "good" quality. When compared to placebo,

heterocyclic antidepressant medications demonstrated a significant treatment effect (Lipsey et al. 1984, Robinson et al. 2000). Robinson et al. (2000) compared a heterocyclic antidepressant with a serotonin reuptake inhibitor and found nortriptyline (a heterocyclic drug) to be more effective than the serotonin reuptake inhibitor fluoxetine. Robinson et al. (2000) observed nortriptyline improved the Hamilton Depression Scale scores significantly more than fluoxetine and/or placebo. In addition, the response rate of nortriptyline was significantly greater than both fluoxetine and placebo.

While the Lipsey et al. (1984) study results were promising, they noted confusion, drowsiness and agitation were significant side effects that may pose risks to elderly patients. Likewise, while the heterocyclic combination of imipramine and mianserin significantly improved melancholia scale scores, Lauritzen et al. (1994) noted that a significant number of patients dropped out of their study because of side effects. In all the studies mentioned, patients with myocardial infarctions were excluded. Furthermore, those with cardiac arrhythmias, heart block, urinary outlet obstructions and narrow-angle glaucoma are advised against the use of heterocyclic antidepressants and, indeed, the use of amine medications (including imipramine, amitriptyline, nortriptyline or desipramine) has been linked to adverse cardiovascular, anticholinergic and antihistamine effects (Kumar, 1999). Most recently, Steffens et al. (2008) demonstrated a significant association between use of tricyclic antidepressants and worsening of white matter lesions (OR = 1.77, 95% CI 1.07 to 2.94). Although the use of SSRI therapy was also associated with an increased risk for progression of white matter lesions, the effect was not significant.

The relatively high incidence of side effects associated with heterocyclic antidepressants, especially in elderly patients, must be taken into account when deciding on their use. Despite the risk profile associated with this class of medications, tricyclic antidepressants have been reported to be used commonly for the treatment of depression in the elderly. In a large collaborative study of aging (Brown et al. 1995), tricyclic antidepressants accounted for over 90% of the antidepressant medications used by study participants.

### ***Q3. What is the Evidence for SSRIs in treatment of Post-Stroke Depression?***

#### ***Answer***

1. There is strong evidence that SSRIs are effective in the treatment of post-stroke depression.

#### ***Discussion***

Selective serotonin-reuptake inhibitors selectively block serotonin-reuptake rather than blocking both serotonin and norepinephrine reuptake. They are commonly used to treat depression and have been studied in the treatment of post-stroke depression. Of the 6 RCTs reviewed on the efficacy of selective serotonin reuptake inhibitors in post-stroke depression, all were of “good” quality. Three of these RCTs demonstrated positive results favouring the treatment of serotonin reuptake inhibitors while two studies demonstrated no evidence for its therapeutic effects. A single RCT demonstrated benefits to quality of life associated with treatment but no improvement in assessments of depression.

Although the drug's effect in the Fruehwald et al. (2003) study was not evident at the first assessment, it should be noted that patients were included at 2 weeks post-stroke and the many therapeutic efforts that take place during the acute phase of stroke rehabilitation may facilitate spontaneous recovery from depression. However, the advantages of treatment with fluoxetine were observed at 12 and 18 weeks after treatment initiation. Response to treatment was reported to be quicker than for the heterocyclic drugs, taking effect 3 weeks into the treatment. Furthermore, side effects were found to be mild and transient and significantly less severe than those associated with the heterocyclic drugs. However, Robinson et al. (2000) noted that there was no significant difference between fluoxetine and placebo. Robinson et al. (2000) observed fluoxetine-induced significant weight loss in the elderly patients studied.

**Q4. What is the role Selective Noradrenaline Reuptake Inhibitors (NARI) in post-stroke depression?**

**Answer**

1. Reboxetine, a noradrenaline reuptake inhibitor, is effective in treating retarded post-stroke depression.

**Discussion**

Selective noradrenaline reuptake inhibitors are a class of antidepressants that function to inhibit noradrenaline reuptake. Patients suffering from depression characterized by lethargy, slowness to initiate action and displaying “*anergia, hypokinesia and hypomimia*” are said to be suffering from a retarded depression (Rampello et al. 2005). Antidepressant treatment with SSRIs may be more appropriate to treatment of anxious depression, characterized by anxiety, insomnia, hostility, restlessness and trepidation. NRIs are proposed as an alternative to SSRIs for individuals experiencing retarded depression (Rampello et al. 2005). A single RCT has examined the effectiveness of the NARI, reboxetine, in the treatment of this specific form of post-stroke depression. Treatment with reboxetine, a NARI, was associated with improvement in “retarded” depression over a 16-week course of treatment. During that time, no serious side effects were reported and no patients in the treatment condition withdrew from the study (Rampello et al. 2005). However, further study is required to assess the safety effectiveness of long-term treatment with reboxetine.

**Q5. What is the role of Serotonin and Noradrenaline Reuptake Inhibitors (SNRIs) in post-stroke depression?**

**Answers**

1. There is some evidence venlafaxine, an SNRI, is a safe and effective treatment for post-stroke depression

**Discussion**

Venlafaxine is an antidepressant characterized by the inhibition of the reuptake of serotonin, norepinephrine and, to a lesser extent, dopamine (Staab and Evans 2000). The use of venlafaxine in the treatment of geriatric depression has been examined in several randomized controlled trials and open label studies. Results of these trials have supported the safety and efficacy of venlafaxine within this population (Staab and Evans 2000). Although venlafaxine has been demonstrated to be safe and effective when used in the treatment of geriatric depression, there is little evidence to support the use of this drug in individuals with PSD. Randomized controlled trials are required.

**Q6. Discuss the role of psychostimulants for post-stroke depression.**

**Answer**

1. Methylphenidate appears to be effective in treating depression post stroke and has an earlier onset of action than traditional antidepressants.

**Discussion**

Methylphenidate, presently approved for treating attention-deficit disorders, has been used in the treatment of depression in the elderly as an alternative to tricyclics or other antidepressants. The states of the depressed elderly are often described as suffering a “*lack of interest and emotional involvement in one’s surroundings*” and this has been attributed to patients described as “*rehabilitation failures secondary to poor cooperation and motivation,*” (Johnson et al. 1992). Psychostimulants such as methylphenidate usually are effective in treating this state of apathy. Several studies suggest that use of psychostimulants in the treatment of post-stroke depression may be an effective treatment. Methylphenidate has its effects in the cortical and subcortical areas of the brain and thus is thought to heighten mood by affecting several neurotransmitter systems, in particular the noradrenergic system. In addition, it blocks the reuptake of serotonin and norepinephrine and has dopaminergic activity. Therefore, it is thought that methylphenidate may affect post-stroke depression by correcting the depletion of biogenic amines caused by stroke and to relieve apathy (Johnson et al. 1992).

Six studies examining the efficacy of psychostimulants for post-stroke depression were identified. One study was a retrospective single group intervention study, two were retrospective cohort studies, two were single group intervention studies and one was a randomized controlled trial. Methylphenidate has been observed to have an early onset of action within 2 to 10 days of treatment onset whereas tricyclic antidepressants onset usually does not begin until 2 to 4 weeks after treatment has begun. The fast action of methylphenidate is of particular interest given patients are treated for a limited amount of time in a rehabilitation setting. It must be used with caution in individuals with cardiovascular disorders.

**Q7. What is the impact of the pharmacologic treatment of depression on functional recovery post stroke?**

**Answer**

1. There is strong evidence that pharmacological treatment of depression is associated with improved functional recovery post stroke

### **Discussion**

As established earlier, depression has a negative impact on function and cognitive recovery and thus the appearance of post-stroke depression is believed to adversely affect the rate of recovery and rehabilitation of stroke survivors.

A non-RCT study by Gainotti et al. (2001) demonstrated that treatment with fluoxetine was associated with an improvement in functional recovery in addition to recovery from depression; a finding which is supported by Gonzalez-Torrecillas et al. (1995), Dam et al. (1996), Miyai and Reding (1998) and Narushima et al. (2003). Although several studies also documented the effectiveness of treatment with nortriptyline in terms of physical function, Miyai and Reding (1998) noted that trazodone and fluoxetine improved self-care function and depression after stroke while nortriptyline improved depression but not self-care. Van de Weg et al. (1999) demonstrated that, in a small group of stroke patients (n=6) treatment with any antidepressant was associated with a mean functional improvement of 30%.

Saxena et al. (2007) examined both depressive symptoms and functional variables in a group of 141 stroke patients. Linear regression analysis demonstrated that greater change in BI scores from rehabilitation admission to 6 months was associated with better mood status at baseline and greater improvement in depressive symptoms ( $p=0.02$  and  $p<0.001$ , respectively). Other significant predictors of functional recovery included baseline neurological status, neurological improvement, baseline functional status and age. The authors concluded that improvement in depressive symptomatology may accelerate functional recovery, but the level of function achieved is determined by neurological and cognitive factors.

Reding et al. (1986) proposed that the *“presumed mechanism [of antidepressant’s facilitation of stroke recovery] is increased patient motivation and more active participation in the rehabilitation program.”* However, variation in impact on functional recovery when comparing drugs with similar effectiveness in the treatment of depression suggests that these effects may be somewhat independent (Gainotti et al. 2001). Serotonergic antidepressants should be further investigated for possible efficacy in promoting functional recovery in stroke patients undergoing rehabilitation (Miyai and Reding 1998; Dam et al. 1996; Gainotti et al. 2001).

In addition, the effect of timing of treatment on the recovery of ADL requires further investigation. While the majority of studies examine the effectiveness of treatment initiated more than one month post stroke, the studies of Narushima et al. (2003) and Gonzalez-Torrecillas et al. (1995) focus on treatment beginning in the first month following the stroke event. Gonzalez-Torrecillas et al. (1995), in an open label study, demonstrated that early treatment, initiated within 4 weeks of the index event, was associated with significant improvements in physical, cognitive and neurological function by the end of the 6-week treatment period. Similarly, Narushima et al. (2003) report a significantly greater improvement in physical function over the active treatment period (12 weeks) for patients with early treatment initiation (within 4 weeks of stroke) than for patients whose treatment started later. In addition, during a “naturalistic” period of observation, patients with late onset of treatment experienced gradual deterioration in function between 12 and 24 months post stroke while patients in the early treatment group continued to improve slowly over the same period of time. These

significant between group differences were not attributable to time since stroke. Logistic regression controlling for treatment type, initial diagnosis, presence/absence of motor impairment, past psychiatric history and continued use of medication past the end of the treatment phase demonstrated a significant effect of early versus late treatment on FIM scores at 12 – 24 months (Narushima et al. 2003).

## **F1.9 Non-Pharmacologic Treatment of Post-Stroke Depression**

**Q8. What non-pharmacological treatments are available to treat post-stroke depression?**

**Answer**

1. Electroconvulsive therapy.
2. Repetitive transcranial magnetic stimulation.
3. Cognitive behavioral therapy.

**Q9. Describe each of these treatments and the degree to which they are helpful in post-stroke depression.**

**Answers**

1. ECT appears to be a safe treatment for post-stroke depression but has not been well studied as to efficacy.
2. Repetitive transcranial magnetic stimulation has been shown to be an effective and well tolerated treatment for post-stroke depression in patients resistant to pharmacotherapy.
3. Cognitive behavioural therapy for post-stroke depression, based on a single RCT, has not been shown to be effective.

### **Discussion**

**Electroconvulsive Therapy (ECT)** is an older treatment for major depression that has traditionally been considered effective (Janicak et al. 1985). Two retrospective studies suggest that ECT is a relatively safe and effective treatment for post-stroke depression, although Currier et al. (1992) reported that patients were at risk for relapse following ECT despite good initial responses and maintenance therapy with antidepressant medications. There have been no prospective controlled clinical trials evaluating the use of ECT in post-stroke patients.

**Repetitive Transcranial Magnetic Stimulation.** Recent randomized controlled trials have demonstrated antidepressant effects associated with repetitive transcranial magnetic stimulation (rTMS) in populations of patients suffering from major depression (Janicak et al. 2002; Grunhaus et al. 2003; Loo et al. 2003). Treatment effects comparable to those associated with ECT have been reported (Janicak et al. 2002; Grunhaus et al. 2003), although more modest results have been demonstrated among patients with resistant depression (Loo et al. 2003). Mild adverse effects were associated with rTMS. A single randomized controlled trial examining the use of rTMS in the treatment of post-stroke depression was identified (Jorge et al. 2004).

Active rTMS treatment was associated with a significant but modest reduction in depressive symptomatology on the HAM-D ( $p < 0.0006$ ). As in previous studies, in non-stroke populations, rTMS appears to be well tolerated by patients and was associated with mild adverse effects only. Whether this might represent an improvement over electroconvulsive therapy is unknown as there are no direct comparisons available within the post-stroke population. In addition, the present study is very small and focuses on a selected group of patients suffering from post-stroke depression that had proven resistant to pharmacotherapy (Jorge et al. 2004). A large trial evaluating the efficacy of rTMS with s-citalopram maintenance therapy is currently underway (Jorge et al. 2004).

**Cognitive Behavioural Therapy** is an active, directive, structured intervention for numerous psychological disorders. The approach is based on the notion that emotion and behaviour are determined by experience. Accordingly, cognitive behavioural therapy concentrates on altering and restructuring the individual's interaction with their environment and their interpretation of their experiences. Therapy tools include behavioural tests, graded task assignments and scheduling of activities (Lincoln et al. 1997). Based on a single RCT of good quality, there is moderate (Level 1b) evidence that cognitive behavioural therapy is ineffective as a treatment for post-stroke depression.

#### **F1.4.3 Guidelines for Treatment of Post-Stroke Depression**

##### **Q10. What do guidelines say about the treatment of post-stroke depression?**

##### **Answers**

1. Guidelines for the treatment of post stroke depression recommend screening, assessment and treatment with an appropriate antidepressant for a period of approximately 6 months.
2. Treatment (and subsequent withdrawal) should be monitored closely by an appropriately trained healthcare professional.

##### **Discussion**

There are several sets of current rehabilitation guidelines that make recommendations for the assessment and treatment of mood disorders following stroke. In general, all acknowledge the importance of identification and diagnosis of depression. All recommend the use of standardized assessment and most indicate that a clinical interview conducted by an appropriate mental healthcare professional is required for diagnosis. Treatment, in the form of antidepressant medication (usually an SSRI), is recommended, though the details and possible duration of treatment are not clearly stated. The possible role of psychotherapy is acknowledged although there is little evidence of its effectiveness within this population. The most recent clinical guidelines are the "*Stroke Rehabilitation Clinical Practice Guidelines*" from the Veterans Affairs-Department of Defense (VaDoD) recently endorsed by the American Heart Association/American Stroke Association (AHA/ASA) (Duncan et al. 2005). These guidelines appear in the Table at the beginning of section F1.4.

While the preferred mode of treatment is specified, there are no guidelines provided regarding how treatment plans should be developed, how or for how long treatment should be provided and what happens at the end of the course of treatment. The National Clinical Guidelines for

Stroke (Royal College of Physicians 2004) suggest that antidepressant treatment for PSD should begin only after a period of “*watchful waiting*” to determine if the depressive episode will become persistent. Following this, treatment may be initiated for persistent episodes by an “*appropriately trained and supervised practitioner*”. Treatment should be kept under review and should continue for at least 6 months, if a good response is achieved. Persistent disorders causing distress or worsening disability “*should be managed by or with advice from an experienced clinical psychologist or psychiatrist*”

In 2005, the British Society of Rehabilitation Medicine and the British Geriatrics Society in association with the Royal College of Physicians published concise guidelines for the use of antidepressant medication following “*acquired brain injury*” (Turner-Stokes and MacWalter 2005). The recommendations were intended for clinicians working with individuals who had sustained brain injury from any cause, including stroke and include recommendations for screening and assessment, issues to consider prior to the commencement of treatment, as well as suggestions for treatment planning, evaluation and withdrawal. A summary of the guidelines is provided in the Table below.

## **Summarized Guidelines for Use of Antidepressant Medication Following Brain Injury (British Society of Rehabilitation Medicine & the British Geriatric Society 2005).**

### **Assessment**

- Recommend informal screening at each assessment point (e.g. ask patient about mood or ask family about behaviours that might suggest depression)
- If depression is suspected, proceed to more formal, detailed assessment (using validated measures, interview and/or observation)

### **Treatment**

- Clinicians should observe patients carefully regarding impact of depression on function, social participation and QOL
- Clinicians should attempt to determine if other, simple, interventions might be appropriate to “boost the patient’s mood”
- Possible risks and contraindications for treatment should be considered carefully along with issues of informed consent and patient/family education
- Antidepressants should be prescribed according to an agreed-upon plan of treatment that includes: baseline assessment using a validated measure, assessment of appropriate baseline biochemical markers, selection of an appropriate agent, clinical review of response to optimize dose (at 2-3 weeks) and repeat assessment at 6 – 8 weeks. Given a positive response to treatment, planned use would extend to 6 months with a procedure for withdrawal at the end of treatment.
- An alternate plan should be in place should treatment with an antidepressant be ineffective.

### **During Treatment**

- Patients should see doctor regularly during treatment (every 2 months) – any clinical deterioration should be investigated – particularly known side effects such as hyponatraemia, seizures, GI bleeding, anti-cholinergic symptoms, sexual dysfunction, sedation, hallucinations, increased confusion, headache
- Antidepressant medication should not be given with repeat prescription and no more than 2 months supply should be written

### **Referral for Formal Psychiatric Interview**

- If depression is severe or resistant to treatment
- Past history of psychiatric disorder and/or use of antidepressant
- Patient shows evidence of suicidal ideation or intent
- Seems that the patient needs to be treated under Mental Health Act 1983 or equivalent (UK)

### **Withdrawal from Treatment**

- At end of treatment (generally 4 – 6 months), there should be a planned period of withdrawal taking place gradually over a period of 1 – 2 months
- Prior to withdrawal, patient mood should be re-evaluated (using same measure as at baseline)
- Patient/family should be warned re: possibility of rebound symptoms. For longer lasting relapse of depression, long-term treatment may be considered. Formal psychiatric advice should be sought.

Though the 2005 guidelines for use of antidepressants post brain injury do not include specific recommendations for a particular antidepressant agent, the authors suggest that SSRIs, while as effective as heterocyclic antidepressants, have fewer reported side effects.

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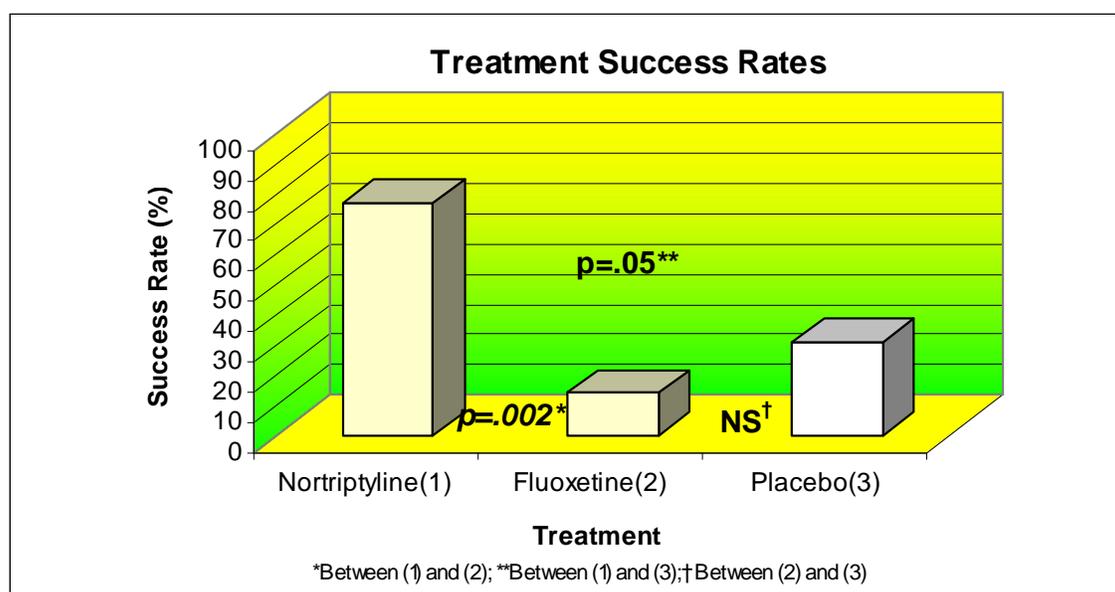
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## Key Study: Treatment of Post-Stroke Depression

Robinson RG, Schultz SK, Castillo C, Kopel T, Kosier JT, Newman RM, Curdue K, Petracca G, Starkstein SE. Nortriptyline versus fluoxetine in the treatment of depression and in short-term recovery after stroke: a placebo-controlled, double-blind study. *Am J Psychiatry* 2000;157:351-359.

Author / Year Country PEDro score	Methods	Outcome
Robinson et al. 2000 USA & Argentina 8 (RCT)	Double blind, placebo controlled randomized crossover trial of 104 patients. Patients randomly assigned to either fluoxetine (10mg/day gradually increased to 40 mg/day) or nortriptyline (dose of 25 mg/day gradually increased to 100 mg/day) or identical placebo given over 12 weeks. Patients received 12 weeks of active treatments and cross-over for 12 weeks of placebo treatment.	A significant time-by-treatment interaction was found on the repeated measure analysis of variance of the mean Hamilton Depression Scale score. Nortriptyline treated group showed significantly greater improvement on the HDRS than the other 2 groups. Nortriptyline produced a significantly higher rate than fluoxetine or placebo in treating post-stroke depression, in improving anxiety symptoms and in improving recovery of activities of daily living as measured by the FIM.



**Importance:** This study compared a heterocyclic antidepressant with a serotonin reuptake inhibitor and found nortriptyline (a heterocyclic drug) to be more effective than the serotonin reuptake inhibitor fluoxetine. It was observed that nortriptyline improved the Hamilton Depression Scale scores significantly more so than fluoxetine and/or placebo. In addition, the response rate of nortriptyline was significantly greater than both fluoxetine and placebo.

### Relevant SREBR Conclusions:

- *Regarding fluoxetine:* There is conflicting evidence (three positive, two negative) as to the effectiveness of selective serotonin reuptake inhibitors in the treatment for post-stroke depression.

- *Regarding nortriptyline:* There is strong evidence that heterocyclic antidepressants improve depression post stroke. Side effects in elderly patients mean that these medications should be used with caution in that population.

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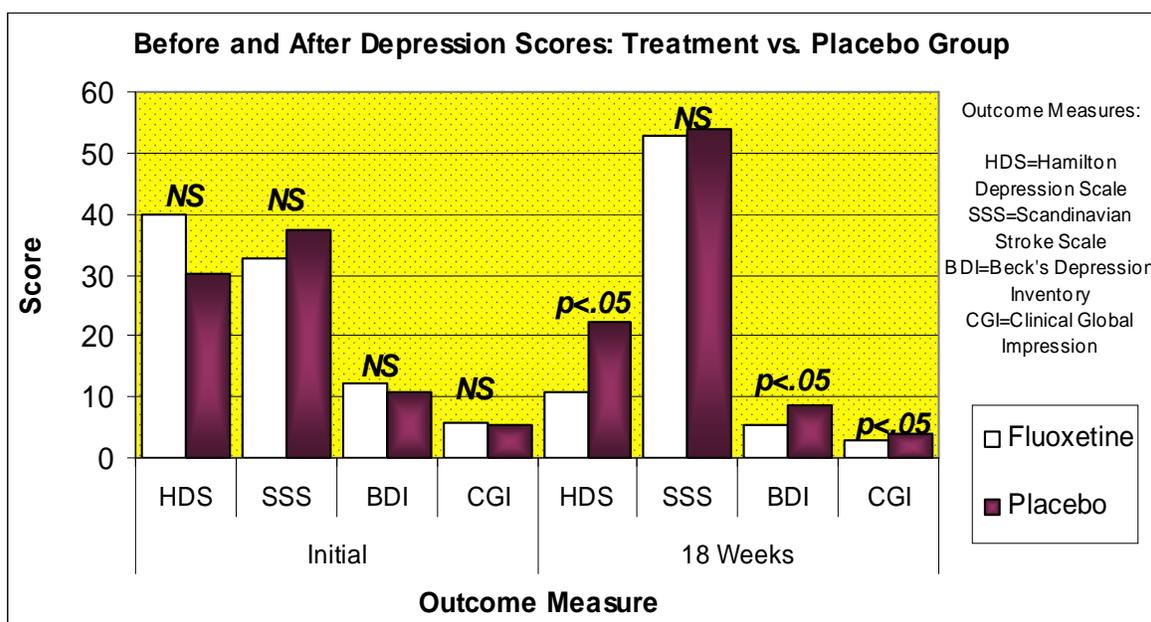
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## Key Study: Treatment of Post-Stroke Depression

Fruehwald S, Gatterbauer E, Rehak P, Baumhackl U. Early fluoxetine treatment of post-stroke depression. A three month double-blind placebo-controlled study with an open-label long-term follow up. *J Neurol* 2003;250:347-351.

Author / Year Country PEDro score	Methods	Outcome
Fruehwald et al. 2003 Austria 9 (RCT)	54 patients suffering from moderate to severe post-stroke depression were randomized within 2 weeks of stroke to either treatment with fluoxetine or to placebo control.	Significant improvement was seen in both groups within 4 weeks; however no advantage of fluoxetine was noted at this time. Beck Depression Inventory scores of patients treated with fluoxetine decreased until the follow-up at 12 weeks whereas the scores increased in the placebo group. At long-term follow up, 18 months after inclusion, patients treated who had been treated with fluoxetine were significantly less depressed than placebo treated patients.



**Importance:** Although both the treatment group and control group experienced improvements in the first 6 weeks following stroke, treatment with the SSRI (fluoxetine) was associated with long-term reduction in depression (18 months).

**Relevant SREBR Conclusion:** There is conflicting evidence (three positive, two negative) as to the effectiveness of selective serotonin reuptake inhibitors in the treatment for post-stroke depression.

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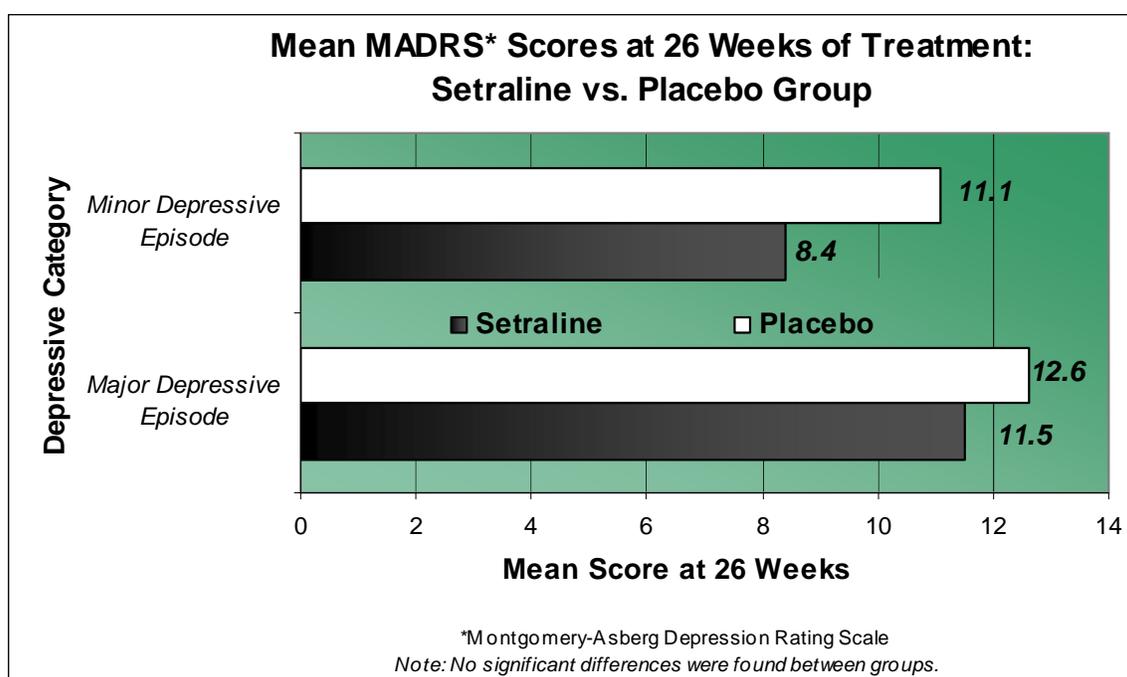
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## Key Study: Treatment of Post-Stroke Depression

Murray V, von Arbin M, Bartfai A, et al. Double-blind comparison of sertraline and placebo in stroke patients with minor depression and less severe major depression. *J Clin Psychiatry* 2005;66:708-716.

Author / Year Country PEDro score	Methods	Outcome
Murray et al. 2005 Sweden 9 (RCT)	123 stroke patients with either a major or minor depressive episode (defined according to the DSM-IV) were assigned to either the treatment or placebo conditions. 62 patients received sertraline (50 – 100 mg/day) and 61 received a matching placebo. Primary study outcome was change in MADRS score from baseline to weeks 6 and 26.	Both groups demonstrated significant improvements over the study period. There were no significant between group differences on the primary study outcomes whether the patient was diagnosed with major or minor depression. There was a significant difference between groups favouring treatment identified on the Emotional Distress Scale ( $p < 0.05$ ). Improvement in global quality of life was greater for those patients treated with sertraline at week 26 than for those patients in the control group ( $p < 0.05$ ).



**Importance:** Although treatment with the SSRI, sertraline, was not associated with greater improvement in depression outcomes than no treatment, use of sertraline was associated with reduced emotional distress and improved global quality of life.

**Relevant SREBR Conclusion:** There is conflicting evidence (three positive, two negative) as to the effectiveness of selective serotonin reuptake inhibitors in the treatment for post-stroke depression.

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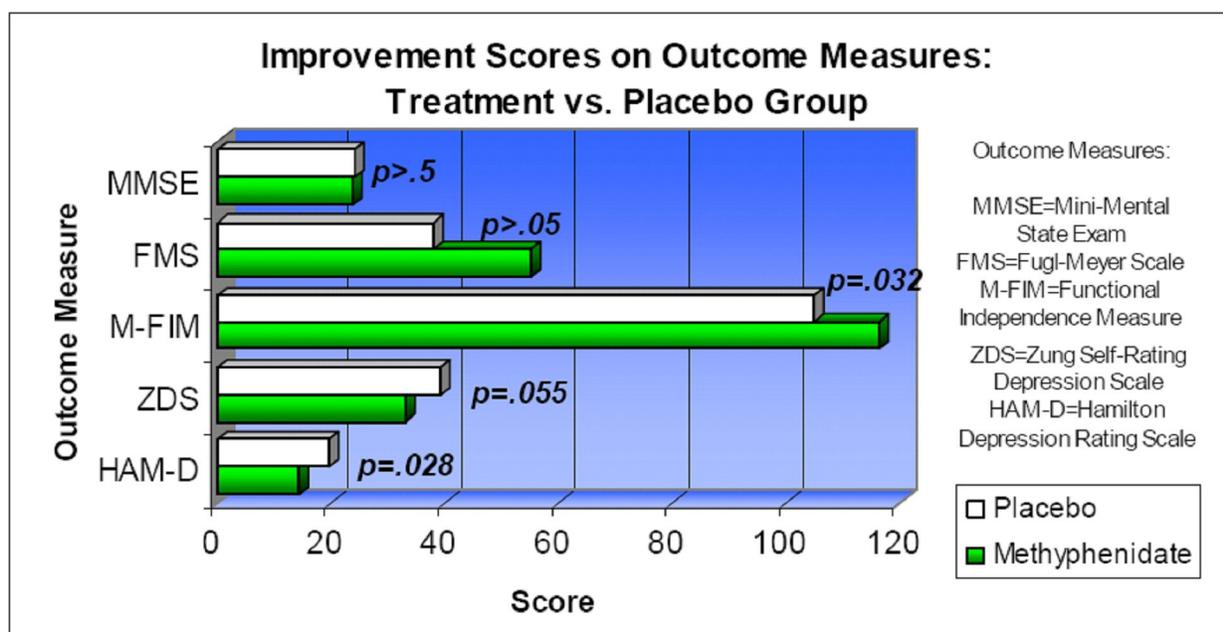
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## Key Studies: Treatment of Post-Stroke Depression

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Author / Year Country PEDro score	Methods	Outcome
Grade et al. 1998 USA 7 (RCT)	A double blind RCT of 21 stroke patients comparing the efficacy of methylphenidate during stroke rehabilitation. Patients were randomized to receive either 5mg in the morning & 30mg before bedtime of methylphenidate or a placebo treatment.	Patients receiving methylphenidate scored lower on HAM-D ( $p=0.028$ ) and the Zung scale ( $p=0.055$ ). Significant improvement was also reported in patients receiving methylphenidate on the motor FIM ( $p=0.32$ ). While scores on the FMA were higher in the treatment group, they did not reach significance ( $p=0.075$ ).



**Importance:** This RCT demonstrated that methylphenidate significantly improves depression scores.

**Relevant SREBR Conclusion:** There is strong evidence that amphetamines do not improve motor recovery and/or functional outcomes.

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**F1.5 Case Study: Post-Stroke Depression**

## F1.5 Case Study: Post-Stroke Depression

### **Case Study**

*A 78 year old male with a large left hemispheric stroke which has rendered him hemiplegic and suffering from a severe motor (Broca's) aphasia is admitted to the rehabilitation unit. He appears to be depressed. The medical student with you is not surprised that the patient is depressed; after all he has had a devastating stroke and cannot speak. The nurse next to you states that many patients who have a stroke do not necessarily become depressed. They ask you as to whether depression is common post stroke and who is most likely to become depressed.*

### **Q1. How common is depression post-stroke?**

#### **Answer**

1. Depression is a common complication post stroke, affecting approximately one-third of stroke patients.

### **Q2. What are the risk factors associated with increased likelihood of depression post stroke?**

#### **Answers**

1. Risk factors associated with an increased risk of post-stroke depression include:
  - Female gender
  - Past history of depression or psychiatric illness
  - Social isolation
  - Functional impairment
  - Cognitive impairment

### **Case Study (continued)**

*The nurse states to the medical student that it has been her experience that left hemispheric stroke patients are more often depressed when compared to their right hemispheric counterparts. They ask you if this is supported by the evidence.*

**Q3. Describe the relationship between PSD and the location of the stroke.**

**Answer**

1. There remains a wide diversity of findings in studies looking at the relationships between stroke location and depression.
2. Not all studies have confirmed this relationship and more recent meta-analysis have failed to establish a definitive relationship between the site of the brain lesion and depression.
3. There is some evidence to suggest that left hemispheric stroke patients are more likely to become depressed shortly after the onset of the stroke while right hemispheric stroke patients are more likely to become depressed later on.

**Q4. Describe the negative impacts of Post-Stroke Depression.**

**Answers**

1. PSD has a powerful negative impact on functional recovery. Although patients with post-stroke depression may experience significant recovery, functional ability will remain at a lower level than non-depressed patients, despite rehabilitation interventions. Physical impairment and post-stroke depression appear to act upon each other, and each influences the recovery of the other.
2. PSD impacts negatively upon social activity and vice versa post-stroke. The effects of stroke alters how patients perceive themselves, their capabilities and self-image (Labi et al. 1980). These perceptions are associated with depression (Feibel and Springer 1982) and are also associated with social withdrawal, which may in turn exacerbate depression. Even after intensive intervention for depression, social function among depressed stroke survivors was significantly less than among non-depressed stroke survivors during the first year following the stroke event.
3. Depression appears to have a negative impact on cognition post-stroke. Overall there appears to be a relationship between cognitive impairment and the presence of depression, although the reported results vary and the relationship appears to be complex. As is the case for many of the factors with which PSD is associated, it is difficult to determine whether cognitive impairment results from depression, is a risk factor for depression, or both (Andersen et al. 1995). Murata et al. (2000) demonstrated that, in 41 stroke patients with major depression diagnosed in an acute hospital setting, improvement in depression over 3-6 months was associated with significantly greater increases in cognitive function when compared to depressed patients with no mood improvements. The authors suggest that, since patients with major depression whose mood improved experienced greater cognitive improvements than any other group of study participants, depression leads to cognitive impairment and produces a “dementia of depression”.
4. Negative thoughts associated with PSD are associated with greater mortality. The results of a more recent large study (Williams et al. 2004) confirmed earlier evidence of increased long-term mortality in stroke patients who experience post-stroke depression. House et al. (2001) and Lewis et al. (2001) suggest that the identified association may not be between depression and mortality per se, but is between a more general psychological distress and mortality instead.

**Case Study (continued)**

*The nurse is concerned about depression and asks the physician to assess the patient for depression. The physician does not think the patient is depressed and questions the value of screening assessments for depression in stroke patients.*

**Q5. What is the consensus on screening/assessment of post-stroke patients for depression?**

**Answer**

1. There is consensus regarding the importance of the identification and diagnosis of PSD.
2. Identification requires the use of standardized assessment instruments.
3. Diagnosis requires a clinical interview conducted by an appropriate mental healthcare professional.
4. While the importance of screening for PSD is commonly acknowledged and is recommended in current guidelines, it has been reported that the compliance rate is as low as 50% (Bowen et al. 2005).

**Case Study (continued)**

*The social worker is asked to see the patient and administers the Hospital Anxiety and Depression Scale. She reports that the patient high on the depression and anxiety subscales of the HADS.*

**Q6. Describe the HADS.**

**Answer**

1. Hospital Anxiety and Depression Scale (HADS).
2. Bidimensional scale to identify cases of depression and anxiety in physically ill patients.
3. 14 items with an anxiety and depression subscales.
4. Easy to administer and score.
5. Has good reliability and validity.

**Discussion**

The Hospital Anxiety and Depression Scale (HADS) is a screening tool which can be administered quickly. It is a bi-dimensional scale developed to identify cases of depression and anxiety disorders among physically ill patients (Zigmond 1983, Herrmann 1997, Bjelland 2002, Flint 2002). Somatic items, such as fatigue, weight loss or headache, that could be attributable to physical illness rather than psychological states were not included. Instead, the evaluation of depression is based largely on items that reflect the concept of anhedonia (Roberts 2001, Flint 2002). The HADS consists of 14 items which can be divided into 2 subscales of 7 items each; the anxiety subscale (HADS-A) and the depression subscale (HADS-D). Scoring is from 0 (absent) to 3 (extreme presence) with a total score of 42. Higher scores indicate greater levels of anxiety and depression. The scale itself is easy to administer and score (Herrmann 1997). Mean time to complete the scale has been reported to be 6.5 minutes when administered to a group of patients post-stroke (Visser 1995). The HADS, in all forms, is comparable to other self-report measures of depression in terms of reliability. Concurrent validity of the HADS has been well established with reported correlations with the Beck Depression Inventory (Bjelland 2002), the General Health Questionnaire (Bjelland 2002), the MADRS (Bjelland 2002) and the "anxiety/depression item" of the EQ-5D (Marinus 2002). One limitation of the HADS is that it focuses on the core symptoms of mood and anhedonia only. However, 5 of the 9 criteria included in the DSM-IV reflect somatic symptomatology, resulting in a reduction in the face validity of the scale (Marinus 2002).

#### ***Case Study (continued)***

*The social worker reports that the patient scored high on the HADS for depression. A psychiatrist is consulted and notes that the patient meeting the DSM-IV criteria for a major depression. The psychiatrist recommends pharmacological treatment.*

#### ***Q7. What pharmacological options are available?***

##### ***Answer***

Drug therapy for depression is based on the notion the depression is associated with an imbalance and under-activity of the cerebral noradrenergic and serotonergic systems. The three pharmacological treatments include:

- Heterocyclic antidepressants
- SSRIs
- Methylphenidate

#### ***Q8. Describe the mechanism of tricyclic antidepressants.***

##### ***Answer***

1. Tricyclic antidepressants function by blocking the reuptake of serotonin or noradrenaline at the level of the presynaptic neuron.

2. Reuptake into the presynaptic neuron is the major mechanism by which neurotransmitters are inactivated.
3. Blocking reuptake leads to increased neurotransmitter in the synaptic cleft.

**Q9. Do tricyclic antidepressants improve depression post stroke?**

**Answer**

1. There is strong evidence that heterocyclic antidepressants improve depression post stroke.
2. Side effects in elderly patients means that these medications should be used with caution in that population.

**Q10. Describe the mechanism of Selective Serotonin Reuptake Inhibitors (SSRIs).**

**Answer**

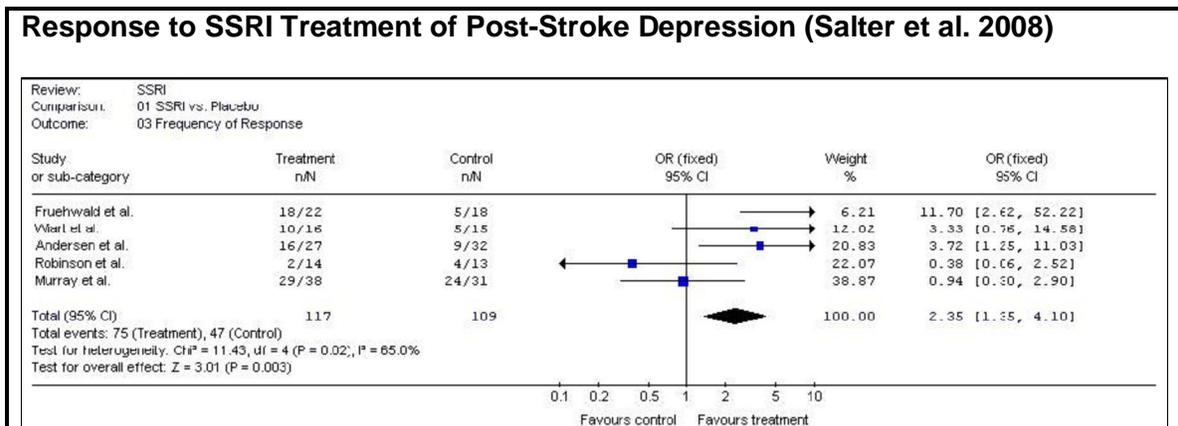
1. Fluoxetine was the first SSRI antidepressant and it results in selective blocking of reuptake of serotonin into presynaptic neurons.
2. It does not block the reuptake of noradrenaline which distinguishes SSRIs from TCAs.

**Q11. Do SSRIs improve depression post stroke?**

**Answer**

1. Based on the results of meta-analysis there is strong evidence that SSRIs are effective in the treatment of post-stroke depression.

**Discussion**



### **Case Study (continued)**

*The nurse asks you whether there are any guidelines for the assessment and management of post-stroke depression.*

### **Q12. What do Guidelines say about the Assessment and Treatment of Post-Stroke Depression?**

#### **Answers**

1. Current guidelines recommend both screening and appropriate assessment of depression in patients with stroke.
2. Treatment with an appropriate antidepressant is recommended for a period of approximately 6 months (given evidence of treatment effectiveness).
3. Treatment and subsequent withdrawal should be monitored closely by an appropriately trained professional.

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**F2. Social Support and Functional Status**

**F2.1 Importance of Social Supports**

## F2.1 Importance of Social Supports

**Q1. Describe the role of social support networks on rehabilitation and recovery post stroke.**

**Answers**

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

**Discussion**

As identified in a review article by Meijer et al. (2004), 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

Suffering 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 (Glass and Maddox 1992, Glass et al. 1993, Colantonio et al. 1993, Tsouna-Hadjjis et al. 2000) as well as lower levels of depression and improved mood and social involvement (Tsouna-Hadjjis 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-Hadjjis 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. 2005).

**Q2. Describe those factors which have a positive and a negative impact on quality of life following a stroke.**

**Answers**

1. Positive factors include independence in ADLs, functional abilities, social support and health care resources.
2. Negative factors include depression, cognitive impairment, stroke severity and aphasia.

**Discussion**

Quality of life is a complex, multidimensional concept that is of increasing interest in stroke rehabilitation research. Bays (2001) 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 of life of stroke survivors was found to be consistently lower than that of comparison groups, although among stroke survivors quality of life was variable as were the patterns of quality of life over time post stroke. 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 (Kim et al. 1999; Gottlieb et al. 2001). In addition, the size of social networks and their perceived quality or effectiveness affect the quality of life post stroke as reported by Kim et al. (1999), MacKenzie and Chang (2002) and Clarke et al. (2002). Individuals with larger social networks who also perceive them to be effective in supporting them have a better quality of life.

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## **F2.2 Social Support Interventions Post Stroke**

## F2.2 Social Support Interventions Post Stroke

**Q1. What evidence is there for social work interventions once the patient is discharged home?**

**Answers**

1. Stroke survivors, once their rehabilitation is complete, often feel abandoned by the healthcare system.
2. Unfortunately, there is strong evidence that social work interventions focusing on providing counseling along with information and education for stroke patients and their families are not associated with improvements in independence or social activity.

**Discussion**

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).

Two RCTs examining the effectiveness of social work interventions were identified. Both social work interventions were provided by qualified social workers and included a schedule of home visits for the provision of information, education and counselling as required. Neither intervention reported significant benefit associated with the intervention in terms of independence or activity. Participation in social work intervention was not associated with changes in either healthcare or community resource utilization. However, despite no significant measured benefit, many participants in the study described by Christie and Weigall (1984) reported satisfaction with the intervention.

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## **F2.3 Family and Stroke**

## F2.3 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 and 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 and 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.

### F2.3.1 Family Caregiving System Post Stroke

**Q1. Describe the family caregiving system following a stroke to one of its members.**

**Answer**

1. The brunt of long-term care of the stroke survivor falls onto family caregivers.
2. Usually there is one primary caregiver who is the primary provider of direct care assistance.
3. Most often the primary caregiver is a spouse; if a spouse is not available it will fall to a daughter or son.
4. Friends and other family members tend to be primary caregivers only if near relatives are not available.

**Discussion**

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 recent 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, Tobin and Kalys 1981).

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). Brocklehurst 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 and Horowitz 1987).

**Q2. Discuss the role of family interactions after a stroke.**

**Answers**

1. Perceived family dysfunction is common post stroke
2. Family function affects treatment adherence, performance of ADLs, and social activity.
3. Effective communication, good problem solving or adaptive coping, and strong emotional interest in each other characterize well-functioning families.

**Discussion**

While it may seem obvious that families play an important role in the rehabilitation and community reintegration of stroke patients, few studies have studied 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 (Schote et al. 2006). In a sample of 64 close relatives of stroke patients, Schote et al. (2006) reported the greatest perceived decline in health-related quality of life while the patient was still involved in inpatient rehabilitation. 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 and Smith 1999a). 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 suffered the stroke all affect the recovery process (Palmer and Glass 2003; Bleiberg 1986). 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 (Alder 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 (1999a) 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 and Smith, 1999a).

Clark and Smith (1999a) 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 and Duffy 1980, Knapp and Hewison et al. 1999).

Family functioning appears to have a direct impact on treatment and rehabilitation adherence. As noted by Evans et al. (1987a), 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. 1987b). 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. 1987b). 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. 1987a), increased ADL function and increased social function (Clark and Smith 1999b), 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 and Smith 1999a). 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 and Smith 1999a).

### **F2.3.2 Caregiver Stress and Breakdown**

***Q3. Describe those factors which contribute to caregiver stress and breakdown post stroke.***

***Answers***

1. Caring for a stroke survivor with severe disabilities can be a formidable task.
2. Caregivers cope better with physical limitations than cognitive or emotional disorders.
3. Lack of rest or time to fulfill obligations, the need for constant vigilance/supervision as well as lack of respite can have a negative impact on caregivers.
4. Caregivers are often required to sacrifice their own personal needs.
5. Chief reasons for reports of less enjoyment of life on the part of caregivers include loss of companionship, increased domestic responsibility and interference with leisure and social activities.

## **Discussion**

The ACHPR (Gresham et al. 1995) 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.*” As noted by Evans (1986) caregivers cope with physical limitations better than cognitive or emotional disorders. 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 (Boxell and McKercher 1990, Colerick and George 1986). Caregivers 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 (Gresham et al. 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. (2004) interviewed 90 caregivers one year following stroke. 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 (NFCA 2002 cited in Grant et al. 2004c) which may have dire effects on the financial wellbeing of the family. 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 (Stewart et al. 1998; Palmer and Glass 2003; Smith et al. 2004, Coombs, 2007). In their 2004 study, Sit et al. 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 and 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 adapt to a new relationship with their spouse (Coombs 2007).

**Q4. What tasks lead to greater caregiver burden?**

**Answer**

1. Provision of emotional support.
2. Provision of transportation.
3. Managing finances, bill and forms related to the stroke.
4. Carrying out household tasks.
5. Managing behaviours.

**Discussion**

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, provision of 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.

**Q5. Describe how the impact of caring for a stroke survivor changes over time.**

**Answers**

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

## **Discussion**

Many studies have examined the effects of caring for the stroke survivor on the primary family caregiver. Most take a cross-sectional approach, providing us with a snapshot in time of the effects of caregiving on the caregiver along with the identification of factors that moderate the identified effects. Some take a longitudinal approach and include an 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 (Tompkins et al. 1988, Schulz et al. 1988). In a report of the FINNSTROKE Study (Kotila et al. 1998), 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. By 12 months, however, the absence of such services was associated with a greater number of severely depressed caregivers. A recent longitudinal study (Franzen-Dahlin et al. 2007) 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.

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 are reported, while upsetting behaviours, feelings of confinement and increased financial difficulties are more frequent. 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. 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. The authors suggest that this may reflect ongoing improvements in the physical and cognitive function of the individual with stroke (Tooth et al. 2005).

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), although White et al. (2003) reported an increasing burden over time among women. Visser-Meily et al. (2008) reported that while reported burden decreased substantially between one and three years post-stroke, life satisfaction and social support deteriorated. Depressive symptomatology remained stable over time (Visser-Meily et al. 2008).

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.

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. However, age, severity of stroke and stroke-related impairments, functional status and cognitive status of the patient have all been reported as influencing caregiver outcomes.

**Q6. Describe the role of social contact and activity in caregiver coping.**

**Answer**

1. After the family member has a stroke, caregivers suffer from smaller social networks, diminishing social contacts as well as less satisfying social contacts.
2. This in turn can have a negative impact on the caregiver's mood, in particular depression.

**Discussion**

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., 2004b). 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).

**Q7. How common are personality disorders post stroke?**

**Answer**

1. Personality disorders are quite common among stroke survivors, most of which are negative.
2. Negative changes noted include irritability, loss of self control, lower frustration tolerance, emotional lability, self-centeredness and reduced initiative.

**Discussion**

According to Coughlan and Humphreys (1982), personality changes were noted by the caregiver in two out of three stroke survivors, 3-8 years after the stroke. The change was positive in 5%, negative in 82% and not clear in 13%. The primary negative changes reported were irritability and loss of self-control, lower frustration tolerance, emotional lability, self-centeredness and reduced initiative.

### F2.3.3 Depression in Caregivers Post Stroke

**Q8. How common is depression among caregivers post stroke? Who is more likely to become depressed?**

**Answer**

1. Stroke caregivers are more susceptible to depression.
2. Incidence of depression ranges from 30-50%.
3. Factors which predict post-stroke depression include the stroke survivor's level of dependence, the amount of tangible support received, opportunities for socialization and a negative orientation towards problem solving.
4. One study showed that caregivers at highest risk of depression tended to be the spouse of younger, more severely impaired patients with lower social incomes, smaller social networks with whom they visited frequently and lower levels of future optimism and expectation.

**Discussion**

Acting as the primary caregiver does not occur without a considerable toll on health (both physical and mental) and disruption of life, overall. The increased risk for depression is substantial. Within the literature, the prevalence of caregiver depression has consistently been documented as higher in stroke caregivers (39% to 52%), when compared to non-caregiving populations (12% to 16.5%) (Kotila et al. 1998, Anderson et al. 1995, Draper et al. 1992, Carnwath et al. 1987, Silliman et al. 1986, Han and Haley 1999). However, most 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 and 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. (2004a) 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 (Grant et al. 2004a).

Mental health or emotional problems experienced by the individual with stroke may also have a negative impact on the informal caregiver. Draper et al. (1992) noted that psychological aspects of the consequences of stroke such as apathy, agitation, wandering and mood disturbances

contributed to caregiver strain. In interviews conducted by Grant et al. (2004c), cognitive, behavioural and emotional changes were identified among the most stressful caregiving challenges encountered during the first month post discharge. Carer participants in interviews conducted by Smith et al. (2004) noted that emotional and cognitive problems of the stroke survivors can be the most difficult problems with which to deal and yet health care professionals largely ignore them.

### **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. 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. Caring for the individual with stroke was seen as a means by which the caregiver could express both love and devotion. In an earlier study by Schulz et al. (1988), caregiving was associated with positive as well as negative influences on the marital relationship.

### **F2.3.4 Summary of Caregiving Post Stroke**

#### **Q9. Summarize the effects of caregiving post stroke.**

##### **Answers**

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

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## F2.4 Family Interventions

## F2.4 Family Interventions

### F2.4.1 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. concluded that helping caregivers to maintain social and leisure activity may result in improved caregiver wellbeing.

#### **Q1. What social support interventions have been shown to help caregivers?**

##### **Answer**

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

##### **Discussion**

Interventions directed toward the family caregiver appear to be positively received and perceived as both useful and necessary. In both the Stewart et al. (1998) and Stewart et al. (2006) studies, the use of peer support, delivered by experienced caregivers, enhanced the perception of support. Caregivers reported that the basis of common experience was important in the provision of emotional and affirmation support (Stewart et al. 1998, Stewart et al. 2006). 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 instance. In addition, given the roles of the individual who has suffered a stroke and the caregiver as members of a family system, it seems more appropriate to offer support in a way that does not exclude one or the other. In the case of the peer visitor intervention, difficulties were reported with providing the intervention solely for the carer (e.g. discomfort or jealousy on the part of the stroke patient) (Stewart et al. 1998). In that instance, the need to include the stroke patient as part of the caregiver/patient dyad was acknowledged and the addition of a parallel intervention for the stroke survivor was suggested. In Stewart et al. (2006), the peer helper intervention was delivered via telephone rather than in person. The impact of this practice on the stroke patient or the caregiver/patient dyad was not reported.

A single study examined the effectiveness of a psychoeducational intervention on the self-care efficacy and well-being of adult caregivers (Won et al. 2008). Overall, participants demonstrated improvement in health risk-taking and well-being; however, caregivers over the age of 65 demonstrated smaller improvements. In addition, the burden of illness of the care

recipient was associated with change in health-risk behaviours such that greater burden was associated with fewer changes.

#### **F2.4.2 Information Provision and Family Education**

**Q2. What is the benefit of providing stroke patients and their families with information and education?**

**Answer**

1. There is strong evidence that a positive benefit, associated with the provision of information and education through a variety of intervention types.

**Q3. What type of information is helpful and how is it best delivered?**

**Answers**

1. Education session may have a greater effect on outcome than the provision of information materials alone.
2. There is strong evidence that skills training is associated with a reduction in depression.
3. There is moderate evidence that training in basic nursing skills improves outcomes of depression, anxiety, and quality of life for both the caregiver and the stroke patient.

#### **Discussion**

Given the impact of stroke on family adjustment, the efficacy of family education as an intervention is gaining considerable importance. Cassas (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. Cassas was unable to detect a significant correlation between education provided to the family of a stroke patient and family adjustment. 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. Bakas et al. (2002) conducted interviews with 14 female, family caregivers of individuals with stroke to examine needs, strategies and advice of caregivers within 6 months of patient discharge to the home environment. From these interviews, 5 central themes of needs and concerns were identified; information, emotions and behaviours, physical care, instrumental care and personal responses to caregiving.

Despite its importance, the issue of family education intervention remains problematic. 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 of individuals undergoing stroke rehabilitation 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. (2003) proposed that further efforts must be made to enhance the knowledge level of family members of patients undergoing rehabilitation. Responses to a UK survey of stroke survivors (n=315) identified provision of

information about stroke, and their own stroke in particular, as the most frequently unmet need of young stroke survivors followed by financial needs, assistance with non-care activities (e.g. social activities), intellectual fulfillment, adaptations, vehicles, social life and physiotherapy (Kersten et al. 2002). A more recent study conducted focus groups and interviews with stroke patients and their carers (Hare et al. 2005). 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. 2005).

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 is stroke 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.

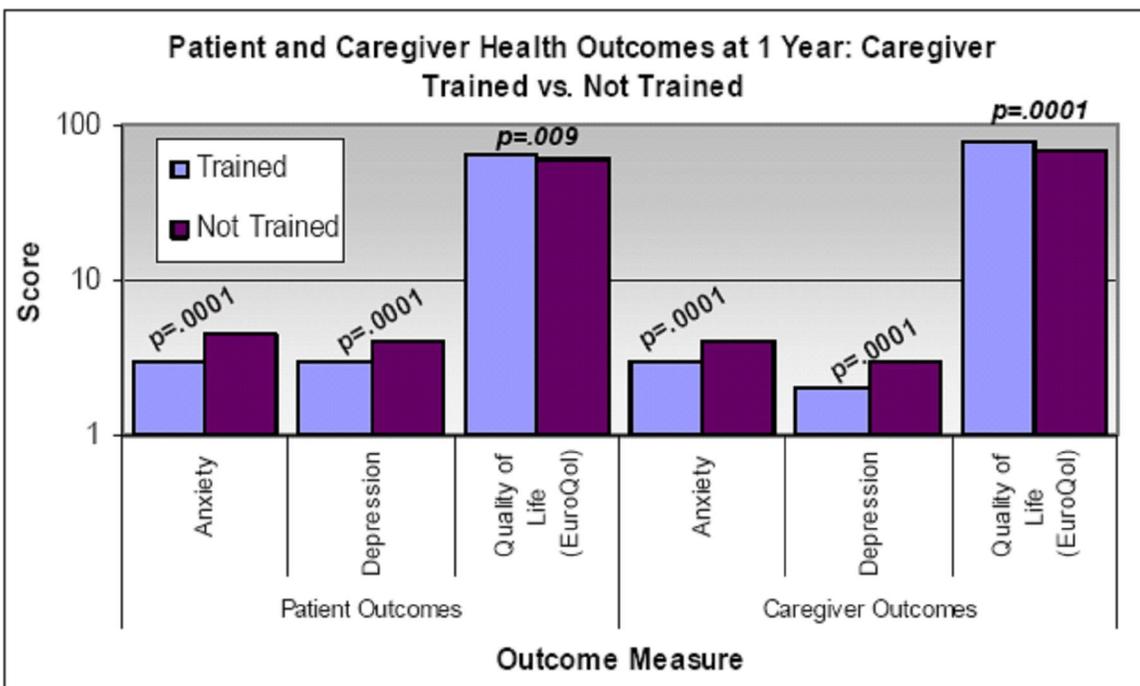
A 1998 review of 10 studies describing family interventions post stroke noted that most interventions focused on the provision of information and that education intervention did improve caregiver knowledge about stroke. Studies including social aspects of support provided less conclusive results, perhaps due to poorer design or the use of more subjective outcomes (Korner-Bitensky et al. 1998). A 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). 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 Interventions 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 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.

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 (Mant et al. 2000; Clark et

al. 2003). 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 (Hoffmann et al. 2007).

**Training carers of stroke patients: a randomized controlled trial (Kalra et al. 2004).**

300 carers of stroke patients were randomised to either training in basic nursing and techniques to facilitate basic personal care or to the control condition. Care costs for patients whose caregivers received training were lower than for those whose carers were untrained ( $p=0.001$ ). Training was associated with less caregiver burden ( $p=0.0001$ ), anxiety ( $p=0.0001$ ), depression ( $p=0.0001$ ) as well as improved quality of life ( $p=0.001$ ). Mortality, institutionalization and functional status of the patient were not associated with caregiver training. Training was associated with lower levels of patient anxiety ( $p<0.0001$ ) and depression ( $p<0.0001$ ). Patients of trained carers also reported higher quality of life than those whose caregivers had not been part of the training intervention ( $p=0.009$ ).



Group education sessions, like information materials, may increase the level of stroke-related knowledge (Evans et al. 1988; Rodgers et al. 1999; van den Heuvel et al. 2002, Schure et al. 2006, Green et al. 2007). In addition, group education sessions may be associated with additional positive effects such as reduced depression (Johnson and Pearson, 2000) improved self-efficacy (van de Heuvel et al. 2002), increased perceived emotional support (Schure et al. 2006), increased competence and lower caregiver burden (Hartke and King 2003). Specific skills training also appeared to have a positive influence on both caregiver (Grant 1999; Grant et al. 2001, Kalra et al. 2004) and patient outcomes (Kalra et al. 2004), and was consistently associated with a reduction in depression. In particular, 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).

#### **F2.4.3 Perceived Needs for Information, Education and Training**

##### ***Q4. Do stroke patients and their families receive adequate information or teaching?***

##### ***Answers***

1. 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.
2. Caregivers rarely receive adequate training in skills they require to care for the stroke survivor.
3. 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.
4. Written materials should be suited to the educational/reading level of the intended recipient.

##### ***Discussion***

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 and Horowitz 1987). The role of caregiver may be perceived simply as an accepted obligation (Sit et al. 2004, Hare et al. 2005). The demands associated with learning how to appropriately care for and support the stroke survivor may be perceived as overwhelming by the carer (Grant et al. 2004a).

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. (2004) 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.

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).

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 ½ 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 is stroke 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.

A recent study by King and Semik (2006) reported categories of unmet needs for a sample of 93 caregivers over a period of two years following stroke. During hospitalization and in the first few months at home following stroke, caregivers reported preparation for caregiving (learning care and skills as well as contact with peers for advice regarding skills and managing uncertainty) as an important area in which needs were not met. Overall, home health care, spiritual support, stroke prevention information, talking to peers, recreation services (survivor), vocational services (survivor), counselling, support groups, stress management and respite were rated as important services by more than ½ of caregiver participants. Despite ratings of importance, many support services were used infrequently. For example, talking to peers was rated as important by 83% of participants, but only 32% actually accessed such a resource. Similarly, support services such as respite and stress management were rated as important, but used infrequently. The most frequently used community support services were home health care and spiritual support. Unfortunately, reasons for disparity between importance of service and frequency of use were not provided.

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## Key Study: Social Support Interventions

Friedland JF, McColl M. Social support intervention after stroke: results of a randomized trial. *Arch Phys Med Rehabil* 1992;73:573-581.

Author / Year Country PEDro score	Methods	Outcome
Friedland and McColl 1992 Canada 5 (RCT)	88 patients randomized to receive either Social Support Intervention (SSI) program consisting of between 6 and 12 sessions that involved the subjects and/or members of their supportive system or to receive no specific intervention, although they were free to engage in any supportive relationships or groups available to them.	SSI scores favoured intervention group on scale of quantity of professional relationships, quality of professional relationships and quality of community relationships after the first assessment.

**Importance:** Social support intervention was associated with improvements in both professional and community relationships. This was the only study identified that examined the effect of intervention on social support networks.

**Relevant SREBR Conclusions:** There is moderate evidence that social support interventions result in improved quality and quantity of professional and community-based informal relationships as well as increased knowledge about stroke and reduced feelings of social isolation.

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Christie D, Weigall D. Social work effectiveness in two-year stroke survivors: A randomised controlled trial. *Community Health Studies* 1984;8:26-32.

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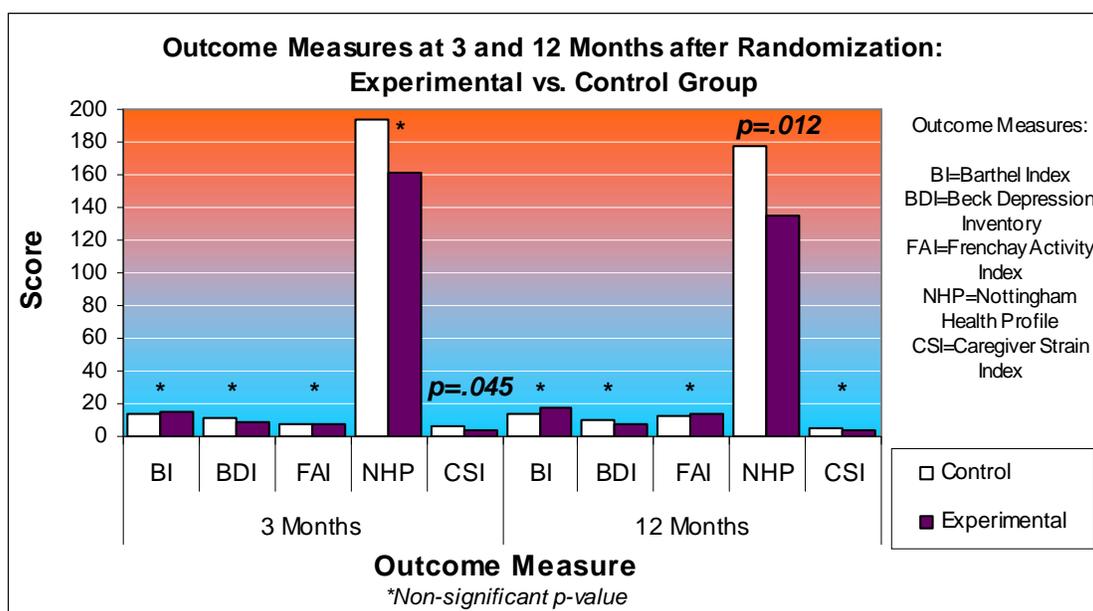
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## Key Study: Social Support Interventions

Burton C, Gibbon B. Expanding the role of the stroke nurse: a pragmatic clinical trial. *J Adv Nurs* 2005;52:640-650.

Author / Year Country PEDro score	Methods	Outcome
Burton and Gibbon 2005 UK 7 (RCT)	176 inpatients with stroke were recruited from 2 district hospitals. Patients were randomly assigned to receive either extended stroke nurse follow-up post discharge (n=87) or usual care (n=89). Intervention included a single visit from a stroke nurse within 2 days following discharge to plan further follow-up. Subsequent follow-up/visits were determined according to need. Average number of contacts was 3. Contact was maintained for an average of 2 months. Control group participants received no further contact from the stroke nurse following discharge. Assessments included the Barthel Index, Nottingham Health Profile, Beck Depression Inventory, Frenchay Activities Index and the Caregiver Strain Index at 3 and 12 months post stroke.	Patients in the intervention group were less likely to experience deterioration on the BI when compared to the control group (p=0.049) over 12 months. Intervention patients experienced greater improvement in perceived health than control patients (NHP, p=0.039). At 3 and 12 months, patients in the intervention group reported lower levels of emotional distress (p=0.01, p=0.037) and social isolation (p=0.045 and p=0.002) than the control group. At 3 months, caregivers of intervention patients reported lower levels of stress than caregivers of control patients (p=0.045). This difference was no longer apparent at the 12 month assessment period.



**Importance:** Patients involved in the Forster and Young (1996) study who had received the specialist nursing intervention, reported that they had received a valuable and individualized service that provided them with practical help, information and social support through the interest and encouragement of the visiting nurse (Dowswell et al. 1997). This large study by

Burton and Gibbon (2005) provided evidence that post-discharge nursing support is associated with improved health status, reduced emotional distress and social isolation for patients as well as reduced stress for caregivers.

**Relevant SREBR Conclusions:** There is strong evidence that social support interventions delivered via social worker or outreach nursing home visits are not associated with increased social activity, well-being, quality of life or perceived social support. There is strong evidence that interventions designed to help survivors access community-based support services are associated with increased social activity. There is conflicting evidence that social support interventions are associated with a reduction in caregiver burden or strain.

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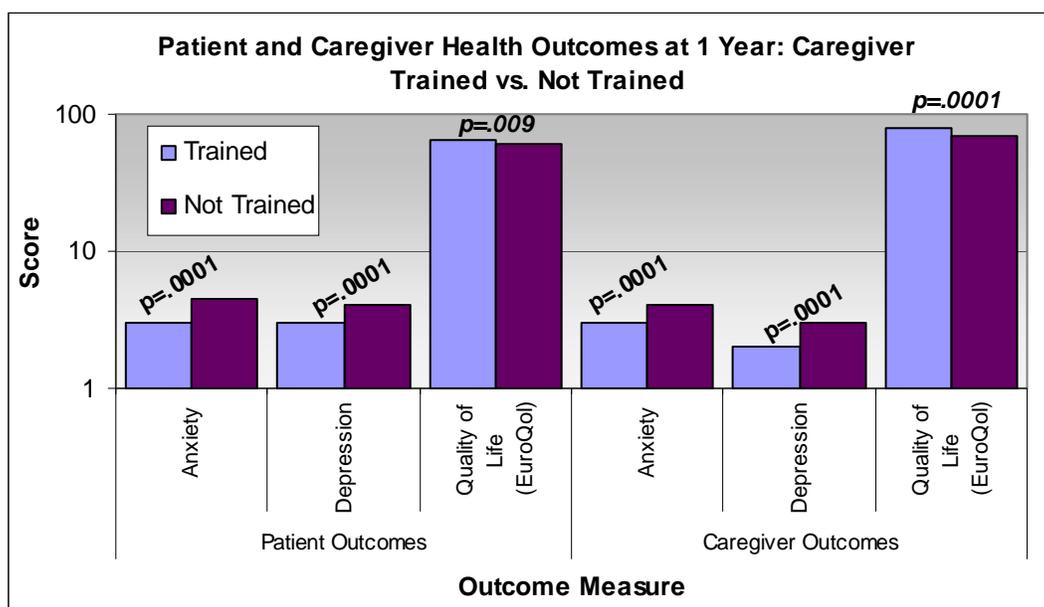
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## Key Study: Social Support Interventions

Kalra L, Evans A, Perez I, et al. Training carers of stroke patients: randomised controlled trial. *BMJ* 2004;328:1099.

Author / Year Country PEDro score	Methods	Outcome
Kalra et al. 2004 UK 7 (RCT)	300 carers of stroke patients were randomised to intervention or control conditions. Participants in the control group received training in basic nursing and techniques to facilitate basic personal care. Outcomes assessed included cost to health and social services systems, caregiving burden, functional status of both patient and carer (BI and FAI), psychological state, quality of life, and patient's institutionalization or mortality at one year post stroke.	Care costs for patients whose caregivers received training were lower than for those whose carers were untrained ( $p=0.001$ ). Training was associated with less caregiver burden ( $p=0.0001$ ), anxiety ( $p=0.0001$ ), depression ( $p=0.0001$ ) as well as improved quality of life ( $p=0.001$ ). Mortality, institutionalization and functional status of the patient were not associated with caregiver training. Training was associated with lower levels of patient anxiety ( $p<0.0001$ ) and depression ( $p<0.0001$ ). Patients of trained carers also reported higher quality of life than those whose caregivers had not been part of the training intervention ( $p=0.009$ ).



**Importance:** This study is important because it demonstrates that specific skills training appears to have a positive influence on both caregiver and patient outcomes, and was consistently associated with a reduction in depression. In particular, 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.

**Relevant SREBR Conclusions:** There is strong evidence that skills training is associated with a reduction in depression. There is moderate evidence that training in basic nursing skills

improves outcomes of depression, anxiety and quality of life for both the caregiver and the stroke patient.

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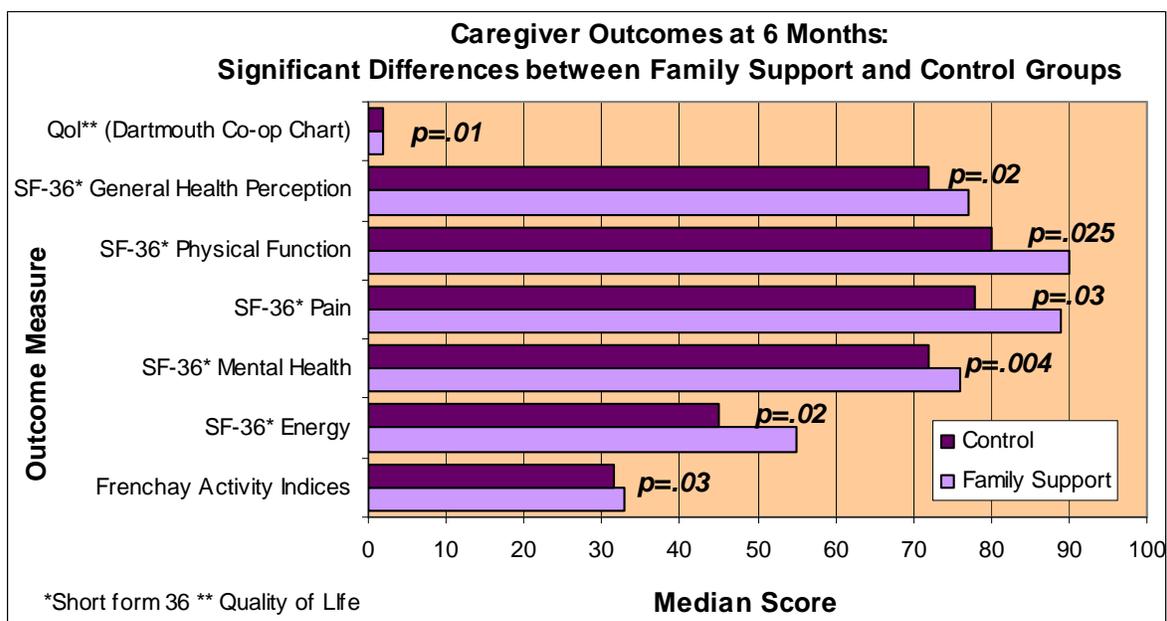
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## Key Study: Social Support Interventions

Mant J, Carter J, Wade DT, Winner S. Family support for stroke: a randomised controlled trial. *Lancet* 2000;356:808-813.

Author / Year Country PEDro score	Methods	Outcome
Mant et al. 2000 UK 8 (RCT)	Single blind trial of 520 patients and carers randomized to receive either family-support care with the use of an information package or usual post-stroke care.	Carers in the intervention group had significantly better Frenchay activity indices, and SF-36 scores of energy, health, pain and physical function. Carers of the intervention group were more satisfied with their understanding of stroke, its causes, and how to prevent another stroke. A further analysis of this study based on data collected at one year post stroke (Mant et al. 2000) demonstrated no evidence of benefit to the stroke patients. Patients with greater contact with the family support organizer were more likely to be followed up. Benefits to carers seen at 6 months (Mant et al. 2000) persisted at one year, although this was no longer significant (Mant et al. 2005).



**Importance:** Information provision and/or education have a generally positive effect on a variety of outcomes (such as health related quality of life and extended activities of daily living) for patients and their families. Information provision alone appears to have the most limited effect. However, the addition of either a family support worker may increase the positive effects associated with the provision of information materials, particularly for carers.

**Relevant SREBR Conclusions:** There is strong 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.

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**F3. Sexuality**

### F3. 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 (Gott et al. 2003). 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 et al. 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 and Harrison 2004).

#### F3.1 Decreased Sexuality Following Stroke

**Q1. Describe reasons for decreased sexual activity following a stroke.**

**Answer**

1. Sexual activity is generally decreased following a stroke.
2. Sexual drive is still present.
3. Main barriers to sexual activity are physical impairments and psychological factors.
4. Physical impairments include physical limitations and lack of communication
5. Psychological factors include a changed body image, reduced self-esteem and fear of another stroke.

**Discussion**

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 and 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 and Harrison 2004); however, little research has been conducted concerning the sexual relationships of stroke survivors and even less has addressed the means by which sexual function, relationships and intimacy following stroke may be improved.

Decreased sexual activity or abstinence is common following a stroke. In some studies, more than 80% of the participants have reported a decline in sexual frequency (Buzzelli et al. 1997). Fugl-Meyer et al. (1980) 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 and 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 (Korpelainen et al. 1999; Cheung 2002; Carod 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). However, few studies (Sjogren and Fugl-Meyer 1981) have linked arousal dysfunction directly to dissatisfaction.

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 (Korpelainen et al. 1999; Cheung 2002; Giaquinto et al. 2003). 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; Cheung 2002; Buzzelli et al. 1997; Murray and Harrison 2004). 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 (1998) 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. Open discussion is the basis of recommendations made as part of recently published Dutch clinical guidelines (van Heugten et al. 2006 – see Table 19.23). In the absence of intervention studies, these recommendations are based on limited and consensus level evidence (van Heugten et al. 2006). 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 and 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 and Fugl-Meyer 1982). A recent 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. 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.

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## F4. Driving

## F4. Driving

### F4.1 The Importance of Driving to Stroke Survivors

#### **Q1. How important is driving to stroke survivors?**

##### **Answer**

1. Driving represents the final step towards independence and reintegration into the community.
2. Failure to resume driving negatively impacts social activities and overall wellbeing.

##### **Discussion**

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.”* Stroke patients who do not resume driving report that this decision negatively impacted social activities and wellbeing (MacKenzie and Paton, 2003).

#### **Q2. How might a stroke compromise driving ability?**

##### **Answer**

1. Visual field deficit.
2. Inattention, particularly left neglect.
3. Cognitive deficits (problem solving).
4. Hemiplegia or hemiparesis
5. Apraxias

##### **Discussion**

The ability to drive is dependent on good vision and reflex response, quick decision-making and keen attentiveness, which may be compromised by perceptual, cognitive and physical disorders that often accompany stroke. Vision and attention are necessary elements for safe driving. Residual cognitive and perceptual deficits often follow a stroke experience and, as noted by Fisk et al. (2002), the vision and attention of stroke survivors are often impaired. A recent study by Smith-Arena et al. (2006) reported that failure on an off-road driving evaluation following discharge from rehabilitation was associated with greater cognitive impairment and motor weakness assessed on admission to rehabilitation. 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). 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

and Paton 2003), there were no significant differences in road sign recognition and comprehension between patients who resumed driving and those who did not.

## F4.2 The Assessment of Driving Post Stroke

### **Q3. What assessment tools are available to assess a stroke survivor's fitness to drive?**

#### **Answer**

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

#### **Discussion**

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).

According to Section 9 of the Canadian Medical Association's Determining Fitness to Drive, 6<sup>th</sup> edition (2000), *"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."*

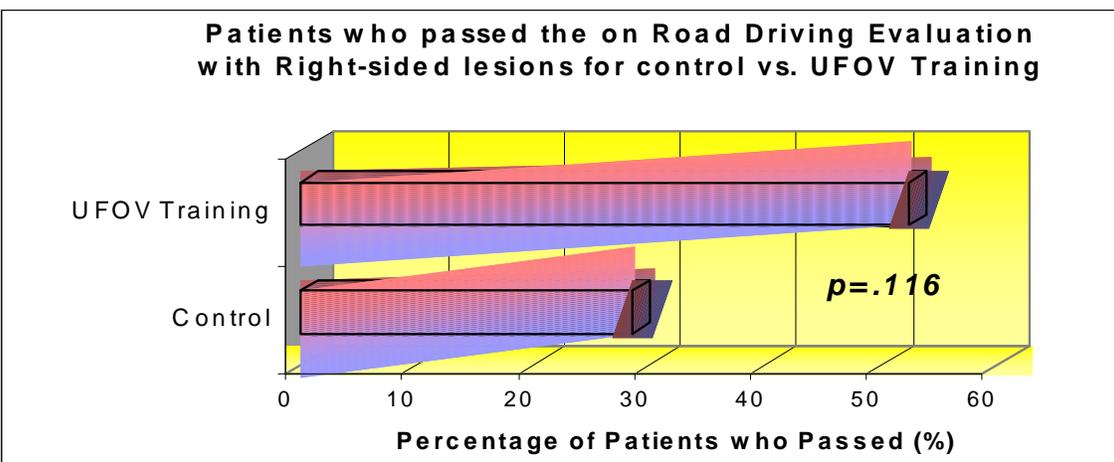
The same document added, *"patients who have had a stroke should not drive for at least one month. During this time they require assessment by their regular physician. They may resume driving if functionally able and if a neurologic assessment discloses no obvious risk of sudden recurrence and any underlying 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."*

Lincoln et al. (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 ( $R^2 = 0.53$ ), the road test's predictive abilities were even lower ( $R^2 = 0.28$ ). 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, Akinwuntan et al. (2005) 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. 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. 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. 2002, Akinwuntan et al. 2007). 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.

**Effectiveness of a visual attention retraining program on the driving performance of clients with stroke (Mazer et al. 2003).**

97 patients with recent hemispheric stroke (within 6 months) and with a license to drive before the referent stroke were randomized to either visual information-processing training using Useful Field of View (UFOV; a visual attention analyzer) or to a control group (visuperceptual retraining with commercially available computer software). Both groups received 20 sessions (2-4, 30-60 minutes session a week).



There were no significant differences between groups on any of the outcome measure. There was however, almost a 2-fold increase (52.4% vs. 28.6%) in the rate of success on the on-road driving evaluation after UFOV training for patients with right-sided lesions.

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) provided a note of caution in relying too heavily upon neuropsychological or cognitive testing alone in the prediction of driving fitness. The authors noted that those patients judged to be not suitable to drive immediately performed well in neuropsychological testing but poorly on the road-driving test. Similarly, Soderstrom et al. (2006) reported no association between the results of neuropsychological testing and on-road driving performance. In addition, patients who failed but were provided with on-road instruction subsequently passed the on-road evaluation, with no corresponding improvement in their cognitive test scores. Akinwuntan et al. (2002) suggested that the inclusion of more real-road-related tests in the pre-driving assessment was necessary.

#### ***Q4. Are stroke survivors good accurate judges of their own ability to drive?***

##### ***Answer***

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

##### ***Discussion***

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. 2008). 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. 2008). 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. 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. (2008) 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.

**Q5. When the stroke patient does return to driving what situations would you advise them to avoid?**

**Answers**

1. Driving in an unfamiliar area.
2. Driving at night.
3. Driving when tired (includes long distances).
4. Parallel parking.
5. Driving in rush hour, especially in a larger city.
6. Driving on busy multi-lane highways.

**Discussion**

Fisk et al. (1997) noted that, despite demonstrable deficits, many stroke survivors make decisions regarding their driving without professional advice and/or evaluation. Although it has been observed that stroke patients may self-regulate their driving and reduce their “*driving exposure*” (Fisk et al. 2002), they also reported more problems in dealing with difficult driving conditions such as driving alone, parallel parking, making left turns through traffic or driving during rush hour than non-stroke drivers. MacKenzie and Paton (2003) reported changed driving habits in aphasic patients who had resumed driving post stroke including increased carefulness, and reduced distance and frequency of driving. However, it would be prudent for rehabilitation professionals to devote more time and resources to driving issues when dealing with stroke survivors and their families (Fisk et al. 1997).

**F4.3 Interventions to Improve Driving Post Stroke**

**Q6. What is the evidence for treatment interventions in patients not able to drive?**

**Answers**

1. There is moderate evidence that a visual attention retraining program is no more effective than traditional visuoperception retraining in improving the driving performance of patients with stroke.
2. There is moderate evidence that a simulator training program involving the use of appropriate adaptations and driving through complex scenarios similar to real life is associated with improvement in driving fitness and successful on road evaluation.
3. Visual attention retraining does not improve driving fitness in stroke survivors more than traditional visuoperception retraining.
4. Driving fitness may be improved through the use of a stimulator training program.

## **Discussion**

Despite the effort applied to determining how to evaluate the driving ability of stroke survivors, very little attention has been paid to how one might intervene to improve the driving ability of stroke survivors.

Akinwuntan et al. (2005) randomized 83 patients to undergo simulator-based training or a control treatment involving driving-related cognitive tasks. After five weeks of training, patients in both groups demonstrated significant improvement on the post-training assessments. Although the experimental group showed a greater degree of improvement, no significant differences were found in terms of the visual or neuropsychological assessments. However, significantly more patients in the experimental group passed an on-road driving test than patients in the control group (73% vs 42%). While these results are promising, further research is needed to evaluate the effectiveness of simulator training. In contrast, there is no evidence that visual attention retraining is more effective than traditional visuoperception retraining in improving post-stroke driving ability (Mazer et al. 2003). There is, however, some indication that younger patients (< 65) may be more likely to improve with training (Klovora et al. 1995) and that training may be most effective if it targets specific skills (Mazer et al. 2003).

## **Case Study**

*A 63-year old gentleman presented with a moderate-sized right middle cerebral artery infarct involving the anterior parietal and temporal regions. He was admitted to rehab 7 days after having suffered his infarct which is as result of occlusion of the internal carotid artery. On initial testing he has evidence of a significant left hemiparesis. He is a Chedoke McMaster Scale 2 in the arm, 2 in the hand, 3 in the leg and 2 in the foot.*

*He responds well to 6 weeks of rehabilitation. Near the time of discharge his motor function has improved. His leg is now a 5/7 and his foot 4/7. His arm is 4 and his hand is 3. His MVPT testing near the time of discharge is 29 and it took him 12 seconds to complete. Therapists report that he still has a tendency to bump into the door jams on the left side but this has improved dramatically. There are no visual field deficits.*

*Just prior to discharge this gentleman informs you that he wishes to drive and asks you if that is a possibility.*

## **Q7. Describe your management of this case with regard to driving.**

1. Inform Ministry of Transport.
2. Occupational therapy testing (MVPT >30 and Brake Reaction Test).
3. Visual field testing (eye specialist).

#### 4. On-The-Road testing.

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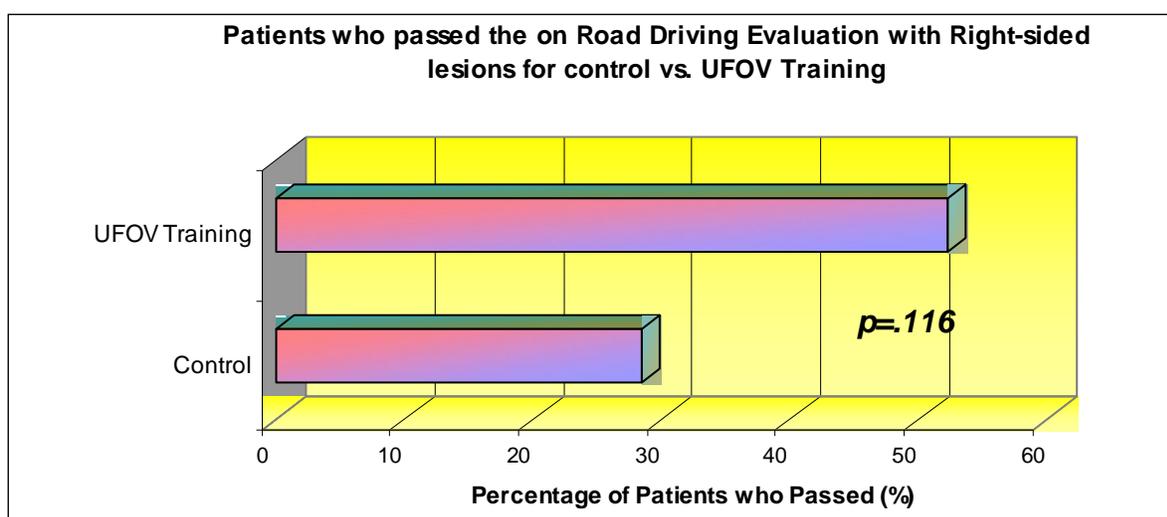
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## Key Study: Psychosocial Interventions

Mazer BL, Sofer S, Korner-Bitensky N, Gelinas I, Hanley J and Wood-Dauphinee S. Effectiveness of a visual attention retraining program on the driving performance of clients with stroke. *Arch Phys Med Rehabil* 2003;84:541-550.

Author / Year Country PEDro score	Methods	Outcome
Mazer et al. 2003 Canada 7 (RCT)	97 patients who had suffered a recent hemispheric stroke within the 6 months and with a license to drive before the referent stroke were randomized to either a experimental group undergoing visual information-processing training using Useful Field of View (UFOV; a visual attention analyzer) or to a control group undergoing visuperceptual retraining with commercially available computer software. Both groups received 20 sessions (2-4, 30-60 minutes session a week). Patients were evaluated on the Useful Field of View, on-road driving evaluation, visuperception tests, and test of everyday attention.	There were no significant differences between groups on any of the outcome measure. There was however, almost a 2-fold increase (52.4% vs. 28.6%) in the rate of success on the on-road driving evaluation after UFOV training for patients with right-sided lesions. Rehabilitation that targets visual attention skills was not significantly more beneficial than tradition perceptual training in improving the outcomes of an on-road driving evaluation. Results suggest that a potential improvement for subjects with right-sided lesion, indicating that training must target specific skills.



**Importance:** Driving represents both independence and a return to life within the community. While both attention training and traditional visuperceptual retraining may result in improved performance of on-road driving evaluations for individuals who have experienced stroke, in general, individuals with right-sided stroke, may derive increased benefit from training that targets specific skills.

**Relevant SREBR Conclusion:** There is moderate evidence that a visual attention-retraining program is no more effective than traditional visuperception retraining in improving the driving performance of patients with stroke.

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**F5. Returning to Work Post Stroke**

## F5. Returning to Work Post Stroke

### **Q1. What approach would you take with getting stroke survivors back to work?**

#### **Answers**

1. A substantial proportion of stroke survivors who were employed prior to the stroke event do not return to work.
2. Factors influencing return to work include the degree of physical and cognitive impairment, age, educational level and type of pre-stroke employment.
3. There is consensus opinion that stroke survivors who worked prior to their stroke should, if their condition permits, be encouraged to be evaluated for their potential to return to work.
4. Vocational rehabilitation strategies to assist the return to work of stroke survivors need to be developed and evaluated.

#### **Discussion**

In a 2002 review of studies reporting on the return to work, Wozniak and Kittner 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 and 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.

A recent survey of unmet needs in young stroke survivors in the UK (mean age = 57) reported that individuals who did not return to work had more unmet needs than those who did (Kersten et al. 2002). Return to work has also been associated with improved subjective wellbeing and life satisfaction (Vestling et al. 2003). Despite its importance, relatively few studies have examined issues surrounding the vocational rehabilitation of the stroke survivor.

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. A stroke patients’ return to work is dependent on several factors. Patients’ educational and occupational status pre-stroke greatly influences the likelihood of their return to work. As noted by Smolkin and Cohen (1974), less educated stroke survivors had difficulties returning to work. Likewise, blue collar workers or those holding farming jobs were less likely to return to work than those who held professional-managerial positions pre-stroke (Howard et al. 1985). Vestling et al. (2003) confirmed that the type of profession, white vs. blue-collar work, is predictive of return to work. In addition to increasing the likelihood for a return to work, employment in a white-collar profession was the most important identified determinant of high levels of subjective wellbeing and life satisfaction (Vestling et al. 2003).

Residual deficits secondary to the stroke also influence the likelihood of a patient’s return to work. Those patients with motor functioning impairments (Fugl-Meyer et al. 1975) and presence

of cognitive impairments and hemiparesis (Kotila et al. 1984) often experience difficulty returning to work. As noted by Weisbroth et al (1971), ambulation, use of affected upper extremity and non-verbal abstract reasoning skills are all factors associated with increased likelihood of left hemiplegic patients returning to work, while lack of verbal cognitive and communicative deficits increases the likelihood of right hemiplegic patients return to work. Likewise, Vestling et al. (2003) identified the ability to walk and the absence of cognitive impairment as important predictors of return to work.

Despite the identification of factors relating to the ability of an individual to resume employment following a stroke event, no studies examine specific vocational rehabilitation strategies that might improve the ability of the stroke survivor to resume a productive working role. 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). Leng (2008) reported that the majority (55%) of individuals receiving employment services from a community-based agency were successful in returning to paid employment. 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.

Recent 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*”: *The committee did “Recommend that all patients, if their condition permits, be encouraged to be evaluated for the potential of returning to work. Recommend that all patients who were previously employed be referred to vocational counselling for assistance in returning to work. 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.*

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