

Individual Analysis of Temporal Processes to
Investigate Memory and Attention in Long-
Term Stroke Survivors

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Author's Declaration

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Abstract

Memory and attention deficits are common sequale following stroke. Despite this, our understanding of these impairments, ways to rehabilitate them and the influence of other variables on these cognitive functions is limited. This thesis incorporates a person-specific methodology to explore in more depth memory and attention problems in long-term stroke survivors. Five studies are reported, the first two are systematic reviews which concluded that there is some evidence in support of memory and attention rehabilitation and physical mobility rehabilitation post-stroke but that the methodological quality of the N-of-1 studies is weak. The second systematic review also revealed that there have been no studies carried out with the aim of increasing overall levels of physical activity in stroke. Studies three and four investigated memory and attention problems in long-term stroke survivors using objective and subjective measures, and assessed the extent to which fluctuations in mood, anxiety and sleep quality and caregiver psychological and behavioural characteristics influenced self-reported memory and attention. Results showed that long-term stroke survivors experience a range of memory and attention deficits but fluctuation in test performance indicates within-person variability. The studies also showed that memory and attention was temporally associated and predicted by their own mood, anxiety and sleep quality and caregiver mood, anxiety and sleep quality, but the patterns of associations and the effects of the predictors varied across stroke survivors. The final study assessed the feasibility of a combined walking and cognitive training programme with the aim of improving memory and attention. It was concluded that the study was not feasible as it stands. Several methodological amendments would have to be made and then the effects of these changes examined

thereafter. Together, the results have implications for the assessment and the rehabilitation of memory and attention functions post-stroke.

Chapter One

Introduction

1.1 Stroke Definition, Prevalence and Incidence Rates, Risk Factors, and Effects of Stroke on Stroke Survivors and Caregivers

Stroke is defined as ‘a syndrome of rapidly developing symptoms and signs of focal, and at times global, loss of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin’ (World Health Organisation, 1988).

There are two main classifications of stroke: ischaemic and haemorrhagic. An ischaemic event occurs when an artery becomes blocked starving the brain of oxygen and nutrients (Adams et al., 2003). This type of stroke accounts for approximately 85% of all cases. Haemorrhagic strokes account for the remainder of stroke events and they can be intracerebral or subarachnoid. An intracerebral stroke occurs when a blood vessel in the brain bursts mainly as a result of hypertension. Subarachnoid stroke is a spontaneous bleed within the subarachnoid space between the arachnoid membrane and pia mater, typically caused by abnormal weak arteries (Donnan, Fisher, Macleod, & Davis, 2008). Both ischaemic and haemorrhagic strokes can lead to impairment, disability, activity limitations and participation restriction (Stephens et al., 2004; Tatemichi et al., 1994).

In the UK, stroke is the third major cause of death after heart disease and all cancers and the most common cause of severe adult disability. Approximately 1.1 million adults in the UK are living with stroke and its consequences, and about 12,500 individuals suffer a stroke each year (Townsend et al., 2012). Around 20% of stroke survivors die within 30 days of stroke onset (Scottish Intercollegiate

Guidelines Network, 2010), and about a third will be left with residual disabilities (The Scottish Government, 2008). In developed countries, advances have occurred in the prevention and treatment of stroke resulting in a reduction of mortality rates (Donnan et al., 2008), but despite a decrease in deaths by stroke, incidence and prevalence rates are likely to rise due to an ageing population and an increase in risk factors.

Risk factors for stroke include hypertension, atrial fibrillation, high cholesterol levels and diabetes. Lifestyle behaviours such as having a poor diet, smoking, drinking alcohol and physical inactivity also increase the risk of stroke (Hart, Benavente, McBride, & Pearce, 1999; Lee, Folsom, & Blair, 2003). Physical activity is a key factor to target. Leading an active lifestyle can have a positive effect on risk factors for cerebrovascular disease such as reducing hypertension and lowering cholesterol levels and has the potential to improve psychological health and cognitive functioning. Despite these benefits, stroke survivors tend to be inactive following a stroke which can lead to subsequent physical and psychological consequences. Physical inactivity may also hinder recovery, independence and participation in activities out-with the home environment. Research studies addressing barriers to physical activity post-stroke are limited, but stroke survivors are likely to need support to assist them to lead a healthier active lifestyle.

A stroke can cause a wide range of both physical and psychological problems. The following list is not exhaustive but to provide a sense of the range of post-stroke effects several difficulties are noted. Physical problems include gait and balance impairment, impaired motor control and muscle tone, and neuropathic and musculo-skeletal pain. Language conditions such as aphasia, apraxia of speech and

dysarthria are also a consequence of stroke, and there may be visual impairments such as reduced peripheral vision. As well as these difficulties, stroke survivors may also experience emotional problems such as depression and anxiety and suffer from cognitive deficits in domains such as memory, attention, perception and executive function (Lincoln et al., 2012).

The psychological well-being of caregivers of stroke survivors can also be compromised. For example, increased levels of depression have been observed in carers of family members who have mild cognitive impairment (Blieszner & Roberto, 2010). This means that the caregivers of those who have suffered brain trauma are affected by it too.

1.2 The Current Literature and its Limitations

The starting point of this thesis was a review of the literature on post-stroke cognitive functioning, cognitive rehabilitation for acquired brain injury, physical activity levels following stroke and on the relationship between physical activity and cognitive functioning. This revealed that, to date, very few studies have focused on memory and attention functions and the rehabilitation of these in long-term stroke survivors. It was typically thought that once brain injury had occurred the damage was lasting and because of this view not much emphasis was placed on the rehabilitation of cognitive functions, particularly one-year post-injury. Now, it is recognised and accepted that brain plasticity, in the form of neuronal re-growth and re-organisation, can take place months and even years following a brain insult. The consequence of this is that there is potential for cognitive deficits to be remediated which could improve the lives and well-being of stroke survivors and their families,

reduce health care costs, and allow younger stroke survivors and carers to continue in employment.

The review of the literature also revealed that a significant proportion of research studies have adopted a group design. The group-based approach allows the researcher to manipulate and test the effects of an independent variable on an outcome using a large number of participants, and is beneficial in designs where there is a need to consider a range of treatments. Randomised control trials are the gold standard for assessing the overall efficacy of interventions for clinical populations, but this approach may lead to difficulties in assessing treatment effects for individual stroke survivors since the varying nature of the brain injuries sustained within stroke make this an heterogeneous clinical group. Therefore, studies that average data with the view of generalising outcomes will provide indications as to whether a treatment will be efficacious, but the effectiveness of the treatment for each individual needs to be assessed. Consequently, this thesis focuses on assessing the use of an individual-based methodology in describing post-stroke abilities and in the development and testing of a complex intervention. Various terms have been proposed for this type of method such as N-of-1 and single-case designs, however there are limitations with these terminologies. As a result, a new term is proposed, Individual Analysis of Temporal Processes (IATP), to capture the individual aspect of the research process, and to highlight that the data are analysed using time series. The term IATP is used for the studies included in this thesis, however the terms case studies and N-of-1 will be used to refer to other studies in the existing literature.

From reading the literature, other research ideas developed. For example, there is limited knowledge of how factors such as mood, anxiety, sleep quality and

caregiver behavioural and psychological characteristics might affect memory and attention in stroke survivors. Research in other areas, such as traumatic brain injury (TBI) and healthy populations, inform us that cognitive functioning can be influenced by affective states and a variety of other factors. Additionally, very few studies have investigated the dyadic relationships between survivor and carer, and how these might impact on cognitive abilities. So, developing more of an understanding of the relationships between memory, attention and other phenomena in stroke survivors is an important research endeavour.

Finally, it is also unknown how best to intervene to assist stroke survivors to increase their levels of physical activity. Similar to the remediation of cognitive deficits, increasing levels of physical activity in stroke survivors has the potential to lead to benefits both at the individual and the societal level.

1.3 Aims of Thesis

To build on previous research and to account for the limitations mentioned above, three studies were designed, implemented and analysed using IATP. Two systematic reviews were also included which support the rationales for the studies.

Following a general review of the literature in Chapter Two, a systematic review of the literature on memory and attention rehabilitation in stroke survivors using a case-study method is presented in Chapter Three. The aim was to review the existing literature in this area to determine how many studies have been carried out, what their outcomes were and to evaluate their methodological quality.

Chapter Four presents a systematic review of the studies using interventions to increase levels of physical activity and mobility outcomes in stroke survivors using the N-of-1 design. The aim was to review and evaluate the existing literature

and to determine if there are guidelines that inform us how best to increase physical activity levels in stroke survivors.

The aim of Chapter Five was to investigate memory and attention profiles in long-term stroke survivors and explore the relationships between mood, anxiety and sleep quality and these cognitive functions. Specifically, the aims were to explore the nature and degree of memory and attention problems in long-term stroke using objective and subjective tests and to evaluate how self-reports of memory and attention changed over a 12-week period. The final aim was to assess the extent to which fluctuations in mood, anxiety and sleep quality predicted ratings of memory and attention.

Subsequently, Chapter Six details a study investigating caregivers' mood, anxiety and sleep quality and how these factors relate to stroke survivors' memory, attention, mood, anxiety and sleep quality. The caregivers were carers of the stroke survivors recruited in Chapter Five. The specific aims were to assess the dyadic temporal associations between caregivers' and stroke survivors' memory and attention, mood, anxiety and sleep quality and determine the predictive value of these factors on stroke survivors' self-reports of memory and attention.

Following on, Chapter Seven evaluates the feasibility of delivering a combined walking and cognitive training intervention in long-term stroke survivors. A physical activity consultation based on a Behavioural Change Model (Prochaska & Diclemente, 1982) was incorporated to facilitate an increase in walking behaviour. This study also explored the effect of the intervention on memory, attention, and levels of walking and whether mood, anxiety and sleep quality influenced these three outcomes. The final chapter discusses and evaluates the findings of this thesis.

1.4 Definitions: Mood, Anxiety and Physical Activity

This section describes what is meant by mood, anxiety and physical activity within this thesis.

Mood and Anxiety. The term mood is often used interchangeably in the literature with other terms such as affect and emotion. In this thesis, participants were informed that if they felt low or sad this would constitute a bad mood and feeling happy and cheerful would be more akin to being in a good mood. Similarly, if participants were worried or nervous they were to consider this as being indicative of anxiety, but if they were calm or relaxed then low levels of anxiety would be reported. In relation to the questionnaire measures used in this study, the term mood is used to describe a depressive state.

Physical Activity. Physical activity and physical exercise are terms also used interchangeably to define body movement that is associated with energy expenditure and physical fitness. Exercise is a sub-component of physical activity that is planned, repetitive and structured (Caspersen, Powell, & Christenson, 1985), so not all bodily movement can be termed exercise. In addition, the author of this thesis feels that the word 'exercise' is implicated with associations of activity that is of a vigorous intensity which is perhaps disadvantageous in interventions that aim to increase active behaviours in clinical populations who have mobility problems. Therefore, for both reasons, the term physical activity will be used in this thesis to encompass physical activity and physical exercise.

Chapter Two

Literature Review

2.1 Cognitive Functioning Post-Stroke

Cognitive impairments are a frequent consequence of acquired brain damage such as stroke (Lincoln et al., 2012). Cognition is an umbrella term that comprises a number of domains, but the main focus of this thesis is on memory and attention. Memory and attention are not unitary constructs but can be divided into different components. For example, the term memory includes types such as short-term, long-term, working memory, memory for verbal and visual material and prospective memory (Lincoln et al., 2012). Attention is also a broad concept that encompasses several processes such as selective, sustained, divided attention and attentional switching (Posner & Peterson, 1990).

Despite the frequent nature of cognitive problems post-stroke, assessment rates are frequently below the accepted standard, and access to clinical psychologists is often poor (Bowen, Knapp, Hoffman, & Lowe, 2005). This means that there may be more stroke survivors with cognitive impairments than current prevalence rates, which is a concern as deficits in cognitive functions can limit recovery, independent living and participation in activities (Hyndman & Ashburn, 2003; Lesniak, Bak, Czepiel, Seniow, & Czlonkowska, 2008; Mercier, Audet, Hebert, Rochette, & Dubois, 2001; Tatemichi et al., 1994; Viscogliosi, Belleville, Desrosiers, Caron, & Ska, 2011).

Between 20% and 50% of stroke survivors complain about memory difficulties (Nys et al., 2005; Rasquin, Verhey, Lousberg, Winkens, & Lodder, 2002), and several studies have shown impairments in immediate and delayed verbal

memory (Duffin et al., 2012; Gillespie, Bowen, & Foster, 2006; Hoffmann & Schmitt, 2004; Schouten, Schiemanck, Brand, & Post, 2009), working memory (Sachdev, Brodaty, Valenzuela, Lorentz, & Koschera, 2004; Zinn, Bosworth, Hoenig, & Swartzwelder, 2007), episodic memory (Viscogliosi et al., 2011) and prospective and retrospective memory (Kim, Craik, Luo, & Ween, 2009). Verbal memory deficits have been demonstrated to occur primarily after left-hemisphere stroke and visuospatial memory deficits mainly after right-hemisphere stroke (Lim & Alexander, 2009). However, this distinction is not absolute. It is possible for someone to experience visuospatial difficulty after suffering from a left-hemisphere infarct (Lincoln et al., 2012).

Impaired attention is also experienced by stroke survivors. Estimates between 46% and 92% of stroke survivors having attentional difficulties are reported (Hyndman, Pickering, & Ashburn, 2008). Similar to memory, different types of attention can be affected by a stroke. Hyndman and Ashburn (2003) reported that stroke survivors who were on average four years post-stroke experienced visual inattention, difficulties with sustained attention, auditory selective, visual selective attention and/or divided attention. Similar findings on attentional functions have been reported elsewhere (Barker-Collo et al., 2009; Duffin et al., 2012; Stapleton, Ashburn, & Stack, 2001). In relation to other cognitive functions, impaired mental flexibility (Sachdev et al., 2004; Zinn et al., 2007), inhibition difficulties (Sachdev et al., 2004; Viscogliosi et al., 2011), visual neglect (Viscogliosi et al., 2011; Wade, Wood, & Hewer, 1988), impaired abstract reasoning (Tatemichi et al., 1994) and reduced information processing speed (Sachdev et al., 2004) have also been observed post-stroke.

2.2 Factors Influencing Cognitive Functioning: Sleep Quality, Depression and Anxiety

Memory and attention processes can be differentially affected by the neurological damage caused by a stroke, but they may also be affected by subsequent complications such as reduced sleep quality, depressive mood and high anxiety. Research studies investigating the effect of these factors on memory and attention in stroke is limited, and of the studies that currently exist, the focus has been on the effects of only one of these factors rather than the combinations of factors that many stroke survivors experience.

Sleep disorders such as insomnia, sleep apnoea and reduced sleep quality are common post-stroke. Sleep quality is defined by the duration of sleep, sleep disturbance, sleep latency, sleep efficiency and daytime sleepiness (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Sleep apnoea has been investigated most in stroke (Pasic, Smajlovic, Dostovic, Kojic, & Selmanovic, 2011), however studies also indicate that stroke survivors in the acute phase of recovery experience poor sleep quality (Bakken, Lee, Kim, Finset, & Lerdal, 2011) and have fragmented sleep patterns (Cavalcanti, Campos, & Araujo, 2012). Later on in recovery stroke survivors can also suffer from poorer sleep and greater daytime sleepiness (Sterr, Herron, Dijk, & Ellis, 2008). Sleep disturbance has been found to be negatively associated with activities of daily living in humans (Bakken, Kim, Finset, & Lerdal, 2012), and a study by Siccoli, Roelli-Baumeler, Achermann and Bassetti (2008) investigated the association between sleep, memory and attention in stroke. The study showed that the number of waking periods after sleep onset was positively correlated with the number of attentional errors made on a selective attention task,

and negatively correlated with performance on an attention and a verbal memory task. Decreases in slow wave sleep and rapid eye movement sleep were associated with an increase in attentional errors and errors on a verbal memory task whilst sleep efficiency was positively correlated with selective attention performance.

In the TBI literature, Bloomfield, Espie and Evans (2010) examined whether poor sleepers had poorer sustained and general attentional functioning than good sleepers in individuals with acquired brain injury. They reported that patients in the poor sleep group had significantly poorer sustained attention ability than those in the good sleep group. Poor sleepers also displayed significantly more symptoms of depression than the good sleepers. However, the participants in this study had suffered a different type of brain injury so the results may not generalise to the stroke population. A further study by Waldron-Perrine et al. (2012) on sleep quality, memory and attention performance in individuals with TBI showed that sleep quality was predictive of memory test performance. However, the authors used a composite memory score making it difficult to determine exactly which aspects of memory were impaired.

Healthy older adults have also been studied to determine the effects of sleep on cognition. Studies have shown that sleep facilitates visual memory (Mednick, Makovski, Cai, & Jiang, 2009), working memory (Kuriyama, Mishima, Suzuki, Aritake, & Uchiyama, 2008) and sleep loss and partial sleep restriction impairs memory consolidation (Roth, Costa e Silva, & Chase, 2001), attention, executive function, information processing (Van Dongen, Maislin, Mullington, & Dinges, 2003) and decision making (Harrison & Horne, 2000).

Post-stroke depression is a mood disorder that may also influence cognitive functioning. Depression is frequently reported post-stroke with estimates varying between 25% and 79% of stroke survivors being affected (Gordon & Hibbard, 1997), with a pooled estimate of 33% (Hackett, Yapa, Parag, & Anderson, 2005). Depression is characterised by low mood, loss of interest in activities, changes in appetite and sleep, suicidal ideas, feeling of guilt or worthlessness, decreased energy and difficulties in thinking and concentrating (American Psychiatric Association, 1994). Studies have shown depression to be negatively correlated with quality of life (Jonkman, de Weerd, & Vrijens, 1998; Kauhanen et al., 1999) and that positive mood states predict functional recovery post-stroke (Chemerinski, Robinson, & Kosier, 2001).

Kauhanen et al. (1999) investigated the relationship between post-stroke depression and memory, attention and executive functioning at three and six months post-stroke. The findings showed that depression was associated with cognitive functioning and the cognitive domains most affected were memory, attention, non-verbal problem solving and psychomotor speed. A study by Pohjasvaara, Vataja, Leppavuori, Kaste and Erkinjuntti (2002) also investigated the relationship between depression and executive functions and reported that depressive symptomology was associated with executive dysfunction in stroke survivors in the acute phase of recovery.

Research studies conducted on healthy older adults have also shown that depressive symptoms are predictive of cognitive decline in sustained attention, attentional switching, working memory, recall, executive dysfunction and general cognitive status (e.g., Dotson, Resnick, & Zonderman, 2008). Negative associations

between depression and working and long-term memory, selective attention and executive function such as response speed have also been documented (Hasler, Drevets, Manji, & Charney, 2004). Since the prevalence of stroke is higher in older adults there is possibly an additive effect of age and injury on the relationship between depression and cognitive function.

Anxiety may also influence cognitive functioning post-stroke. Anxiety has been studied less than depression in stroke research but estimates of between 22% and 25% of stroke survivors experience anxiety problems (De Wit et al., 2008).

Anxiety disorders are a range of conditions that include generalised anxiety disorder, panic attacks, obsessive-compulsive disorder and post-traumatic stress disorder. Comorbidity can also occur between anxiety and depression (Dean & Vanderploeg, 2010).

To the best of the author's knowledge, there have been no research studies assessing the relationships between anxiety and cognitive functioning in stroke survivors. Nonetheless, anxiety may play a role in memory and attention impairment. One of the characteristics in the clinical diagnosis of generalised anxiety disorder is being unable to concentrate (American Psychiatric Association, 1994) suggesting that impaired sustained attention may arise as a consequence of high levels of anxiety. Anxiety has also been shown to negatively affect processing speed and other cognitive functions in healthy adults (Elliman, Green, Rogers, & Finch, 1997) and in another study it was found that aspects of panic disorder, obsessive-compulsive disorder and social phobia were associated with impairments in episodic memory and executive functioning. Generalised anxiety disorder though was not related to performance in any of the cognitive domains (Airaksinen, Larsson, & Forsell, 2005).

2.3 Cognitive Rehabilitation Following Acquired Brain Injury

Cognitive rehabilitation aims to lessen the effect of cognitive impairment in those who have suffered brain trauma. Two strategies are typically employed. The first approach is restitution training that attempts to retrain cognitive processes that have been impaired by injury. The second approach incorporates strategy training that seeks to develop new compensatory skills to enhance performance on everyday tasks. Attention rehabilitation generally adopts restitution training whereas remediation of memory typically involves the use of compensatory strategies (Cicerone et al., 2005).

Two meta-analyses have examined the effectiveness of cognitive rehabilitation for stroke and TBI (Park & Ingles, 2001; Rohling, Faust, Beverly, & Demakis, 2009). Rohling et al.'s (2009) meta-analysis investigated the effect of rehabilitation on attention, executive, memory, visuospatial and language domains. The analysis included one hundred and fifteen studies with 2,014 participants. Seventy of the studies had single group pre-test post-test designs and 45 used independent group pre-test post-test study designs. Of the 54 that were included on stroke as a pure aetiologic group, 30 of the studies addressed language and 23 were on visuospatial treatments. Only one study (Sturm & Willmes, 1991) examined an attention programme and this showed significant improvements for selective attention and alertness but not vigilance. There were no memory rehabilitation studies on a stroke only population.

Overall, the results of Rohling et al.'s (2009) meta-analysis produced a small treatment effect size ($ES = .30$) for rehabilitation interventions for cognitive problems. A large effect size ($ES = .71$) was found for single-group pre and post-test

designs, indicating that studies that have no control groups produce larger effect sizes. A modest effect size ($ES = .41$) was found for groups that received no treatment, suggesting an effect of practice or natural recovery. Regarding memory and attention, significant effect sizes of ($ES = .61$) and ($ES = .27$) respectively, were found for studies with single-group pre and post-test designs. For the independent group design studies a significant small effect size was found for attention ($ES = .27$), however the effect size for memory was non-significant ($ES = .18, p > .30$).

Park and Ingles (2001) also carried out a meta-analysis but primarily focused the analysis on the effect of attention rehabilitation following stroke, TBI or surgical lesion. Thirty studies involving 359 participants were included. Four of these studies were on stroke survivors (Carter, Oliveira, Duponte, & Lynch, 1988; Hajek, Kates, Donnelly, & McGree, 1993; Sturm & Willmes, 1991; Sturm, Willmes, Orgass, & Hartje, 1997). Carter and colleagues (1988) reported that cognitive skills retraining delivered over a period of 26 days (on average) improved auditory attention. Sturm et al. (1997) examined the effect of a computerised training programme delivered over 14 one-hour sessions and found that alertness and vigilance improved significantly as well as response rate in the selective attention task and error rate in the divided attention task. Whereas, Hajek et al. (1993) found that four weeks of computerised visuo-spatial attention training did not significantly improve visuo-spatial attention.

Overall Park and Ingles' (2001) meta-analysis produced a large ($d = .68$) and a modest effect size ($d = .35$) for direct training for attention, and learning and memory respectively, a result partially consistent with the results reported by Rohling et al. (2009). The abilities of focusing/executing and encoding of

information improved significantly whereas sustained attention did not. Studies using control groups indicated that, attention, learning and memory did not improve significantly after direct attention training. However, significant effects were found for activities of daily living (ADLs) ($d = .49$) and driving ($d = 1.15$) suggesting that specific skills training that require attentional processes is an effective strategy to use. It should be noted though that this meta-analysis failed to examine the effects of rehabilitation in relation to the aetiology of brain injury therefore it is unclear if there were specific effects for stroke only populations.

Three other reviews have examined the effectiveness of cognitive rehabilitation following stroke and TBI (Cicerone et al., 2000; Cicerone et al., 2005; Cicerone et al., 2011). Unlike the meta-analysis carried out by Rohling et al. (2009), these reviews included single-case studies as well as randomised controlled trials (RCTs). Generally, all three reviews conclude that there is evidence for the effectiveness of language and perception rehabilitation programmes after left and right hemisphere stroke, respectively, which echos the conclusions reported by Rohling et al. (2009). The latter two reviews (Cicerone et al., 2005; Cicerone et al., 2011) also reported evidence for the treatment of apraxia after left hemisphere stroke.

The most recent review (Cicerone et al., 2011) included one hundred and twelve studies that assessed the effects of memory, attention, vision and visuospatial functioning, language and communication skills, executive functioning, problem solving and awareness, and comprehensive-holistic rehabilitation. With regards to memory rehabilitation, 15 studies were reviewed, however only four included stroke survivors. One of these studies showed that Process Oriented Training improved verbal memory in stroke survivors who were on average five months post-stroke

onset (Huildebrandt, Bussman-Mork, & Schwendermann, 2006). Two studies had mixed aetiology groups with only two stroke patients in each and showed that errorless learning and rehearsal/repetition of information had a positive effect on memory performance in individuals who were at least 12 months post-stroke (Thickpenny-Davis & Barker-Collo, 2007), and that stroke participants who were 13 and 52 months post-stroke were able to participate in a computerised memory rehabilitation programme (Bergquist, Gehl, Lepore, Holzworth, & Beaulieu, 2008). Finally, Fish, Manly, Emslie, Evans and Wilson (2008) compared the effects of a paging system in stroke and TBI and found that a pager was an effective compensatory tool for memory deficits following stroke. However, stroke survivors stopped using the pager following the intervention whereas those with TBI did not suggesting that stroke survivors may need continued support when using external memory aids.

Two Cochrane reviews have been carried out in stroke only populations in the areas of memory (Das Nair & Lincoln, 2008) and attention (Lincoln, Majid, & Weyman, 2000) rehabilitation. Das Nair and Lincoln's (2008) review included studies that attempted to directly retrain poor memory function or teach stroke survivors compensatory skills. Only studies delivering a memory intervention and those that adopted an RCT design were included. Consequently, only two studies involving 18 participants were reviewed. One of them reported mnemonic techniques as effective strategies to improve memory performance in stroke survivors three to five months post-stroke (Doornhein & de Haan, 1998) and the other, an imagery intervention, did not improve memory performance in stroke survivors (Kaschel et al., 2002). Based on the results of the two studies it was concluded that there is

insufficient evidence supporting or refuting the premise that cognitive rehabilitation is beneficial for memory deficits following stroke (Das Nair & Lincoln, 2008).

The review by Lincoln, Majid and Weyman (2000) included studies that attempted to improve attention and/or functional independence. Only RCTs and quasi-randomised trials were included. Two studies with 56 participants were included in the review (Schottke, 1997; Sturm & Willmes, 1991). Schottke (1997) investigated the efficacy of attention training to improve attentional deficits in 16 stroke survivors and showed marked improvements on attention functions. Sturm and Willmes (1991) found computerised attentional training also improved attention. Lincoln et al. (2000) concluded that attention training was beneficial for alertness and sustained attention but the effect of attention training was not transferred to functional independence measures.

Since Rohling et al.'s (2009) meta-analysis and Cicerone et al.'s (2011) review a few more studies have been published. The effectiveness of Attention Process Training (APT) in stroke survivors who were 18 months post-stroke was examined by Barker-Collo et al. (2009). They found that those who received APT demonstrated significantly greater improvements in attentional functioning. Another study by Chen, Hartman, Priscilla Galarza and DeLuca (2012) found that Global Process Training significantly improved visuospatial memory deficits in people who were on average 48 days post-stroke. A memory self-efficacy intervention showed that stroke survivors' memory self-efficacy increased post-stroke but this outcome had no effect on verbal memory capacity (Aben, Busschbach, Ponds, & Ribbers, 2008).

Overall, from the meta-analyses, reviews and independent studies it can be concluded there is partial evidence to support the effectiveness of cognitive rehabilitation for memory deficits following stroke, although the evidence is limited and not strong. There is also limited evidence that attention rehabilitation can improve some aspects of attention such as focus, alertness and sustained attention post-stroke.

2.4 Physical Activity

“The potential benefits of physical activity to health are huge. If a medication existed which had a similar effect, it would be regarded as a ‘wonder drug’ or ‘miracle cure’.”

(Sir Liam Donaldson, 2009)

Despite the benefits of being physically active it has been reported that stroke survivors do not meet the minimum physical activity recommendations (Rand, Eng, Tang, Jeng, & Hung, 2009). Exercise after stroke guidelines propose that stroke survivors should aim to achieve moderate levels of physical activity for 20-30 minutes each day and should include cardiorespiratory activities, and balance, co-ordination, and flexibility exercises to improve functional strength (Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings, 2010).

Patterns of physical activity and inactivity in stroke survivors in the acute phase of recovery have been observed showing that between the hours of 8am and 5pm, more than 50% of the time was spent lying in bed, 28% was spent sitting and

only 13% of time was spent engaged in activities (Bernhardt, Dewey, Thrift, & Donnan, 2004). Physical inactivity is also evident from the point of hospital discharge. On returning home many stroke survivors lead sedentary lifestyles, walk less than their aged-matched counterparts (Moore, Roth, Killian, & Hornby, 2010) and have low mean oxygen consumption levels indicating poor physical fitness (Michael, Allen, & Macko, 2005). This is particularly concerning as reduced levels of physical activity after stroke can lead to physical deconditioning, further reducing the efficiency of the cardiovascular system and increasing the risk of a further stroke. Reduced participation in activities may also contribute to psychological problems and social isolation (Rand et al., 2009).

The literature on motivators and barriers to physical activity participation post-stroke is limited. However, several studies have started to investigate predictors of physical activity, namely walking behaviour. Better quality of life, physical functioning, balance and performance on the six-minute walk test were predictors of daily step counts (Tiedemann et al., 2012). Bonetti and Johnston (2008) found that perceived behavioural control and self-efficacy predicted walking recovery and another study showed that balance and falls self-efficacy predicted walking (Robinson, Shumway-Cook, Matsuda, & Ciol, 2011).

With regards to barriers, factors such as low levels of perceived control (Bonetti & Johnston, 2008), low levels of self-efficacy and confidence, and fear of falling are reported as preventing physical activity participation (Shaughnessy, Resnick, & Macko, 2006). Other studies have found that feeling tired, poor general health (Payne, Greig, Young, & Mead, 2001), finances, and lack of transport (Rimmer, Wang, & Smith, 2008) prevent stroke survivors from taking part in

physical activity. Stroke survivors may also experience post-stroke fatigue which may make it more difficult for them to engage in physical activity and maintain active living (McGeough et al., 2009).

As there are barriers preventing participation in physical activities, stroke survivors may benefit from interventions that assist them to increase their physical activity behaviour. Simple interventions involving repeated verbal encouragement are not effective in the attempt at increasing active behaviours post-stroke (Boysen et al., 2009), which is not surprising given that physical activity is a complex behaviour and interventions to increase physical activity in stroke may need to be more comprehensive addressing issues like barriers, motivation and goal setting (Morris & Williams, 2009).

2.5 Physical Activity and Cognitive Functioning

Apart from the physical improvements that might result from physical activity there may be beneficial effects on cognitive functioning. To date, several reviews and meta-analyses have investigated the relationship between physical activity on cognition in stroke, in people with cognitive impairment and dementia as well as healthy adults. Each review and meta-analysis concludes that there is some evidence that physical activity has a beneficial effect on cognitive function. The review and meta-analysis in stroke and cognitive impairment will be detailed first followed by the articles on healthy older adults with no known cognitive impairment.

A recent systematic review evaluated the relationships between increased physical activity and cognitive performance in stroke survivors (Cumming, Tyedin, Churilov, Morris, & Bernhardt, 2012). Only RCTs and controlled studies were included. Fifteen studies were identified but three were excluded due to insufficient

data. Of the remainder, 11 studies involved stroke only populations. The other study (Bateman et al., 2001) had mixed aetiology groups. The majority of the studies assessed global cognitive function, whilst others examined attentional switching (Ploughman, McCarthy, Bosse, Sullivan, & Corbett, 2008), executive functions (Quaney et al., 2009), and memory, visual neglect, visuospatial function and language (Pyoria et al., 2007).

Quaney and colleagues (2009) found that aerobic exercise improved performance on a reaction time test but there were no differences between the intervention and the control group of performance on executive function tasks following an eight-week cycle ergometry intervention. Similarly, Ploughman et al. (2008) did not find an improvement on executive functioning and attentional switching tasks following a bout of treadmill exercise. The study by Pyoria and colleagues (2007) summed cognitive responses making it difficult to determine the effects of physical activity on specific cognitive domains.

Nine of the twelve studies in the review by Cumming et al. (2012) had sufficient data for a meta-analysis to be carried out. The results showed that physical activity had a small but positive effect on cognitive function ($SMD = 0.20$). However, it should be noted that there are some limitations with the studies included in this meta-analysis. Most studies used either the Mini Mental State Examination (MMSE) or the Functional Independence Measure (FIM) to assess cognitive function rather than using objective measures of cognitive function. Additionally, cognitive function was rarely the primary outcome and the physical activity interventions varied widely making it difficult to assess what type of activity stroke survivors should be doing, how often and for how long.

Two studies were excluded from the review because they did not have a control group (Pyun et al., 2009; Rand, Eng, Liu-Ambrose, & Tawashy, 2010). The study by Rand and colleagues (2010) found that a six month exercise programme involving two one-hour sessions each week focusing on aerobic exercise, stretching and balance exercises lead to significant improvement in memory and response inhibition at a three-month follow-up. The second study by Pyun et al. (2009) found that a 12-week individualised exercise programme significantly improved global cognition when assessed by general cognitive measures such as the MMSE. However, performance on the domain specific cognitive tests on memory, attention and executive functions did not improve.

Independent studies, reviews and meta-analyses with healthy and non-stroke populations have also been conducted showing beneficial effects on cognition (Audiffren, Tomporowski, & Zagrodnik, 2008; Barnes, Yaffe, Satariano, & Tager, 2003; Colcombe & Kramer, 2003; Etnier et al., 1997; Kramer, Erickson, & Colcombe, 2006; Whitbourne, Neupert, & Lachman, 2008; Yaffe, Barnes, Nevitt, Lui, & Covinsky, 2001). The meta-analysis by Colcombe and Kramer (2003) identified several training and participant characteristics that indicate the conditions under which physical activity affords the most benefits, are for whom.

Modest effect sizes were found for non-clinical ($ES = .47$) and clinical ($ES = .48$) populations for the effect of physical exercise on all cognitive tasks. Overall, global cognitive function also improved significantly in control groups pre-test to post-test, however the effect size was small ($ES = .16$). In relation to specific cognitive domains, physical activity had the greatest effect on executive functions but there was also a significant improvement on controlled processes, and spatial and

speeded tasks. However, the analysis on cognitive domains was not split by type of population therefore it is not possible to determine if these effects were similar for both non-clinical and clinical samples (Colcombe & Kramer, 2003).

Moderator analyses showed that combined strength and aerobic programmes were more beneficial than aerobics programmes on their own. Short exercise programmes (1 – 3 months) were as effective as moderate exercise programmes (4 – 6 months) but that longer programmes were most beneficial (6+ months). It was also shown that short exercise sessions (15 – 30 minutes) did not influence cognitive function, whereas moderate (31 – 45 minutes) and long sessions (46 – 60 minutes) did. Finally, participants aged 66 – 70 years benefitted more from exercise than those aged 55 – 65 years and 71 – 80 years (Colcombe & Kramer, 2003).

2.6 Limitations of Current Research

The majority of the research studies on memory, attention and physical activity in stroke rehabilitation are group-based. Group-based studies such as RCTs are considered gold-standard for good reason. Independent variables can be manipulated allowing for cause and effect, selection bias and confounding can be eliminated, or at least reduced, the process of randomizing participants to groups can facilitate blinding of group allocation from participants and assessors and group studies are often easier to replicate. As a result, RCTs are considered Class I studies in systematic reviews (Cicerone et al., 2011). However, the group-based approach may not be a wholly suitable method to use when the participants are not a homogenous group. Given the variability that exists between stroke survivors, average scores from group-based designs are unlikely to reflect the performance of any one individual. A further problem with group-based studies is it is not known

who might and might not benefit from an intervention and why. Sub-group analyses can be carried out but in stroke research sample sizes tend to be small thus fractioning the data further to investigate the effect of an intervention on a sub-set of the participants may produce spurious results.

Another limitation of group-based studies is that interventions tend not to be tailored to the specific needs of an individual. RCTs in stroke treatment often fail to capture aspects of recovery that are important to stroke survivors whether they are physical or cognitive. We know that different aspects of memory and attention may be impaired and other functions preserved post-stroke, and we know that stroke survivors, depending on a number of factors, may have varying physical ability levels. Therefore, cognitive rehabilitation and physical activity prescription should not be considered as a 'one size fits all' approach. Rather specific personalized interventions should be delivered in light of an individual's circumstance.

An alternative approach may be to use an individual-based methodology. Like the group approach, using an individual approach allows the researcher to manipulate an independent variable and assess the effect on an outcome. However, in group designs, participants are randomised to receive either the intervention or are allocated to the control group. Whereas, in individual-based studies it is the independent variable that is randomised across phases; participants act as their own control. With the individual approach, participant heterogeneity can also be taken into account to be able to determine the most appropriate intervention to improve specific outcomes post-stroke. Additionally, this type of methodology is useful when there may be practical obstacles in recruiting large number of research participants. However, it should be pointed out that the individual based-method can be time-

consuming for both researcher and participant, it may be difficult to obtain a stable baseline to compare the effects of an intervention to, it is difficult to design interventions that involve various treatments where the aim is to compare their effectiveness and they are likely to be more costly than group-based studies.

Chapters three and four of this thesis systematically review the studies which have focused on individual participants. In terms of methodological complexity, case studies and case reports are more simplistic in nature merely describing processes and outcomes. In contrast, single-case experimental studies and N-of-1 studies tend to be more complex involving the manipulation of an independent variable, which strengthens and supports the premise that studies which focus on the individual can be designed and delivered in the same way that group-based studies can.

Chapter Three

Interventions to Improve Memory and Attention in Stroke Survivors Using Case Study and N-of-1 Designs: A Systematic Review

“The individual is of paramount importance in the clinical science of human behaviour change”

(Barlow, Nock, & Hersen, 2009)

3.1 Abstract

Background: Group-based designs limit our understanding of cognitive functions at the individual level. The single-case or N-of-1 approach is person-specific and takes inter-individual variability into account and so may be a viable alternative to the group method.

Objectives: The aim was to review the literature on single case and N-of-1 intervention studies designed to improve memory and attention functioning in stroke survivors and assess their methodological quality using the Single-Case Experimental Design scale.

Data Sources: The following databases were searched: ASSIA, CINAHL, EMBASE, Medline, PubMed, PsychInfo, PsycArticles, Web of Knowledge, Web of Science and Proquest Dissertations and Theses (UK & Ireland) and reference lists from relevant articles. Date of searches May 2013.

Selection Criteria: Case studies or N-of-1 intervention studies designed to improve memory and/or attention in stroke survivors. Studies with mixed aetiology groups were included if individual raw data was reported for stroke participants.

Data Collection and Analysis: Inter-rater reliability of the studies was carried out by the primary author (JC) and the primary supervisor (MG). JC extracted the data, appraised the studies and assessed the methodological quality of the studies.

Main Results: Nine studies were included in the review. All studies showed some benefits from training aspects of memory and attention. However, the findings should be considered with caution as reported improvements in memory were not always supported by improvements on objective memory tasks, and practice effects and spontaneous recovery may be responsible for some of the findings. The methodological quality of the studies was below average with only two studies achieving a score greater than five out of a possible ten.

Limitations: The search strategy yielded a voluminous number of citation hits indicating issues with the sensitivity of the search terms and their combinations.

Conclusions: There is some indication that memory and attention training improves memory and attention at the individual level but the findings should be interpreted in light of the limitations of the studies.

3.2 Background

The application of person-specific methodologies has been slow in applied research as more importance has been placed on group comparison studies that aim to generalize their findings beyond that of the population studied (Molenaar & Campbell, 2009). However, the nature of an acquired brain injury means that stroke

survivors are not a homogenous group making it difficult to generalize study findings beyond the particular cohort of stroke survivors included in a study.

Due to these limitations associated with group-based designs, the N-of-1 approach appears to be a viable alternative to use within the field of memory and attention rehabilitation in stroke. It has been proposed that N-of-1 designs are particularly well suited to examining the processes and outcomes of psychological and behavioural interventions (Backman, Harris, Chisholm, & Monette, 1997; Smith, 2012). The MRC (2008) also supports the use of single-case experimental design studies in the feasibility, piloting and evaluation stages of a study. The N-of-1 study can be used to inform and develop theory, examine within-individual variability, study the behaviour of individuals and establish the effectiveness of psychological interventions. However, N-of-1 studies should not be viewed simply as precursors of RCTs to evaluate the effectiveness of interventions; instead the N-of-1 methodology could and perhaps should be used to develop interventions.

N-of-1 designs are methodologically complex. A representative baseline needs to be established, non-independence of sequential observations need to be managed and the matter of missing observations need to be addressed (Smith, 2012). In N-of-1 intervention studies participants act as their own control. Variables are manipulated across phases and repeated assessments are taken from an individual throughout the study from baseline to follow-up (Backman et al., 1997) using daily diaries or momentary assessment methods (Smith, 2012). An in-depth idiographic study of this nature allows for the monitoring and tracking of individual processes over a period time. Observations can be made of possible fluctuations such as

upward and downward patterns meaning that processes of the phenomena under investigation and potential correlates can be assessed (Barlow et al., 2009).

Research Designs. There are typically four N-of-1 designs: the AB design, withdrawal, multiple baseline and alternating treatment designs. The AB design is the most basic of the designs but also the weakest as it does not control for possible confounds such as history or maturation. Withdrawal designs, which require the introduction and removal of an independent variable, can control for these sources of threats to validity. However, the withdrawal design is not suitable for interventions that aim to provide long-lasting changes in behaviour; therefore this design can be problematic within the field of rehabilitation where treatments are given based on the premise that there may be irreversible improvement gains. Multiple baseline designs alter the length of the baseline phase across participants, settings or outcome behaviours. Finally, the alternating treatments design compares two or more treatment conditions on a dependent variable. The treatments can be compared to each other and to the baseline (Backman et al., 1997; Smith, 2012).

In all designs there is a baseline phase which is the initial period of observation that should involve the systematic repeated measurement of the natural frequency of the behaviour under investigation. The number of data points required at baseline remains a disputed area. It has been suggested that a minimum of three data points need to be taken to judge the presence of stability (Barlow & Hersen, 1973), whilst others recommend that baseline testing should continue until a stable pattern emerges (Baer, Wolf, & Risley, 1968). Intervention phases are typically referred to as the B phase which can be alternated to determine the effects of an intervention on the target variables. Other designs may involve a C phase. The C

phase can denote a second treatment or is applied in the attempt to control for attention an individual receives during the intervention phase (Barlow et al., 2009).

Visual and Statistical Analysis of N-of-1 Data. Traditionally, single-case researchers have not used statistical analysis to support their conclusions; rather they have relied primarily on visual analysis to determine the effects of a treatment. Single-case researchers have cited clinical importance as justification for supporting the use of visual inspection, as statistical analyses may show that an intervention has been effective but this effect may not translate to a meaningful effect that is of benefit to the individual (Kazdin, 1982). However, relying solely on graphical description of an intervention is problematic due to the subjective nature of attempting to determine an effect if there is one. Research studies have shown that raters do not always agree as to whether an effect has occurred or not (Deprospero & Cohen, 1979; Matyas & Greenwood, 1990). Therefore, visual analysis should be supplemented with statistical analysis where possible.

Data in N-of-1 designs can be autocorrelated meaning that the measurement of a variable at one particular point in time is likely to be influenced by measurement of preceding observations. Subsequent observations tend to be more related than observations more temporally distant. If the value for the presence of autocorrelation is significantly different from zero, it indicates that the performance at a given point in time can be predicted from performance on the previous occasion. As such, the assumption of independence that is required when using conventional tests such as t-tests, analysis of variance and regression techniques are often violated increasing the likelihood that a Type 1 error will occur (Barlow et al., 2009). Therefore, if statistical

analyses are to be conducted on N-of-1 data it is important to use the appropriate techniques.

Overall, research within the field of cognitive functioning may benefit from studies using the N-of-1 approach to disentangle relationships between domains such as memory and attention and other potential influencing factors. To date, there are no systematic reviews of N-of-1 studies on cognitive rehabilitations interventions for stroke survivors. Therefore, it seems appropriate to evaluate the effectiveness of N-of-1 interventions for memory and attention deficits following stroke and to assess their methodological quality.

3.3 Objectives

The aim was to review case study and N-of-1 studies that have delivered an intervention with the aim of improving memory and attention functioning in stroke survivors. This systematic review utilised the PRISMA framework (Moher, Liberati, Tetzlaff, & Altman, 2009).

The review also assessed the methodological quality of the studies using the Single-Case Experimental Design (SCED) scale (Tate et al., 2008) to determine the extent to which current research in stroke using the single-case approaches meets extant standards. The SCED scale is the only psychometrically validated tool for assessing the rigour of single-case designs and has been used in another review of N-of-1 designs (e.g., Smith, 2012). The scale focuses on ten weaknesses of studies in terms of their validity. The quality score therefore ranges from zero to ten, with higher scores indicating better methodological quality.

3.4 Methods

Protocol and Registration. There is no review protocol for this systematic review.

Eligibility Criteria

Study Designs. Studies included in the review were single-case or N-of-1 intervention studies where an independent variable(s) had been actively manipulated. All types of designs were eligible for inclusion, i.e. AB, multiple baseline, withdrawal, and alternating treatments. All studies had to report results separately for each participant.

Participants. The review was confined to studies that included adult participants (>18 years) who had suffered a stroke event, either ischaemic or haemorrhagic confirmed by neurological examination and/or computerised tomography or by self-report. Studies that included participants who had other forms of brain trauma, brain tumour, aneurysms or any other brain conditions were excluded.

Intervention Types. All types of non-pharmacological interventions were eligible for inclusion (e.g., memory and attention rehabilitation/training, physical activity). Drug treatments and studies using neuro-stimulation treatments such as transcranial direct-current stimulation/transcutaneous electrical nerve stimulation were not included.

Outcome Measures. Primary outcomes were memory and attention functions. No restriction was placed on the type of measure used; studies using either objective neuropsychological tests, screening or self-report memory and/or attention questionnaires were eligible for inclusion. Studies involving interventions to improve executive functions, unilateral neglect, information processing speed, language and communication disorders were excluded.

Search Methods for Identification of Studies

Characteristics of Studies. Studies written in English and peer-reviewed (if published in a journal) were eligible for inclusion, as were studies reported in book chapters.

Information Sources. No time restriction was selected at the time of the search to allow for identification of many studies as possible. Searches in the following databases were carried out: ASSIA, CINAHL, EMBASE, Medline, PubMed, PsychInfo, PsycArticles, Web of Knowledge, Web of Science and Proquest Dissertations and Theses (UK & Ireland).

Search Terms. Searches were conducted using combinations of the following descriptors/key words: (stroke OR “cerebrovascular accident*” OR “neuro* disab*” OR “brain trauma” OR “acquired brain injury” OR ABI) AND (rehabilitation OR “remedial therapy” OR treatment* OR intervention) AND (case stud* OR “case report” OR “N-of-1” OR “N of 1” OR “single case” OR “single-case” OR “single subject” OR “single-subject”) AND (cog* OR memory OR recall OR recognition OR visuospatial OR attention OR “attentional deficits” OR inattention OR concentration).

Study Selection. The titles and abstracts of all publications identified from the preliminary searches were reviewed by the primary author (JC). Studies not meeting inclusion criteria were excluded. Selected studies were cross-checked by the primary supervisor (MG). The AC_1 statistic (Gwet, 2002) was calculated to assess the extent of agreement between raters yielding 83% agreement ($AC_1 = 0.8283$). Any disagreements were resolved by consensus.

Data Items. The following information was recorded: age of participants, sex, time since stroke onset, type of stroke, type of intervention, dose of intervention and outcome. Information relating to the methodological quality of the studies was also recorded. This focused on target behaviours being operationally defined, the design of the study, sufficient sampling during the baseline and follow-up phase, the recording of raw data points, observer bias, independence of assessors, the use of statistical analysis, replication across subjects, therapists or settings and evidence of generalisation.

Risk of Bias. The methodological quality of the studies was assessed by one of the reviewers (JC) using the SCED scale (Tate et al., 2008).

3.5 Results

Study Selection

The search returned 18,187 articles. There were 7,121 duplicates which were immediately excluded. Then the titles and abstracts were screened by JC and a further 11,034 were excluded. For the remaining 32 articles the full text was assessed and exclusion criteria applied, this resulted in nine articles meeting the criteria and were included in the review (See Figure 3.1 for flow diagram of study selection).

From the 32 articles identified for possible inclusion, 23 were excluded as the participants had other types of brain injury or disease (Mateer, Sira, & O'Connell, 2005; Preissner, 2010; Shimelman & Hinojosa, 1995; Sohlberg & Mateer, 1987; Wilson & Robertson, 1992), had used the Mini-Mental State Examination but did not report performance scores for the memory and attention components (Kim et al., 2008; Patel, Coshall, Rudd, & Wolfe, 2003), had used the Stroke Impact Scale (Duncan et al., 1999) to measure memory which contains a number of items relating to other cognitive functions such as processing speed (Butler, Blanton, Rowe, & Wolf, 2006), was not an intervention study (Bisiker & Bickerton, 2013; Chafetz, Friedman, Kevorkian, & Levy, 1996; Cushman & Caplan, 1987; Hampstead & Koffler, 2009; Klonoff, Sheperd, O'Brien, Chiapello, & Hodak, 1990; Maeshima & Osawa, 2007; Maeshima, Osawa, & Kunishio, 2010; Robinson, Pope, & Mace, 2009; Wilson, 1999), did not assess memory and/or attention (Katz, Hefner, & Reuben, 1990; Rebmann & Hannon, 1995; Skidmore et al., 2011; Wagenaar, van Wieringen, Netelenbos, Meijer, & Kuik, 1992), reported only baseline performance scores with no follow-up (Boman, Tham, Granqvist, Bartfai, & Hemmingsson, 2007; Carelli et al., 2009) and involved electroencephalograph driven stimulation (Rozelle &

Budzynski, 1995). This process was checked by a second researcher (MG).

Characteristics of included studies are shown in Table 3.1.

PRISMA Flow Diagram

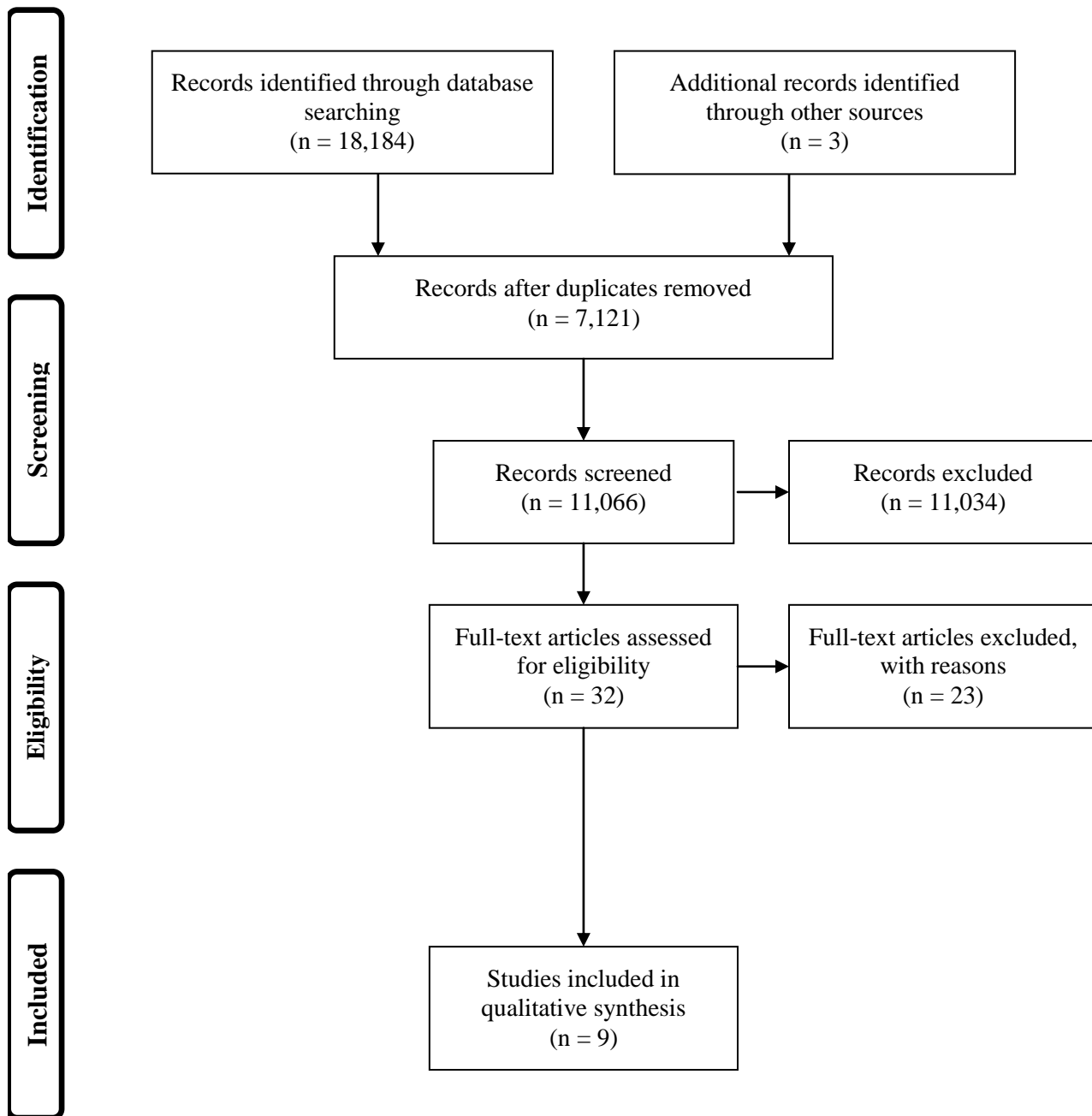


Figure 3.1: PRISMA Flow Diagram

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

Table 3.1

Characteristics of Included Studies

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Boman et al. (2012)	5	33-58	4 female, 1 male	12-96	3 Haemorrhagic 2 Ischaemic	External memory aid	Daily	More activities completed
Gauggel et al. (1996)	4 (2 stroke, 2 CHI)	40-55	Unclear	1-3	not reported	Computerized training	30 mins, 5 days	Improved attention
Nordvik et al. (2011)	1	60	1 male	4.5	Haemorrhagic	Computerized training	60 mins, 3-4 days	Improved WM
Sturm et al. (1997)	7-12	24-64	Unclear	2-35	not reported	Computerized training	14 one-hour sessions, twice	Improved alertness and vigilance
Squires et al. (1996)	1	70	1 male	5	Ischaemic	External memory aid	10 sessions over 16 days	Decrease in questions asked
Vallat et al. (2005)	1	53	1 male	>14	Ischaemic	WM training	60 mins, 3x per week	Improved WM
van den Broek et al. (2000)	5 (2 stroke, 2 ENC, 1 trauma)	25-56	1 female, 4 male	19-47	Haemorrhagic	External memory aid	3 weeks	Improved PM
Weber (1990)	2 (1 stroke, 1 CHI)	37&59	2 male	4-7	unknown	APT	60-120 mins per week, 6 months	Improved attention
Wilson (1982)	1	51	1 male	6	Ischaemic	Mnemonics	4 days per week, 6 weeks	Improvement on some activities

Note: CHI = closed head injury, ENC = encephalitis, WM = working memory, APT = Attention Process Training

Results of Individual Studies. The studies are classified in terms of intervention type. Three studies utilized external memory aids (Boman, Bartfai, Borell, Tham, & Hemmingsson, 2010; Squires, Hunkin, & Parkin, 1996; van den Broek, Downes, Johnson, Dayus, & Hilton, 2000), three delivered computerized training (Guggel & Niemann, 1996; Nordvik, Schanke, & Landro, 2011; Sturm et al., 1997) and the remainder of the studies delivered attention process training (Weber, 1990), verbal working memory training (Vallat et al., 2005) and mnemonic strategies (Wilson, 1982).

A number of studies recruited participants of different aetiologies (e.g., stroke and closed head injury). Results in relation to stroke survivors only are reported.

External Memory Aids. Boman and colleagues (2010) assessed the effectiveness of a home-based electronic memory aid with sensors for stroke survivors who were one to eight years post-stroke. The participants identified a number of activities that they usually forgot to carry out. The electronic aid delivered reminders either visually or through a speaker. The results showed that four of the participants completed most of their self-chosen activities when assisted by the external aid. The intervention was not effective for one participant who attempted to try to remember to carry out her activities without the use of the reminders.

Additionally, memory performance, assessed by the Rivermead Behavioural Memory Test, did not improve after the intervention phase or at the follow-up.

Squires et al. (1996) introduced the use of the diary method to a stroke patient who suffered severe amnesia resulting in continually asking his spouse questions. Using errorless learning, the participant was trained to use a diary, and then record and look-up information that was written in the diary. Pre and post-comparisons

showed that there was a decrease in questions asked post-training indicating a beneficial effect from using this strategy. Similarly, van den Broek et al. (2000) evaluated the effectiveness of a voice organiser for individuals with prospective memory impairments. Of the five participants, two were stroke survivors (19 and 47 months post-stroke). The study showed that both stroke survivors' performance improved on one prospective memory task during the intervention phase when using the voice organiser but decreased afterwards when the use of the organiser was withdrawn. Performance on a second prospective memory task improved for only one of the participants.

Computerized Training. Sturm et al. (1997) examined the efficacy of game-like computerized training on alertness and vigilance, and selective and divided attention with stroke survivors. Group-based analyses were carried out alongside results from individual participants. Case-by-case analysis showed that participants demonstrated improved performance on alertness and vigilance tasks, particularly after receiving alertness and vigilance training suggesting that specific training that works a particular cognitive function is required for benefits to occur.

Nordvik and colleagues (2012) found that computerized cognitive training with a stroke survivor four months post-stroke had a positive effect on working memory, immediate and delayed recall, and executive and general cognitive function. However, there was a general trend of an upward increase across the study phases for all cognitive functions apart from working memory performance which improved and deteriorated with training /no training, respectively.

Gauggel and Niemann (1996) evaluated the effectiveness of a computer-assisted programme designed to remedy attention deficits. Four participants

participated of whom two were stroke survivors one to three months post-stroke. Participants received computerised training in alertness, vigilance, divided and selective attention. One stroke survivor showed a significant improvement on one of the attention tests post-training. However, similar to the results from Nordvik et al's. (2012) study, improvement was evident during the baseline therefore it is difficult to conclude if the improved performance was the result of spontaneous recovery or a consequence of the training.

Attention Process Training. Weber (1990) delivered attention process training, which is a hierarchical treatment programme addressing focused, sustained, selective, alternating and divided attention, alongside other strategies and tasks such as feedback, homework assignments and relaxation training. The author found that sustained, selective, alternating and auditory divided attention improved to within normal limits post-intervention. Other attentional functions such as focused and visual divided attention showed either no change or deteriorated from baseline to follow-up.

Verbal Working Memory Training. Vallat and colleagues (2005) assessed the effectiveness of a rehabilitation programme for verbal working memory. The training included tasks involving the reconstitution of words from oral spelling, reconstituting words from syllables and word sorting in alphabetical order. The participant was approximately 14 months post-stroke and suffered from poor working memory performance at baseline. The findings showed that performance improved on the working memory tasks post-intervention but that performance on related cognitive tasks did not improve. This suggested that there was a specific

effect gained from the training with no transfer effects to other cognitive domains which is a similar finding to that reported by Sturm et al. (1997).

Mnemonic Strategies. Wilson (1982) investigated the effectiveness of imagery and mnemonic strategies for an individual who had suffered a stroke and had difficulty remembering his daily timetable, people's names, shopping lists and short routes. Following the intervention, the participant showed improvements in remembering names and items on a shopping list using visual imagery and a first letter mnemonic, respectively. However, re-testing on the memory tests at the follow-up failed to show any significant improvements.

Methodological Quality of Included Studies. The SCED scale (Tate et al., 2008) was used to evaluate the methodological quality of the studies included in the review. Inter-rater reliability for the scale was high for both individual raters ($ICC = 0.84$) and for consensus ratings between pairs of raters ($ICC = 0.88$). Item reliability was good for consensus ratings between pairs of raters ($k = 0.48 - 1.00$). The scale contains 11 items relating to study characteristics that threaten internal validity. Item number one refers to clinical history of participants (age, sex, aetiology and stroke severity) and is not included in the overall score.

All studies reported age, sex and aetiology (Boman et al., 2010; Gauggel et al., 1996; Nordvik et al., 2011; Squires et al., 1996; Sturm et al., 1997; Vallat et al., 2005; van Den Broek et al., 2010; Weber, 1990; Wilson, 1982). Although, three studies reported participants suffered from a cerebrovascular accident but did not state whether it was ischaemic or haemorrhagic (Gauggel et al., 1996; Sturm et al., 1997; Weber, 1990). Table 3.2 below details the studies that met/did not meet the SCED scale criteria and their overall score.

Table 3.2

Studies Meeting/Not Meeting the SCED Scale Criteria

Authors	Specified Target Behaviour	Good Study Design	Baseline Measures (>3)	Continuous Measure of Behaviour	Raw Data Provided	Inter-rater Reliability	Independent Assessors	Statistical Analysis	Replication	Generalisation	Overall score
Boman et al. (2010)	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	7/10
Wilson (1982)	Yes	Yes	Yes	Yes	Yes	No	No	No	No	Yes	6/10
Gauggel et al. (1996)	Yes	Yes	No	No	Yes	No	No	No	Yes	Yes	5/10
Squires et al. (1996)	Yes	Yes	Yes	No	Yes	No	No	Yes	No	No	5/10
Sturm et al. (1997)	Yes	Yes	No	No	Yes	No	No	Yes	Yes	No	5/10
Vallat et al. (1990)	Yes	Yes	No	No	Yes	No	No	Yes	No	No	4/10
v. Broek et al. (2000)	Yes	Yes	No	No	Yes	No	No	No	Yes	No	4/10
Weber (1990)	Yes	No	Yes	No	Yes	No	No	No	Yes	No	4/10
Nordvik et al. (2011)	Yes	Yes	No	No	Yes	No	No	No	No	No	3/10

3.6 Interpretation, Discussion and Limitations

From this review there appears to be some support for treating memory and attention deficits in stroke survivors in areas such as prospective memory, working memory, and in attentional domains such as alertness and vigilance, sustained, selective, alternating and divided attention.

The methodological quality of the studies overall was below average (score of 4.8). Only two studies scored higher than five on the SCED scale (Boman et al., 2010; Wilson, 1982). A number of studies failed to take measures on more than three occasions during the baseline. It has been argued that a minimum of three data points is required to determine stability (Barlow & Hersen, 1973) so that one can evaluate the effect of an intervention. If during the baseline phase there was an upward trend indicating an improvement and this continued throughout the intervention phase it is difficult to determine if the continued improvement is the result of natural recovery or due to the intervention. A similar effect to this was also observed in Nordvik et al's. (2012) study.

Most studies also failed to take repeated measurements throughout the intervention phase but instead took measures before and after the delivery of the intervention. Taking only a small number of observations limits the type of analysis that can be carried out on the data which perhaps explains why several studies in this systematic review relied on descriptive statistics and visual analysis (e.g., Boman et al., 2010; Nordvik et al., 2011; van den Broek, 2000; Weber, 1990; Wilson, 1982). In the review of N-of-1 research studies conducted by Smith (2012) it was reported that visual analysis was the most common analytical method. It appears there is a reliance on this type of analysis in N-of-1 studies in stroke also.

Four studies did report the use of statistical tests but the level of analysis was limited for most of them (Squires et al., 1996; Sturm et al., 1997; Vallat et al., 2005). Squires and colleagues (1996) used t-tests reporting that serial dependency was not observed in the data. A review of N-of-1 studies found the level of dependency to be significantly different from zero suggesting that autocorrelation was present in the data (Shadish & Sullivan, 2011). In any case, researchers conducting N-of-1 studies must endeavour to take repeated measurements throughout each of the phases and apply the most appropriate statistical analysis on the data so that conclusions can be made on the effectiveness of interventions.

Other criteria that the studies failed to meet were inter-rater reliability and independence of assessors. No studies reported if reliability was established for at least one of the target measures and similarly no information was given on who carried out the assessments and who delivered the interventions. Therefore, independence of assessors could not be determined. Smith's (2012) review of N-of-1 studies reported that 97% of the studies described inter-rater reliability procedures, thus it is being carried out in other areas using the N-of-1 design. As these methodological aspects threaten interval validity it is important that inter-rater reliability is established and independent assessors are used, and that this information is reported. Then we will be able to confidently defend the use of N-of-1 designs in research.

Most studies also failed to meet the criterion generalization of effects beyond the target measure (Nordvik et al., 2011; Squires et al., 1996; Sturm et al., 1997; Vallat et al., 2005; van den Broek et al., 2000; Weber, 1990). Although it may be useful to determine generalisation, this item may not be wholly suitable for

intervention studies designed to improve cognitive functions. Studies may only include specific measures in relation to a particular cognitive domain especially as there is no robust evidence showing transfer effects from one cognitive domain to another. Consequently, it is questionable if such studies should lose a mark when the authors did not aim to assess for generalisation of effects beyond the intended target measure.

The current systematic review evaluated the effectiveness of interventions for memory and attention deficits following stroke, and assessed the methodological quality of the included studies. There appears to be some support for the use of cognitive rehabilitation for memory and attention, however, caution is warranted due to the methodological quality of some of the studies. Only two studies achieved a score greater than five on the SCED scale (Tate et al., 2008). These more robust studies indicate that external memory aids and mnemonic strategies were useful in helping stroke survivors remember but as mentioned above the removal of the aid resulted in stroke survivors forgetting daily activities and the use of the mnemonic strategy did not have a positive effect on memory performance when assessed using neuropsychological tests.

Methodological challenges have precluded the general acceptance of N-of-1 designs by the scientific community, therefore, for this methodology to be valued as a complimentary method to the group design studies researchers must strive to ensure that they minimize threats to internal validity as much as possible so they can be confident in concluding the effects of an intervention.

Finally, there are limitations of the systematic review process which should be noted. The results yielded from each database search were combined and then a

screen of the titles was carried out. The search terms and their combinations produced a large number of citation hits indicating a lack of sensitivity with the strategy and the terms were simple likely providing an inadequate search of the literature overall.

Chapter Four

Interventions to Increase Levels of Physical Activity and Mobility in Stroke Survivors Using Case Studies and N-of-1 Designs: A Systematic Review

4.1 Abstract

Background: The nature and extent of single case and N-of-1 studies delivering physical activity interventions, and knowledge of how to improve physical activity levels in stroke survivors, is unknown.

Objectives: The primary aim was to review the literature on single-case and N-of-1 studies to determine if behavioural change interventions designed to increase overall levels of physical activity have been delivered to a stroke population. A second aim was to assess interventions designed to increase mobility outcomes using the single-case method in stroke survivors. Ancillary aims were to assess the outcomes of these studies to determine how informative they are and to evaluate their methodological quality.

Data Sources: Databases ASSIA, CINAHL, EMBASE, Medline, PubMed, PsychInfo, PsycArticles, SPORTDiscus, Web of Knowledge, Web of Science, Proquest Dissertations and Theses (UK & Ireland) and reference lists from relevant articles were searched. Date of searches June 2013.

Selection Criteria: Single-case and N-of-1 intervention studies designed to increase physical activity. Studies with mixed aetiology groups were included if individual raw data was reported for stroke participants.

Data Collection and Analysis: Inter-rater reliability was carried out by the primary author (JC) and the primary supervisor (MG). JC extracted the data, appraised the studies and assessed the methodological quality of the studies.

Main Results: No studies involving a behavioural change intervention to increase overall levels of physical activity post-stroke were identified. Forty-four studies that aimed to increase mobility outcomes such as gait speed, endurance, stride and step length and symmetrical gait were included. Improvements on walking parameters were noted, however, not all participants benefitted from the interventions. The overall methodological quality of the studies was below average indicating that the internal validity of the studies had been compromised.

Limitations: The search strategy produced an extensive number of citation ‘hits’ indicating issues with the sensitivity of the search terms and their combinations.

Conclusions: There is some support for the effectiveness of interventions to improve mobility outcomes post-stroke. However, one should be mindful that interventions will not be of benefit to all, and an improved walking ability does not necessarily mean that stroke survivors will adopt an active lifestyle. Research studies that focus on individualised behaviour change interventions with the aim of increasing overall levels of physical activity are much needed in this area.

4.2 Background

Physical activity recommendations propose that stroke survivors should aim to participate in aerobic activity at least 3 days per week for durations between 20 to 30 minutes per day of continuous or accumulated activity and that strength, flexibility and neuromuscular training should be carried out on two to three days per

week (Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings, 2010).

Although these recommendations exist, the best way to increase physical activity levels in stroke survivors is unclear. Systematic reviews and independent group-based studies inform us that aerobic activity (Luft, Macko, Forrester, Goldberg, & Hanley, 2008; Pang, Charlesworth, Lau, & Chung, 2013; Rimmer, Rauworth, Wang, Nicola, & Hill, 2009), circuit training (English & Hillier, 2011) and strength, balance and endurance activities (Ada, Dorsch & Canning, 2006; Morris, Dodd & Morris, 2004) can improve health and functional outcomes in stroke survivors. Therefore, it is important that stroke survivors receive support to assist them in increasing their physical activity behaviour.

A group-based study involving simple verbal encouragement was shown to be ineffective in increasing levels of physical activity in stroke survivors (Boysen et al., 2009). It may be that the simple verbal encouragement was not effective enough to tackle the complexities involved in increasing levels of physical activity, or alternatively, the intervention may have been of benefit to some but not all stroke survivors which led to non-significant findings using means testing. Variability in reported levels of physical activity was evident in the data in Boysen et al.'s study suggesting that interventions, such as N-of-1 studies, that allow for evaluation of the effectiveness of interventions at the individual level would be of benefit.

The N-of-1 methodology equips researchers with the ability to individually tailor physical activity interventions so that they suit the needs of an individual and their current level of activity. Response to physical activity varies between individuals (Lam et al., 2010), therefore, this approach may be more beneficial for

stroke survivors rather than delivering the same dose of an intervention with the view and likelihood that it will be suitable for each participant.

In the studies that have used group-based designs, walking speed and endurance have been the main focuses of attention, as improved walking ability is seen as a priority in lower limb rehabilitation. In particular, walking speed is considered one of the most important predictors of post-stroke functional and community ambulation (Bowden, Balasubramanian, Behrman, & Kautz, 2008). Dickstein (2008) carried out a critical review of intervention approaches to improve walking speed and reported evidence to support the use of treadmill training (Moseley, Stark, Cameron, & Pollock, 2005), over-ground walking with body-weight support (Pohl, Mehrholz, Ritschel, & Ruckriem, 2002) and motor imagery (Bogataj, Gros, Kljajic, Acimovic, & Malezic, 1995). There was also some evidence supporting the use of robotic orthoses on gait performance (Mayr et al., 2007) but not walking speed per se. Additionally, there was inconclusive evidence for electrical stimulation (Duncan et al., 2005) and biofeedback methods (Moreland, Thomson, & Fuoco, 1998).

Although several intervention types in the review had a positive effect on gait outcomes (Dickstein, 2008) very few of the interventions enhanced community ambulation. So, although mobility outcomes improved as a result of the interventions, it appears that interventions that focus solely on physical outcomes are limited in their ability to increase overall levels of physical activity and social participation in activities. As such, intensive strategies involving behavioural and motivational components are likely to be required to assist stroke survivors in increasing and maintaining their levels of physical activity.

Overall, there have been a small number of group-based systematic reviews (Ada et al., 2006; English & Hillier, 2011; Morris et al., 2004; Pang et al., 2013) conducted on the effectiveness of physical activity interventions for physical outcomes in stroke survivors. The aim of the present study was to systematically review the literature to identify single-case and N-of-1 physical activity interventions in a stroke population to determine the nature of these interventions, to examine how informative these interventions are and to assess their methodological quality.

4.3 Objectives

The primary aim was to review the literature on single-case and N-of-1 studies to determine if behavioural change interventions designed to increase overall levels of physical activity in stroke survivors had been delivered. Additional aims were to review previous research studies that delivered interventions to improve mobility outcomes post-stroke, to assess the outcomes of these studies to determine how informative they are and to evaluate their methodological quality. As in Chapter Three, the systematic review utilised the PRISMA framework (Moher et al., 2009) and the Single-Case Experimental Design scale (Tate et al., 2008) was used to determine the extent to which current research in stroke using a single-case or N-of-1 approach meets extant standards for high quality designs.

4.4 Methods

Protocol and Registration

There is no review protocol for this systematic review.

Eligibility Criteria

Types of Studies. Single-case and N-of-1 intervention studies were included in the review. All types of designs i.e., AB, multiple baseline, withdrawal and

alternating reversal treatments were eligible for inclusion. All studies had to report results separately for each participant.

Types of Participants. The review was confined to studies that included adult participants (>18 years) who had suffered a stroke event, either ischaemic or haemorrhagic confirmed by neurological examination and/or CT scan or by self-report. Studies that included participants who had other forms of brain trauma, brain tumour or any other brain damaged conditions were excluded.

Types of Intervention. Interventions that required participants to be physically active during the intervention with the aim of increasing levels of physical activity (e.g., behavioural consultations, social support programmes, pedometers) were included. By definition mobility outcomes such as walking speed and endurance come under the rubric of physical activity (Caspersen et al., 1985), therefore interventions designed to improve mobility outcomes were also included in the review (e.g., exercise sessions, body-weight supported treadmill, over-ground walking). Studies involving interventions that did not require participants to be active during the treatment phase were excluded from the review (e.g., receiving functional electrical stimulating sessions on their own), as were interventions involving a one-off acute bout of physical activity and interventions designed solely to improve balance.

Types of Outcome Measures. The primary outcome was physical activity and secondary ones were physical mobility outcomes. No restriction was placed on how physical activity and/or mobility was measured; studies using objective measures such as accelerometry, oxygen consumption, performance on gait tests, or by self-report were eligible for inclusion.

Search Methods for Identification of Studies

Characteristics of Studies. Studies written in English and peer-reviewed (if published in a journal) were eligible for inclusion, as were studies reported in book chapters.

Information Sources. No time restriction was selected at the time of the search to allow for identification of many studies as possible. Searches in the following databases were carried out: ASSIA, CINAHL, EMBASE, Medline, PubMed, SPORTDiscus, PsychInfo, PsycArticles Web of Knowledge, Web of Science and Proquest Dissertations and Theses (UK & Ireland).

Search Terms. Searches were conducted using combinations of the following descriptors/key words: (stroke OR “cerebrovascular accident*” OR “neuro* disab*” OR “brain trauma” OR “acquired brain injury” OR ABI And rehabilitation OR therapy OR treatment* OR intervention OR “beh* change” And case stud* OR “case report” OR “N-of-1” OR “N of 1” OR “single case” OR “single-case” OR “single subject” OR “single-subject” And “physical activity” OR “physical exercise” OR “physical fitness” OR “aerobic exercise” OR “aerobic capacity” OR “cardiorespiratory fitness” OR exercise OR “heart rate” OR “oxygen consumption” OR VO₂ OR METS OR “leisure active*” OR strength OR training OR cycling OR gym OR walk* OR swim* OR danc* OR yoga OR “mixed training” OR run* OR jog*).

Study Selection. The titles and abstracts of all publications identified from the preliminary searches were reviewed by the primary author (JC). Studies not meeting inclusion criteria were excluded. Selected studies were cross-checked by the primary supervisor (MG). The AC₁ statistic (Gwet, 2002) was calculated to assess the

extent of agreement between raters yielding 82% agreement ($AC_1 = 81.92$). Any disagreements were resolved by consensus. The methodological quality of the studies was assessed by one of the reviewers (JC) followed by study characteristics and outcomes being assessed.

Data Items. The following information was recorded: age of participants, sex, time since stroke onset, type of stroke, type of intervention, dose of intervention and outcome. Information relating to the methodological quality of the studies was also recorded. This focused on target behaviours being operationally defined, the design of the study, sufficient sampling during the baseline and follow-up phase, the recording of raw data points, observer bias, independence of assessors, the use of statistical analysis, replication across subjects, therapists or settings and evidence for generalisation.

Risk of Bias. The methodological quality of the studies was assessed by one of the reviewers (JC) using the SCED scale (Tate et al., 2008).

4.5 Results

Study Selection

The search returned 12,853 articles of which 3,087 were duplicates. After these were removed a further 9,705 were excluded leaving 61 articles identified for inclusion. After reading the full articles 44 met the criteria and were included in the review with the remaining 17 studies being excluded (See Figure 4.1 for flow diagram of study selection).

Studies were excluded due to group-based analyses (Brouwer, Parvataneni, & Olney, 2009; Jorgensen et al., 2010; Macko, Ivey, & Forrester, 2005; Sibley, Tang, Brooks, Brown, & McIlroy, 2008; Van Nunen, Gerrits, Janssen, & De Haan, 2012)

performance on outcome measure(s) reported were too brief (Khattar, Banerjee, Reddi, & Dutta, 2012; McEwen, Polatajko, Huijbregts, & Ryan, 2009; Numata, Murayama, Takasugi, & Oga, 2008; Punt, 2000), there were no pre and post-measures reported (Bennett et al., 2009), physical activity was not part of the intervention (Bensoussan, Mathelin, Viton, Collado, & Delarque, 2010; Daly et al., 2000; Mercier, Bourbonnais, Bilodeau, Lemay, & Cross, 1999; van Swigchem et al., 2011), the aim of the study was to assess feasibility of the intervention (Malouin, Potvin, Prevost, Richards, & Wood-Dauphinee, 1992), outcome assessment was on the upper limb (Dawes, Bateman, Wade, & Scott, 2000) and the participant was younger than 18 years old (Tappan, 2002).

Description of Included Studies and Intervention Effects. From the systematic review no study was identified that involved an intervention aimed at changing behaviour to increase overall levels of physical activity. The studies that were included were designed to improve mobility outcomes such as gait speed, endurance, stride and step length, and gait symmetry. A number of studies combined treatments (e.g., walking and strength training). For ease of description they have been classified into an intervention type.

Seven studies delivered walking training using a treadmill (Combs & Miller, 2011; Hesse, Waldner, & Tomelleri, 1995; Kendrick, Holt, McGlashan, Jenner, & Kirker, 2001; Mudge, Rochester, & Recordon, 2003; Reisman, McLean, & Bastian, 2010; Veneri, 2011; Waagfjord, Levangie, & Certo, 1990) and one study delivered running sessions on a treadmill (Miller et al., 2008). Other studies combined treadmill training with another treatment such as over-ground walking (McCain & Smith, 2007; Miller, 2001; Miller, Quinn, & Seddon, 2002; Vidoni, Tull, & Kluding,

2008), strengthening exercises (Combs, Miller, & Forsyth, 2007; Combs, Kelly, Barton, Ivaska, & Nowak, 2010), cycling (Sullivan, Klassen, & Mulroy, 2006), balance activities (Fritz et al., 2011) and treadmill walking combined with an orthosis (Roehrig & Yates, 2008). Three studies delivered over-ground walking sessions (Bassile, Dean, Boden-Albala, & Sacco, 2003; Fritz, Pittman, Robinson, Orton, & Rivers, 2007; Kollen, Rietberg, Kwakkel, & Emmelot, 2000).

Four studies incorporated functional electrical stimulation into their physical activity intervention (Bogataj, Gros, Kljajic, & Acimovic-Janezic, 1997; Krishnamoorthy et al., 2008; Lindquist et al., 2007; Tong, Ng, Li, & So, 2006). Three studies used robotic devices (Hesse, Waldner, & Tomelleri, 2010; Krishnan, Kotsapouikis, Dhaher, & Rymer, 2012; Wong, Bishop, & Stein, 2012), three studies incorporated biofeedback (Ambrosini et al., 2011; Jonsdottir et al., 2007; Lewek, Feasel, Wentz, Brooks, & Whitton, 2012) and three studies used motor imagery (Deutsch, Maidan, & Dickstein, 2012; Dickstein, Dunsky, & Marcovitz, 2004; Dunsky, Dickstein, Ariav, Deutsch, & Marcovitz, 2006). Three studies used cycling as the intervention (Brown, Nagpal, & Chi, 2005; Holt, Kendrick, McGlashan, Kirker, & Jenner, 2001) or part of the intervention (Marklund & Klaessbo, 2006), three involved an aerobic component involving jump training (Mehrholz, Rutte, & Pohl, 2006), rapid stepping (Mansfield et al., 2011) and stepping using an elliptical machine (Jackson, Merriman, & Campbell, 2010).

Virtual reality was the intervention used in two other studies (Dunning, Levine, Schmitt, Israel, & Fulk, 2008; Flynn, Palma, & Bender, 2007). One study involved strength training (Killington, Mackintosh, & Ayres, 2010), one delivered yoga sessions (Bastille & Gill-Body, 2004) and one study involved the use of a dog

to aid walking (Rondeau et al., 2010). Results in relation to stroke survivors only are reported. Characteristics of included studies are shown in Table 4.1.

Methodological Quality of Included Studies. Inter-rater reliability values for the SCED scale are reported in Chapter Three.

PRISMA Flow Diagram

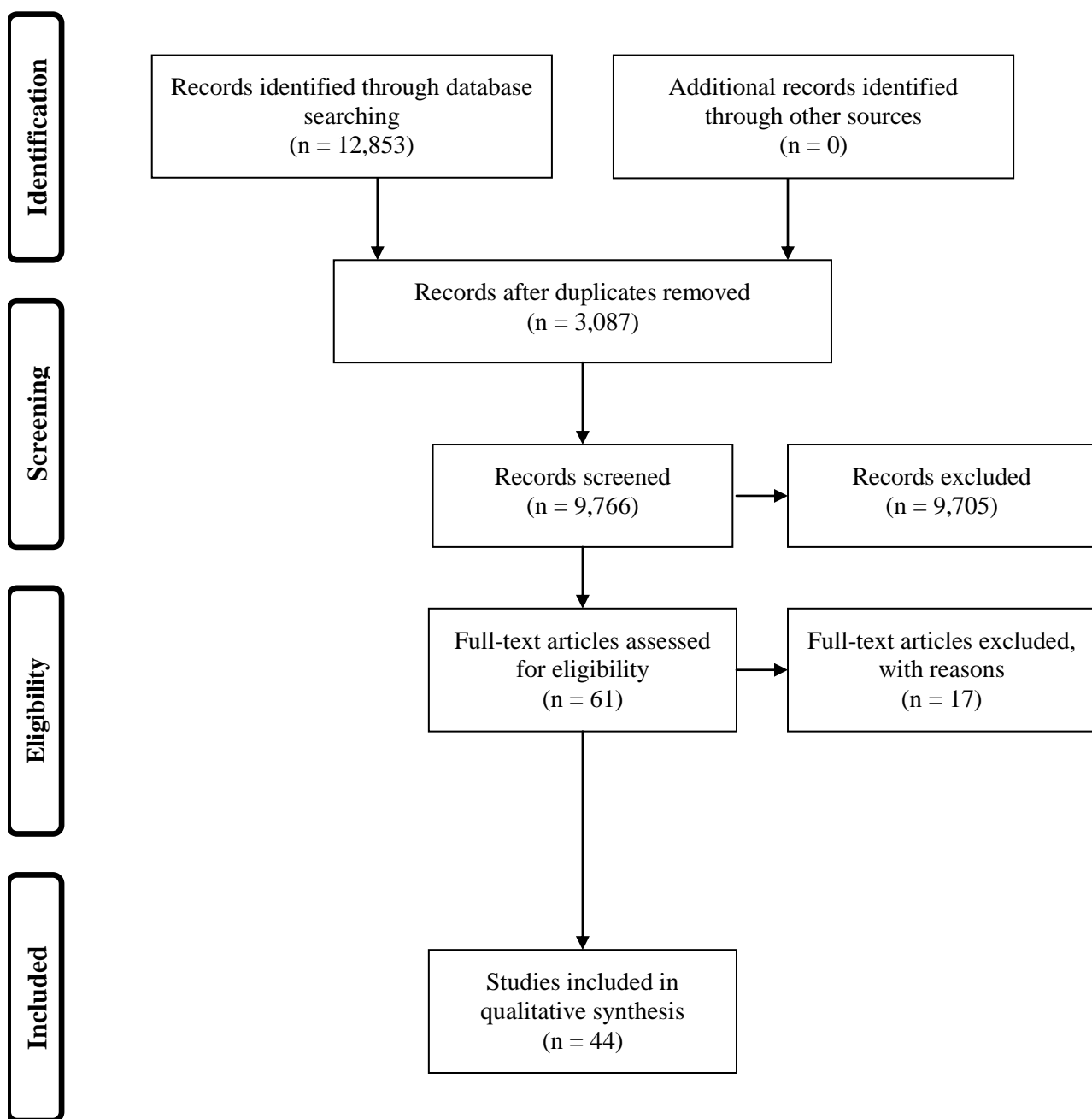


Figure 4.1: PRISMA Flow Diagram

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

Table 4.1

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Combs et al. (2011)	1	66	Female	12	Not reported	Treadmill walking	5 days per week, 2 weeks	Improved speed, 6-min walking & SIS
Hesse et al. (1995)	7	52-72	6 Male, 1 Female	3-12	Ischaemic	Treadmill walking	30 mins per day, 3 weeks	Improved walking speed
Kendrick et al. (2001)	1	67	Male	31	Not reported	Treadmill walking	20 sessions, 8 weeks	Improved speed, endurance & TUG
Mudge et al. (2003)	1	48	Male	30	Not reported	Treadmill walking	3x per week, 4 weeks	Improved balance
Veneri et al. (2011)	1	54	Female	10	Ischaemic	Treadmill walking	10 mins, 3x per week, 10 weeks	Improved speed, distance, balance & strength
Waagfjord et al. (1990)	1	40	Female	36	Not reported	Treadmill walking	3x per week, 3 weeks	Improved step length & symmetry

Note: SIS = stroke impact scale, TUG = timed get up and go

Table 4.1 continued

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Reisman et al. (2010)	1	36	Female	18	Haemorrhagic	Treadmill walking	20 mins, 3 days per week, 4 weeks	Improved speed, symmetry and SIS
Miller et al. (2008)	1	38	Male	29	Ischaemic	Treadmill running	8 weeks	Improved sprint speed, step width & balance
McCain & Smith (2007)	1	60	Male	18	Ischaemic	Treadmill & over-ground walking	16 sessions, 3 weeks	Improved walking and stair climbing
Miller et al. (2001)	1	71	Female	19	Ischaemic	Treadmill & over-ground walking	3x per week, 8 weeks	Improved speed, endurance & balance
Miller et al. (2002)	2	87&93	Female	>24	Ischaemic	Treadmill & over-ground walking	3x per week, 6-7 weeks	Improved speed, step length & balance
Vidoni et al. (2008)	1	61	Male	60	Ischaemic	Treadmill & over-ground walking	2x per week, 6 weeks	Improved speed, endurance & balance

Note: SIS = stroke impact scale

Table 4.1 continued

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Combs et al. (2007)	1	51	Female	6	Ischaemic	Treadmill walking & strength	3 days per week, 6 weeks	Improved speed, endurance & balance
Combs et al. (2010)	9	45-78	6 Male 3 Female	24-240	Not reported	Treadmill walking & strength	4 hours per day, 5 days, 2 weeks	Improved endurance, balance and TUG
Fritz et al. (2011)	4 (1 stroke, 1 SCI, 1 P, 1 CH)	21-56	3 Male 1 Female	36-144	Not reported	Treadmill walking, balance & strength	3 hours per day, 10 days	Improved speed, step symmetry, length & balance
Sullivan et al. (2006)	1	38	Female	15	Ischaemic	Treadmill walking & cycling	4x per week, 6 weeks	Improved speed & distance
Roehrig & Yates (2008)	1	69	Male	54	Ischaemic	Treadmill & orthotic use	24 sessions, 11 weeks	Improved speed, cadence, step length
Fritz et al. (2007)	8	43-80	6 Male 2 Female	11-78	Not reported	Over-ground walking	3 hours per day, 5 days, 2 weeks	Improved speed & stride length

Note: SCI = spinal cord injury, P = Parkinson's disease, CH = cerebral hemispherectomy, TUG = timed get up and go

Table 4.1 continued

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Kollen et al. (2000)	3	46-70	2 Male 1 Female	36-54	Ischaemic	Over-ground walking	3 walks, 5 days	Improved speed
Bassile et al. (2003)	5	41-88	2 Male 3 Female	6-72	Not reported	Over-ground walking & obstacles	2 sessions per week, 5 weeks	Improved speed & endurance
Bogataj et al. (1997)	2	43	Male	>30	Haemorrhagic	FES	33 sessions, 6 weeks	Improved stride speed, time & length
Krishnamoorthy et al. (2008)	1	58	Male	36	Ischaemic	FES	15 sessions, 5 weeks	Improved speed stride length & symmetry
Lindquist et al. (2007)	8	56	6 Male 2 Female	17 (mean)	6 Haemorrhagic 2 Ischaemic	FES	6 weeks	Improved mobility & lower limb function
Tong et al. (2006)	2	75&59	Male	<1.5	Ischaemic	FES	20 mins per day, 4 weeks	Improved speed, distance & balance

Note: FES = functional electrical stimulation

Table 4.1 continued

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Hesse et al. (2010)	1	72	Male	not reported	Ischaemic	Robotics	30 mins, 5 days, 5 weeks	Improved mobility, walking & balance
Krishnan et al. (2013)	1	62	Male	10	Ischaemic	Robotics	3 sessions per week, 4 weeks	Improved speed, endurance & TUG
Wong et al. (2011)	3	44, 46 & 47	2 Male 1 Female	26, 27 & 40	Ischaemic	Robotics	18 one hour sessions, 6 weeks	Improved speed, endurance & balance
Ambrosini et al. (2011)	3	2, 27 & 51	2 Male 1 Female	12, 108 & 120	2 Ischaemic 1 Haemorrhagic	Biofeedback	6 sessions, 2 weeks	Improved stride length, swing speed & stance
Jonsdottir et al. (2007)	1	55	Male	42	Ischaemic	Biofeedback	3 sessions per week, total 20 sessions	Improved speed, step & stride length and stride frequency
Lewek et al. (2012)	2	60&53	1 Male 1 Female	18&21	Ischaemic	Biofeedback	18 sessions, 6 weeks	Improved speed, step length & stance time

Note: TUG = timed get up and go

Table 4.1 continued

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Deutsch et al. (2012)	1	38	Female	120	Haemorrhagic	Motor imagery	45-60 mins, 3x per week, 4 weeks	Improved speed and TUG
Dickstein et al. (2004)	1	69	Male	3	Not reported	Motor imagery	15 mins, 3 x per week, 6 weeks	Improved speed
Dunsky et al. (2006)	4	47-64	Male	23-108	3 Ischaemic 1 Haemorrhagic	Motor imagery	20 mins, 3 days per week, 6 weeks	Improved speed, cadence and stride length
Brown et al. (2005)	2	77&68	1 Male 1 Female	10 days & 7.5 weeks	Not reported	Cycling	13 sessions	Improved endurance
Holt et al. (2001)	1	55	Male	18	Haemorrhagic	Cycling	12-40 mins, 20 sessions, 8 weeks	Improved speed & distance
Marklund & Klassbo (2006)	5	46-81	2 Male 3 Female	6-78	Not reported	Cycling	6 hours per day, each day, 2 weeks	Improved distance & TUG

Note: TUG = timed get up and go

Table 4.1 continued

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Mansfield et al. (2011)	1	68	Male	52	Haemorrhagic	Aerobic (rapid stepping)	30-60 mins, 6 sessions	Improved speed & functional ambulation
Jackson et al. (2010)	3	65, 69 & 73	Male	36, 60 & 72	2 Haemorrhagic 1 Ischaemic	Aerobic (stepping)	20 mins, 2-3 x per week, 8 weeks	Improved balance & TUG
Mehrholz et al. (2006)	6	41-67	5 Male 1 Female	3-12 weeks	4 Ischaemic 2 Haemorrhagic	Aerobic (jump training)	5-7 mins each weekday, 6 weeks	Improved walking quality, capacity & endurance
Dunning et al. (2008)	1	51	Female	9	Not reported	VR	60 mins, 3x per week, 8 weeks	Improved speed
Flynn et al. (2007)	1	76	Female	17	Haemorrhagic	VR	20 one hour sessions	Improved speed & stepping
Killington et al. (2010)	12 (4 stroke, 8 TBI)	39-53	3 Male 1 Female	15-36	Not reported	Strength	2 days per week, 12 weeks	Improved speed, strength & TUG

Note: TBI = traumatic brain injury, VR = virtual reality, TUG = timed get up and go

Table 4.1 continued

Characteristics of Included Studies Classified by Intervention Type

Authors	No. of Participants	Age (years)	Sex	Post-Injury (months)	Stroke Type	Intervention	Dose	Outcome
Bastille et al. (2004)	4	49-71	1 Male 3 Female	9-96	2 Ischaemic 2 Not reported	Yoga	1.5 hours, 2x per week, 8 weeks	Improved forward & backward walking
Rondeau et al. (2010)	4	56-63	3 Male 1 Female	24-144 (days)	Haemorrhagic	Rehabilitation dog	60 mins, 4 weeks	Improved speed & gait

Methodological Quality. Table 4.2 below details the studies that met/did not meet the SCED scale criteria and their overall score. As noted in Chapter Three, the first item on the SCED scale is in relation to clinical history and is not included in the overall score. For completeness, all studies reported age, sex and aetiology. Only nine studies measured severity, six of which used the Stroke Impact Scale (Bastille et al., 2004; Combs et al., 2010; Combs et al., 2011; Miller et al., 2008; Reisman et al., 2010; Sullivan et al., 2006), two used the Barthel Index (Kendrick et al., 2001; Tong et al., 2006) and the other utilizing the Oprington Prognostic Scale (Miller, 2000). One study used the NIHSS but only reported scores for the sensation subcomponent (Wong et al., 2011).

Table 4.2

Studies Meeting/Not Meeting the SCED Scale Criteria

Authors	Specified Target Behaviour	Good Study Design	Baseline Measures (>3)	Continuous Measure of Behaviour	Raw Data Provided	Inter-rater Reliability	Independent Assessors	Statistical Analysis	Replication	Generalisation	Overall score
Bastille et al. (2004)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8/10
Combs et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	8/10
Combs et al. (2010)	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	7/10
Killington et al. (2010)	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	7/10
Marklund et al (2006)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	7/10
Miller et al. (2008)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	7/10
Mudge et al. (2003)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	7/10
Waagfjord et al (1990)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	7/10
Combs et al. (2007)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No	6/10
Hesse et al. (1995)	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	6/10
Jonsdottir et al. (2007)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No	6/10

Table 4.2 continued

Studies Meeting/Not Meeting the SCED Scale Criteria

Authors	Specified Target Behaviour	Good Study Design	Baseline Measures (>3)	Continuous Measure of Behaviour	Raw Data Provided	Inter-rater Reliability	Independent Assessors	Statistical Analysis	Replication	Generalisation	Overall score
Miller (2001)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No	6/10
Roehrig et al. (2008)	Yes	No	No	No	Yes	No	No	No	No	No	6/10
Rondeau et al. (2010)	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	6/10
Tong et al. (2006)	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Yes	6/10
Ambrosini et al (2011)	Yes	Yes	No	No	Yes	No	No	Yes	Yes	No	5/10
Bassile et al. (2003)	Yes	Yes	No	No	Yes	No	No	No	Yes	No	5/10
Fritz et al. (2007)	Yes	Yes	No	No	Yes`	No	No	No	Yes	Yes	5/10
Fritz et al. (2011)	Yes	Yes	No	No	Yes	No	No	No	Yes	Yes	5/10
Kollen et al. (2000)	Yes	Yes	No	Yes	No	No	No	Yes	Yes	No	5/10
Lindquist et al. (2007)	Yes	Yes	No	No	Yes	No	No	No	Yes	Yes	5/10
Miller et al. (2002)	Yes	No	No	Yes	Yes	No	No	No	Yes	Yes	5/10

Table 4.2 continued

Studies Meeting/Not Meeting the SCED Scale Criteria

Authors	Specified Target Behaviour	Good Study Design	Baseline Measures (>3)	Continuous Measure of Behaviour	Raw Data Provided	Inter-rater Reliability	Independent Assessors	Statistical Analysis	Replication	Generalisation	Overall score
Bogataj et al. (1997)	Yes	Yes	No	Yes	Yes	No	No	No	No	No	4/10
Deutsch et al. (2012)	Yes	Yes	No	No	Yes	No	No	Yes	No	Yes	4/10
Dunsky et al. (2006)	Yes	Yes	No	No	Yes	No	No	No	Yes	No	4/10
Flynn et al. (2007)	Yes	Yes	No	No	Yes	No	No	No	No	Yes	4/10
Jackson et al. (2010)	Yes	No	No	No	Yes	No	No	No	Yes	Yes	4/10
Kendrick et al. (2001)	Yes	No	No	Yes	Yes	No	No	No	No	Yes	4/10
Lewek et al. (2012)	Yes	Yes	No	No	Yes	No	No	No	Yes	No	4/10
Sullivan et al. (2006)	Yes	Yes	No	No	Yes	No	No	No	No	Yes	4/10
Veneri et al. (2011)	Yes	No	No	Yes	Yes	No	No	No	No	Yes	4/10
Vidoni et al. (2008)	Yes	No	No	Yes	Yes	No	No	No	No	Yes	4/10
Wong et al. (2011)	Yes	Yes	No	No	Yes	No	No	No	Yes	No	4/10

Table 4.2 continued

Studies Meeting/Not Meeting the SCED Scale Criteria

Authors	Specified Target Behaviour	Good Study Design	Baseline Measures (>3)	Continuous Measure of Behaviour	Raw Data Provided	Inter-rater Reliability	Independent Assessors	Statistical Analysis	Replication	Generalisation	Overall score
Brown et al. (2005)	Yes	No	No	No	Yes	No	No	No	Yes	No	3/10
Dickstein et al. (2004)	Yes	Yes	No	No	Yes	No	No	No	No	No	3/10
Dunning et al. (2008)	Yes	No	No	No	Yes	No	Yes	No	No	No	3/10
Hesse et al. (2010)	Yes	No	No	No	Yes	No	No	No	No	Yes	3/10
Holt et al. (2001)	Yes	No	No	No	Yes	No	No	No	No	Yes	3/10
Krishnamoorh et al. (2008)	Yes	Yes	No	No	Yes	No	No	No	No	No	3/10
Krishnan et al. (2013)	Yes	Yes	No	No	Yes	No	No	No	No	No	3/10
Mansfield et al. (2011)	Yes	No	No	No	Yes	No	No	No	No	Yes	3/10
McCain et al. (2007)	Yes	No	No	No	Yes	No	No	No	No	Yes	3/10
Mehrholz et al. (2006)	Yes	No	No	No	Yes	No	No	No	Yes	No	3/10
Reisman et al. (2010)	Yes	Yes	No	No	Yes	No	No	No	No	No	3/10

4.6 Interpretation, Discussion and Limitations

At the time the literature was reviewed there were no published single-case or N-of-1 studies on behavioural change interventions to increase stroke survivors' overall levels of physical activity. There were forty-four studies that focused on mobility outcomes such as gait speed, endurance, step length, stride length and symmetrical gait. Various types of interventions were found to be effective suggesting that irrespective of the type of intervention, doing more than the standard level of physical therapy is beneficial for mobility outcomes. It also raises the question as to whether expensive equipment is needed if lower-cost interventions produce similar benefits.

However, although the studies indicate that physical activity interventions improve physical outcomes this does not necessarily equate to an increase in overall levels of physical activity and active community living that will benefit health. Simply, because one can walk does not mean that one will walk. Physical activity interventions combined with behavioural change techniques may be beneficial in the pursuit of increasing levels of physical activity in stroke survivors.

There is no agreed cut-off that separates good quality single-case or N-of-1 studies from poorer ones. However, overall the methodological quality of the studies in the present systematic review was below average (4.6 out of 10). The better quality studies (score > 6) indicate that aerobic, strength and balance activities can improve walking speed, endurance, balance, step length and step symmetry (Bastille et al., 2004; Combs et al., 2010; Combs et al., 2011; Killington et al., 2010; Marklund & Klassbo; 2006; Miller et al., 2008; Mudge et al., 2003; Waagfjord et al., 1990). These findings are in line with previous systematic reviews and group-based

research which have reported the beneficial effects of aerobic and strength training on physical outcomes in stroke survivors (Dickstein 2005; Luft et al., 2008; Mead et al., 2007; Morris et al., 2004; Pang et al., 2013). As this is so it perhaps raises questions as to why N-of-1 studies should be carried out if group-based research produces the same or similar outcomes.

The reasons why N-of-1 studies should be conducted is that group-based studies fail to take heterogeneity into account and the analysis depends on averages meaning that an outcome is unlikely to reflect performance of any one individual. As such, it cannot be determined if all participants improved post-intervention or if some did and others did not. In N-of-1 studies, this can be achieved. A number of the studies included in the present systematic review reported that not all stroke survivors benefited from the intervention or that improvements were observed for some participants on one outcome but not on other outcomes, e.g. improved step-length symmetry but no improvement on walking speed or cadence (Ambrosini et al., 2011; Bastille et al., 2004; Combs et al., 2010; Fritz et al., 2007; Jackson et al., 2010; Lewek et al., 2012; Marklund & Klassbo, 2006; Mudge et al., 2003; Rondeau et al., 2010; Waagfjord et al., 1990).

Therefore, the results from group-based and N-of-1 studies can result in two very different conclusions being drawn about the effectiveness of interventions. The first is that physical activity interventions are beneficial for physical mobility outcomes; therefore if stroke survivors carry out a certain type of activity, for a certain frequency and duration, mobility outcomes will likely improve. The second conclusion is that physical activity interventions have the potential to improve

physical mobility outcomes *but* not all stroke survivors may benefit from a particular type of intervention.

If the first conclusion, which is based on a generalised outcome, is accepted the individual is being over-looked and there is limited scope to advance knowledge as the intervention is believed to be effective. On the other hand, the latter conclusion provides the capacity to progress research by investigating why some stroke survivors improve and others do not which ultimately develops evidence-based knowledge which then has the potential to impact upon recommendations and guidelines for stroke rehabilitation.

In terms of moving forward it is vital that methodological quality is assured in N-of-1 studies. From the present systematic review, problem areas appear to be lack of sufficient baseline testing, insufficient measurement throughout the intervention phase, no inter-rater reliability checks, lack of independent assessment, the use of descriptive analysis and the absence of replication of the study.

Taking only one measure at baseline limits the possibility of assessing for stability and assessing for the effects of natural recovery over time. Similarly, non-assessment of intervention effects throughout the intervention period and providing descriptive statistics only is problematic. Pre and post-data collection is typically integrated in group-based designs. To avoid this, N-of-1 researchers need to appreciate the methodological differences between N-of-1 designs and group-based designs and understand that taking pre and post-measures limits the type of analysis that can be carried out on the data thereby limiting the strength of the findings.

Moreover, N-of-1 studies that provide only descriptive statistics and/or visual analysis may contribute to the limited acceptance of the N-of-1 study as a viable

alternative to the group-based method. It is understandable why some may be cautious about the interpretation of N-of-1 studies reporting descriptive results. However, individual level studies designed properly can produce data to which appropriate inferential statistics can be applied. In the future, N-of-1 researchers must strive to achieve this.

It is also important that inter-rater reliability, independence of assessors and replication of the study is carried out. Reliability checks and independent assessors are often incorporated in group-based designs; therefore there is no reason why these design aspects should be excluded in N-of-1 studies. Finally, replicating the study across participants in particular provides the N-of-1 researcher with the opportunity to evaluate intervention effects across participants to determine who may benefit from an intervention and to assess if some did not, why not.

Overall, the current systematic review examined the literature on physical activity interventions using single-case and the N-of-1 method. No studies involving a behavioural intervention to increase overall levels of physical activity post-stroke were identified. Therefore, it is still unknown how best to assist stroke survivors to increase their levels of physical activity. Studies that were included focused on mobility outcomes resulting in some support for the value of intervening to improve such outcomes. However, one should remember that an improved physical ability does not necessarily transform into an increase in physical activity, and that physical activity interventions may not be equally effective for everyone. Finally, overall the methodological quality of the studies was below average. As such, future research studies using the N-of-1 approach must be designed to meet the current standard for good quality studies.

Like the systematic review carried out in Chapter Three, the search terms gave rise to a large number of potential articles suggesting that they lacked sensitivity, and were not the most appropriate terms to have used.

Methodology Used in Subsequent Chapters. As a result of carrying out both systematic reviews, JC had a greater understanding of the individual-based methodology and factors that need to be taken into consideration when adopting this method. However, to further the development of the N-of-1 methodology, a new process for studying fluctuations in memory and attention functions in stroke survivors was developed and assessed. The term used to describe this method is Individual Analysis of Temporal Processes (IATP). This was used to capture the individual aspect and emphasise that the study is not simply descriptive in nature but that analyses have been conducted to determine relationships between variables over time.

In particular, the study presented in Chapter Five (below) was designed and implemented to assess the suitability of the individual-based method with long-term stroke survivors and to determine if the methodology could be applied in an intervention study. The experience of using the daily diaries, administering the neuropsychological tests and questionnaires and the wear of the activPALTM monitor in Chapter Five allowed JC to then design a complex intervention with the aim of improving memory and attention in stroke survivors (Chapter Seven).

Chapter Five

A Series of IATP Studies to Investigate the Relationships between Memory, Attention, Mood, Anxiety and Sleep Quality in Long-Term Stroke Survivors

5.1 Introduction

A recent survey carried out in association with the James Lind Alliance reported that cognition, and how to improve it, was number one on the list of research priorities (Pollock, St George, Fenton, & Firkins, 2012). However, we do not have complete understanding of memory and attention deficits following stroke, particularly in the longer-term phase of recovery and our knowledge of possible influences on these cognitive functions is limited.

Although there are strengths associated with the group design, as discussed in Chapter Three, understanding the effect a stroke may have on memory and attention at the level of the individual may be better captured using a non-group approach, and this approach has been less popular within the stroke literature. A further issue with existing studies is that there is a tendency for researchers to focus on stroke survivors in the short-term phase of stroke recovery (Rohling, et al., 2009). Some studies have reported deficits in global cognitive function up to two (Grenthe Olsson & Sunnerhagen, 2007) and three years post-stroke (Patel et al., 2003), however, these studies have used composite cognition scores and screening tools making it difficult to determine the effect of a stroke on different memory and attention functions. Therefore, it is important that a detailed neuropsychological assessment is carried out to identify the exact nature of the cognitive deficit.

Additionally, because stroke is heterogeneous a multi-measurement system may be necessary to adequately capture the different components of memory and attention deficits. Use of both objective and subjective measurements of memory and attention can be utilized. One should be mindful though that objective tests measure performance, whereas questionnaires typically ask about memory and attention errors in daily functioning. Thus, the instruments are likely to measure different but related aspects of these cognitive functions yielding a discrepancy between the two. Indeed, Hermann (1982) reported that the relationship between objective and subjective memory is weak, but significant moderate correlations between objective memory tests and questionnaire scores have been reported elsewhere (Lincoln & Tinson, 1989), indicating that the relationship between objective and subjective memory is not entirely clear.

From the literature reviews in Chapters Two, Three and Four it is also evident more research is needed, not only to describe the memory and attention deficits of stroke survivors, but also of the factors that may exacerbate the difficulties such as mood state, anxiety, sleep quality and physical activity levels. Previous research has provided some evidence that these factors affect memory and attention functions in other clinical populations (see Chapter Two). Thus, these psychological and behavioural factors could potentially associate with memory and attention abilities in stroke survivors.

Aims. The aims of this study were to:

- i) Explore the nature and degree of memory and attention problems in long-term stroke survivors using objective neuropsychological memory and attention tests, and investigate subjective memory and attention.

- ii) Assess temporal associations between memory, attention, mood and anxiety and determine if self-reports of memory and attention can be predicted by mood and anxiety.
- iii) Assess the relationships between objective, subjective and diary measures of memory and attention.
- iv) Assess the temporal and predictive associations over time between memory, attention and sleep quality and use sleep quality questionnaires and activPAL™ activity monitoring to determine sleep quality.

5.2 Method

Study Design

A series of Individual Analysis of Temporal Processes (IATP) studies lasting 12 weeks were carried out with stroke survivors. Participants completed a daily diary, twice every day, where they self-reported on their memory, attention, mood, anxiety and sleep quality. Objective memory and attention tasks and the questionnaires were completed at baseline (Time 1) and 12 weeks later (Time 2). The activPAL monitor was worn for seven consecutive nights also at Time 1 and Time 2.

Participants

Twelve stroke survivors entered the study. Twelve other potential participants expressed an interest in the study but were not included as they did not reply to follow-up requests/decided not to take part (5 participants), lived out-with Scotland (3 participants), did not self-report problems with memory and/or attention (2 participants), had communication impairments that would prevent understanding of the study requirements (1 participant), and felt they would not commit to the study (1

participant). Participant demographics of those included in the study are shown in Table 5.1.

The inclusion criteria were broad to aid recruitment of stroke survivors with a range of deficits. The inclusion criteria were: (1) adults between 18 and 80 years old; (2) who had sustained a stroke (ischaemic/haemorrhage) at least 6 months prior to the study commencing; (3) who self-reported problems with memory and attention and (4) who were community dwelling residents within Scotland. Exclusion criteria were: (1) individuals who had visual or hearing impairments not corrected with visual and hearing devices, (2) had inadequate English language ability that would prevent understanding of the test instructions/study requirements and (3) suffered from dementia.

The primary researcher (JC) met with potential participants and caregivers prior to the study commencing. If stroke survivors met the inclusion criteria and the exclusion criteria were not applicable, and it was clear that they understood the study requirements they were considered suitable for the study. If however JC felt that the stroke survivor did not understand what was asked of them, despite meeting the inclusion criteria JC discussed potential inclusion with the primary supervisor (MG) and then a decision was made on whether the participant should be included in the research study or not.

Measures

The Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) was used to assess global cognition. The MoCA is a 30-item measure administered in 10 minutes and covers eight cognitive domains including short-term recall, delayed recall, visual-spatial ability, executive functions, attention, working memory,

language and orientation. The total possible score is 30; a score of 26 or above is considered normal. Cronbach's alpha = .83, test-retest reliability = .92, indicating excellent reliability. The MoCA has been shown to be a feasible tool assessing cognitive function in stroke (Cumming, Linden, & Bernhardt, 2011) with high values of specificity and sensitivity (Pendlebury, Cuthbertson, Welch, Mehta, & Rothwell, 2010).

The MOCA was also used as a screening measure to assess for the presence of dementia as those who were suffering from dementia were excluded from the study. An average score of 16 is indicative of Alzheimer's disease (AD). Therefore, if potential participants obtained a score less than 17 on the MOCA a conversation between the primary researcher (JC), the stroke survivor and caregiver would ensue to find out if the stroke survivor had received a diagnosis of AD or dementia, and whether they considered themselves able to take part in the research study. Discussions between JC and the primary supervisor (MG) would also take place in such circumstances to clarify if a potential participant should be excluded based upon diagnoses they may have had and this cut-off.

The line-bisection test (Schenkenberg, Bradford, & Ajax, 1980) was administered to detect the presence of spatial neglect. This condition is characterized by a lack of awareness of the personal space opposite to the damaged brain region. Individuals are asked to manually bisect a series of horizontal lines by marking the perceived mid-point with a pencil. Errors made where the left side of the line is ignored are interpreted as left spatial neglect as a result of right hemisphere trauma. Test-retest reliability = 0.84 (Schenkenberg et al., 1980).

Neuropsychological Memory and Attention Tests. To assess the nature of the memory deficits experienced by the participants the Rivermead Behavioural Memory Test – Third Edition (RBMT-3) (Wilson et al., 2008) was used. This is a standardised test battery that contains a number of subtests assessing verbal, visual, spatial and prospective memory, orientation/date and new learning. Reliability of the RBMT-3 was estimated by alternate-form reliability and reliability coefficients of the subtests which ranged from .57 – .86. Inter-scorer reliability was also performed yielding a total correlation coefficient of .99 (Wilson et al., 2008). RBMT-3 scores significantly correlate with the Prospective and Retrospective Memory Questionnaire (Smith, Della Sala, Logie, & Maylor, 2000). The test is sensitive in measuring memory problems in clinical populations (Wilson et al., 2008).

The Test of Everyday Attention (TEA) (Robertson, Nimmo-Smith, Ward, & Ridgeway, 1996) was used to assess aspects of attention. This is a standardised test battery with subtests that focus on selective, sustained, divided attention, attentional switching and speed of processing. Alternate-form reliability analyses were carried out on a normal sample and a stroke sample. For both populations the reliability of the TEA is good for almost all subtests (.77 – .90), apart from the Telephone Search whilst Counting subtest (.41) (Robertson et al., 1996).

Subjective Measures of Memory and Attention. To capture the extent to which participants felt their memory and attention deficits impacted on their everyday life the Everyday Memory Questionnaire revised version (EMQ-R) (Royle & Lincoln, 2008) was used. The EMQ-R is a 13-item self-report questionnaire. Each item is scored on a 5-point rating scale ranging from (0) ‘Once or less in the last month’ to (4) ‘Once or more in a day’. Participants are asked to indicate how often

on average they think each one has happened to them over the past month and write the appropriate number in the box beside the item. Higher scores indicate more reported difficulties. Cronbach's alpha = .89.

No studies have been identified that assesses the reliability of the EMQ-R in a stroke only sample. However, Royle and Lincoln (2008) assessed the reliability based on the responses of all participants who took part in their study, i.e. healthy controls, patients with multiple sclerosis (MS) and stroke survivors with memory impairment. The scores of the three groups differed with stroke patients scoring higher than healthy controls and MS patients indicating that the scale is sensitive in detecting differences between clinical and non-clinical populations.

Subjective Measures of Depression, Anxiety and Sleep Quality. The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to measure depression and anxiety. The HADS is a 14-item measure and each item is scored on a 4-point rating scale ranging from 0 – 3. Participants are asked to underline the reply which comes closest to how they have felt in the past week. Higher scores on both subscales indicate more reported difficulties. The HADS has been reported to be a satisfactory measure assessing anxiety and depression in both clinical and non-clinical populations (Bjelland, Dahl, Haug, & Neckelmann, 2002) and has been validated in stroke. Cronbach's alpha = .85 (Aben, Verhey, Lousberg, Lodder, & Honig, 2002).

Measures of Sleep and Night Activity. The Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989) was used to subjectively assess sleep quality. This is a 19-item questionnaire with specific components of sleep assessed such as sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances,

use of sleeping medication and daytime dysfunction. Each item is scored on a 4-point rating scale ranging from (0) 'Not during the past month to (4) 'Three or more times a week'. Participants are asked to indicate the most accurate response in relation to their sleep quality over a one-month period. The component scores are summed to yield a global PSQI score. A score equal to or less than five indicates good sleep quality, whilst a score greater than five indicates poor sleep quality. Cronbach's alpha = .83 (Buysse et al., 1989).

To gain more objective measures of movement patterns during the night the activPAL™ (PAL Technologies LTD, Glasgow, UK) activity monitor was used. This is a small (53 x 35 x 7 mm) lightweight (20g) single axis accelerometer worn on the midline of the anterior thigh. The accelerometer has been used to measure movement post-stroke (Britton, Harris, & Turton, 2008). The monitor produces a detailed pattern of movement behaviours such as time spent sitting and lying, standing, walking and frequency of sit-to-stand transitions.

Daily Diaries. Participants were asked to complete a diary checklist each day for 12 weeks (see Appendix I). They were asked to rate on a 7-point Likert scale ranging from 'Very Bad' (-3) to 'Very Good' (+3) how well they slept the night before and to self-report how their memory, attention, mood and anxiety had been. Sleep quality was recorded once per day whilst the other variables were recorded twice each day.

Procedure

Ethical approval was granted by the University of Strathclyde Ethics Committee. All participants provided written consent and all data was pseudo-anonymized (see Appendices II-V for ethics application form, approval letter,

participant information sheet and consent form, respectively). Recruiting community-based stroke survivors can be a difficult task (Lloyd, Dean, & Ada, 2010), thus organisations that support stroke survivors were contacted. The Stroke Association and Different Strokes were two organisations that were particularly helpful in aiding the recruitment of participants by distributing flyers to non-NHS affiliated stroke groups across Scotland and placing adverts on the organisations' websites. Flyers were also delivered to local churches and a small number of participants were recruited through word of mouth. If potential participants wanted further information, or said that they would like to take part, an information pack giving more information about the study was posted to their home address.

The baseline testing at Time 1 took place over two visits one week apart. During the first visit participants completed the MoCA, the line-bisection test, demographic questions and provided information about their stroke (i.e. time since stroke onset, type of stroke, side affected). Following this, instructions on how to complete the diary were given. Then participants completed the RBMT-3 and/or the TEA. Some participants completed both batteries of neuropsychological tests on the first testing session, whereas others completed the RBMT-3 on the first session and the TEA the following week, as although breaks were offered to minimize fatigue some participants complained of feeling tired. The questionnaires were also administered. Participants often choose to complete these the day(s) following the testing session and were collected the following week.

During the first study visit the activPAL's were given to the participants. To reduce participant burden of re-attaching the monitors each night and given that participants self-reported memory problems the monitors were placed in a nitrile

sleeve and wrapped in a waterproof transparent dressing (Tegaderm™) to allow for continuous wear. The waterproofed monitor was then placed on the thigh with the distal end of the monitor pointing towards the knee. The monitor was held in place by an 8cm x 10cm strip of Tegaderm. The researcher demonstrated on her arm how to place the Tegaderm over the monitor when attaching it. Participants then attached the monitors to themselves. If the stroke survivor suffered from lower limb hemiparesis they were asked to wear the monitor on their less-affected limb. Otherwise, they were asked to attach the monitor to their right thigh. The activity monitors were collected during the second visit seven days later.

The same procedure was carried out at the end of the study 12 weeks later (Time 2) apart from the administration of the screening measures and demographic questionnaires.

Data Analysis

The result section is presented in sections. The first section is concerned with memory, attention, mood and anxiety. The second section focuses on memory, attention and sleep quality. In both sections, the data were analysed using several techniques. First, descriptive data of RBMT-3 and TEA performance and questionnaire results (EMQ-R, HADS) are given for each participant. This is followed by difference testing of neuropsychological test scores at the group level between Time 1 and Time 2 using a Related Samples Wilcoxin Signed Rank Test. Spearman correlation analyses were then performed to test for associations between performance on the neuropsychological tests and the questionnaires results.

In the sleep quality section, descriptive information is given on the activPAL outcomes (time spent sitting/lying, number of up/down transitions and number of steps taken) and results from the sleep quality questionnaire (PSQI).

For both sections, the diary data were analysed using *R* software to first to prepare the data and then in SPSS (Version 19) to conduct cross-correlations and fit multiple regressions models. In terms of preparation, the diary ratings of memory, attention, mood, anxiety and sleep quality were imported into the *R* software environment and converted into scales from 1-7. *R* was used to allow for imputation of missing data and to transform non-normal distributed data where possible. Data were pre-whitened to remove the presence of autocorrelation as this violates the assumptions of multiple regression analyses. The *R* software package was designed by a statistician (Sion Philpott-Morgan).

Following this, the data were transferred to SPSS to carry out the cross-correlations and multiple regressions. When carrying out multiple comparisons between variables corrections methods such as Bonferroni correction could be applied to control for Type 1 error. However, such correction methods were not applied to the data within the studies of this thesis as it was felt that these would be too conservative since there was a large number of comparisons being performed (as discussed by Field (2009)). This is a limitation of this method and should be taken into consideration when interpreting the data.

The procedure proposed by Professor Derek Johnson on time series analysis was followed for the analyses of the diary data (*personal communication, 2013*). When cross-correlating variables a different number of lags can be selected, and the direction of the lag indicates the temporal relationship between variables. A positive

lag indicates that the first variable entered precedes the second, and a negative lag indicates that the second variable precedes the first. The analysis first assessed the concurrent relationship between the variables and then the lagged relationships.

Taking mood and memory as the example, if a +1 lag was significant this would indicate that mood measured at time one was associated with memory at time two. If a significant -1 lag was evident this would show that mood at measurement time two was associated with memory at measurement time one.

5.3 Results

Participant Demographics. Table 5.1 details participant demographics and test scores on the Montreal Cognitive Assessment (MoCA) and the line-bisection test. Five participants were female and seven were male and ages ranged from 38 – 83 years and four were taking anti-depressant medication. Of the 12 participants, only two scored greater than 26 on the MoCA (P3 and P6) indicating that the majority had some form of cognitive impairment as measured by this global cognitive functioning measure. No participants were excluded on the basis of their MoCA scores. Only one participant (P2) had a score greater than 6 mm on the line bisection test which would be indicative of unilateral spatial neglect. However, P2's performance on the visuospatial tests on the MoCA (cube and clock drawing) was normal suggesting that he did not have neglect.

Table 5.1

Participant Demographics (MoCA score ≥ 26 is Considered Normal. Line-bisection Score > 6 mm from Mid-Point Indicates Presence of Neglect)

P	Sex	Age (years)	Education (years)	Employment	Marital Status	Time Since Stroke (months)	Stroke Type	Side Affected	MoCA score	LB (mm)
1	Female	39	13	Cleaner	Single	252	Unknown	Right	21	1.8
2	Male	63	11	Retired	Married	90	Unknown	Left	24	6.4
3	Male	62	20	Minister	Married	220	Brainstem	Both	27	1.5
4	Female	38	15	Retired	Married	46	Ischaemic	Right	24	1.4
5	Female	61	13	Retired	Married	14	Unknown	Both	18	1.8
6	Male	46	11	Self- employed	Married	22	Ischaemic	Left	30	4.6
7	Female	65	10	Retired	Married	68	Haemorrhagic	Right	25	3.7
8	Female	83	Not reported	Retired	Widowed	17	Unknown	Left	20	4.2
9	Male	61	13	Retired	Married	Unknown	Ischaemic	Right	25	2.6
10	Male	69	15	Retired	Married	28	Ischaemic	Left	25	5.9
11	Male	80	19	Retired	Married	25	Ischaemic	Left	20	0.9
12	Male	60	11	Retired	Married	8	Ischaemic	Right	24	4.2

Note: MoCA = Montreal Cognitive Assessment, LB = line-bisection

Rivermead Behavioural Memory Test. Table 5.2 shows participants' percentile ranks for each subtest on the Rivermead Behavioural Memory Test-3rd Edition (RBMT-3) at Time 1 and Time 2. A difference score between the time points is also provided (deterioration in performance is indicated by the minus sign). The RBMT-3 contains subtests of verbal, visual, spatial and prospective memory, new learning and orientation/date.

In terms of percentile scores, a higher rank reflects a better degree of cognitive performance. As an illustrative example, if a person obtains a percentile rank of 5 it is estimated that only 5% of the normative population will obtain lower scores. The RBMT-3 also produces a General Memory Index score (GMI) which is a score representing overall memory performance. This index is standardised to have a mean of 100 and standard deviation of 15. Therefore, if someone obtained a GMI score of 85 they would be one standard deviation below the mean indicating poorer performance. This GMI score is also presented in Table 5.2.

Table 5.2

RMBT-3 General Memory Index Scores (mean = 100, $SD = 15$) and Percentile Scores for Verbal Memory Subtests at Times 1 and 2.

P	Verbal Memory											
	General Memory Index			Names			Story Immediate Recall			Story Delayed Recall		
	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1
1	80	74	-6	1	9	-8	25	9	-16	9	16	7
2	91	105	14	50	75	-25	9	63	54	25	63	38
3	95	80	-15	16	2	-14	25	37	12	25	16	-9
4	79	74	-5	1	2	-1	16	0	-16	5	0	-5
5	63	61	-2	9	5	-4	16	5	-11	9	16	7
6	107	99	-8	75	37	-38	25	63	38	37	50	13
7	114	127	13	75	84	9	50	37	-13	63	50	-13
8	71	69	-2	25	25	0	37	37	0	37	16	-21
9	90	90	0	2	9	7	37	16	-21	37	9	-28
10	103	81	-22	37	16	-21	63	63	0	75	16	-59
11	106	99	-7	63	50	-13	16	63	47	37	63	26
12	71	70	-1	2	0	-2	5	16	11	2	16	14

Note. Percentile scores have been rounded up to the nearest whole number

Table 5.2 continued

RMBT-3 Percentile Scores for Visual and Spatial Memory Subtests at Times 1 and 2

P	Visual Memory						Spatial Memory					
	Picture Recognition			Face Recognition			Route Immediate Recall			Route Delayed Recall		
	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1
1	63	16	-47	9	37	28	63	63	0	63	63	0
2	63	75	12	63	63	0	75	75	0	75	25	-50
3	63	75	12	63	37	-26	75	75	0	75	75	0
4	63	25	-38	2	25	23	63	63	0	63	63	0
5	25	9	-16	9	63	54	75	9	-64	16	9	-7
6	63	63	0	37	9	-28	63	63	0	63	63	0
7	63	75	12	63	98	35	75	84	9	75	75	0
8	63	9	-54	0	2	2	5	9	4	2	16	14
9	25	63	38	16	63	47	75	75	0	16	75	59
10	75	63	-12	9	0	-9	84	37	-47	75	75	0
11	75	25	-50	84	16	-68	84	16	-68	84	16	-68
12	9	9	0	16	5	-11	75	75	0	75	75	0

Note. Percentile scores have been rounded up to the nearest whole number

Table 5.2 continued

RMBT-3 Percentile Scores for Prospective Memory Subtests at Times 1 and 2

Prospective Memory												
P	Messages Immediate Recall			Messages Delayed Recall			Belongings			Appointments		
	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1
1	63	9	-54	5	5	0	9	9	0	63	16	-47
2	63	63	0	63	63	0	9	63	54	75	5	-70
3	63	5	-58	63	63	0	9	0	-9	25	16	-9
4	63	50	-13	63	63	0	75	9	-66	16	9	-7
5	1	16	15	1	2	1	1	0	-1	1	1	0
6	63	2	-61	63	63	0	75	63	-12	37	63	26
7	63	63	0	63	63	0	37	75	38	16	37	21
8	25	1	-24	9	0	-9	16	37	21	25	50	25
9	63	63	0	63	63	0	63	9	-54	16	75	59
10	63	63	0	63	63	0	75	84	9	75	50	-25
11	63	63	0	63	63	0	50	50	0	75	84	9
12	63	63	0	63	9	-54	1	9	8	16	25	9

Note. Percentile scores have been rounded up to the nearest whole number

Table 5.2 continued

RMBT-3 Percentile Scores for New Learning and Orientation/Date Subtests at Times 1 and 2

P	New Learning						Orientation/Date		
	Learning Immediate Recall			Learning Delayed Recall			Orientation/Date		
	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1
1	37	16	-21	63	63	0	5	9	-4
2	9	37	28	16	63	47	9	25	16
3	50	16	-34	75	25	-50	9	25	16
4	50	37	-13	25	9	-16	0	63	63
5	2	0	-2	5	2	3	2	0	-2
6	84	50	-34	75	63	-12	16	63	-47
7	50	63	13	84	75	-9	75	63	-12
8	16	16	0	16	9	-7	63	37	-26
9	84	37	-47	63	75	12	9	0	-9
10	9	5	-4	25	0	-25	9	16	7
11	9	63	54	50	84	34	9	25	16
12	16	37	21	9	9	0	1	0	-1

Note. Percentile scores have been rounded up to the nearest whole number

From Table 5.2 it is clear that the stroke survivors in this study performed poorly on a number of the subtests. Most of the participants obtained a GMI score less than the mean of 100 at both Time 1 and Time 2.

Regarding percentile scores, there is no agreed values of what constitutes good cognitive performance other than the higher the percentile score the better the performance. However, by counting the number of participants who obtain scores lower than the 75th and 50th percentile at either Time 1 or Time 2 showed that 11/12 participants obtained scores \leq 75th percentile rank on all the subtests of the RBMT-3 and 10 participants obtained scores \leq 50th percentile rank on new learning and orientation/date. Eight participants scored less than the 50th percentile on verbal, visual and prospective memory and four participants obtained scores lower than the 50th percentile on spatial memory.

The further point to note is that the participants' performance fluctuated between Time 1 and Time 2. To illustrate, P10's verbal memory performance deteriorated by 59 percentile points over the time period. For visual memory, P8's performance deteriorated by 54 percentile from Time 1 to Time 2. P5's spatial memory scores deteriorated by 64 percentile points and P9's performance on the prospective memory task improved by 59 percentile points with similar difference scores obtained with new learning and orientation/date. This fluctuation in test performance is discussed later.

Test of Everyday Attention. Participants' percentile scores for each of the subtests on the Test of Everyday Attention (TEA) are detailed in Table 5.3. Percentile scores are within a range rather than being specified as a single value as in the RBMT-3. However, to aid interpretation the average of this range is shown in

Table 5.3. The TEA contains subtests of selective, sustained, divided attention, attentional switching (auditory and visual) and speed of processing.

Table 5.3

TEA Percentile Scores (average of range) for Selective Attention Subtests at Times 1 and 2

Selective Attention												
P	Map Search 1			Map Search 2			Telephone Search			Elevator Counting with Distraction		
	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1
1	16	50	34	2.5	2.5	0	25.5	9.5	-16	1.5	0.5	-1
2	2.5	25.5	23	5	2.5	-2.5	5	2.5	-2.5	16	9.5	-6.5
3	2.5	9.5	7	5	0	-5	9.5	1.5	-8	74.5	74.5	0
4	16	5	-11	5	0	-5	74.5	50	-24.5	63	84	21
5	5	9.5	4.5	9.5	0.5	-9	2.5	0	-2.5	16	16	0
6	25.5	25.5	0	9.5	5	-4.5	5	0	-5	37	84	47
7	5	37	32	25.5	16	-9.5	25.5	0	-25.5	84	50	-34
8	2.5	9.5	7	9.5	0	-9.5	9.5	0	-9.5	37	25.5	-11.5
9	25.5	50	24.5	2.5	37	34.5	25.5	5	-20.5	1.5	25.5	24
10	5	2.5	-2.5	0	0	0	0	5	5	1.5	16	14.5
11	9.5	16	6.5	0	16	16	0	25.5	25.5	25.5	63	37.5
12	25.5	2.5	-23	1.5	5	3.5	0	2.5	2.5	1.5	5	3.5

Note: Percentile scores have been rounded up to the nearest whole number

Table 5.3 continued

TEA Percentile Scores (average of range) for Attentional Switching and Speed of Processing Subtests at Times 1 and 2

P	Attentional Switching						Speed of Processing		
	Elevator Counting with Reversal			Visual Elevator			Visual Elevator		
	T1	T2	T2-T1*	T1	T2	T2-T1	T1	T2	T2-T1
1	9.5	2.5	-7	16	37	21	2.5	0	-2.5
2	37	37	0	84	84	0	1.5	0.5	-1
3	50	9.5	-40.5	37	84	47	2.5	16	13.5
4	90.5	63	-27.5	63	37	-26	25.5	16	-9.5
5	5	0	-5	84	9.5	-74.5	5	0	-5
6	74.5	25.5	-49	90.5	84	-6.5	25.5	1.5	-24
7	63	63	0	16	63	47	74.5	90.5	16
8	0	0	0	2.5	0.5	-2	37	0	-37
9	2.5	5	2.5	16	84	68	5	50	45
10	0	0	0	1.5	2.5	1	0	0	0
11	50	1.5	-48.5	5	16	11	0.5	63	62.5
12	0	0	0	84	9.5	-74.5	0	0	0

Note: Percentile scores have been rounded up to the nearest whole number

* = significant difference between Time_1 and Time_2 ($p < .05$)

Table 5.3 continued

TEA Percentile Scores (average of range) for Sustained and Divided Attention Subtests at Times 1 and 2

P	Divided Attention			Sustained Attention		
	Telephone Search with Counting			Lottery		
	T1	T2	T2-T1	T1	T2	T2-T1
1	5	0.5	-4.5	1.5	2.5	1
2	5	5	0	74.5	84	9.5
3	25.5	9.5	-16	25.5	1.5	-24
4	5	37	32	25.5	74.5	49
5	9.5	1.5	-8	1.5	2.5	1
6	63	16	-47	9.5	1.5	-8
7	0	16	16	25.5	25.5	0
8	63	63	0	1.5	0	-1.5
9	0	16	16	74.5	74.5	0
10	0.5	0	-0.5	0	0	0
11	37	25.5	-11.5	84	84	0
12	1.5	25.5	24	1.5	9.5	8

Note: Percentile scores have been rounded up to the nearest whole number

As can be seen from Table 5.3, similarities in terms of performance are observed on the TEA as in the RBMT-3 in that the participants had varying levels of cognitive performance across the subtests. Participants' percentile scores on the TEA subtests also indicated that these stroke survivors in the long-term phase of recovery had attention difficulties. As noted above, there is no defined cut-off reflecting good cognitive performance but counting the number of participants who obtain scores equal to or below the 50th percentile either Time 1 or Time 2 gives an indication of the deficits experienced by these participants. All participants obtained scores equal to or below the 50th percentile on the selective attention sub-test Map Search and 11 and nine participants scored lower than this percentile on the other selective attention sub-tests, Telephone Search and Elevator Counting with Distraction. Ten participants also scored less than this percentile on speed of processing and divided attention, and eight and seven participants obtained scores equal to or less than the 50th percentile on the sustained attention and attentional switching sub-tests, respectively.

As with the RBMT-3, performance on the TEA also fluctuated between Time 1 and Time 2. To illustrate, P6's performance on selective attention improved by 49-45 percentile scores from Time 1 to Time 2. P4's sustained attention score improved by 49 percentile scores. On the divided attention task, P12's performance improved by 24 percentile scores, whilst P11's performance on attentional switching deteriorated by 48.5 percentile scores even though their speed of processing task score improved by 62.5 percentile ranks. Table 5.4 details a summary of the memory and attention domains participants were impaired on. Impaired areas were classified

as obtaining scores below the 50th percentile on the RBMT-3 and below than the 43rd-57th percentile rank on the TEA.

Table 5.4

Summary of Memory and Attention Problem Areas for P1-P4

Impaired memory and attention domains at Time 1 (T1) and Time 2 (T2)	
P1	<p>Memory: verbal memory (all subtests T1,T2), visual memory (face recognition T1,T2, picture recognition T2), prospective memory (belongings & messages delayed recall T1,T2, messages immediate recall & appointments T2), new learning (learning immediate recall T1,T2) & orientation/date (T1,T2).</p> <p>Attention: selective attention (map search1 T1, map search2, telephone search & elevator counting with reversal T1,T2), sustained attention (both subtests T1,T2), divided attention (T1,T2), attentional switching (both subtests T1,T2) & speed of processing (T1,T2).</p>
P2	<p>Memory: verbal memory (story immediate & delayed recall T1), spatial memory (route delayed recall T2), prospective memory (belongings T1 & appointments T2), new learning (learning immediate recall T1,T2 & learning delayed recall T1) & orientation/date (T1,T2).</p> <p>Attention: selective attention (all subtests T1,T2), sustained attention (elevator counting T1,T2), divided attention (T1,T2), attentional switching (elevator counting with reversal (T1,T2) & speed of processing (T1,T2).</p>
P3	<p>Memory: verbal memory (all subtests T1,T2), visual memory (face recognition T2), spatial memory (route delayed recall T2), prospective memory (messages immediate recall T2, belongings & appointments T1, T2), new learning (both subtests T2) & orientation/date (T1,T2).</p> <p>Attention: selective attention (map search1 & 2, telephone search T1,T2), sustained attention (both subtests T1, T2, divided attention (T1,T2), attentional switching (elevator counting with reversal T2, visual elevator T1) & speed of processing (T1,T2).</p>
P4	<p>Memory: verbal memory (all subtests T1,T2), visual memory (picture recognition T2, face recognition T1, T2), prospective memory (belongings T2 & appointments T1,T2), new learning (learning immediate recall T1 & learning delayed recall T1,T2) & orientation/date (T1).</p> <p>Attention: selective attention (map search 1 & 2 T1,T2), sustained attention (elevator counting T1, T2 & lottery T1) divided attention (T1,T2), attentional switching (visual elevator T2) & speed of processing (T1, T2).</p>

Table 5.4 continued

Summary of Memory and Attention Problem Areas for P5-P9

Impaired memory and attention domains at Time 1 (T1) and Time 2 (T2)	
P5	<p>Memory: verbal memory (all subtests T1, T2), visual memory (picture recognition T1, T2 & face recognition T1), spatial memory (route immediate recall T2 & route delayed recall T1,T2), prospective memory (all subtests T1,T2), new learning (both subtests T1,T2) & orientation/date (T1,T2).</p> <p>Attention: selective attention (map search1 T2, map search2, telephone search & elevator counting with distraction T1,T2), sustained attention (both subtests T1,T2), divided attention (T1,T2), attentional switching (elevator counting with reversal T1,T2 & visual elevator T2) & speed of processing (T1,T2).</p>
P6	<p>Memory: verbal memory (names T2, story immediate & delayed recall (T1), visual memory (face recognition T1,T2), prospective memory (messages immediate recall T2 & appointments T1) & orientation/date (T1).</p> <p>Attention: selective attention (map search 1 & 2, telephone search T1,T2 & elevator counting with distraction T1), sustained attention (both subtests T1,T2), divided attention (T2), attentional switching (elevator counting with reversal T2) & speed of processing (T1,T2).</p>
P7	<p>Memory: verbal memory (story immediate recall T2), prospective memory (belongings T1, appointments T1,T2).</p> <p>Attention: selective attention (map search 1 & 2 & telephone search T1,T2), sustained attention (both subtests T1,T2), divided attention (T1,T2) & attentional switching (visual elevator T1).</p>
P8	<p>Memory: verbal memory (all subtests T1,T2), visual memory (picture recognition T2 & face recognition T1,T2), spatial memory (both subtests T1,T2), prospective memory (all subtests T1,T2), new learning (all subtests T1,T2) & orientation/date (T2).</p> <p>Attention: selective attention (all subtests T1,T2), sustained attention (both subtests T1,T2), attentional switching (both subtests T1,T2) & speed of processing (T1,T2).</p>
P9	<p>Memory: verbal memory (all subtests T1,T2), visual memory (picture & face recognition T1), spatial memory (route delayed recall T1), prospective memory (belongings T2 & appointments T1), new learning (learning immediate recall T2) & orientation/date (T1,T2).</p> <p>Attention: selective attention (map search 1 T1 & all other subtests T1,T2), sustained attention (elevator counting T1,T2), divided attention (T1,T2), attentional switching (visual elevator T1) & speed of processing (T1).</p>

Table 5.4 continued

Summary of Memory and Attention Problem Areas for P10-P12

Impaired memory and attention domains at Time 1 (T1) and Time 2 (T2)	
P10	<p>Memory: verbal memory (names T1,T2 & story delayed recall T2), visual memory (face recognition T1,T2, spatial (route immediate recall T2), new learning (both subtests T1,T2) & orientation/date (T1,T2).</p> <p>Attention: selective attention (all subtests T1,T2), sustained attention (both subtests T1,T2), divided attention (T1,T2), attentional switching (both subtests T1,T2) & speed of processing (T1,T2).</p>
P11	<p>Memory: verbal memory (story immediate & delayed recall T1), visual memory (picture recognition T2 & face recognition T2), spatial memory (route immediate & delayed recall T2), new learning (learning immediate recall T1) & orientation/date (T1,T2).</p> <p>Attention: selective attention (map search 1 & 2 & lottery T1,T2, elevator counting with distraction T1), sustained attention (elevator counting T1,T2), divided attention (T1,T2), attentional switching (elevator counting with reversal T2 & visual elevator T1,T2) & speed of processing (T1).</p>
P12	<p>Memory: verbal memory (all subtests T1,T2), visual memory (both subtests T1,T2), prospective memory (messages delayed recall T2, belongings & appointments T1,T2), new learning (both subtests T1,T2) & orientation/date (T1,T2).</p> <p>Attention: selective attention (all subtests T1,T2), sustained attention (both subtests T1,T2), divided attention (T1,T2), attentional switching (elevator counting with reversal (T1,T2) & speed of processing (T1,T2).</p>

Subjective Reports of Memory and Attention. The results from the Everyday Memory Questionnaire-Revised (EMQ-R) and the Hospital Anxiety and Depression Scale (HADS) are shown in Table 5.5. The EMQ-R contains two subscales: memory retrieval and attentional tracking. The minimum score that can be achieved on both subscales is zero and the maximum is four with a higher score indicating more reported difficulties. The HADS also contains two subscales: anxiety and depression and the severity classifications are noted below Table 5.5.

Table 5.5

Everyday Memory Questionnaire and Hospital Anxiety and Depression Scale Scores at Times 1 and 2

P	EMQ-R Memory			EMQ-R Attention			HADS Anxiety			HADS Depression		
	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1	T1	T2	T2-T1
1	2	2.6	.6	2	0.8	-1.2	17	15	-2	12	7	-5
2	3.6	2.9	-.7	2.8	2.3	-.5	9	11	2	6	7	1
3	3.3	3.7	.4	2.8	2.5	.3	6	9	3	14	10	-4
4	4	4	0	4	4	0	12	15	3	7	9	2
5	2.7	2.6	-.1	3	1.5	-1.5	2	2	0	1	1	0
6	2.3	2	-.3	2	0.5	-1.5	8	8	0	7	8	1
7	2.6	0.1	-2.5	2.3	2.8	.5	10	9	-1	4	3	-1
8	0.9	1	.1	0	0.8	.8	8	6	-2	3	2	-1
9	3.7	3.9	.2	3	2.5	-.5	5	6	1	7	4	-3
10	1.7	1.4	-.3	1	1.5	.5	2	3	1	6	8	2
11	1.4	0.9	-.5	0.3	0.8	.5	12	9	-3	6	8	2
12	4	3.7	-.3	3.8	3.5	-.3	19	19	0	18	16	-2

Note: EMQ scores have been rounded to 1 decimal place

EMQ Memory Stroke sample mean = 1.8, healthy controls mean = 0.9, EMQ Attention Stroke sample mean = 1.3, healthy controls mean = 0.6 (Royle & Lincoln, 2008)

HADS: normal = 0-7, mild = 8-9, moderate = 10-14, severe = 15-19, extremely severe = 20+

Table 5.5 shows that the majority of the participants reported memory and attention difficulties. Eight of the twelve participants had higher memory scores than the mean normative scores for the stroke sample and healthy controls. Two participants (P10 and P11) obtained scores that were lower than the mean normative score for the stroke sample and one participant reported memory problems at the same level as healthy controls (P8). In terms of self-reported attention, seven participants scored higher than the mean normative stroke sample and healthy controls at both Time 1 and Time 2. The remaining participants obtained scores lower than the mean normative stroke sample and/or healthy controls at either Time 1 or Time 2.

Four participants obtained scores within the normal range on the HADS anxiety subscale, three obtained scores within the mild range, three within the moderate range and two participants reported anxious symptoms within the severe classification. On the HADS depression subscale, at Time 2 seven participants obtained scores within the normal range, three within the mild, one within the moderate range and one participant reported severe depressive symptomology.

Changes in Subjective and Objective Measures over Time. Although this thesis argues in favour of participant data to be analysed at the individual level as opposed to group-based analysis in stroke survivors, difference testing between Time 1 and Time 2 for the whole sample for each subtest on the neuropsychological tests was carried out. These analyses were performed to assess the stability of the cognitive deficits and the possibility of improvement over time at the group level. A Related Samples Wilcoxin Signed Rank Test was used to assess differences between Times 1 and 2 for each subtest. These tests revealed a significant difference between Time 1 and Time 2 only on the attentional switching subtest (elevator counting with

reversal). Participants' scores on this subtest were significantly higher at Time 1 ($Mdn = 7.50$) than at Time 2 ($Mdn = 4.50$), $z = -2.20$, $p < .05$, $r = -.64$). All other difference tests across time points for subtests on the RBMT-3 and the TEA were non-significant ($p > .05$).

It is not surprising that there were no significant differences across the group from Time 1 to Time 2 on all but one of the subtests given the level of fluctuation in scores in both directions of improvement and deterioration. It also seems unlikely that an individual had improved/deteriorated by the margins noted in the results of the neuropsychological tests, particularly when these changes do not correspond with the self-reported scores from the questionnaires. This variability in test performance could be due to several factors impacting on performance such as the testing conditions and possible unintentional influences from the primary researcher (JC) who delivered the neuropsychological tests. Every effort was made to try and ensure that testing conditions were similar at each time point and that the tests were administered in the same manner in accordance to the standardised instructions. However, it is still possible that effects from these external influences have impacted upon test performance.

In addition, the disparity in test performance scores may be explained by the influence of other factors. Chapter Two documents some evidence from previous literature that mood, anxiety and sleep quality can influence memory and attention functions in both clinical and non-clinical populations. To assess this at group level, Spearman's correlation analyses between the neuropsychological subtests, the HADS anxiety and depression subscales and the PSQI scores (participant data reported in the sleep section below) at Time1 and Time 2 were carried out. The analyses

revealed a significant association at Time 1 between divided attention and sleep quality ($r = -.68, p < .05$) indicating that better sleep quality is associated with improved performance, and at Time 2 between selective attention (telephone search) and sleep quality ($r = .69, p < .05$) indicating poorer sleep quality was associated with better performance on this subtest. There were no significant associations on the remainder of the variables ($p > 0.5$).

This suggests that mood, anxiety and sleep quality had not consistently and globally influenced test performance in these participants and suggests that a more complex pattern will emerge from analysing the individuals separately. It should be noted though that only a few of the participants completed their questionnaires immediately before or after the completion of the neuropsychological tests. Since the neuropsychological testing sessions were long they were generally spread over two sessions so the lack of temporal proximity in completing the tests and questionnaires may have influenced these findings.

However, given the large fluctuations in the neuropsychology test scores it is still possible that mood, anxiety and fatigue influenced how well stroke survivors performed on the neuropsychological tests. The effects of mood, anxiety and sleep quality on self-reported memory and attention will be explored further with an individual analysis of temporal processes (IATP) later.

A further point to note relates to the differences in scores over time on the neuropsychological tests was far greater than the difference in scores obtained on the questionnaires. The range of scores that can be obtained on the EMQ-R is between 0-4 and on the HADS it is 0-20 and in comparison the percentile ranks on the neuropsychological tests ranged from 0-100. A one point difference on the EMQ-R

would signify a 20 percent change whereas a one point increase on the RBMT-3 signifies much less change unless the score is close to a boundary in which case it can move an individual from the 37th to the 50th percentile rank. This difference in margins may explain the score consistency on the questionnaires and the lack of consistency between the self-report questionnaires and neuropsychological tests.

Not all of the objective memory and attention test performances matched with the subjective memory and attention scores. Spearman correlation analyses were carried out between the subtests of the RBMT-3, the TEA and the EMQ-R memory and attention subscales at Time 1 and Time 2. The tests revealed a significant relationship at Time 1 where better verbal memory (RBMT-3 story delayed recall) ($r = .61, p < .05$) and better visual memory (picture recognition) ($r = .66, p < .05$) was associated with poorer subjective memory. At Time 2 there was a significant association between verbal memory (names and story delayed recall) ($r = -.74, p < .01, r = -.66, p < .05$) and prospective memory (belongings) ($r = -.63, p < .05$) indicating that as performance on these subtests improved so did subjective memory. A significant association was also found between attentional switching (visual elevator) and the EMQ-R attention subscale at Time 1 ($r = .62, p < .05$) indicating that improved attentional switching was associated with poorer subjective attention. All other associations between the subtests and the EMQ-R memory and attention subscales were non-significant ($p > .05$). Discrepancies between objective cognitive test performances and subjective reporting of memory and attention difficulties have been documented (Hermann, 1982) and will be discussed in more detail in the discussion section.

Individual Analysis of Temporal Processes (IATP). Analyses were carried out to assess the temporal relationships between self-reported memory, attention, mood, anxiety and sleep quality recorded in daily diaries, and to determine if attention and memory predicted each other and if mood, anxiety and/or sleep quality predicted memory and attention.

Specifically, the analyses focused on cross-correlations between memory and attention, memory and mood, memory and anxiety, attention and mood and attention and anxiety. The association between sleep quality and memory and attention is reported in the section below on sleep quality, memory and attention. As mentioned in the data analysis section above, when cross-correlating variables a different number of lags can be selected. In the present study data were recorded twice per day for memory, attention, mood and anxiety therefore, concurrent relationships and lags between +2 and -2 were examined. This captured the extent to which current memory and attention were influenced by, or were influencing mood and anxiety over a 24-hour period. In terms of missing data, there was between 1% and 16% of the data was missing for 11 participants. For the other participant (P10), 60% of the data was missing.

An example of the output from this analysis for one participant (P12) is displayed in Table 5.6.

Table 5.6

Cross-Correlations and Associated Lags between Memory, Attention, Mood and Anxiety for P12

P12	-2 lag (SE)	-1 lag (SE)	CC (SE)	+1 lag (SE)	+ 2 lag (SE)
Memory & Attention	.05 (.08)	-.09 (.08)	.28 (.08)*	.52 (.08)*	.06 (.08)
Memory & Mood	.04 (.08)	.01 (.08)	.44 (.08)*	.07 (.08)	.06 (.08)
Memory & Anxiety	-.06 (.08)	.07 (.08)	-.18 (.08)*	-.33 (.08)*	-.10 (.08)
Attention & Mood	-.00 (.08)	.66 (.08)*	.24 (.08)*	-.07 (.08)	-.04 (.08)
Attention & Anxiety	.08 (.08)	-.21 (.08)*	-.61 (.08)*	-.19 (.08)*	-.14 (.08)

Note: CC = Concurrent, SE = Standard Error

* = significant cross-correlations

Table 5.6 shows that memory and attention had significant concurrent relationships with each other and with mood and anxiety. The concurrent relationships between memory and attention, memory with mood, and attention with mood were positive indicating that as one improved so did the other. Significant negative relationships were evident with memory and anxiety and attention and anxiety indicating that as anxiety ratings decreased reports of memory and attention improved.

There was also a significant +1 lag relationship between memory and attention, memory and anxiety and attention and anxiety. The relationship between memory and attention was positive indicating that improved memory in the morning was associated with improved attention in the evening/improved memory in the evening was associated with improved attention the following morning. The relationships between memory and anxiety, and attention and anxiety were negative indicating that improved memory and attention in the morning was associated with a decrease in anxiety in the evening/improved memory and attention in the evening was associated with a decrease in anxiety the following morning.

A significant -1 lag relationship between attention and mood and attention and anxiety was also observed indicating that current mood and anxiety were associated with attention at the next measurement point.

The variables that were significantly cross-correlated were entered into separate regression models to predict memory and attention. An example of this for P12 is shown in Table 5.7.

Table 5.7

Multiple Regression Predicting Memory and Attention for P12

P12	Memory				Attention			
	B	SE	B	p	B	SE	B	p
Constant	1.44	.70			Constant	4.99	.95	
Attention	.22	.07	.27	.003*	Memory	.25	.09	.20
Attention +1 lag	-.10	.07	-.13	.17	Memory -1 lag	-.06	.09	-.04
Mood	.32	.06	.42	.000**	Mood	-.02	.09	-.02
Anxiety	.09	.08	.12	.23	Mood -1 lag	.04	.08	.04
Anxiety +1 lag	-.02	.07	-.02	.84	Anxiety	-.56	.07	-.58
					Anxiety -1 lag	-.04	.07	-.04

Note: ** = $p < .001$, * = $p < .05$

A significant memory model emerged with two predictors explaining 25% of the variance in the data ($R^2 = .25$, $F(5, 151) = 9.67$, $p < .05$). These were attention ($\beta = .27$, $p < .05$) and mood ($\beta = .42$, $p < .001$). The attention regression model was also significant with 40% of the variance ($R^2 = .40$, $F(7, 150) = 13.79$, $p < .05$) being explained by memory ($\beta = .20$, $p < .05$) and anxiety ($\beta = -.58$, $p < .001$). These results indicated that current levels of mood and anxiety influenced P12's self-reported memory and attention. Referring back to the scores on the HADS anxiety and depression subscales it is noted that P12 had scores indicative of severe anxiety and depression.

The same procedure was carried out for all participants. A summary of the regression models for the remainder of the participants is shown in Table 5.8.

Table 5.8

Summary of Multiple Regression Models Predicting Memory and Attention for P1-P6

Memory					Attention				
P1	$(R^2 = .74, F(4, 163) = 118.58, p < .001)$				P1	$(R^2 = .73, F(4, 163) = 111.87, p < .001)$			
	B	SE	β	p		B	SE	β	p
Attention	0.76	.05	.76	.000	Memory	0.80	.05	.80	.000
Anxiety	-0.17	.04	-.17	.000	Mood	0.14	.04	.15	.002
P2	$(R^2 = .38, F(3, 163) = 32.90, p < .001)$				P2	$(R^2 = .38, F(3, 163) = 33.21, p < .001)$			
	B	SE	β	p		B	SE	β	p
Attention	0.45	.06	.53	.000	Memory	0.61	.08	.52	.000
					Mood	0.21	.09	.18	.02
P3	$(R^2 = .61, F(6, 156) = 40.88, p < .001)$				P3	$(R^2 = .61, F(6, 156) = 40.88, p < .001)$			
	B	SE	β	p		B	SE	β	p
Attention	0.57	.06	.61	.000	Memory	0.70	.07	.66	.000
Mood	0.19	.05	.27	.000	Memory +2lag	0.15	.07	.14	.03
P4	$(R^2 = .90, F(8, 155) = 159.08, p < .001)$				P4	$(R^2 = .89, F(8, 154) = 150.48, p < .001)$			
	B	SE	β	p		B	SE	β	p
Attention	0.86	.04	.87	.000	Memory	0.89	.04	.88	.000
Anxiety	-0.11	.04	-.10	.01					
P5	$(R^2 = .05, F(3, 160) = 2.62, p = .05)$				P5	$(R^2 = 0.3, F(4, 158) = 1.28, p = ns)$			
	B	SE	β	p					
Mood	0.52	.22	.19	.02					
P6	$(R^2 = .95, F(4, 160) = 723.40, p < .001)$				P6	$(R^2 = .95, F(4, 160) = 699.28, p < .001)$			
	B	SE	β	p		B	SE	β	p
Attention	0.94	.02	.94	.000	Memory	0.98	.02	.97	.000
Mood	0.05	.02	.05	.02					

Table 5.8 continued

Summary of Multiple Regression Models Predicting Memory and Attention for P7-P11

Memory					Attention				
P7	$(R^2 = .25, F(3, 163) = 18.16, p < .001)$				P7	$(R^2 = .67, F(3, 163) = 108.20, p < .001)$			
	B	SE	β	p	B	SE	β	p	
Attention	0.15	.05	.33	.004	Memory	0.33	.12	.15	.004
Anxiety	-0.16	.05	-.28	.000	Mood	0.71	.05	.72	.000
P8	$(R^2 = .41, F(3, 162) = 37.81, p < .001)$				P8	$(R^2 = .41, F(3, 165) = 38.03, p < .001)$			
	B	SE	β	p	B	SE	β	p	
Attention	0.53	.05	.64	.000	Memory	0.77	.07	.63	.000
P9	$(R^2 = .27, F(4, 160) = 14.56, p < .001)$				P9	$(R^2 = .28, F(4, 160) = 16.74, p < .001)$			
	B	SE	β	p	B	SE	β	p	
Attention	0.72	.12	.44	.000	Memory	0.28	.04	.44	.000
Anxiety	-0.20	.07	-.15	.03	Mood	0.22	.09	.17	.02
P10	$(R^2 = .90, F(8, 155) = 159.08, p < .001)$				P10	Model was not fitted due to no significant cross-correlations between the variables			
	B	SE	β	p					
Mood	0.08	.04	.18	.02					
P11	$(R^2 = .15, F(4, 161) = 6.91, p = .001)$				P11	$(R^2 = 0.11, F(4, 159) = 4.65, p < .001)$			
	B	SE	β	p	B	SE	β	p	
Attention	0.36	.08	.32	.000	Memory	0.28	.07	.32	.000
Anxiety	0.14	.05	.19	.01					

Summary. For the majority of the participants there were significant concurrent cross-correlations between memory, attention, mood and anxiety. The significant lagged cross-correlations varied across participants. For example, there was a significant -1 lag relationship between memory and anxiety and attention and anxiety for P1. For P8, there was a significant +1 lag relationship between memory and mood and for P11 there was a significant -1 lag relationship between memory and mood, memory and anxiety, attention and mood, and attention and anxiety, additionally for P11 there was a significant -2 lag relationship between attention and anxiety. Consequently, different predictors were entered into the regression models for each participant.

The regression models revealed that for ten participants, attention was a significant predictor of memory, and memory was a significant predictor of attention. All participants performed poorly on both the memory and attention neuropsychological subtests either at Time 1 or Time 2. However, this does not appear to be the case for P5 and P10. Both of these participants show deficits in a number of memory and attention domains when measured by the memory and attention tests, yet the regression model of attention for P5 was non-significant indicating that memory did not predict attention. For P10, the cross-correlation between memory and attention was non-significant suggesting that the variables were not related for this participant. Therefore, although all participants obtained low scores on both memory and attention tests, performance on such tests may not be indicative of stroke survivors' subjective reports of how memory and attention relate to each other and of the daily temporal relationship between memory and attention.

Likewise, the interpretation is not straightforward when evaluating if subjective memory and attention when measured by questionnaires is suggestive of the potential temporal relationship between memory and attention. As mentioned, all twelve participants displayed memory and attention problems on the neuropsychological tests. For ten participants' memory and attention emerged as significant predictors of each other in the regression models, and for eight participants', questionnaire data revealed self-reported memory and attention difficulties. These findings indicate that there is some consistency across test performance scores, questionnaire scores and the regression models results for eight participants. However, for the remaining participants the picture is less clear. P8 and P11 reported low levels of memory and attention difficulties on the questionnaires, yet memory and attention emerged as significant predictors of each other. Whilst, P5 and P10 reported high levels of difficulties on the memory and attention questionnaires but in the regression models memory and attention were not predictive of each other. Thus, for some stroke survivors, scores on memory and attention questionnaires may not shed light on the potential relationship between objective memory and attention performance.

This ambiguity continues as the regression models in relation to mood and anxiety as predictors of memory and attention and mood and anxiety questionnaire scores do not always match. Of the twelve participants, mood was a significant predictor of memory for five participants and of attention for four participants, however, self-reported mood for six of these nine participants was within the normal or normal/mild classification. Therefore, despite there being an association between mood and memory not all participants reported mood difficulties even though they

reported memory problems. Additionally, P4 self-reported mild mood difficulties at Time 2 on the HADS depression subscale, yet mood did not emerge as a significant predictor of memory nor attention for this participant.

Anxiety was a significant predictor of memory for five participants and of attention for one participant. Five of these participants reported anxious symptoms that ranged from mild to severe suggesting that anxiousness when measured by questionnaires may be a good indicator of how it might relate to memory and attention. However, the other participant was within the normal classification and several other participants reported mild/moderate levels of anxiety (P2, P3, P6 and P8) without anxiety emerging as a predictor of memory or attention. Therefore, there should not be an expectation that scores on mood and anxiety questionnaires could be used to predict possible relationships with memory and attention.

Relationship between Sleep Quality, Memory and Attention. The sleep quality data could not be incorporated into the analyses above as sleep quality was assessed only once daily whilst the other variables (memory, attention, mood and anxiety) were measured twice daily. Therefore, to assess the relationship with sleep quality the times series for memory, attention, mood and anxiety were first of all split into two (am and pm). Only cross-correlation analyses are reported.

The Pittsburgh Sleep Quality Index (PSQI) and activPAL data are shown in Table 5.9. A score less than or equal to 5 on the PSQI is considered good sleep quality, whilst a score greater than 5 is considered poor sleep quality. Additionally, activPAL parameters such as time spent lying or seated, number of steps and number taken and number of sit/lie to stand transitions taken during the night are also presented. The activPAL monitor does not distinguish between a lying position and a

seated position rather both behaviours are classified as sedentary behaviours.

Participants wore the activPAL for seven continuous nights, however, the time the monitors were attached and taken off varied across participants. Therefore, to obtain a standard recording for the outcomes of interest data was taken from the second night to the sixth night of activPAL wear. The data was then averaged for the five nights.

In relation to the activPAL parameters, there are no recordings for P1 as she did not wear the activPAL monitor, and for P3, P4 and P12 there are no Time 2 recordings. P3 attached the monitor upside down thus data was not recorded. P4 complained of skin irritation whilst wearing the monitor at Time 1 and requested that she discontinue activPAL wear at subsequent time points and P12 reported that the monitor had fallen off after a few hours of wear.

Table 5.9

activPAL Parameters (average minutes spent sitting/lying, number of sit/lie to stand transitions and number of steps taken) and Pittsburgh Sleep Quality Index Scores at Times 1 and 2 for P1-P6

P1	activPAL		PSQI		P4	activPAL		PSQI	
	T1	T2	T1	T2		T1	T2	T1	T2
Lie/Sit (mins)	523	-	10	12	Lie/Sit (mins)	410	-	12	13
Lie/Sit-Stand	3	-			Lie/Sit-Stand	0	-		
No. Steps	90	-			No. Steps	7	-		
P2	activPAL		PSQI		P5	activPAL		PSQI	
	T1	T2	T1	T2		T1	T2	T1	T2
Lie/Sit (mins)	354	506	12	11	Lie/Sit (mins)	560	578	5	4
Lie/Sit-Stand	23	7			Lie/Sit-Stand	1	2		
No. Steps	4260	645			No. Steps	5	71		
P3	activPAL		PSQI		P6	activPAL		PSQI	
	T1	T2	T1	T2		T1	T2	T1	T2
Lie/Sit (mins)	634	-	2	3	Lie/Sit (mins)	453	390	2	5
Lie/Sit-Stand	3	-			Lie/Sit-Stand	2	0		
No. Steps	221	-			No. Steps	105	0		

Table 5.9 continued

activPAL Parameters (average minutes spent sitting/lying, number of sit/lie to stand transitions and number of steps taken) and Pittsburgh Sleep Quality Index Scores at Times 1 and 2 for P7-P12

P7	activPAL		PSQI		P10	activPAL		PSQI	
	T1	T2	T1	T2		T1	T2	T1	T2
Lie/Sit (mins)	523	467	12	15	Lie/Sit (mins)	520	510	3	5
Lie/Sit-Stand	3	3			Lie/Sit-Stand	0	0		
No. Steps	90	86			No. Steps	0	0		
P8	activPAL		PSQI		P11	activPAL		PSQI	
	T1	T2	T1	T2		T1	T2	T1	T2
Lie/Sit (mins)	462	316	3	3	Lie/Sit (mins)	535	494	10	8
Lie/Sit-Stand	7	1			Lie/Sit-Stand	6	27		
No. Steps	248	31			No. Steps	164	179		
P9	activPAL		PSQI		P12	activPAL		PSQI	
	T1	T2	T1	T2		T1	T2	T1	T2
Lie/Sit (mins)	510	516	13	12	Lie/Sit (mins)	383	-	17	19
Lie/Sit-Stand	0	4			Lie/Sit-Stand	1	-		
No. Steps	3	20			No. Steps	66	-		

Table 5.9 shows that P2 had a noticeable sleep disruption at Time 1. The participant was lying or seated on average for six hours during the night but during this time P2 stood up on average 23 times and walked on average 4260 steps (approximately 42 minutes) over the five nights. Sleep was less disrupted at Time 2 getting up on average only seven times. Despite this difference in activPAL recordings similar scores were obtained on the PSQI at both time points. All other participants had similar activPAL recordings at both Time 1 and Time 2. Overall, participants were lying or seated for six to ten hours during the night, got up between zero and seven times and took between seven and 248 steps.

Diary Data: Sleep Quality, Memory and Attention. When assessing the relationships between sleep quality, memory and attention no lags were specified as there is a natural lag for sleep due to the data being recorded the following morning for sleep quality the night before.

The cross-correlation, for all twelve participants are displayed in Table 5.10. For P10, cross-correlations could not be computed due to missing data and there were no significant associations between sleep quality and memory and attention in the morning or evening for four participants.

Table 5.10

Cross-Correlations between Memory (am & pm), Attention (am & pm) and Sleep Quality

	P1	P2	P3	P4	P5	P6
	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)
Memory (am) with Sleep	-.04 (.11)	.42 (0.11)*	-.05 (.11)	-.02 (.11)	.10 (.11)	-.21 (.11)
Memory (pm) with Sleep	-.18 (.11)	.19 (0.11)	.03 (.11)	-.09 (.11)	.10 (.11)	-.01 (.11)
Attention (am) with Sleep	.01 (.11)	.31 (0.11)*	-.01 (.11)	-.05 (.11)	.00 (.11)	-.21 (.11)
Attention (pm) with Sleep	.33 (.11)*	-.14 (0.11)	-.03 (.11)	.37 (.11)*	.34 (.11)*	-.01 (.11)
	P7	P8	P9	P10	P11	P12
	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)
Memory (am) with Sleep	-.12 (.11)	.23 (.11)*	-.18 (.11)	-	-.22 (.11)	-.08 (.12)
Memory (pm) with Sleep	-.01 (.11)	.07 (.11)	-.17 (.11)	-	-.15 (.11)	.35 (.12)*
Attention (am) with Sleep	-.16 (.11)	.25 (.11)*	.00 (.11)	-	-.25 (.11)*	-.11 (.11)
Attention (pm) with Sleep	.02 (.11)	.06 (.11)	-.13 (.11)	-	-.11 (.11)	.36 (.11)*

Note: CC = concurrent, SE = standard error

PSQI = Pittsburgh Sleep Quality Index

* = significant cross-correlations

As shown in Table 5.10, sleep quality was significantly associated with attention the following evening for P1, P4 and P5. There was also a significant relationship between sleep quality and memory and attention the following morning for P2 and P8 and between sleep quality and memory and attention the following evening for P12. The relationships were positive indicating that as sleep quality improved so did ratings of attention. Conversely for P11, there was a significant negative relationship between sleep quality and attention the following morning indicating that as sleep quality deteriorated level of attention improved.

Scores obtained on the PSQI are not consistently indicative of the relationships between sleep quality, memory and attention. For six participants, sleep quality was significantly cross-correlated with memory and/or attention in the morning and/or evening. Three of these participants were poor sleepers whilst two were good sleepers, and one reported poor sleep quality initially and then reported good sleep quality at the second time point. Additionally, a couple of participants were poor sleepers as measured by the questionnaire but no significant cross-correlations emerged between sleep quality, memory and attention. Therefore, scores on the sleep questionnaires do not appear to provide an initial indication as to the potential relationships between subjective sleep quality, memory and attention.

Relationship between Sleep Quality, Mood and Anxiety. To explore possible relationships between sleep quality, mood and anxiety, cross-correlations were carried out on these variables. These are reported in Table 5.11.

Table 5.11

Cross-Correlations between Sleep, Mood (am & pm) and Anxiety (am & pm) for P1-P6

Variables	P1	P2	P3	P4	P5	P6
	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)
Sleep & Mood (am)	.01 (.11)	.62 (.11)*	.06 (.11)	.16 (.11)	.02 (.11)	-.18 (.11)
Sleep & Mood (pm)	.17 (.11)	.15 (.11)	.15 (.11)	.36 (.11)*	.23 (.11)*	.03 (.11)
Sleep & Anxiety (am)	-.02 (.11)	-.50 (.11)	-.14 (.11)	-.24 (.11)*	-.21 (.11)	.14 (.11)
Sleep & Anxiety (pm)	-.06 (.11)	-.09 (.11)	-.00 (.11)	-.39 (.11)*	-.14 (.11)	-.03 (.11)
Mood (am) & Anxiety (am)	-.78 (.11)*	-.57 (.11)*	-.65 (.11)*	-.87 (.11)*	-.57 (.11)*	-.62 (.11)*
Mood (am) & Anxiety (pm)	-.43 (.11)*	-.15 (.11)	-.48 (.11)*	.04 (.11)	-.07 (.11)	-.36 (.11)*
Mood (pm) & Anxiety (pm)	-.72 (.11)*	-.46 (.11)*	-.72 (.11)*	-.88 (.11)*	-.27 (.11)*	-.56 (.11)*

Note: CC = Concurrent, SE = Standard Error

* = significant cross-correlation, **cross-correlations for P10 could not be computed due to missing data

Table 5.11 continued

Cross-Correlations between Sleep, Mood (am & pm) and Anxiety (am & pm) for P7-P12

Variables	P7	P8	P9	P10**	P11	P12
	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)	CC (SE)
Sleep & Mood (am)	-.17 (.11)	.08 (.11)	-.05 (.11)	-	.49 (.11)*	-.18 (.12)
Sleep & Mood (pm)	.05 (.11)	.04 (.11)	.14 (.11)	-	.25 (.11)*	.46 (.12)*
Sleep & Anxiety (am)	-.39 (.11)*	-.05 (.11)	-.37 (.11)*	-	-.37 (.11)*	-.82 (.12)*
Sleep & Anxiety (pm)	-.13 (.11)	-.03 (.11)	-.17 (.11)	-	.00 (.11)	-.44 (.12)*
Mood (am) & Anxiety (am)	-.07 (.11)	-.51 (.11)*	.10 (.11)	-	-.58 (.11)*	.08 (.12)
Mood (am) & Anxiety (pm)	-.23 (.11)*	-.10 (.11)	.01 (.11)	-	-.08 (.11)	-.10 (.12)
Mood (pm) & Anxiety (pm)	-.55 (.11)*	-.52 (.11)*	-.42 (.11)*	-	.02 (.11)	-.67 (.12)*

Note: CC = Concurrent, SE = Standard Error

* = significant cross-correlation, **cross-correlations for P10 could not be computed due to missing data

Table 5.11 shows concurrent associations between sleep, mood and anxiety. The table shows a significant relationship between sleep quality and mood in the morning and sleep quality and mood in the evening for two and four participants, respectively. The relationship was positive indicating that as sleep quality improved so did mood. There was also a significant negative relationship between sleep quality and anxiety in the morning and sleep quality and anxiety in the evening for five and two participants, respectively. Indicating that as sleep quality improved levels of anxiety decreased.

5.4 Discussion

This is the first study to show a link between memory and attention and mood, anxiety and sleep quality in stroke survivors. Previous research has shown that these constructs can affect memory and attentional processes in individuals with TBI and in adults with no brain trauma (Airaksinen et al., 2005; Bloomfield et al., 2010; Kauhanen et al., 1999; Sicolli et al., 2008). Future research should endeavour to investigate if these determinants have differential effects on the varying types of memory and attention.

The present study adopted an individualised approach to the study of memory and attention due to the problems noted with the use of group-based designs. This method allowed for a more in-depth investigation revealing all stroke survivors had impaired functioning in a number of memory and attention domains and most of the participants' self-reported memory and attention problems were predictive of each other. This finding that memory and attention were closely related was not surprising; if one cannot attend to stimuli in their environment then it would be

difficult for memories to be formed suggesting that there is co-morbidity of impairments in memory and attention following a stroke event.

However, for a small number of participants memory and attention were not predictive of each other despite showing impairment on both the memory and attention tests suggesting that memory and attention deficits can exist independently of each other. This has implications for rehabilitation. If a stroke survivor has poor memory as a consequence of impaired attention, then an intervention to improve attention would be most appropriate in the first instance. If, however, a stroke survivor has difficulty with both their memory and attention but they do not influence each other, then targeted intervening to improve both memory and attention functions would be needed.

This is not the first study to adopt the individual method of analysis in stroke. Chapter Three presented a systematic review of single-case studies on memory and attention in stroke survivors. However, the present study advances the study designs of previous research by using IATP to capture daily measurements of self-reported memory, attention, mood, anxiety and sleep quality over an extended period of time and supplemented these measurements with objective memory and attention tests and questionnaires. But by doing so poses some difficulty in determining if neuropsychological tests, and/or questionnaires and/or diary measures should be used in clinical environments. Clinicians are unlikely to have the resources to administer batteries of neuropsychological tests and questionnaires repeatedly and monitor diary responses; especially when psychological services for stroke survivors are not as available as they should be (Bowen et al., 2005).

Administering neuropsychological tests solely, however, may be problematic. The present study showed large variation in memory and test performance. It seems unlikely that an individual improves or deteriorates with such a noticeable difference over a period of twelve weeks. Several reasons have been noted that may explain this variability. These include the testing conditions and the possible confounding effects from the primary researcher (JC) when administering the tests. Secondly, neuropsychological test performance may also be influenced by other factors. It is well known that changes in motivation, practice effects and spontaneous recovery can affect performance. However, if practice effects had been influential only an improvement in test scores would have been expected and given that the stroke survivors were six months or more post-stroke it seems unlikely that spontaneous recovery would have occurred. So, other factors that have not been previously taken into account may be affecting how well an individual performs on the tests. In the present study, at the subjective level, mood, anxiety and sleep quality was associated with memory and attention therefore it is not unreasonable to suggest that test performance may be affected by these factors too. Both researchers and clinicians should aim to bear this in mind when evaluating stroke survivors' performance on memory and attention tests.

The administration of both neuropsychological tests and questionnaires may produce a discrepancy between the two. The present study showed that performance on the neuropsychological tests was not always consistent with self-reported memory and attention. However, the two types of measurement tools measure different aspects of memory and attention as they have been designed for different purposes, they have different scales and sensitivities and have been validated on different

stroke populations. This adds to the complexity in deciding what should be administered to stroke survivors to assess the effect a stroke has had on an individual's memory and attention functioning.

The diary method on its own might not be wholly suitable either. Keeping a diary is an appropriate way to track how an individual feels about a particular problem over time which can then be statistically analysed given the right amount of measurement points. However, there are limitations with this method too.

Retrospective diary entries can be open to criticism especially in stroke survivors who have memory problems. In addition, at one end of the continuum some stroke survivors reported that if it was not for their caregiver reminding them to fill in their diary they probably would not have done so and at the other, stroke survivors who lived on their own found it difficult to self-reflect and report how their memory had been, or if their mood was low, for example.

Moreover, the diary method can be consuming and demanding for stroke survivors. It is a necessity for studies adopting the individualised approach to incorporate statistical analysis in to their designs to strengthen findings and conclusions made. Depending on the frequency of observations measured determines study length. If recordings were taken daily in the present study, it would mean that the study would need to last for more than three months. However, to avoid this one diary measurement was recorded for sleep quality and two for memory, attention, mood and anxiety over twelve weeks which is why there was a separate section on sleep. This meant however that that the time-series for sleep quality was likely too short and underpowered. Therefore, considering these aspects of the suitability of the diary method is a must for future research protocols.

Methodological Quality of the Present Study. The SCED scale (Tate et al., 2008) that was used to evaluate the methodological quality of the studies included in the systematic reviews (Chapter Three and Four) could not be used for the present study. The SCED scale is only useful for studies that have delivered an intervention. As such, items addressing study design, baseline and treatment sampling and generalisation effects were not applicable in the present study thus a quality score could not be generated.

Chapter Six

Exploring Dyadic Relationships between Caregiver and Stroke

Survivor Psychological and Behavioural Outcomes: A Series of

IATP Studies

6.1 Introduction

It is not just stroke survivors who are affected by stroke, those who care for someone who has had a stroke are affected too. Caring for a stroke survivor is likely to be undertaken informally by family, friends or neighbours, and the level of care can be an all-consuming task particularly as caregivers of stroke survivors are rarely prepared for their role.

Research has shown that caring for someone can have adverse physical and psychological effects on the caregiver. In an early study, depression rates were reported to be two and a half to three times higher than non-caregiving samples (Schulz, Tompkins, & Rau, 1988). More recently, a systematic review of twenty studies on caregiving for individuals with stroke showed that caregivers of stroke survivors had increased levels of depression when the stroke survivors were at both the acute and the chronic phase of recovery (Han & Haley, 1999). Other research studies have also found caregivers of stroke survivors experience high levels of burnout, depression, burden and physical illness (Anderson, Linto, & Stewartwynne, 1995; Blake & Lincoln, 2000; Blake, Lincoln, & Clarke, 2003; Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Draper & Brocklehurst, 2007; Wyller et al., 2003).

Generalised anxiety disorder is another emotional disorder that caregivers may experience. A recent study found a significant number of caregivers' reported anxiety levels of clinical significance when the stroke survivor was three months

post-stroke (Greenwood & Mackenzie, 2010). Similarly, Dennis et al. (1998) examined anxiety levels in caregivers when stroke survivors were six months post-stroke and found a third of the caregivers had increased levels of anxiety.

As well as experiencing low mood and anxiety, caregivers' sleep quality may also be affected. Research into the sleep quality of caregivers of stroke survivors is limited, but in caregivers of other clinical conditions sleep quality is affected. For example, a study on the sleep quality of caregivers of patients with Alzheimer's disease and Parkinson's disease found that the caregivers experienced difficulty falling asleep, disturbed sleep and reduced sleep quality overall (Cupidi et al., 2012). Similarly, sleep disturbance has been reported as a prevalent condition affecting caregivers (Kim & Rose, 2011).

Most of the studies above have assessed caregiver emotional distress in relation to the severity of the stroke survivors' level of physical disability. However, research has also shown that caring for someone who has mild cognitive impairment affects caregivers' well-being also. The psychological well-being of caregivers who support and assist older adults with cognitive problems was examined by Blieszner & Roberto (2010). They reported that the caregivers experienced depression, stress, strain and frustration indicating that they were finding it difficult to care for someone whose cognitive functioning had been affected.

Given the psychological disturbance caregivers experience, several studies have attempted to explore dyadic relationships between caregiver and stroke survivor outcomes. Previous research has also shown that caregivers' confidence was correlated with stroke survivors' ambulation recovery and self-efficacy for recovery (Molloy et al., 2008), and perception of pain in stroke survivors was influenced by

caregivers own depressive symptomology and pain (Hung, Pickard, Witt, & Lambert, 2007).

In a more related study, Perrin, Heesacker, Stidham, Rittman, & Gonzalez-Rothi (2008) examined caregiver psychosocial functioning and functioning of stroke survivors and found a link between caregivers' level of depression and perceived burden and stroke survivors' cognitive deficits and level of depression. Caregiver and stroke survivor dyads have also been examined on measures of depression, cognitive impairment and mastery (Cameron, Cheung, Streiner, Coyte, & Stewart, 2006). The results showed that caregivers' experienced more depressive symptoms, more lifestyle interference and lower levels of mastery when they assisted and supported stroke survivors who had memory and comprehension difficulties. In a later longitudinal study, the same authors showed a dyadic positive relationship between level of stroke survivor depression and level of caregiver depression. This study also showed that caring for stroke survivors with impairments in cognitive functioning was associated with caregiver emotional distress (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011). However, both studies by Cameron et al. (2006, 2011) are limited as stroke survivors did not complete their own behavioural and psychological measures, their caregivers did. Thus, a comparison between caregivers' perception of the stroke survivors' behavioural and psychological symptoms and the stroke survivors' self-ratings of their symptoms could not be carried out.

In addition, the dyadic studies have been group-based which limits understanding of the relationships between the dyads at the individual level. Testing relationships as they occur within caregivers and stroke survivors using longitudinal

repeated assessment methods may be more suitable. Also, previous researchers have primarily examined depressive mood states between caregiver and stroke survivor. The effects of anxiety and sleep quality in dyadic relationships and how they might relate to cognitive functions such as memory and attention within a stroke population have yet to be explored.

Aims

The aims of this study were to:

- i) Investigate subjective mood, anxiety and sleep quality in caregivers of stroke survivors using questionnaires.
- ii) Assess the dyadic temporal associations between caregivers' mood, anxiety and sleep quality, along with their perceptions of the stroke survivors' memory and attention and stroke survivors' own self-reports of memory, attention, mood, anxiety and sleep quality.
- iii) Determine if the caregivers' perceptions of the stroke survivor's memory and attention along with their own mood, anxiety and sleep quality are significant predictors of stroke survivors' self-reports of memory and attention.

6.2 Method

Study Design

A series of IATP studies lasting 12 weeks were carried out with eight caregivers of the stroke survivors who were recruited into the study in Chapter Five. Caregivers completed daily diary measures of their own mood, anxiety and sleep quality and provided ratings of the stroke survivor's memory and attention. Questionnaires were also completed at baseline (Time 1) and 12 weeks later (Time 2).

Participants

Of the twelve stroke survivors who entered the study in the previous chapter, eight caregivers were also recruited producing eight dyads. For the other four stroke survivors, one caregiver dropped out of the study after the first week due to relationship problems, two declined to participate due to already having a busy life schedule and one stroke survivor did not have a live-in caregiver. The participants were caregivers of P2, P3, P4, P5, P6, P9, P11 and P12 of the previous study, thus the dyads were C2&P2, C3&P3, C4&P4, C5&P5, C6&P6, C9&P9, C11&P11 and C12&P12, where 'C' represents the caregiver and 'P' represents the participants from the previous study.

The inclusion criteria were: (1) adults between 18 and 80 years old; (2) lived with and cared for a stroke survivor who was six months or more post-stroke. Participants were excluded if they had inadequate English language ability that would prevent understanding of the study requirements.

Measures

Questionnaires. Caregivers completed a demographic questionnaire, the Hospital Anxiety and Depression Scale (HADS) and the Pittsburgh Sleep Quality Index (PSQI) details of which are reported in Chapter Five.

Daily Diaries. Caregivers were asked to complete a diary checklist each day for 12 weeks (Appendix VI). They were asked to rate on a 7-point Likert scale ranging from 'Very Bad' (-3) to 'Very Good' (+3) how well they slept the night before and to self-report how their mood and anxiety had been. They were also asked to record how they thought the memory and attention of the stroke survivor they

were caring for had been. Sleep quality was recorded once per day whilst the other variables were recorded twice each day.

Procedure

Ethical approval was granted by the University of Strathclyde Ethics Committee. All participants provided written consent and all data was pseudo-anonymised (See Appendix II and III for ethics application form and approval letter, and Appendix VII and VIII for participant information sheet and consent form). At the time of recruiting stroke survivors for the study reported in Chapter Five, it was advertised that there was interest in recruiting caregivers too. Thus, the recruitment methods reported in the previous chapter are also applicable here.

At Time 1 the questionnaires were administered. As stroke survivors were given the option of completing the questionnaires following the testing session, caregivers were informed that they could complete them the day(s) following the testing session to be collected the following week. The same procedure was carried out 12 weeks later at Time 2 apart from the administration of the demographic questionnaire.

Data Analysis

As in Chapter Five, the results are presented in two sections. The first is on dyadic relationships between the stroke survivors' memory and attention and caregivers' perception of the stroke survivor's memory and attention and caregiver mood and anxiety. The second section is focused on dyadic relationships between caregiver sleep quality and stroke survivor sleep quality, memory and attention.

In both sections, descriptive information is given on questionnaire results (HADS and PSQI) and then the diary data is analysed using cross-correlations and

multiple regression modelling. The same process in terms of data preparation and analysis described in the data analysis section in Chapter Five was carried out on the data in the present chapter.

6.3 Results

Participant Demographics. Table 6.1 details caregiver demographics. Six participants were female and two were male and ages ranged from 40 – 78 years. C2 and C6 were taking anti-depressant medication throughout the study.

Table 6.1

Caregiver Demographics

C	Sex	Age (years)	Education (years)	Employment Status	Marital Status
2	Female	59	10	Retired	Married
3	Female	55	11	Part-time	Married
4	Male	40	12	Driving Instructor	Married
5	Male	71	7	Retired	Married
6	Female	44	12	Employed	Married
9	Female	57	13	Retired	Married
11	Female	78	10	Retired	Married
12	Female	50	Not reported	Retired	Married

Table 6.2

Caregiver Hospital Anxiety and Depression Scale scores at Times 1 and 2

C	HADS Anxiety			HADS Depression		
	T1	T2	T2-T1	T1	T2	T2-T1
2	12	11	-1	6	9	3
3	10	11	1	11	7	-4
4	11	11	0	4	11	7
5	12	10	-2	4	3	-1
6	6	1	-5	2	0	-2
9	6	3	-3	3	6	3
11	3	2	-1	1	1	0
12	6	14	8	8	15	7

Note: C = caregiver; HADS: normal = 0-7, mild = 8-9, moderate = 10-14, severe = 15-19, extremely severe = 20+

Questionnaire Results. The results from the Hospital Anxiety and Depression Scale (HADS) are shown in Table 6.2 and the severity classifications are

noted below the table. Table 6.2 shows that four participants obtained scores within the moderate range on the HADS anxiety subscale, three obtained scores within the normal range and one participant reported normal levels of anxiety at Time 1 and moderate levels of anxiety at Time 2. On the HADS depression subscale, four participants obtained scores within the normal range and the other four participants reported normal/mild, mild/moderate, normal/moderate and mild/severe depression. There was consistency in anxiety and depression scores across time for the majority of the participants. There was some discrepancy in anxiety symptoms for C6 and C9 where ratings improved between Time 1 and Time 2 (but were still within the normal classification) and for C12 where anxiety worsened over time. There was a noticeable difference in depression scores for some participants at Time 1 and Time 2. C3 showed an improvement in depression whereas depressive symptoms got worse for C4, C9 and C12.

Investigating Dyadic Caregiver and Stroke Survivor Relationships Using IATP. Analyses were carried out to assess the temporal relationships between caregivers' perceptions of the stroke survivors' memory and attention, caregivers mood and anxiety and stroke survivors' self-reported memory, attention, mood and anxiety. This was done to determine if caregivers' perceptions of the stroke survivor and their own mood and anxiety levels were significant predictors of the stroke survivors' memory and attention.

To prepare the data for analysis the same procedure carried out in Chapter Five was also applied here. A lag of 2 was also set to capture associations over a 24-hour period. Sleep quality was recorded only once; consequently associations

between caregiver and stroke survivor sleep quality and sleep quality and stroke survivor memory and attention are reported in a separate section on sleep below.

In terms of missing data, C11 had no missing data. Between 1% and 15% of the data was missing for six participants and for C9 there was 35% of the data missing. Most of C9's missing data was the ratings of the stroke survivors memory and attention reporting that she did not see her spouse in the mornings due to work commitments therefore she could not state how his memory and attention had been.

Specifically, the analyses focused on cross-correlations between caregiver ratings of stroke survivor memory and attention and stroke survivor ratings of memory and attention, caregiver mood and anxiety with stroke survivor memory and attention and caregiver mood and anxiety with stroke survivor mood and anxiety. An example of the results from this analysis for dyad C2 and P2 is displayed in Table 6.3.

Table 6.3

Cross-Correlations and Associated Lags between Caregiver Perceptions of the Stroke Survivor's Memory and Attention and Caregiver's Own Mood and Anxiety and the Stroke Survivor's Memory, Attention, Mood and Anxiety for C2&P2

	-2 lag (SE)	-1 lag (SE)	CC (SE)	+1 lag (SE)	+ 2 lag (SE)
C2&P2					
Memory C (perc) & Memory (SS)	-.02 (.08)	-.13 (.08)	.01 (.08)	-.19 (.08)*	-.11 (.08)
Attention C (perc) & Attention (SS)	-.14 (.08)	-.05 (.08)	-.11 (.08)	-.13 (.08)	-.16 (.08)*
Mood C (self) & Memory (SS)	-.07 (.08)	-.15 (.08)	-.08 (.08)	-.01 (.08)	-.16 (.08)*
Mood C (self) & Attention (SS)	-.08 (.08)	-.13 (.08)	.03 (.08)	-.09 (.08)	-.23 (.08)*
Anxiety C (self) & Memory (SS)	.03 (.08)	.11 (.08)	.15 (.08)	.01 (.08)	.16 (.08)*
Anxiety C (self) & Attention (SS)	.13 (.08)	.08 (.08)	.06 (.08)	.12 (.08)	.25 (.08)*
Mood C (self) & Mood (SS)	.08 (.08)	-.03 (.08)	.10 (.08)	.04 (.08)	-.04 (.08)
Anxiety C (self) & Anxiety (SS)	.00 (.08)	.08 (.08)	.12 (.08)	.10 (.08)	.03 (.08)

Note: C(perc) = caregiver's perception of the stroke survivor's memory/attention, C(self) = caregiver's self-rating of their own mood and anxiety
 SS = stroke survivor, CC = Concurrent, SE = Standard Error

* = significant cross-correlations

Table 6.3 shows that there was a significant +1 lag and +2 lag between the caregiver's rating of the stroke survivor's memory and attention and the stroke survivor's rating of memory and attention, respectively. The relationships were negative indicating that lower caregiver perception of the stroke survivor's memory in the morning was associated with stroke survivor rating their memory higher in the evening, and lower caregiver perception of memory performance in the evening was associated with stroke survivor rating their memory higher the following morning. For attention, the +2 lag indicates that lower caregiver perception of the stroke survivor's attention in the morning was associated with the stroke survivor reporting higher levels of attention the following morning and lower caregiver perception of attention in the evening was associated with the stroke survivor reporting their attention higher the following evening.

There were also significant +2 lag relationships between the caregiver's own mood and anxiety and the stroke survivor's reports of their memory and attention. The relationship between the caregiver's mood and the stroke survivor's ratings of their memory and attention was negative indicating that as caregiver mood decreased in the morning, stroke survivor ratings of memory and attention improved the following morning. The relationship between the caregiver's levels of anxiety and the stroke survivor's report of their memory and attention was positive indicating that if the caregiver's anxiety levels were high in the morning the stroke survivor reported better memory and attention the following morning. There were no significant relationships between the caregiver's self-report of mood and anxiety and the stroke survivor's self-reported mood and anxiety.

The variables that were significantly cross-correlated and the variables that significantly predicted stroke survivors memory and attention in Chapter Five were entered into separate regression models to predict stroke survivor memory and attention. An example of this for C2 and P2 is shown in Table 6.4.

Table 6.4

Multiple Regression Predicting Memory and Attention for P2 with Additional Caregiver Variables

C2&P2	Memory				Attention			
	B	SE	B	p	B	SE	B	p
Constant	3.22	1.18			Constant	.62	1.3	
Attention (SS)	.52	.06	.60	.000*	Memory (SS)	.59	.07	.51 .000*
Memory +1 lag C (perc)	-.15	.09	-.10	.12	Mood (SS)	.26	.08	.22 .001*
Mood +2 lag C (self)	-.09	.13	-.06	.50	Attention +2 lag C (perc)	-.02	.17	-.01 .89
Anxiety +2 lag C (self)	-.06	.12	-.04	.61	Mood +2 lag C (self)	-.07	.16	-.04 .65
					Anxiety +2 lag C (self)	.24	.14	.15 .08

Note: C (perc) = caregiver's perception of stroke survivor's memory/attention, C (self) = caregiver's self-rating of their own mood and anxiety

SS = stroke survivor

** = $p < .001$, * = $p < .05$

A significant memory model emerged with one predictor explaining 40% of the variance in the data ($R^2 = .40$, $F(4, 161) = 25.81$, $p < .001$) which was the stroke survivor's rating of their attention ($\beta = .60$, $p < .001$). The attention regression model was also significant with 45% of the variance ($R^2 = .45$, $F(5, 162) = 26.16$, $p < .001$) being explained by the stroke survivor's rating of their memory ($\beta = .51$, $p < .001$) and their mood rating ($\beta = .22$, $p < .05$).

The results show that the stroke survivor's attention predicted their memory and the stroke survivor's memory and mood predicted their attention, which are the same results that emerged in Chapter Five for P2. Caregiver predictors of the stroke survivor's memory and attention and mood and anxiety were non-significant indicating that there was no added variance explained by the inclusion of the caregiver variables.

The same procedure was carried out for all participants. A summary of the regression models for the remainder of the participants is shown in Table 6.5. No models were fitted for P4 of the previous study as there were no significant associations between caregiver and stroke survivor variables. Additionally, for P5 in the previous study the regression model was non-significant (see Chapter Five, Table 5.8) and in the present study caregiver mood was the only variable associated with the stroke survivor's attention thus a model of attention could not be fitted.

Table 6.5

Summary of Multiple Regression Models Predicting Memory and Attention for P3, P5, P6 and P9 of the Previous Study with Caregiver

Variables Added

Memory					Attention				
C3&P3	$(R^2 = .62, F(3, 164) = 89.25, p < .001)$				C3&P3	$(R^2 = .60, F(3, 162) = 78.64, p < .001)$			
	B	SE	β	<i>p</i>		B	SE	β	<i>p</i>
Attention (SS)	0.59	.06	.62	.000	Memory (SS)	0.80	.05	.80	.000
Mood (SS)	0.17	.04	.24	.000	Memory +2 lag (SS)	0.14	.04	.15	.002
					Attention +1 lag C(perc)	0.08	.04	.10	.049
C5&P5	$(R^2 = .06, F(2, 163) = 5.27, p < .05)$				C5&P5				
	B	SE	β	<i>p</i>					
Mood (SS)	0.44	.21	.16	.04					
Anxiety +2 lag C(self)	0.22	.10	.16	.04					
C6&P6	$(R^2 = .95, F(6, 164) = 492.72, p < .001)$				C6&P6	$(R^2 = .94, F(6, 163) = 440.51, p < .001)$			
	B	SE	β	<i>p</i>		B	SE	β	<i>p</i>
Attention (SS)	0.93	.02	.94	.000	Memory (SS)	0.98	.02	.96	.000
Mood (SS)	0.05	.02	.05	.03					
C9&P9	$(R^2 = .37, F(6, 164) = 15.56, p < .001)$				C9&P9	$(R^2 = .29, F(3, 163) = 21.70, p < .001)$			
	B	SE	β	<i>p</i>		B	SE	β	<i>p</i>
Attention (SS)	0.58	.11	.36	.000	Memory (SS)	0.27	.04	.43	.000
Memory CC C(perc)	0.67	.15	.31	.000	Mood (SS)	0.25	.08	.20	.003
Anxiety -2 lag C(self)	0.35	.14	.17	.01					

Note: SS = stroke survivor, C (perc) = caregivers' perception of stroke survivors' memory/attention, C (self) = caregivers' self-rating of their own anxiety
CC = concurrent relationship

Table 6.5 continued

Summary of Multiple Regression Models Predicting Memory and Attention for P11 and P12 of the Previous Study with Caregiver

Variables Added

Memory					Attention				
C11&P11	$(R^2 = .19, F(4, 165) = 9.70, p = .05)$				C11&P11	$(R^2 = .20, F(4, 165) = 9.76, p < .001)$			
	B	SE	β	<i>p</i>	B	SE	β	<i>p</i>	
Attention (SS)	0.40	.08	.35	.000	Memory (SS)	0.30	.06	.47	.000
Anxiety (SS)	.12	.05	.17	.02	Anxiety +1 lag C(self)	0.37	.12	.23	.002
C12&P12	$(R^2 = .39, F(7, 146) = 12.48, p < .001)$				C12&P12	$(R^2 = .42, F(5, 147) = 20.61, p < .001)$			
	B	SE	β	<i>p</i>	B	SE	β	<i>p</i>	
Attention (SS)	0.11	.06	.14	.05	Memory (SS)	0.22	.09	.17	.02
Mood (SS)	0.21	.06	.27	.001	Anxiety C(self)	-0.50	.07	-.51	.000
Memory +2 lag C(perc)	0.29	.06	.37	.000					

Note: SS = stroke survivor, C (perc) = caregivers' perception of stroke survivors' memory/attention, C (self) = caregivers' self-rating of their own anxiety

Summary. The significant cross-correlations varied across participants. For three dyads, caregivers' perceptions of the stroke survivors' memory and attention were associated with stroke survivors' self-ratings of memory and attention. For three other dyads, there were no significant cross-correlations between caregiver ratings of the stroke survivors' memory and attention and stroke survivors' own ratings of memory and attention. For the final dyad, caregiver ratings of memory and stroke survivor ratings of memory were significantly associated, but no significant relationship emerged between caregiver and stroke survivor for attention.

The relationships between caregivers' own mood and anxiety and the stroke survivors' memory and attention also differed. For four dyads, caregiver mood was significantly associated with stroke survivor ratings of memory and attention. However, the lags varied. For the remaining dyads, there were no significant associations between caregiver mood and stroke survivors' memory and attention. In terms of anxiety, the caregivers' ratings of their own anxiety were associated with stroke survivors' memory for six dyads. In contrast, caregiver anxiety was significantly associated with stroke survivors' attention for only two dyads, again the lagged relationships differed.

Caregiver mood and stroke survivor mood was significantly associated for three dyads while for four dyads there were no significant relationships between these variables. In comparison, for two dyads caregiver anxiety was associated with stroke survivor anxiety. Accordingly, different predictors were entered in to the regression models for each participant.

The regression models revealed that the addition of caregiver variables as predictors of stroke survivors' memory and attention produced diverse results. For

some caregivers, their variables emerged as significant predictors whereas for others they did not. For those that did emerge as significant predictors, the amount of explained variance differed from there being no change at all to an increase in 14% more of the variance being explained.

Similar to the results in Chapter Five, caregiver self-reported mood and anxiety measured by questionnaires are not always indicative of the relationship between these variables and stroke survivors' memory and attention. C5 and C12, caregivers of the present study, reported moderate and normal/moderate levels of anxiety and caregiver anxiety emerged as a significant predictor of the stroke survivors' memory and attention. However, C3 obtained scores indicative of moderate levels of anxiety and normal/moderate levels of depression yet mood and anxiety did not emerge as significant predictors in the regression models. Additionally, caregiver anxiety was a significant predictor of the stroke survivor's memory for C9 and a significant predictor of attention for C12 despite scores on the anxiety questionnaire falling into the normal classification.

Relationship between Caregiver Sleep Quality and Stroke Survivor Sleep Quality, Memory and Attention. There was insufficient data to include sleep in the above analyses as caregivers completed twice daily ratings of the stroke survivor's memory, attention and their own mood and anxiety whereas caregiver sleep quality was recorded once. Therefore, separate data series for morning and evening had to be created and no lags were specified in the present analyses due to the natural lag for sleep that exists.

Table 6.6

Pittsburgh Sleep Quality Index Scores at Times 1 and 2

	PSQI			PSQI	
	T1	T2		T1	T2
C2	2	15	C6	5	4
C3	9	10	C9	12	11
C4	10	11	C11	5	3
C5	14	11	C12	13	14

Table 6.6 shows that five caregivers had poor sleep quality, two had good sleep quality and one caregiver had good sleep quality at Time 1 but poor sleep quality at Time 2. Scores on the sleep questionnaire do not appear to provide an initial indication as to the potential relationships between subjective caregiver sleep quality and stroke survivor memory and attention. Some caregivers were poor sleepers and some were good sleepers, but despite this difference in sleep quality, for some dyads caregiver sleep quality was associated with stroke survivors' memory and attention.

Caregiver results from the Pittsburgh Sleep Quality Index (PSQI) are also in this section which are shown in Table 6.6. The cross-correlations for all eight dyads are displayed in Table 6.7.

Table 6.7

Cross-correlations between Caregiver Sleep Quality and Stroke Survivor Sleep Quality,
Memory and Attention (am/pm) for all Eight Dyads

	C2&P2	C3&P3	C4&P4	C5&P5
	CC (SE)	CC (SE)	CC (SE)	CC (SE)
Sleep (C) & Memory am (SS)	-.31 (.11)*	.07 (.11)	-.12 (.11)	.12 (.11)
Sleep (C) & Memory pm (SS)	-.36 (.11)*	.13 (.11)	-.10 (.11)	.09 (.11)
Sleep (C) & Attention am (SS)	-.23 (.11)*	.08 (.11)	-.16 (.11)	.07 (.11)
Sleep (C) & Attention pm (SS)	-.20 (.11)	-.03 (.11)	-.09 (.11)	.06 (.11)
Sleep (C) & Sleep (SS)	-.00 (.11)	.11 (.11)	.15 (.11)	.06 (.11)
	C6&P6	C9&P9	C11&P11	C12&P12
	CC (SE)	CC (SE)	CC (SE)	CC (SE)
Sleep (C) & Memory am (SS)	-.04 (.11)	-.13 (.11)	.07 (.11)	-.03 (.12)
Sleep (C) & Memory pm (SS)	.15 (.11)	-.03 (.11)	.05(.11)	.25 (.12)*
Sleep (C) & Attention am (SS)	.04 (.11)	-.23 (.11)*	.22 (.11)*	-.06 (.12)
Sleep (C) & Attention pm (SS)	.15 (.11)	-.00 (.11)	.31 (.11)*	.22 (.12)*
Sleep (C) & Sleep (SS)	-.10 (.11)	.09 (.11)	.15 (.11)	.67 (.12)*

Note: C – caregiver, SS = stroke survivor, CC = concurrent, SE = standard error

- = significant cross-correlations

Table 6.7 shows that caregiver sleep quality was significantly associated with the stroke survivor's self-rating of memory in the morning and evening and attention in the morning for dyad C2& P2. For dyad C9&P9, caregiver sleep quality was associated with the stroke survivor's self-rating of attention the following morning. The relationships were negative indicating that as caregiver sleep quality got poorer the stroke survivors' self-ratings of memory and attention improved. There were also significant cross-correlations between caregiver sleep quality and stroke survivor self-ratings of attention in the morning and evening for dyad C11&P11, and between caregiver sleep quality and stroke survivor memory and attention in the evening for dyad C12&P12. The relationships were positive, thus as caregiver sleep quality was good so was the stroke survivors' rating of their memory and attention. There were no significant cross-correlations between caregiver sleep quality and stroke survivors' ratings of memory and attention for the remaining four dyads. In relation to caregiver sleep quality and stroke survivor sleep quality, only one significant cross-correlation emerged for dyad C12&P12. Again, this relationship was positive signifying that good caregiver sleep quality was associated with good stroke survivor sleep quality.

6.4. Discussion

This is the first study to explore dyadic relationships between caregivers and stroke survivors' behavioural and psychological outcomes using an Individual Analysis of Temporal Processes (IATP). Previous research on caregiver and stroke dyads has shown significant relationships on a number of outcomes such as caregiver depression, distress and mastery, and stroke survivor depression and cognitive functioning (Cameron et al., 2006, 2011; Perrin et al., 2008). However, apart from

the limitations of being group-based, two of these studies are limited as they were cross-sectional in design which restricts the ability to test for temporal relationships as they occur within caregivers and stroke survivors. The present study was able to capture these relationships due to the methodology used, and also advance previous research by including other constructs such as anxiety and sleep quality which are neglected areas in stroke research.

Half of the caregivers in the present study suffered from low mood, anxiety and poor sleep quality which is in line with previous research (Greenwood & Mackenzie, 2010; Han & Haley, 1999). However, the picture concerning the dyadic relationships between caregiver and stroke survivor outcomes is less clear. The caregivers tended to under-estimate the stroke survivors' memory and attention by rating it worse than what the stroke survivor had rated. Previous research has shown that caregivers' own depression levels and pain influenced the perception of pain in stroke survivors (Hung et al., 2007), thus the caregivers perception of the stroke survivors' memory and attention in the present study may have been influenced by other factors such as their own mood or how well they slept the night before. Or indeed, another point to consider is that stroke survivors were over-estimating how good their memory and attention was. Stroke survivors may be in denial as to how poor their memory and attention is, or they may lack the insight and awareness needed to give an accurate self-report of how well their memory and attention is functioning. Irrespective, there appears to be a discrepancy between caregiver ratings of the stroke survivors' memory and attention and stroke survivors' own rating of memory and attention which researchers should be mindful of when including significant others in future research projects.

Previous research using dyadic analyses has shown that stroke survivors who have high levels of depression so do caregivers (Cameron et al., 2011), or if stroke survivors have cognitive difficulties caregivers experience high levels of depression and low levels of mastery (Cameron et al., 2006). Thus, the relationships appear to be congruent. In the present study, the cross-correlation analyses revealed that for some dyads the relationships were in the direction opposite to what would be expected. When caregivers reported that the stroke survivors' memory and attention was poor, stroke survivors' were more likely to report that their memory and attention was good that evening or the following day. Likewise, when caregivers reported that their mood was low, or that their anxiety levels were high, or that they had a poor night's sleep, stroke survivors would report good memory and attention subsequently.

Why this is so is not entirely clear as this is the first study to assess daily temporal relationships using the diary method. Stroke survivors with cognitive difficulties are likely to depend on caregivers to assist with daily functioning. It may be that caregivers have voiced that they are experiencing day-to-day stresses and strains making the stroke survivor feel the need to report that they are better than they are in an attempt to reduce the burden and associated worry the caregivers are experiencing. Or again, non-intended over-estimation on the stroke survivors' behalf, for whatever reason, may explain the findings. In either case, future research studies should aim to look more closely at the dynamic relationships that have emerged in the present study.

Although there were some congruent relationships between caregiver and stroke survivor mood and anxiety, i.e. if caregiver mood and anxiety improved so did

stroke survivor mood and anxiety, for some of the dyads, caregivers' mood, anxiety and sleep quality was not associated concurrently or lagged with the stroke survivors' mood, anxiety and sleep quality. This is in contrast to findings from previous research which have shown caregiver and stroke survivor behavioural and psychological outcomes to be related (e.g., Cameron et al., 2006, Cameron et al., 2011; Perrin et al., 2008).

Again, it is ambiguous as to why this is so. It may depend on the amount of time caregivers spend with stroke survivors each day or whether they sleep in the same bedroom at night. If little time is spent with each other, then there is unlikely to be a feedback loop between caregiver and stroke survivor. Whereas, if caregivers and stroke survivors are in each other's company throughout the day it may be more likely that one's mood or anxiety will affect the other person. Similarly, if caregiver and stroke survivor are sleeping in separate rooms, which was the case for some of the dyads in the present study, then their sleep quality may be unlikely to affect each other. Additionally, the very nature of asking both caregivers and stroke survivors to report on their mood, anxiety and sleep quality may have created a situation where they have concealed behaviourally and/or verbally how they are feeling or how well they slept. These issues need to be well thought out in subsequent research.

The addition of caregiver variables had little impact in predicting stroke survivors' memory and attention for the dyads in the present study. In particular, caregiver anxiety was a predictor of stroke survivor's memory and attention for only four dyads. Despite this, it is still important to think about how caregiver variables may be playing a role and what can be done to reduce the effect if it is detrimental to the stroke survivor's recovery.

Therefore, in terms of rehabilitation of memory and attention functions post-stroke it may be that cognitive-behavioural therapy, which has been shown to be useful in treating anxiety disorders (Goldstein & McNeil, 2013), is offered to caregivers to help them manage their anxiety levels so that there is less of an influence on the stroke survivor's memory and attention recovery. Likewise, a non-pharmacological intervention to improve sleep quality may be beneficial in this pursuit. In any case, helping stroke survivors to regain memory and attention functions post-stroke is imperative, thus the effects of negative external influences must be minimized.

Methodological Quality of the Present Study. For reasons noted in Chapter Five, the SCED scale (Tate et al., 2008) could also not be used in the present study.

Chapter Seven

A Feasibility Study of a Combined Walking and Cognitive Training Programme to Improve Memory and Attention in Long-Term Stroke Survivors

“Walking is the nearest activity to perfect exercise”

(Morris & Hardman, 1997)

7.1 Introduction

The present study developed and assessed the feasibility of an intervention that consisted of walking combined with memory and attention games. The rationale for this study was based on the findings that currently there are no studies involving a behavioural change intervention to improve physical activity in stroke (Chapter Four), and the interventions for memory and attention rehabilitation are limited (Chapter Two). The intervention made use of the Transtheoretical model of Behaviour Change (Prochaska & Diclemente, 1982) whilst engaging in cognitive exercises.

From the existing literature (Chapter Two) it is evident that cognitive rehabilitation and physical activity as independent treatments have the potential to improve cognitive function post-stroke. Therefore, it may be that combining physical activity and cognitive training could have an additive effect on improving cognitive domains such as memory and attention following brain trauma. The research studies that have begun to investigate this area have used two paradigms; one is where participants receive a physical activity and a cognitive rehabilitation intervention that

are carried out sequentially, and the other where physical activity and cognitive tasks are performed simultaneously.

Using the sequential paradigm, several studies have investigated the effect of physical activity and cognitive training on cognitive performance in stroke and older adult samples, where the treatments have been delivered on different days. Pyun et al. (2009) evaluated the effectiveness of a 12-week training programme that consisted of cognitive rehabilitation, cognitive games, story retelling and aerobic activity. The results showed that global cognitive function significantly improved when measured with the Mini-Mental State Examination test but performance on the tests assessing different cognitive domains did not.

In healthy older adults, memory performance was shown to improve following physical and cognitive training, physical training on its own and cognitive training on its own with the combined group showing the greatest improvement (Fabre et al., 1999; Fabre, Chamari, Mucci, Masse-Biron, & Prefaut, 2002). However, both studies used a composite score comprised of memory performance on subtests of the Wechsler memory test; when assessing the effect of the treatments on the memory subtests, such as logical memory and paired associated learning, there was no difference between the groups in terms of performance.

Similarly, Oswald, Gunzelmann, Rupperecht, & Hagen (2006) examined the effects of psychoeducational training, cognitive training, psychoeducational and physical training or cognitive and physical training on cognitive function. Using a composite score of memory, attention and information processing speed, a large effect size ($d = .75$) was reported for the effect of the combined cognitive and physical treatment group. Small to modest effect sizes were reported for the other

treatment groups. In relation to specific cognitive domains, memory and attention improved significantly in the combined treatment group. However, there were also significant effects on these cognitive functions following cognitive training on its own again suggesting that the combined treatment afforded no more benefit on individual cognitive domains than the single treatment.

In summary, to date there is little evidence to suggest that combined physical and cognitive treatments, when delivered in different sessions, are more beneficial than individual treatments delivered alone.

The other area of study is dual-tasking studies where the effect of adding a cognitive task to a motor task is investigated. Several research studies (Beauchet et al., 2009; Beauchet et al., 2007; Bootsma-van der Wiel et al., 2003) have shown that those who experience cognitive-motor interference from doing two or more tasks at once are more likely to fall than those who do not. Other studies have examined the effect of adding a cognitive task whilst walking on walking speed, cadence, stride length and stride time. These studies have shown that an additional cognitive task negatively affected walking (Al-Yahya et al., 2011; Plummer-Da Amato, Shea, & Dowd, 2012) and cycling performance (Dawes et al., 2003). However, other research has shown that walking ability improved post dual-task training (Yang, Wang, Chen, & Kao, 2007).

In contrast to assessing the effect of adding a cognitive task on motor outcomes, several studies have examined the effect of cognitive-motor dual-tasking on cognitive performance in stroke survivors. These have shown that performance on the Stroop task during obstacle crossing (Smulders, van Swigchem, de Swart, Geurts, & Weerdesteyn, 2012), remembering a 7-item shopping list (Hyndman, Ashburn,

Yardley, & Stack, 2006) and performance on a visuo-spatial task deteriorated (Dennis et al., 2009). These findings suggest that doing two or more tasks at once is detrimental to cognitive function. However, these studies have assessed the effect of cognitive-motor dual-tasking during the completion of the tasks not following the dual-task activity.

Potential benefits of combined physical and mental stimulation on cognitive function may occur subsequently over time. Using the effect of physical activity on cardiovascular functioning as an example, a one-off bout of activity is unlikely to improve cardiovascular health, there may even be detrimental effects such as pain and fatigue initially. However, over time continuous bouts of activity would improve the cardiovascular system, and the negative effects may diminish. So despite the above findings, it is possible that combining physical activity with cognitive tasks may have a positive effect on cognition when they are performed over an extended period of time.

Research studies using animal models have also shown that enriched environments that provide a lot of mental stimulation (van Praag, Kempermann, & Gage, 1999) and physical exercise that involves complex in-depth cognitive processing can promote angiogenesis (new blood vessels forming from pre-existing vessels) and synaptogenesis (the formation of new synapses) in the cerebellar regions of the brain (Black, Isaacs, Anderson, Alcantara, & Greenough, 1990). Although there are caveats when extrapolating findings from animal research to humans this evidence provides a potential mechanism by which the combination of a physical and cognitive task together may be beneficial for individuals who have sustained brain injury.

In humans, Evans, Greenfield, Wilson, & Bateman (2009) assessed the effect of a cognitive-motor dual-tasking training programme to improve dual-tasking in those with acquired brain injury. Twice daily two minute walking sessions were completed whilst listening to an auditory stimulus, completing a verbal fluency task and answering autobiographical questions over a period of five weeks. The results showed that the ability to walk and carry out a cognitive task, which was sentence verification, improved significantly post-training. However, shortcomings of the study include the 'dose' of walking that participants were asked to do, the use of mixed aetiology groups and the non-tailoring of the intervention. Research studies involving longer walking sessions, with a pure aetiologic brain injury group involving individualised interventions would be of benefit.

Walking as a Mode of Physical Activity for Stroke Survivors. Walking is likely to be challenging for stroke survivors as it is a complex activity requiring cognitive flexibility to address motor requirements whilst attending to a range of environmental stimuli and/or attending to and carrying out concurrent tasks (Sheridan & Hausdorff, 2007; Woollacott & Shumway-Cook, 2002). However, walking offers a simple approach to exercise that can be incorporated into everyday life in comparison to other exercise modes that require equipment or membership access. Not only is it a simple approach but potential health benefits can be gained from walking such as an enhancing the cardiovascular system, strengthening the muscles, increasing bone density, regulating lipids, insulin and glucose and improving psychological health and well-being (Hart, 2009). As stroke survivors have reported financial and transport barriers to physical activity participation (Rimmer et al., 2008) walking may be an ideal mode of exercise for stroke survivors.

Indices have been proposed to classify walking behaviour in healthy adults, older adults and for those living with chronic conditions (Tudor-Locke & Bassett, 2004; Tudor-Locke et al., 2011). Tudor-Locke and colleagues (2011) propose that special populations, which stroke survivors would be considered to be, should aim to achieve a minimum of 7000 steps per day. This includes walking at moderate intensity carried out in accumulated bouts of 10 minutes amounting to 150 minutes over the week in addition to habitual background daily activities. These recommendations are in line with exercise after stroke guideline (Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings, 2010).

Although guidelines exist, many stroke survivors are still sedentary. A recent systematic review on walking promotion reported that motivated individuals can be encouraged to walk more by targeted, tailored interventions (Ogilvie et al., 2007). However, little is known about the best way to promote walking in stroke survivors. Additionally, our knowledge of strategies to assist stroke survivors to continue living an active lifestyle is also limited. In non-clinical populations more than half of those who start a physical activity programme drop out within the first few months (Dishman & Buckworth, 1996), therefore, it is important to consider not just how to initially encourage stroke survivors to be more physically active but also educate, raise awareness and support them in the use of cognitive and behavioural strategies that will assist them in maintaining participation in physical activities.

A number of theoretical models have been used in an attempt to understand physical activity behaviour. These include the Health Belief Model (Becker & Maiman, 1975) which proposes that health behaviour change occurs in the attempt to

protect against disease and improve health. Self-efficacy theory (Bandura, 1977) focuses on individuals' belief in their ability to successfully perform a behaviour. The Theory of Planned Behaviour (Ajzen, 1991) examines perceived behavioural control, social norm, attitudes and intentions to perform a behaviour and the Transtheoretical model of Behaviour Change (Prochaska & Diclemente, 1982) which is a stage-based approach that involves cognitive and behaviour strategies.

The Transtheoretical model suggests that behaviour change is a dynamic process involving stages of change, self-efficacy, the pros and cons of a behaviour and behavioural and cognitive processes of change. The model has been used to promote behaviours such as healthy eating (Di Noia, Contento, & Prochaska, 2008) and medicinal drug adherence. It has also been used to facilitate physical activity behaviour in cardiac populations (Hughes, Mutrie, & MacIntyre, 2007) and with those living with diabetes (Kirk, Barnett, & Mutrie, 2007) with it being concluded that it is a useful model to measure stroke survivors' readiness to participate in physical activity (Garner & Page, 2005).

Although the Transtheoretical model shows promising results it has received some criticisms. For example, it has been argued that the model is only beneficial for short-term behaviour change, the evidence for its effectiveness is mainly based on cross-sectional data (Brug, Conner, Harre, Kremers & Mckellar, 2005), there is little information informing how the stages of change occur with regards to intentions and behaviours (Armitage & Conner, 2000) and there are very few validation studies supporting the processes of change (Spencer, Adams, Malone, Roy & Yost, 2006). Despite the limitations, the model was chosen for the present study as it closely underpins the facets of the physical activity consultation that was used (Fitzsimons et

al., 2008). This consultation was developed and tested by Professor Mutrie who also trained JC in its delivery.

Goal setting has also been used to facilitate an increase in physical activity levels. In particular, pedometers are increasingly being used as self-monitoring devices to assist with goal setting interventions. Currently, there is no published research investigating the effectiveness of pedometer-based walking programmes in stroke survivors. However, in a recent systematic review, it was concluded that pedometer use in outpatient adults is associated with significant increases in physical activity (Bravata et al., 2007). Daily step counts have also increased in cardiac populations (Furber, Butler, Phongsavan, Mark, & Bauman, 2010) and in those living with diabetes (De Greef, Deforche, Tudor-Locke, & De Bourdeaudhuij, 2010; Tudor-Locke et al., 2004) when pedometers were used. Although the above studies show a positive relationship between pedometer wear and levels of walking, walking behaviour often returns to baseline levels post-intervention (Tudor-Locke et al., 2004) suggesting that the use of pedometers are effective mainly in the short term.

In addition, the accuracy of steps counts using pedometers may be underestimated. Level of agreement between pedometers and step counts was evaluated showing that the pedometers failed to detect step counts when walking speed was below 0.5 m/s and undercounted steps above this rate of walking speed (Carroll et al., 2012). Therefore, although pedometers appear to be a feasible physical activity monitoring tool, the use of them may be limited in stroke survivors who have a slow walking speed and in those who have upper-limb paresis. Accelerometers such as the activPAL have received more support. A recent systematic review of accelerometry-based measures concluded that accelerometers

produce valid and reliable data when monitoring physical activity after stroke (Gebruers, Vanroy, Truijen, Engelborghs, & De Deyn, 2010).

Aims

The aims of the present study were to assess the feasibility of combined walking with memory and attention games on objective and subjective memory and attention. A further aim was to explore the effects of mood, anxiety and sleep quality on memory, attention and walking behaviour. To achieve these aims guidance was sought from the MRC framework for developing and evaluating complex interventions and the decision making process for feasibility trials (ADePT) was used (Bugge et al., 2013). ADePT is a systematic process that tests the research findings against 14 methodological issues commonly found in feasibility and pilot research. It guides researchers in making a balanced decision about whether or not to proceed, and it provides guidelines to address the problems identified.

7.2 Method

Intervention

The intervention comprised:

1. A physical activity consultation based upon the Transtheoretical model of Behaviour Change (Prochaska & Diclemente, 1982) and making use of goal setting techniques
2. Weekly guided walks where cognitive games were played.
3. In addition, throughout all phases of the study pedometers were used to record daily step counts and daily diaries were used to record aspects of cognition, mood, anxiety and sleep.

Study Design

A series of IATP studies were carried out over 25 weeks involving an A-B-C design. The A phase was the baseline phase (weeks 1 – 8) where memory, attention, mood, anxiety, sleep quality and walking behaviour were recorded daily. The physical activity consultation was delivered in the week following the baseline phase but prior to the intervention phase (week 9).

The B phase involved the intervention (weeks 10 -17) which consisted of playing memory and attention games whilst undertaking planned walks. Participants were assisted on one walking session per week by the primary researcher (JC) but were encouraged to maintain their walking on other days of the week. The C phase was the follow-up phase (weeks 18 – 25). During this phase participants were no longer assisted on their walking sessions but again were encouraged to try and maintain their walking and cognitive games behaviours.

Participants completed neuropsychological memory and attention tests, questionnaires and wore the activPAL at the beginning (Time 1, week 1) and end of the baseline phase and beginning of the intervention (Time 2, week 8), at the end of the intervention phase (Time 3, week 18), and at the end of the follow-up phase (Time 4, week 25). Participants also completed a daily diary throughout the 25 weeks rating their memory, attention, mood, anxiety and sleep quality, and recorded steps walked and memory and attention games played.

Participants

Fifteen ambulatory stroke survivors were recruited over a period of 13 months. Four participants dropped out of the study due to being unable to commit to the study requirements. Six other potential participants expressed an interest in the

study but were excluded from taking part because they lived too far away for it to be feasible to deliver the intervention, or they had not returned follow-up calls after an information pack was sent out. Participant information is shown in Table 7.1.

Participants were included if they were: (1) adults between 18 and 80 years old, (2) who had sustained a stroke (ischaemic/haemorrhage) at least 6 months prior to commencing the study, (3) could walk independently – with or without a walking aid, (4) self-reported memory and attention problems and (5) who were community dwelling residents.

Participants were excluded if they had: (1) the presence of dementia. Vascular dementia was assessed using the MoCA (Nasreddine et al., 2005) with an exclusion cut-off of 16, (2) absolute contraindications to physical activity such as unstable heart disease/angina, myocardial infarction, uncontrolled hypertension, arrhythmia and/or diabetes, acute progressive heart failure, acute aortic dissection, acute myocarditis or pericarditis, pulmonary infarction, deep venous thrombosis, extreme obesity (> 159kg), suspected/known aneurysm, acute infections, uncontrolled visual or vestibular disturbances, recent injurious fall without medical assessment, (3) had recently been hospitalized, (4) visual or hearing impairments that were not corrected with visual and hearing devices, (5) inadequate English language ability that would prevent understanding of the test instructions/study requirements and (6) a diagnosis of a mental illness such as major depressive disorder or schizophrenia.

As in Chapter Five, if potential participants met the inclusion criteria and the exclusion criteria did not apply they were considered suitable for the study unless

they showed signs that they did not understand what was being asked of them within the remit of the study.

Measures

Neuropsychological tests and questionnaires that were used in Chapter Five were also used in this study. These were the MoCA (Nasreddine et al., 2005), the line-bisection test (Schenkenberg et al., 1980), the Everyday Memory Questionnaire-Revised version (EMQ-R) (Royle & Lincoln, 2008), the Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1988), the Rivermead Behavioural Memory Test – Third Edition (RBMT-3) (Wilson et al., 2008) and the Test of Everyday Attention (TEA) (Robertson et al., 1996).

In the present study, several other questionnaires were also administered. These were the Physical Exercise Readiness Questionnaire (PAR-Q) (Chisholm, Collis, Kulak, Davenport, Gruber, 1975), the Test of Premorbid Functioning (TOPF) (Wechsler, 2009), the Beck Depression Inventory (BDI-II) (Beck, Steer, Ball, & Ranieri, 1996) and the anxiety scale of the Depression, Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1995). The BDI-II and the anxiety scale of the DASS replaced the HADS that was used in Chapter Five as an issue was raised at the UK Stroke Forum Conference (2012) that the HADS was a suitable screening measure for depression and anxiety but that it was not the most appropriate measure to detect change over time.

The PAR-Q was administered to ensure no-one was at risk from health complications before the study started. The PAR-Q is a 7-item questionnaire that asks participants to answer questions such as ‘Do you feel pain in your chest when you do physical exercise?’ and ‘Do you lose your balance because of dizziness or do

you ever lose consciousness?’ If participants answered ‘yes’ to one or more questions they are advised to seek guidance from their GP before consenting to take part in the walking study.

The TOPF, which is a revision of the Wechsler Test of Adult Reading – UK Edition (WTAR), was used to obtain an estimate of premorbid intellectual abilities. The TOPF is a list of 70 words with atypical grapheme – phoneme translation, for example ‘cough’, ‘knead’, ‘subtle’, ‘piquant’, ‘lascivious’, ‘ubiquitous’ and ‘hyperbole’. The test takes less than 10 minutes to complete. Participants score one point if they pronounce the word correctly and zero points if they do not. After five consecutive scores of zero the test is discontinued.

The BDI-II is a questionnaire consisting of 21 groups of statements and takes a few minutes to complete. Each statement is scored on a 4-point rating scale ranging from 0 – 3. Higher scores indicate more reported difficulties. The BDI-II has been reported to be a satisfactory measure assessing depression in stroke (Turner et al., 2012). Cronbach’s alpha = .92 (Beck et al., 1996).

The anxiety scale of the DASS (short version) was used to measure levels of state anxiety. The anxiety sub-scale is a seven-item questionnaire that takes less than 10 minutes to complete. Each item is scored on a 4-point rating scale ranging from 0 – 3. Higher scores indicate more reported difficulties. The anxiety sale of the DASS is a reliable measure assessing anxiety in clinical populations. Cronbach’s alpha = .89 (Brown, Chorpita, Korotitsch, & Barlow, 1997).

Daily Diary. Participants were also asked to complete a diary checklist throughout the study (see Appendix IX). Participants were asked to rate from 1 (Very Bad) to 10 (Very Good) how they slept the night before, and aspects of their memory

and attention, along with a rating of their mood and anxiety levels that day. There were three items for both memory and attention. The memory items were ‘remembering, names, faces and objects’, ‘remembering to do things’ and ‘remembering information’. The attention items were ‘being able to concentrate’, ‘being able to do two things at one’ and ‘being able to change topics’.

From the second week of the baseline phase to the end of the follow-up phase, participants were also asked to record their step counts from the pedometer. The pedometer was not given to the participants at week 1 given the amount they were asked to do, thus the decision was made for the provision of the pedometers to be supplied the following week. From the start of the intervention phase to the end of the follow-up phase, participants were also asked to record whether they played a memory and/or attention game or not whilst out walking.

Measurement of Physical Activity. Physical activity was measured with the activPAL™, the NL-1000 pedometer and the Omron-III pedometer. A description of the activPAL has been described in Chapter Five. The NL-1000 pedometers were chosen as they have been used successfully in a previous research study that aimed to increase levels of walking in an older adult population (*personal communication, Professor Nanette Mutrie, 2012*). Participants were asked to record their step counts at the end of each day to prevent the possibility of recording the wrong values from the memory store. Participants were advised that the pedometer should be attached to their waistband half way between their navel and hip. If they had lower-limb hemiparesis they were advised to wear the pedometer at the side opposite to their affected limb.

A number of participants had difficulty attaching the pedometer to their waistband due to upper-limb hemiparesis therefore they were provided with the Omron – III pedometer which they wore around their neck.

Procedure

Ethical approval was granted by the University of Strathclyde Ethics Committee. All participants provided written consent and all data was pseudo-anonymised (See Appendix X – XIII for ethics application form, ethics approval letter, participant information sheet and consent form, respectively). A letter was written to the participants' GP informing them that their patient had volunteered to take part in the study. The GP's were asked to respond if they had any concerns over their patient's involvement in the study. A small number of the GP's replied indicating that they had no concerns.

Similar to the recruitment strategy reported in Chapter Five, the recruitment process involved a number of strategies such as advertising the study via stroke organisations, social networking sites and in community places. In addition to these, an advertisement was placed in the local newspapers within Glasgow. Potential participants were sent an information pack and were given a minimum of three days to decide whether they would like to take part before the researcher contacted them.

Baseline Phase (Weeks 1 – 8). All testing sessions took place in the participants' home. During the first session the study was explained to the participant. If participants consented they then completed the MoCA, the Line-bisection test, the TOPF, and demographic and stroke-specific questions. Following which they completed either the neuropsychological battery of memory or attention tests, followed by the questionnaires (EMQ-R, BDI-II, DASS and PSQI). Some

participants completed the questionnaires during the first session, and others completed them that evening/following day due to fatigue. During this first session the activPAL was also provided and they were asked to wear this for seven days. The same procedure as in Chapter Five with regards to the attachment of the activPAL was applied.

At week 2, participants completed outstanding tests and were then given a pedometer. The questionnaires and the activPAL were collected at the end of this session. At week 8, the neuropsychological tests and questionnaires were re-administered. The activPAL was also provided again to be worn for seven consecutive days.

The Intervention: Physical Activity Consultation, Walking Goals and Memory and Attention Games (Week 9 -17). Part of the intervention involved a physical activity consultation delivered by JC who received consultation training from Professor Nanette Mutrie who has worked extensively in this area. At week 9 participants completed the tests that were not completed at week 8 and then completed the PAR-Q followed by the physical activity consultation. The consultation involved a one-to-one semi-structured discussion covering the key elements of the Transtheoretical model. It has been proposed that the consultation style should involve a guiding style where the participants are encouraged to take responsibility for their behaviour change rather than a directing style that involves methods of persuasion (Rollnick et al., 2005).

The approach is person-centred and was adapted according to the needs of the each participant. Consultations began with an explanation of the different forms of physical activity stroke survivors could do although emphasis was placed upon

walking as the study was interested in increasing walking behaviour. A description of intensity levels was provided and a decision balance table was also completed. This allowed participants to weigh up the pros and cons of becoming more physically active. The aim of the decision balance table is to encourage participants to perceive more pros for becoming more physically active. Barriers to walking and strategies to overcome these barriers were also discussed

The next stage of the consultation involved developing walking goals. Walking goals were provisionally planned by JC based on walking at baseline measured by the activPAL. However, participants had input into the development of the goal plan. Research has shown that self-management approaches that involve individuals in their own behaviour change have had considerable success among those with long-term illnesses (Lorig, Ritter, & Plant, 2005). Participants were encouraged to take responsibility for their goals so that they were acceptable to them. They considered if they could adhere to the goal plan and they re-structured the plan where necessary. Participants also choose when and where and at what time they would go out walking thereby increasing ownership of the goals. The setting of the goals was centred upon the SMARTER approach where goals are specific, measurable, attainable, realistic, time-bound, evaluated and revised (Doran, 1981). The consultation ended with a discussion on support required to allow the participants to achieve and maintain their walking goals. If participants indicated that they might need support from a significant other there was discussion as to how this could be achieved.

Some participants, despite already achieving a high number of daily steps at baseline, wanted to increase their walking behaviour outdoors. They too received the

physical activity consultation but they also received information on relapse prevention and improving long-term maintenance. The relapse prevention strategies involved identifying situations that could potentially affect their levels of walking and then ways to prevent a relapse and/or ways to facilitate getting back to a physical activity plan were discussed.

The memory and attention games were developed based upon the participants' performance on the neuropsychological tests at week 1. With the RBMT-3 there is an average scaled-score for each of the subtests and scores that were two standard deviations below this were considered to reflect poor performance. The TEA does not provide an average scaled-score for the subtests so achieving a scaled-score of five or less was taken to indicate poor performance. This was equivalent to approximately 7% of people of the same age as a participant gaining a lower score. For participants not scoring at least two standard deviations below the mean, the memory and/or attention domains they had most difficulty with were chosen as the areas to be targeted. A series of 'games' were devised as cognitive exercises after it was established the domains participants were struggling with. An exemplar of the games is given in Appendix XIV.

To illustrate, participant P5 had difficulty with prospective memory, attentional switching and counting with distraction. Therefore, she was provided with a booklet that contained the following games; the 'Intend to Do Game' (prospective memory), 'Alternating Letter and Name Game' (attentional switching) and the 'Food Price Game' (counting with distraction). In the Intend to Do Game, P5 was given tasks to do both during and at the end of the walk such as telling JC what she had for breakfast that morning or what she had watched on the TV the night before. JC

prompted the participant with either a time-based or event-based cue. With the time-based cue, if P5 decided to go for a 20-minute walk she was asked to monitor the time and give the answer to the question JC had asked her prior to setting off on the walk. With the event-based cue, returning to the participant's home following the walk was the cue. So, upon return P5 was to provide JC with the answer to the question that was posed prior to setting off on the walk. If the participant did not freely provide the information when expected a prompt was used in an attempt to aid the response. The participant was informed that this game could be adapted if she was out walking on her own. They were given examples as to exercises they could do, one of which was deciding on an action to be carried out when she returned home from their walk, such as putting a washing on. They were informed to write down on a notepad before leaving the house the action to be carried out and tick it off when it was completed following their return.

With the Alternating Letter and Name Game, P5 was asked to work through the alphabet starting with a girl's name that begins with the letter A, then stating a boy's name that begins with the letter B and then continue to switch between girls and boys names as she moved through the alphabet. For example, A Andrea, B Brian, C Caroline, D Derek and so on. The participant was informed that she could change this and start the letter A with a boy's name. This game was suitable to be played when P5 walked on her own.

With the Food Price Game, P5 was asked to pay attention to a list of food items and prices and the task was to count the number of items mentioned whilst ignoring items of a particular price. For example a list of items such as bread 75p, yoghurt 45p, milk 99p, banana 30p, coleslaw 99p and grapes 90p were read aloud by

JC. P5 was asked to count how many items were mentioned excluding those mentioned at 99p. The list of items became longer when P5 completed the previous shorter list. P5 was informed that this game was only suitable if she was assisted on a walk by JC or was accompanied on a walk by a significant other who was willing to play the game.

Follow-Up (Weeks 18 – 25). At week 18/19 and 25/26 the neuropsychological tests and questionnaires were re-administered and the activPAL was worn for seven consecutive days. Participants were provided with a pedometer at the end of the study as a thank-you gift for participating in the study.

Data Analysis

Similar to Chapter Five and Six, different analytical techniques are used to analyse the data. Descriptive information on neuropsychological test performance (RBMT-3 and TEA), questionnaire results (EMQ-R, BDI-II, DASS and PSQI), number of steps walked at each time point (Time 1, 2, 3 and 4) measured by the activPAL and pedometer and number of memory and attention games played during the intervention and follow-up phase are presented for each participant.

As in Chapter Five, different testing of test performance at the group-level across the four time points using the Related Samples Wilcoxin Signed Rank Test was performed alongside Spearman correlation analyses to test for associations between the scores on the RBMT-3, the TEA and the questionnaire results. Growth curve analysis was also carried out on the data in the present chapter to explore the rate of change of memory, attention and walking over time.

Following this, the diary data was subjected to IATP. The same procedure for data preparation and analysis of this data that was applied in Chapter Five and Six was applied here also.

7.3 Results

Participant Demographics. Table 7.1 details participant demographics and screening test scores. One participant was taking anti-depressant medication and three were taking anti-convulsants which also affect mood regulation. Of the 11 participants, only two scored equal to or greater than 26 on the MoCA (P2 and P7) indicating that the majority had some form of cognitive impairment. No participants had unilateral spatial neglect. Scores on the TOPF ranged from 23–59.

Rivermead Behavioural Memory Test and Test of Everyday Attention. Figure 7.2 shows participants' performance across the four time points on the memory and attention subtests that were targeted in the intervention. Time 1 is the start of the baseline phase, Time 2 is at the end of baseline, Time 3 is at the end of the intervention and Time 4 is at the end of the follow-up phase. Percentile scores for the RBMT-3 were rounded up to the nearest whole number and the mean percentile scores for the TEA are given instead of the range. This shows, with the exception of a small number of participants on selected sub-tests, that performance on the memory and attention tests was poor. The majority of participants achieved scores at each time point that were or below the 20th percentile rank. Others achieved scores within or below the 40th percentile indicating that they had memory and attention difficulties.

Table 7.1

Participant Demographics (MoCA score ≥ 26 is considered normal. Line-bisection score > 6 mm indicates presence of neglect and a higher TOPF score reflects higher premorbid intelligence)

P	Sex	Age (years)	Education (years)	Employment	Marital Status	Time Since Stroke (months)	Stroke Type	Side Affected	MoCA score	LB (mm)	TOPF
1	Male	57	11	Retired	Married	67	Ischaemic	Left	25	5.1	35
2	Female	76	NR	Retired	Widowed	69	Ischaemic	Left	27	3.2	46
3	Male	67	10	Retired	Married	79	Ischaemic	Left	25	3.5	38
4	Female	67	15	Retired	Married	212	Ischaemic	Left	18	4.0	23
5	Female	70	11	Retired	Widowed	62	Ischaemic	Left	21	2.7	40
6	Male	63	13	Retired	Married	134	Ischaemic	Left	20	1.8	48
7	Female	38	17	Employed	Single	125	Ischaemic	Left	26	1.8	59
8	Female	49	19	Retired	Single	197	Unknown	Right	25	1.3	58
9	Female	33	11	Unemployed	Single	17	Ischaemic	Left	25	2.9	30
10	Female	81	10	Retired	Widowed	51	Haemorrhagic	Left	19	2.6	48
11	Male	59	10	Retired	Married	30	Haemorrhagic	Right	18	5.9	32

Note: MoCA = Montreal Cognitive Assessment, LB = line-bisection, TOPF = Test of Premorbid Functioning

Figure 7.1

RBMT-3 and TEA Subtest Percentile scores at Times 1, 2, 3 and 4 for P1-P4

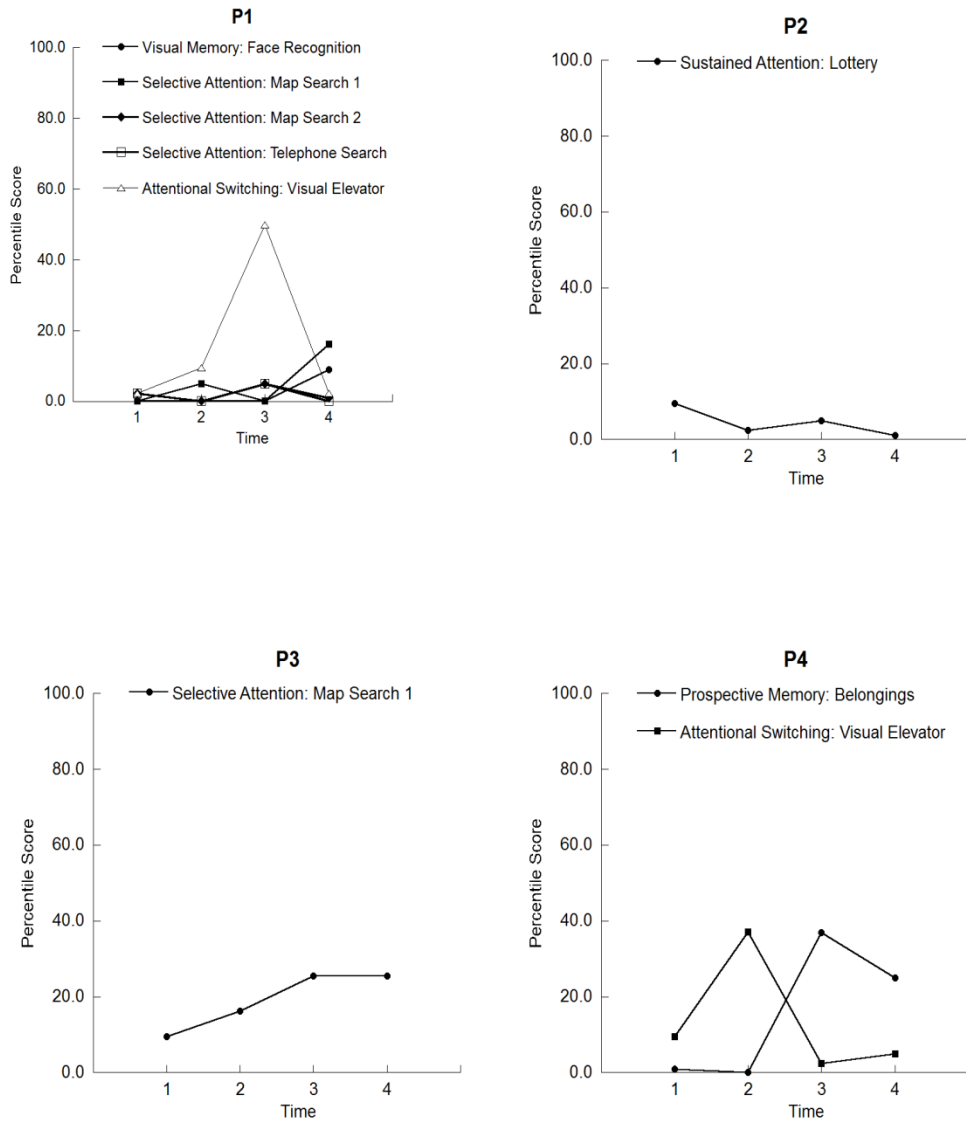


Figure 7.1 continued

RBMT-3 and TEA Subtest Percentile Scores at Times 1, 2, 3 and 4 for P5-P8

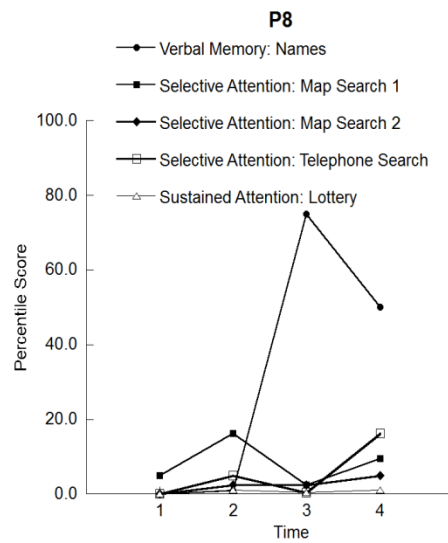
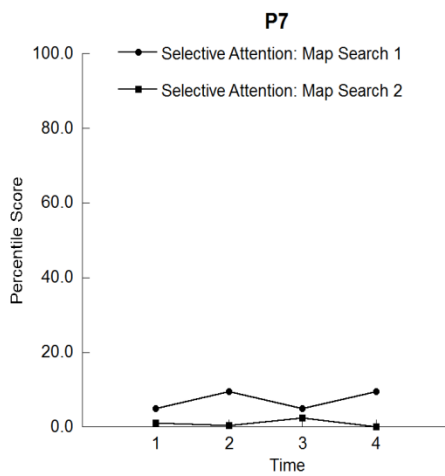
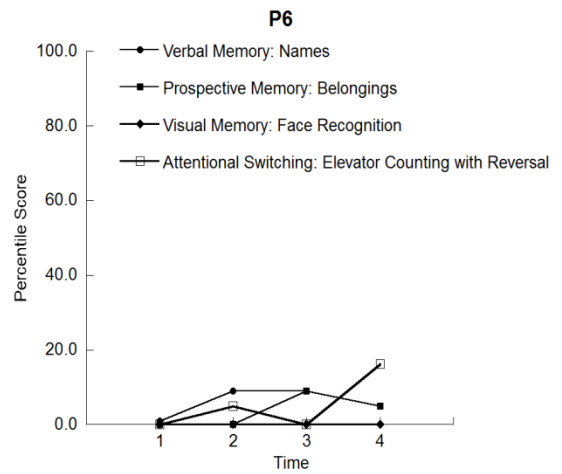
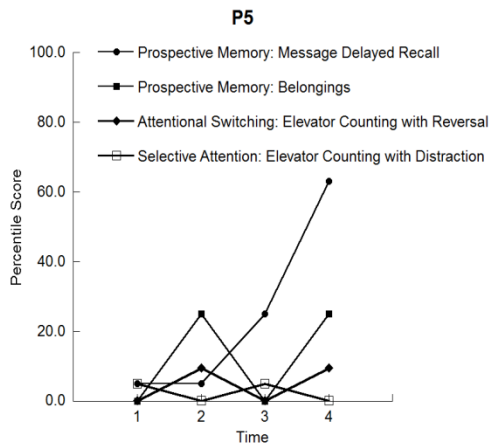
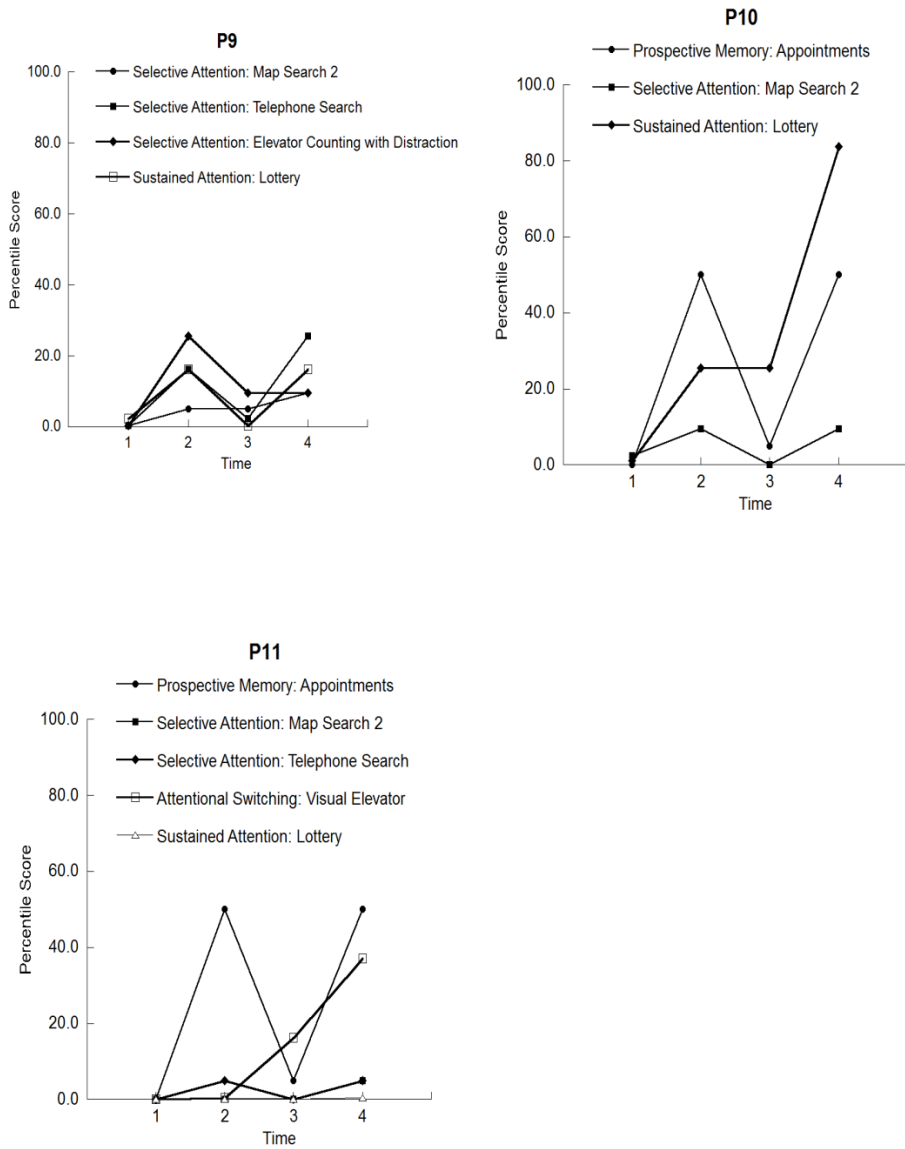


Figure 7.1 continued

RBMT-3 and TEA Subtest Percentile Scores at Times 1, 2, 3 and 4 for P9-P11



Self-Report Measures. The EMQ-R, the BDI-II, the anxiety subscale of the DASS and the PSQI scores are shown in Table 7.2. With all four questionnaires, an increase in score indicates more reported symptoms/higher severity. These data showed that five out the 11 participants had poorer memory in comparison to the normative scores obtained by the stroke sample. Four participants had poorer memory than healthy controls and two participants reported better memory than the mean for the healthy controls. Similarly, five participants self-reported attention difficulties greater than the normative stroke sample, five participants obtained scores lower than the stroke sample but higher than healthy controls and one participant self-reported less attention problems than healthy controls.

On the BDI-II, four participants reported minimal depression, four reported minimal/mild depression, one reported depressive symptoms in the minimal/moderate classification and two reported moderate/severe depressive symptomology. In relation to the anxiety subscale of the DASS, seven participants reported minimal levels of anxiety, two reported normal/moderate levels of anxiety, one participant reported mild/moderate levels of anxiety and one participant reported extremely severe anxiety symptoms.

In terms of sleep quality, five participants reported poor sleep quality at each measurement point, three reported good sleep quality and three participants fluctuated between good and poor sleep throughout the study (Table 7.2).

Table 7.2

Everyday Memory Questionnaire Scores at Times 1, 2, 3 and 4

EMQ-R														
P	Memory							Attention						
	T1	T2	T3	T4	T2-T1	T3-T2	T4-T3	T1	T2	T3	T4	T2-T1	T3-T2	T4-T3
1	3	3.1	3.7	2.4	.1	.7	-1.3	1.8	1.3	2.3	1.3	-.5	1	-1
2	1.3	2	1.4	1.9	.7	-.6	.5	1	0.8	0.3	0.5	-.2	-.5	.2
3	2.7	2	0.3	1	-.7	-1.7	.7	1.3	1	0.3	0	-.3	-.7	-.3
4	0.7	0.6	0.1	0.4	-.1	-.5	.3	0.8	0.5	0.5	0	-.3	0	-.5
5	2	1.4	1.7	1	-.6	.3	.7	0.6	0.8	0.5	0.8	.2	-.3	.3
6	3.4	3.4	3.4	3.6	0	0	.2	3	4	0.8	3.3	1	-3.2	2.5
7	0.9	1.3	2.1	0.9	.4	.8	-1.2	1.3	1.3	3.3	2.3	0	2	-1
8	2.1	1.4	1.7	2.3	-.7	.3	.6	1.8	1	1.3	1.5	.8	.3	.2
9	3	4	1.1	3	-1	-2.9	-1	4	4	0.8	2	0	-3.2	1.2
10	2.3	2	3.1	2	-.3	1.1	-1.1	2.3	1	2.5	0.8	-1.3	1.5	-1.7
11	0.3	0	0	0.1	-.3	0	-.2	0.3	0	0	0	-.3	0	0

Note: EMQ-R scores have been rounded to 1 decimal place

EMQ-R Memory: Stroke sample mean = 1.8, healthy controls mean = 0.9; EMQ-R Attention: Stroke sample mean = 1.3, healthy controls mean = 0.6 (Royle & Lincoln, 2008)

Table 7.2 continued

Beck Depression Inventory-II and Anxiety Subscale of the DASS at Times 1, 2, 3 and 4

P	BDI-II							DASS						
	T1	T2	T3	T4	T2-T1	T3-T2	T4-T3	T1	T2	T3	T4	T2-T1	T3-T2	T4-T3
1	15	11	8	12	-4	-3	4	0	0	2	2	0	2	0
2	13	18	18	12	5	0	-6	4	2	2	4	-2	0	2
3	16	12	7	6	-4	-5	-1	8	12	4	6	-4	-8	2
4	6	7	9	5	1	2	-4	2	4	0	0	2	-4	0
5	17	12	14	11	-5	2	-3	6	8	8	14	2	0	6
6	8	10	4	6	-2	-6	2	0	0	0	2	0	0	2
7	10	8	9	5	-2	1	-4	0	0	0	0	0	0	0
8	22	14	10	12	-8	-4	2	6	4	6	4	-2	2	-2
9	27	32	19	NR	5	-13	-	8	10	14	14	-2	4	0
10	27	32	33	30	5	1	-3	24	20	22	24	-4	2	2
11	2	4	1	3	2	-3	2	2	0	0	0	-2	0	0

Note: BDI-II – minimal 0-13, mild 14-19, moderate 20-28, severe 29-63, NR= not recorded

DASS Anxiety subscale – normal 0-7, mild 8-9, moderate 10-14, severe 15-19, extremely severe 20+

Table 7.2 continued

Pittsburgh Sleep Quality Index Scores at Times 1, 2, 3 and 4

PSQI							
P	T1	T2	T3	T4	T2-T1	T3-T2	T4-T3
1	6	5	4	5	-1	-1	1
2	10	11	8	9	1	-3	1
3	4	5	5	4	1	0	-1
4	9	11	7	6	2	-4	-1
5	6	6	10	7	0	4	-3
6	3	2	2	2	-1	0	0
7	2	0	1	1	-2	1	0
8	10	10	7	8	0	-3	1
9	11	16	8	14	5	-8	6
10	4	5	6	5	1	1	-1
11	2	2	1	0	0	-1	-1

Note: scores < five are indicative of good sleep quality, scores > than five indicate poor sleep quality

Change Over Time of Performance on Neuropsychological Tests and

Questionnaire Scores. In terms of performance on the neuropsychological tests, no consistent patterns emerged across Times 1, 2, 3 and 4. In particular there was lack of stability in the data over the baseline phase. Only the memory and attention domains that were targeted in the intervention are displayed in Figure 7.1, however, all participants completed the full test battery of the RBMT-3 and the TEA to allow for the same testing procedure to be carried out at each time point. Difference testing across the four time points was carried out on all the neuropsychological subtest scores using a Related Samples Wilcoxin Signed Rank Test. The tests revealed a significant difference between Time 3 and Time 4 on the visual memory subtest (picture recognition). Participants' scores on this subtest were significantly higher at Time 4 ($Mdn = 63$, mean = 58) than at Time 3 ($Mdn = 63$, mean = 46), $z = -2.0$, $p <$

.05, $r = -.60$). Difference testing on the remainder of the neuropsychological tests was non-significant ($p > .05$).

Regarding questionnaire scores, there was fluctuation across the time points for most of the participants. Between Time 1 and Time 2, which was at the start and end of the baseline phase, only one participant reported the same symptom severity on the memory questionnaire, two participants on the attention and anxiety questionnaire and three participants reported no change on the sleep quality measure.

From Time 2 to Time 3, which was the end of the baseline phase and end of the intervention phase, six participants reported lower symptom severity on the depression and sleep quality measures, five reported less attention difficulties, four participants reported less memory difficulties and two participants reported lower anxiety symptoms. The remainder of the participants reported either no change or symptom severity got worse.

From Time 3 to Time 4, which was from the end of the intervention to the end of the follow-up phase, six participants reported less depressive symptom severity, five participants reported less memory, attention and sleep quality symptoms and one participant reported lower anxiety symptoms.

Difference testing across the four time points was also carried out on the questionnaire scores using a Related Samples Wilcoxin Signed Rank Test. All test results were non-significant ($p > .05$).

Correlations between Neuropsychological Test Performance and Self-Report Measures. To assess for association between objective memory and attention and self-reported memory and attention measured by the EMQ-R, Spearman's correlation analyses were carried out. The results revealed a significant

association at Time 1 between novel learning and self-reported attention ($r = -.61, p < .05$), and at Time 2, there was a significant relationship between visual memory and self-reported memory ($r = -.84, p < .05$) and self-reported attention ($r = -.70, p < .05$). At Time 4, prospective memory was significantly associated with self-reported attention ($r = -.68, p < .05$) indicating better performance on this subtest was also associated with less attention difficulties. All other associations were non-significant ($p > .05$). The findings reiterate that there appears to be a discrepancy between psychometric memory and attention test performance and the memory and attention difficulties reported by stroke survivors. Reasons for the discrepancies have been noted in Chapter Five.

Spearman correlations were used to assess if mood, anxiety and sleep quality scores were associated with neuropsychological test outcomes. At Time 2, there was a significant association between prospective memory and mood ($r = .65, p < .05$), novel learning and mood ($r = .73, p < .05$) and visual memory and anxiety ($r = .70, p < .05$) indicating that when performance on these subtests was high stroke survivors reported worse mood and anxiety levels. At Time 3, there was a significant correlation between visual memory and mood ($r = .86, p < .05$), anxiety ($r = .74, p < .05$) and sleep quality ($r = .72, p < .05$) indicating that higher performance on this subtest was associated with more reported mood and anxiety difficulties and poorer sleep quality. There were no significant associations on the remainder of the variables ($p > .05$). Similar to what was found in Chapter Five; it appeared that levels of mood, anxiety and sleep quality had not globally and consistently influenced test performance. Further associations between self-reported memory, attention, mood, anxiety and sleep quality using IATP are presented later.

Number of Steps Walked. Table 7.3 shows the daily average steps measured using the activPAL. The daily average steps were calculated from day 2 to day 7 so there was a continuous period of wear that was standard across participants. Out of the seven participants who wore the activPAL continuously at each time point, five increased their step count from Time 1 to Time 2 and two decreased. Four participants increased their steps and three decreased between Time 2 and Time 3. Only one participant increased their steps between Time 3 and Time 4, the remaining six had decreased. Table 7.4 shows a comparison between pedometer and activPAL daily average steps at the end of the baseline phase (Time 2), at the end of the intervention (Time 3) and at the end of the follow-up phase (Time 4). A comparison between pedometer and activPAL steps could not be carried out at the start of the baseline phase (Time 1) as participants started wearing the pedometer from week 2 onwards.

There is also a slight discrepancy between the activPAL steps detailed in Tables 7.3 and 7.4. This is due to matching activPAL steps to the days that the pedometer was worn, and because participants were asked to remove their pedometer before bed, whilst the activPAL recorded steps. Therefore steps taken at night recorded with the activPAL were not included. Due to ill-health P2 did not wear the activPAL at Time 4 and for some participants there was not continuous wear of the monitor due to it falling off.

Table 7.3

activPAL Daily Average steps at Times 1, 2, 3 and 4

	T1	T2	T3	T4
P	Daily Average	Daily Average	Daily Average	Daily Average
1	2,484	4,070	3,406	2,762
2	4,781	6,226	5,717	-
3	6,126	7,402	9,276	7,379
4	2,256	1,151*	2,887	3,163
5	6,169	6,449	8,004	14,120
6	3,564	2,878	3,910*	3,518
7	8,479	7,302	8,819	6,971
8	11,178	13,859	12,746	9,757
9	2,818	1,611*	848*	1,588
10	8,416	8,371	7,885	6,456
11	2,475	3,753	4,437	2,946

Note: * activPAL not worn continuously due to it falling off

Table 7.4

Comparison between Daily Average Pedometer and activPAL Steps at Time 2, 3 and 4

(pedometers were not worn with activPAL's simultaneously at Time 1 thus comparisons are given for each time point thereafter)

P	Pedometer			activPAL		
	T2	T3	T4	T2	T3	T4
1	2,283	5,076	2,597	4,065	3,368	2,741
2	3,238	3,265	-	6,201	5,699	-
3	5,511	6,665	5,987	7,304	9,191	12,186
4	608	1,591	1,209	1,148	2,882	3,160
5	6,082	7,349	12,887	6,397	8,006	14,114
6	2,454	5,423	2,672	2,822	3,767	3,495
7	6,255	7,810	7,825	7,279	8,803	6,941
8	14,145	11,947	8,400	13,786	12,694	9,708
9	214	1,073	-	1,611	833	-
10	3,755	4,117	2,818	8,370	7,867	6,382
11	1,060	1,246	579	3,751	4,431	2,943

Note: There was no activPAL data recorded at follow-up for P2 and P9 therefore pedometer data has not been entered for these time points

Table 7.4 shows that for most of the participants, at each study phase, the pedometer step counts were lower than those recorded by the activPAL. Several reasons may account for this. Firstly, the pedometer may not have captured steps if the participant had a slow walking speed as research has shown that steps are not recorded for speeds that are less than 0.5 m/s (Carroll et al., 2012). Secondly, there may have been non-compliance of continuous wear of the pedometer from the point of getting dressed in the morning until bedtime, and thirdly although participants were asked to record the step count just prior to retiring to bed they may have recorded the data earlier on in the evening therefore providing an inaccurate reading of steps taken.

Memory and Attention Games Played Whilst Walking. The average number of memory and attention games that participants played whilst walking throughout the intervention and follow-up phase are shown in Table 7.5.

Table 7.5

Average Number of Memory and Attention Games Played Whilst Walking during the Intervention and Follow-Up Phase for all Participants

P	Intervention		Follow-up	
	Weekly Average	Total Games	Weekly Average	Total Games
1	1.8	14	2.3	18
2	1.5	12	1.4	11
3	4	32	4.4	35
4	2.4	19	2.6	21
5	3.3	26	2.6	21
6	1.9	15	0.6	5
7	3.1	25	2.9	23
8	1.1	9	0.1	1
9	0.9	7	0.4	3
10	3.1	25	2.6	21
11	1.3	10	0.1	1

All participants were able to incorporate the memory and attention games into their walks throughout the intervention phase and this was largely maintained during the follow-up phase. Overall, for five participants there was a decrease in steps and games from the intervention to the follow-up phase (P6, P7, P8, P10 and P11), an increase in both steps and games for two participants (P3 and P4), an increase in steps and decrease in games for P5 and a decrease in steps and an increase in games for P1.

Diary Data: Growth Curve Analysis. Prior to the individual analyses, growth models were fitted to determine whether there were significant changes of memory, attention and walking over time for the group as a whole. Separate growth models were fitted at the baseline, intervention and follow-up phase and then a model was applied combining all three phases together.

A significant quadratic trend emerged for walking at baseline ($F = (1, 590.01) = 3.88, p < .05$) and at follow-up ($F = (1, 488.01) = 3.88, p = .05$). A significant cubic trend ($F = (1, 1145.00) = 8.09, p < .01$) also emerged for walking across all three phases. None of the other models reached significance. It is not surprising that the remainder of the growth curve models were non-significant given the variability in the data.

Individual Analysis of Temporal Processes (IATP). Analyses were then carried out to assess for relationships between self-reported memory, attention, mood, anxiety, sleep quality and walking. In the daily diaries, participants were asked to self-report their memory for names, faces and objects, remembering to do things and remembering information. They were also asked to rate their attention for being able to do two things at once, to change topics and to concentrate over a period of time. From this, one memory and one attention item were chosen for analysis. These were chosen based upon the domain targeted for the intervention. When more than one domain was targeted the one with the lowest score on the neuropsychological tests at baseline was used.

Missing data were imputed as in Chapter Five. This ranged from zero to 25% for memory, attention, mood, anxiety and sleep quality. For the pedometer the range was zero to 27% and for the games zero to 35%. Data were pre-whitened to remove the presence of autocorrelation and was then exported into SPSS (Version 19) for cross-correlation analyses and multiple regression modelling.

Concurrent relationships and lags between +1 and -1 were examined. This captured the extent to which current memory and attention were influenced by, or

were influencing mood, anxiety, sleep quality and number of steps over a 24 hour period. An example of the output from this analysis for P5 is displayed in Table 7.6.

Table 7.6

Cross-Correlations and Associated Lags between Memory, Attention, Mood, Anxiety, Sleep Quality and Steps at Baseline, Intervention and Follow-Up for P5

P5	Baseline			Intervention			Follow-up		
	-1 lag (<i>SE</i>)	CC (<i>SE</i>)	+1 lag (<i>SE</i>)	-1 lag (<i>SE</i>)	CC (<i>SE</i>)	+1 lag (<i>SE</i>)	-1 lag (<i>SE</i>)	CC (<i>SE</i>)	+1 lag (<i>SE</i>)
Memory & Attention	.09 (.14)	.40 (.14)*	.20 (.14)	.06 (.14)	.12 (.14)	-.14 (.14)	-.05 (.14)	.36 (.14)*	.03 (.14)
Memory & Mood	.03 (.14)	.42 (.14)*	.16 (.14)	-.03 (.14)	.30 (.14)*	-.05 (.14)	-.00 (.14)	.34 (.14)*	-.06 (.14)
Memory & Anxiety	.02 (.14)	.53 (.14)*	-.03 (.14)	-.02 (.14)	.22 (.14)	.01 (.14)	.05 (.14)	.24 (.14)	.14 (.14)
Memory & Sleep	.29 (.14)*	-.10 (.14)	.04 (.14)	.14 (.14)	.18 (.14)	.01 (.14)	.05 (.14)	.14 (.14)	.07 (.14)
Memory & Walking	.08 (.14)	.01 (.14)	.14 (.14)	.11 (.14)	.32 (.14)*	-.03 (.14)	.09 (.14)	.01 (.14)	-.05 (.14)
Attention & Mood	.15 (.14)	.31 (.14)*	.32 (.14)*	-.15 (.14)	.32 (.14)*	-.10 (.14)	.10 (.14)	.44 (.14)*	-.19 (.14)
Attention & Anxiety	.12 (.14)	.34 (.14)*	.29 (.14)*	-.03 (.14)	-.01 (.14)	-.16 (.14)	.05 (.14)	.19 (.14)	-.03 (.14)
Attention & Sleep	.17 (.14)	.14 (.14)	.08 (.14)	-.06 (.14)	-.03 (.14)	.17 (.14)	.11 (.14)	.17 (.14)	.25 (.14)
Attention & Walking	.17 (.14)	.06 (.14)	.09 (.14)	-.03 (.14)	.24 (.14)	-.34 (.14)*	-.12 (.14)	-.02 (.14)	-.11 (.14)
Walking & Mood	-.11 (.14)	.31 (.14)*	.07 (.14)	.04 (.14)	.52 (.14)*	-.14 (.14)	.01 (.14)	.21 (.14)	.05 (.14)
Walking & Anxiety	-.08 (.14)	.14 (.14)	.18 (.14)	.01 (.14)	.30 (.14)*	.11 (.14)	-.21 (.14)	-.11 (.14)	.01 (.14)
Walking & Sleep	.06 (.14)	.14 (.14)	.15 (.14)	.30 (.14)*	.12 (.14)	.01 (.14)	.15 (.14)	-.06 (.14)	.08 (.14)

Note: CC = cross-correlations, SE = standard error

* = significant cross-correlations

The variables that were significantly cross-correlated were entered into separate regression models to predict memory, attention and number of steps. Separate models were run for each phase. An example of this for P5 is shown in Table 7.7. For the baseline phase, a walking model was not fitted due to non-significant cross-correlations between walking and the other variables. For the intervention phase, no significant predictors emerged in the memory model, and although mood was a significant predictor of attention, the overall model was non-significant. For the follow-up phase, there were no significant predictors of memory and a walking model could not be fitted at the follow-up phase due to non-significant correlations between walking and the other variables.

Table 7.7

Significant Models from the Multiple Regression Predicting Memory, Attention and Steps for P5 at the Baseline, Intervention and Follow-Up Phase (non-significant models are not shown)

P5	Baseline			Intervention			Follow-up								
	Memory			Attention			Walking			Attention					
	B	SE	B	B	SE	B	B	SE	B	B	SE	B			
Con	1.134	1.074		Con	0.10	2.14	Con	25154.1	12213.6	Con	4.71	.71			
Att	0.19	.09	.25*	Mem	0.47	.20	.34*	Att -1	488.98	985.68	.07	Mem	0.15	.08	.24
Mood	0.06	.13	.07	Mood	0.20	.19	.17	Mem	1009.79	765.91	.17	Mood	0.24	.09	.35*
Anx	0.63	.25	.40*	Mood +1	0.12	.19	.11	Mood	2115.25	685.35	.42*				
				Anx	0.16	.38	.08	Anx	845.76	1073.92	.11				
				Anx +1	0.07	.35	.03	Sleep -1	-198.96	492.77	-.05				

Note: * = $p < .05$

Con = constant, Mem = memory, Att = attention, Anx = anxiety, +1 and -1 = +1 lag and -1 lag

Baseline Phase (P5). Two predictors explained 33% of the variance of memory ($R^2 = .33$, $F(3, 51) = 8.52$, $p = .000$), which were attention ($\beta = .25$, $p = .05$) and anxiety ($\beta = .40$, $p < .05$). This indicates that as attention increased by one unit on the rating scale, memory increased by a quarter of a unit. As anxiety increased by one unit, memory increased by approximately a third of a unit. The attention regression model was also significant with 26% of the variance ($R^2 = .26$, $F(5, 48) = 3.28$, $p < .05$) being explained by memory ($\beta = .34$, $p < .05$) meaning that as memory increased by one unit, attention increased by a third of a unit.

Intervention Phase (P5). The walking model was significant. Mood ($\beta = .42$, $p < .05$) was a predictor of walking explaining 29% of the variance ($R^2 = .29$, $F(5, 48) = 3.94$, $p < .05$) indicating that as mood improved by one unit on the rating scale, there was an increase of 1447 steps.

Follow-Up Phase (P5). The attention model was significant. Mood ($\beta = .35$, $p < .05$) was a significant predictor of attention explaining 24% of the variance ($R^2 = .24$, $F(2, 51) = 8.09$, $p = .001$) indicating that as mood improved by one unit, attention improved by a quarter of a unit.

The same procedure was carried out for all participants. A summary of the regression models for the remainder of the participants is given in Table 7.8. For P1 and P8, no models were fitted for any of the phases due to non-significant cross-correlations between the variables and non-variability in the data. Non-variable data does not allow for missing data to be imputed when using the *R* statistical software package.

Table 7.8

Summary of Multiple Regression Models Predicting Memory, Attention and Walking at the Different Study Phases (X Indicates That a Model Could Not Be Fitted Due to Non-Significant Cross-Correlations between the Variables and Non-Variability in the Data, or There Were No Significant Predictors. Figures in Brackets Denote Significant β in the models, Me = Memory, At = Attention An = Anxiety, Mo = Mood, St = Steps, S = Sleep, + and – indicate lags)

Models	Baseline	Intervention	Follow-up
P2			
Memory	X	At (.35), S (.41) $R^2 = .27$	X
Attention	Me (.31), An (.35), St (-.30) $R^2 = .42$	Me (.29), Mo (.40) $R^2 = .33$	Me (.25), An (.40) $R^2 = .40$
Walking	X	X	X
P3			
Memory	At (.77), Mo +1 (.29), An +1 (-.31) $R^2 = .66$	At (-.24), An (.31), S (.67) $R^2 = .71$	X
Attention	Me (.80) $R^2 = .65$	Me (-.43), Mo (.46), An (.30), S (.46) $R^2 = .48$	An (.49) $R^2 = .34$
Walking	X	X	Mo (-.35) $R^2 = .14$
P4			
Memory	At (.47) $R^2 = .39$	Mo (.47) $R^2 = .33$	X
Attention	Me (.53) $R^2 = .33$	X	X
Walking	X	X	X
P6			
Memory	X	X	At (.33), An (.26) $R^2 = .20$
Attention	X	X	X
Walking	X	X	S (-.36) $R^2 = .13$

Table 7.8 continued for P7, P9, P10 and P11

Models	Baseline	Intervention	Follow-up
P7			
Memory	X	X	X
Attention	X	X	Mo (.55) $R^2 = .34$
Walking	X	X	X
P9			
Memory	At (.49) $R^2 = .23$	At (.69), An (.20) $R^2 = .63$	Mo (.50) $R^2 = .25$
Attention	Me (.43), Mo (.30) $R^2 = .31$	Me (.74) $R^2 = .60$	X
Walking	X	X	Mo (.36) $R^2 = .12$
P10			
Memory	X	X	Mo (.56) $R^2 = .24$
Attention	X	An (.42) $R^2 = .23$	An (.44) $R^2 = .19$
Walking	X	X	X
P11			
Memory	At (.45) $R^2 = .20$	X	X
Attention	Me (.43), Mo (.30) $R^2 = .28$	X	X
Walking	X	X	X

Note: Me = memory, At = attention, Mo = mood, An = anxiety

X = models were either not fitted due to non-significant cross-correlations between the variables and non-variability in the data, or there were no significant predictors that emerged in the models

Summary. Overall, the models explained between 12% and 71% of the variance in memory, attention and walking and the β values ranged from .19 to .77 with the majority of these values within the .30 to .50 range. In addition, most of the relationships between the predictor and the outcome variables were positive meaning that as one factor improved so did the other. A few relationships did not follow this pattern however. For example, walking negatively predicted attention at baseline for P2 indicating that as walking levels increased self-reported attention deteriorated. For P3 there was negative relationship between memory and anxiety at baseline meaning that as memory improved anxiety levels got worse, at the intervention phase there were negative relationships between memory and attention, and at the follow-up there was a negative relationship between walking and mood indicating that as walking increased mood deteriorated. For P6, there was a negative relationship between sleep quality and walking at follow-up, suggesting that as sleep quality improved levels of walking decreased. Similar negative relationships were evident in Chapter Five suggesting that these relationships are complex and do not uniformly follow the rule that if one domain improves so will another.

Some models could not be fitted due to non-variability in the data. This opens up questions regarding the suitability of the diary method that uses rating scales to capture self-reports from stroke survivors. Making a meaningful judgement as to how one feels about their memory, for example, may be difficult for stroke survivors to do especially if they lack insight and awareness to accurately reflect on their memory performance. Therefore, they may be more inclined to consistently select the same integer on the rating scale.

In a similar vein, some models were not fitted due to a lack of significant cross-correlations between the variables. Mainly, it was walking models that could not be fitted, however, the step counts entered into the regression models may not be accurate due to underestimation and non-compliance of wear. Consequently, it is imperative that pedometers and other physical activity devices measure step counts accurately and consideration is taken regarding the usefulness of such monitors with clinical populations so that the effectiveness of interventions can be properly evaluated.

For the models that were significant, there was some consistency across the phases. For example, for P2 the attention model was significant at the baseline, intervention and follow-up phase, and for P3 the memory and attention models were significant across the three phases. For P9, the memory and attention models were significant at both baseline and intervention, however at the follow-up phase the attention model became non-significant and the walking model emerged as significant.

For the significant memory and attention models, memory and attention mainly emerged as significant predictors of each other. There are some exceptions to this. For example, for P3 memory and attention did not predict each other at the follow-up phase, for P4 attention did not predict memory at the intervention phase and for P9 and for P10 memory and attention did not predict each other at the follow-up phase.

For the models where memory and attention predicted each other, performance on the neuropsychological tests did not always reflect this. To illustrate, P2 and P3 had difficulty on only one attention domain on the neuropsychological

tests. Their memory performance was above average yet despite this, memory was a predictor of attention for both of these participants. Additionally for P10, memory and attention did not predict each other in the models yet this participant performed poorly on some of the objective memory and attention tests. Thus, as in Chapter Five, performance on neuropsychological tests is not always counterpart to self-reports of memory and attention profiles.

Likewise, the subjective reports of memory and attention difficulties measured by questionnaires were not always consistent with memory and attention as predictors in the regression models. For example, on the memory and attention questionnaire, P4 reported very little memory and attention difficulties yet memory and attention were predictive of each other. In contrast, for P10 memory and attention were not predictive of each other in the regression models yet this participant reported high levels of memory and attention problems on the memory and attention questionnaire.

In terms of mood, anxiety and sleep quality, mood emerged as a significant predictor of memory for four participants, of attention for five participants and of walking for one participant. P9 reported up to severe levels of depression and mood was a significant predictor of memory, attention and walking for this participant. However, despite mood appearing to play a significant role in the prediction of memory and attention in particular, the remainder of the participants reported minimal/mild levels of mood on the depression questionnaire.

Anxiety was a significant predictor of memory and attention for four and three participants, respectively. Of these participants, P3 and P9 reported up to moderate levels of anxiety on the anxiety questionnaire and P10 reported extremely

severe levels of anxiety, whereas P2 and P6 reported normal levels of anxiety. Therefore, although anxiety has been predictive of memory and attention, self-reported anxiety measured by the questionnaire does not always fit in accordance.

Finally, sleep had less impact on the outcomes than did mood and anxiety. Sleep was a predictor of memory for P2 and P3, attention for P3 and walking for P6. Despite this, P3 and P6 reported good sleep quality on the sleep questionnaire, thus the measurement of sleep using sleep questionnaires may not always elucidate the relationships between this construct and memory, attention and walking behaviour.

Feasibility of the Combined Walking and Cognitive Training

Programme. A summary of the findings in relation to the methodological criteria proposed by Bugge et al. (2013) for assessing study feasibility is presented in Table 7.9. A more detailed commentary follows highlighting the issues that would need to be rectified in subsequent research studies.

Table 7.9

Summary of Findings in Relation to the 14 Methodological Issues for Assessing Feasibility

Methodological Issues	Findings	Evidence
1. Did the feasibility study allow a sample size calculation for the main trial?	More participants would be required for other statistical techniques such as MLM.	Eleven participants completed the study which is not sufficient for MLM.
2. What factors influenced eligibility and what proportion of those approached were eligible?	All participants were eligible although issues were identified that would impact on eligibility in subsequent trials.	All participants met the inclusion/exclusion criteria.
3. Was recruitment successful?	Recruitment was difficult due to problems reaching long-term stroke survivors.	Not all stroke organisations were keen to advertise the study. No one came forward as a result of advertising the study via social networking and placing adverts in community organisations.
4. Did eligible participants consent?	All participants who volunteered to take part were eligible to take part.	All participants who volunteered and who were eligible consented.
5. Was the intervention successfully randomized within-person?	Sufficient but issues identified for future studies.	A baseline and a follow-up phase was achieved prior to and following the delivery of the intervention, respectively.
6. Were blinding procedures adequate?	No. Blinding did not take place.	JC carried out all assessments and devised the intervention.
7. Did participants adhere to the intervention?	Participants were able to engage with the walking sessions and cognitive games. Some issues identified with regards to filling in the diaries and pedometer wear.	Participants increased their walking and reported playing the games.
8. Was the intervention acceptable to the participants?	Acceptable to a degree; some issues were raised regarding wear of pedometer and filling in the diaries.	No one expressed dissatisfaction with the 8-week intervention phase but became 'fed up' with filling in the diary.

Note: MLM – Multilevel Modelling

Table 7.9 continued

Summary of Findings in Relation to the 14 Methodological Issues for Assessing Feasibility

Methodological Issues	Findings	Evidence
9. Possible to calculate intervention costs and duration?	Financial costs and time required were calculated but varied due to participant's location.	Financial costs ranged from £48 per person for those living in Glasgow to £144 per person for those living in Stranraer Time required per person for assessments was 24 hours, for walking sessions 16 hours and time for travel per person ranged from 16 hours for participants in Glasgow to 32 hours for those in Stranraer.
10. Were outcome assessments completed?	Outcome assessments were completed but issues identified with the neuropsychological tests, the diaries and pedometers.	All tests were completed but missing data in the diaries and one participant did not complete the BDI-II at the final follow-up.
11. Were outcomes measured those that were the most appropriate?	Issues with the neuropsychological tests were identified and problems identified with self-reporting using paper diaries.	Fluctuation in neuropsychological test performance and response non-variability of diary data.
12. Was retention to the study good?	Eleven of the 15 participants recruited completed the study.	All participants completed their assessments at each time point.
13. Logistics of running a multicentre trial	This was not part of the study but some organisations facilitated recruitment more than others.	Different Stroke: 5 participants Self-funding stroke group in Stranraer: 4 participants Stroke Association: 2 participants.
14. Did all components of the protocol fit together?	Each aspect of the study worked well together but some issues raised in terms of scheduling sessions.	All participants completed each phase of the study and what was required of them.

Sample Size Calculation. The aim of the present study was to analyse the data based on an individual method therefore sample size calculations for a subsequent RCT cannot be calculated. The number of participants recruited was small ($n = 15$) but to apply more advanced statistical techniques such as multilevel modelling more participants would be required; especially to assess for both within and between-person effects, and if there is interest in assessing the effects of other variables on specific outcome measures. The general rule of thumb for assessing predictors in regression models is a minimum of 10 participants per variable (Tabachnick & Fidell, 2006) but preferably more, therefore investigating the effect of mood, anxiety and sleep quality alone on memory and attention would require at least 30 participants.

The number of data points needed for time-series analysis also needs to be sufficient. In the present study, approximately 56 data points were collected per phase but ideally longer phases would be implemented. However, there would need to be consideration of the length of the study and the demands it places on participants. The present study lasted six months and over that period of time participants completed many aspects of the study which required commitment, time and effort. A balance between achieving the aims of the study and potential participant burden needs to be addressed in the first instance.

Eligibility. Eligibility criteria was applied such as age, time since-stroke onset, self-report of memory and attention problems, ability to walk independently and no contraindications to physical activity. In the present study, participants were not approached initially based on their suitability. All participants volunteered and then the eligibility criteria were applied and all who that applied met the criteria.

Recruitment. Recruitment was difficult. Fifteen participants were recruited between February 2012 and March 2013 so one participant was recruited approximately every four weeks. One issue seems to be reaching long-term stroke survivors. Recruitment was not carried out through the NHS, therefore other advertisement methods were used and there was reliance on stroke/head injury organisations and self-help groups. No participants were recruited as a result of placing advertisements on social networking sites and in local community organisations. Therefore, although these strategies perhaps raised awareness of the study, they were ineffective in terms of participant up-take. Additionally, one stroke organisation, which co-ordinates a significant number of self-help groups, refused to advertise the study stating that they felt it was too demanding for stroke survivors indicating that there would be potential concerns over participants' involvement in the study.

Consent. Participants volunteered to take part in the present study indicating that they were initially motivated to participate therefore gaining consent was not an issue.

Randomization Procedures. In individual-based studies participants act as their own control with the use of a baseline phase so that the effects of an intervention can be compared. This was achieved in the present study but using pedometers and the diaries at the baseline phase is, in part, intervening on normal behaviours. However, the outcomes need to be measured in some manner to determine possible change over time so an uninfluenced baseline phase is unlikely to be achieved in studies such as this. In addition, cognitive and behavioural change strategies were part of the intervention therefore there cannot be a withdrawal phase

per se following the intervention, so the final phase was more of a retention phase. What is more, there are potential health benefits to be gained from physical activity; it would be unethical to ask participants to stop doing an activity that is effectively good for them. The randomization of the intervention in future studies is unlikely to be an issue but one should bear in mind the influences on behaviour noted.

Blinding Procedures. All assessments, walking sessions and cognitive games were carried out by JC therefore no blinding was achieved. In subsequent trials where a team of researchers are involved procedures would need to be applied to achieve blinding so the internal validity of the study is not compromised.

Adherence to Intervention. Some participants engaged more with the walking and game sessions than others which was evident by the number of steps walked and the number of games the participants played. A couple of participants did not walk every week due to the onset of tendonitis of their foot reducing their ability to go out walking despite wanting to.

Some issues were evident in relation to adherence of diary completion. Some participants failed to complete diary entries each day. There was more missing data on number of games played in comparison to the recording of number of steps walked or ratings on the other constructs. Furthermore, some participants expressed that if it was not for their caregiver reminding them to fill in their diaries they would have forgotten to do so. Thus, the traditional paper method of the daily diary may be more suitable for stroke survivors who have live-in caregivers. For those who do not, the use of personal digital assessment tools that prompt participants with reminders may be more suitable.

There were also issues with both the pedometer and the activPAL that were used in the studies of this thesis. Some participants with upper-limb hemiparesis/hemiplegia or sensory impairments had difficulty attaching the pedometer to their waistband. The participants expressed that at times this made them feel frustrated and they had to rely on their caregiver attaching and removing the pedometer for them. Although there are other pedometers now available that can be worn in different locations such as around the neck, these need to be validated especially in a stroke population where gait and walking speed can be affected.

For most participants there were no issues with the wear of the activPAL. However, for others there were complaints of skin irritation and of the monitor falling off following activities such as bathing, and reports from one participant that he was having nightmares that the monitor was causing leg pain leading to sleep disruption.

Acceptability of Intervention. The low recruitment rate and the non-support from a stroke organisation perhaps indicate that the study was too demanding. However, of the participants that took part, all managed to adhere to the study indicating that the intervention was acceptable. Though, the continuing contact between participants and JC is likely to have contributed to adherence.

The walking sessions were, on the whole, enjoyed by the participants. They reported that they were keen to go out walking but expressed that they were more likely to go walking with JC assisting them or having someone walk with them rather than walking on their own. One participant mentioned that she would only go out walking on her own if she had a purpose to go out, for example to go to the shops.

Likewise, the games were acceptable but again some issues were noted. Some games were ‘two player games’ meaning that they could only be played if the participant was assisted on a walk by either JC or a significant other. For example, the ‘I Spy’ game, which was played as a game to try and improve selective attention, was only suitable when there were two people playing it. Thus, when participants walked on their own they were limited to a small selection of games and because of this some expressed that they felt at times that the games were tedious. Enjoyment of activities is one factor likely to lead to adherence of them therefore it is important that interventions aimed to improve cognitive functioning are designed with this in mind.

The RBMT-3 and the TEA, generally, were completed by all participants but an issue, specifically with the sub-test Elevator Counting with Reversal, raised concerns. A number of participants expressed that this test made them feel stressed and agitated. One participant had said that he had been worrying about this test in the days leading up to JC visiting. The effect this task potentially has on participants’ well-being and test performance needs to be taken into consideration and evaluated as to whether a measure of attentional switching should be taken at the expense of how participants feel and the effect it could have on them.

Cost and Duration of the Intervention. The financial cost and time required to deliver the testing and walking sessions was calculated (see Table 7.9).

Participants lived in Glasgow, Edinburgh and Stranraer. In an attempt to reduce costs, especially for those who lived in Edinburgh and Stranraer, JC attempted to schedule a couple of participants at each visit. This was managed for most visits, but

at times participants rescheduled for a number of reasons contributing to an increase in costs.

Outcome Assessment. Overall, all outcomes were completed. There were issues with testing, diary completion and pedometer wear which have been mentioned above under the adherence section.

Selection of Most Appropriate Outcomes. There is no general agreement as to how best to measure cognitive functions, therefore, the decision was made for neuropsychological tests to be supplemented with subjective reports. There are many tests of memory and attention however the RBMT-3 and TEA are batteries of tests that measure different types of these cognitive functions. They have also been validated on stroke populations and are promoted as measures of everyday memory and attention functioning. Similarly, there are many questionnaires measuring the constructs that were investigated in this study but the ones used in the present study, excluding the PSQI, were chosen as they have been used in previous studies on stroke survivors.

Retention. Eleven of the 15 participants recruited completed the study. Four participants dropped-out prior to the intervention phase as a result of not being able to adhere to study requirements which again indicates that a study of this nature is not suitable for everyone, particularly those whose have a lot of competing demands in their lives.

Logistics of Multicentre Trial. A multicentre trial was not part of the study therefore is not part of the assessment. However, in terms of assistance from stroke organisations, some stroke charities facilitated recruitment more so than others

indicating that there may be difficulties in recruiting a larger sample in subsequent studies.

All Components of the Protocol Work Together. The study was complex involving both methodological and practical issues. Each aspect worked well on the whole and the progression of the study flowed adequately. At times however, when several participants were active in the study there was some difficulty scheduling sessions to suit participant needs and requests. This was achieved but an element of flexibility was required to be able to do so.

Methodological Quality of the Present Study Assessed by the SCED Scale. Although the above on the feasibility of the study has been provided, the SCED scale (Tate et al., 2008) was also used for the present study as this scale evaluates individual-based studies. The study achieved a score of 7 out of 10. The three criteria that were not met was inter-rater reliability of at least one target behaviour, independence of assessors and evidence of generalisation beyond the intended measures. As this piece of research was conducted as part of a doctoral thesis it is understandable why inter-rater reliability and the use of different investigators was not adopted. JC carried out all the assessments, developed the games and assisted on the walking sessions. In terms of generalisation, the aim of the study was to assess changes in the particular outcomes specified, i.e. memory, attention and walking, not explore possible effects of the intervention beyond them.

7.4 Discussion

This is the first study to implement an intensive, tailored combined walking and cognitive training programme to improve memory and attention functioning in stroke survivors. A number of feasibility issues have been identified that would need

to be rectified in subsequent research studies. The issues include sample size, eligibility, recruitment, randomization of intervention, blinding, adherence to study requirements, acceptability of intervention, financial and time costs and most appropriate outcomes to measure. As a result of these issues, it has been concluded that the intervention, as it stands, would not be feasible. Several substantial amendments would have to be made and subsequently tested prior to the application of a similar intervention delivered within the clinical context. Some of the most problematic ones are detailed below.

A larger sample size would be required which may be a problem in a real world context. The issues of eligibility and recruitment is discussed subsequently, but having a greater sample size would allow for the investigation of the effects of influences on memory and attention functioning which should be part of research studies as this thesis has shown that mood, anxiety and sleep quality are associated with these cognitions. Additionally, a larger sample of participants would permit the application of advanced statistical techniques.

Eligibility was not an issue for the present study as participants who felt they matched the inclusion/exclusion criteria volunteered to take part but amendments would need to be made for subsequent application of the study. In the present study participants self-reported that they had a stroke but, ideally, medical records would be consulted to determine more specific details about the stroke and rehabilitation participants received following the insult and to determine who would be eligible to take part. The question is who would do this. JC was involved in a research project that tested the feasibility of a walking intervention for older adults who were recruited via a GP practice. A GP on the trial examined all medical records to

determine who was eligible but it was reported during a post-study interview that this was an onerous process and time-consuming.

Recruitment was an issue in the present study and would likely be an issue in the real world. It is not clear why recruitment was difficult but previous research has shown that if a study is recommended by a health professional then stroke survivors are more than likely to take part in the research (Lloyd et al., 2010). This means that the context of the trial would need to be changed to one that involved input from doctors or stroke nurses who would promote the study to facilitate recruitment. However, health professionals' time is already comprised and GP's may not be willing to devote some of their time for a research project. It may be that having a stroke research nurse involved would be more suitable in this circumstance.

As well as changing the context, the trial design may need to be amended to aid recruitment if the perception has been that the study was too demanding. By reducing the demands on stroke survivors will likely benefit retention. Some participants in the present study reported that the length of the study was too long and it became tedious having to fill in the diaries every day and record step counts. A shorter study would perhaps be more appealing but this has to be decided against having a physical activity and cognitive intervention of sufficient length that will have a positive effect on cognitive functions. Currently, for a stroke population this is unknown making it difficult to decide how long the intervention should be but previous research with healthy older adult has shown that physical activity participation of one-month or longer is beneficial for cognitive health (Colcombe & Kramer, 2003). Therefore, reducing the intervention length for a study in the real world is a viable option.

In the present study, eligible participants went on to consent which is likely due to participants volunteering to take part in the study indicating they were motivated to do so. However, in the real world, particularly in the clinical context, potential participants would likely be approached, thus the conversion of number approached to number who consent may be somewhat different. This would need to be tested in subsequent studies and reasons for non-consent investigated.

Another issue that was highlighted was that JC was not blinded in the present study. This would need to be amended for a study in the real world but can be achieved but would require resources. In addition, acceptability of the intervention would need to be amended. This is particularly so for the real world where there is a need to know that the intervention is tolerable as it will likely impact upon adherence. Some participants, particularly those who lived alone and did not come in to contact with many others, expressed that they had difficulty with the ability of rating how good or poor their memory had been, or if their mood was low or not. They felt that had they been interacting with others on a regular basis they might have a better indication of their memory and attention functioning and so on. If they had forgotten to do something there was not a significant other informing them of this so it may have gone unnoticed. This would have likely impacted upon how they provided a rating of the phenomena under investigation.

Participants in the present study also expressed some issues with walking on their own therefore a buddy system or walking groups may be more suitable for those stroke survivors who feel that the presence of another individual would be of benefit to them. The difficulty is how the cognitive games would be implemented and who would implement them. Some of the games are well known games such as I

Spy, which would likely be easier to incorporate into walking sessions than games that are unheard of.

Other games were difficult to implement especially whilst walking. For example, the RBMT-3 manual recommends that for the rehabilitation of face recognition individuals should pay attention to particular features and try to verbalise the face. This is difficult to do during a walk without having to stop. Therefore, to try and provide a continuous bout of walking participants were shown faces prior to setting off on the walk and asked to concentrate on the eyes, nose, mouth, face shape and hair colour. On their return they were asked to pick from a selection of faces the ones that were previously shown to them. So, this game in particular, was not simultaneously carried out whilst walking. But the more pertinent issue is who would implement such games. The individual would need to have some knowledge of memory and attention functions, of the games and of cognitive-motor interference and distractibility as these factors can increase the risk of falls.

There are also a couple of issues that it is worth noting in relation to the physical activity consultation. Rollnick and colleagues (2005) proposed that the consultation should be delivered using a guiding style rather than a directive one and every attempt was made by JC to deliver the consultation in this way. However, some participants appeared to have lacked the ability to be insightful which JC felt at times led her to adopt more of a leading role in the consultation than perhaps should have been. For example, it is known that stroke survivors experience barriers to physical activity participation (Payne et al., 2001; Rimmer et al., 2008), however, some participants had difficulty suggesting potential barriers that would/could prevent them from increasing their walking, some reported that they did not require

any support from significant others to help them maintain their walking goals, when they indeed needed support, and others had difficulty planning when and where they would go for a walk. When this happened, JC felt that she was providing the examples, mentioning potential barriers and possible sources of support rather than the participants generating their own thoughts on these. Therefore, although the consultation has been successful with other clinical populations, such as those with diabetes (Kirk et al., 2007), the use of it with individuals with brain trauma may not always be suitable particularly if the individual has difficulty with the ability to plan ahead, think about obstacles that may arise or have awareness of problems regarding situations in which they need support.

Furthermore, for a similar study to be implemented in a real world context costs, in terms of both finance and time, would need to be reduced. A higher cost accrued for participants living the furthest from the researcher, thus the intervention would need to be delivered in local areas to where the organisation is located.

The measurement of memory and attention functions would need to be changed also. The results from the present study show variability in test performance over time and that a discrepancy exists between objective and subjective memory and attention performance. The difficulty is deciding how best to measure and monitor cognitive function. As well as making a judgement on tests to use, there would need to be a decision made about the context in which subsequent studies would be implemented. The present study was community based, but if one was considering using multicentre trials the context would need to be changed to a clinical environment and then the effectiveness of this assessed thereafter.

Overall, several amendments would have to be made prior to the delivery of the intervention in a real world context. More feasibility studies would be required, in the first instance, to test the effectiveness of the amendments made and then decisions made thereafter as to the aspects of the intervention that would remain unchanged and those that would change. An iterative process is therefore required that would confidently lead to the delivery of a definitive trial.

Study Findings and Intervention Effectiveness. In terms of increasing walking behaviour, some participants in the present study were able to increase their daily steps with a number of participants walking less than the recommended 7000 steps per day (Tudor-Locke et al., 2011) and others walking more than this. Although previous research has shown that daily steps decreased to baseline levels following a pedometer-based intervention (Mutrie et al., 2004), five participants in the present study were able to maintain a higher step count at follow-up than at baseline. This step increase cannot be attributed to one particular factor; it may be the very act of using a pedometer and monitoring steps, or taking part in a physical activity consultation, or being assisted on walks by JC contributed to the increase.

The present study also shows that for some participants, there was a link between mood, anxiety and sleep quality, and memory, attention, and walking. Therefore, the findings in relation to the effect of these factors on memory and attention, in particular, replicate those in Chapter Five. The present study does however advance the study in Chapter Five by assessing the effect of these constructs on specific memory and attention functions, such as remembering to carry out activities and being able to change topics, rather than treating memory and attention as unitary constructs.

In terms of the findings of the present study, it is difficult to evaluate the effects of the intervention due to fluctuation in performance and scores on the tests and questionnaires. For these reasons, every effort must be maintained to ensure that neuropsychological tests and questionnaires are not solely relied upon in research and in clinical practice to obtain a measure of cognitive functioning or to evaluate the effect of interventions.

Cognitive rehabilitation typically adopts a restitution training strategy or a compensatory one (Cicerone et al., 2005). The memory and attention games participants played in the present study fall into the restitution classification as the aim was to retrain the underlying memory and attention processes. There is some evidence, from both RCTs and case studies, that restitution training can improve memory (Chen et al., 2012; Doornhein & de Han, 1998; Hildebrandt et al., 2006; Thick-Penny et al., 2007; Vallat et al., 2005; Westerberg et al., 2007) and attention functions post-stroke (Barker-Collo et al., 2009; Carter et al., 1988; Gauggel & Niemann et al, 1996; Nordvik et al., 2012; Schottke, 1997; Sturm et al., 1997; Sturm & Willmes, 1991; Weber et al, 1990).

Although there is some evidence, there are difficulties when designing and implementing memory and attention restitution training because there is no guidance available on the type and dose of training stroke survivors should do to improve memory and attention functioning. Previous research studies have incorporated training strategies such as attention process training, computerised working memory training, process oriented training and have used mnemonic strategies. Additionally, the dose of the training sessions, in terms of frequency and duration, has varied.

The memory and attention games delivered as part of the intervention in the present study were therefore different from the types of training previous research has incorporated. This is due to implementing the games whilst participants were walking. In terms of the dose of training, participants in the present study played between one and four games per week whilst walking. The duration of the games was unknown and it is also unknown as to what types of games were played when participants were not assisted by JC, which are limitations of the study.

Similar to cognitive rehabilitation, there is some evidence that physical activity improves cognitive functioning (Colcombe & Kramer, 2003; Cumming et al., 2012; Heyn et al., 2004). With research studies on stroke only populations, however, the evidence is limited as the studies have primarily assessed global cognitive functioning using measures such as the MMSE (Cumming et al., 2012), or positive effects have been found on global cognition but not on specific cognitive domains (Pyun et al., 2009), or no significant effects have been reported (Ploughman et al., 2008).

Additionally, it is unknown the type of physical activity, how often and for how long stroke survivors would need to do in order to improve memory and attention deficits. Like cognitive rehabilitation, there are no recommendations guiding this. Colcombe and Kramer (2003) reported the mode and dose of physical activity that was most beneficial for cognitive functioning, which was strength and aerobic activity carried out for at least one month, with each session lasting between 30 and 60 minutes. However, this research was based on healthy older adults; the findings may not apply to stroke survivors who have sustained brain trauma.

Some participants in the present study increased their walking which is considered an aerobic activity and were able to maintain this over a two month period. However, the intensity of the walking sessions and the duration of walks was not measured, which are other limitations of the study, but it must be remembered that stroke survivors can experience physical deconditioning post-stroke (Rand et al., 2009), and experience other conditions such as spasticity, muscle weakness and fatigue (Lincoln et al., 2012), therefore doing activities that are of a moderate-vigorous intensity for long periods of time may be beyond them.

In summary, this was the first study to test the feasibility of a combined walking and cognitive training programme to improve memory and attention functions in long-term stroke survivors. Both physical activity and cognitive rehabilitation have the potential to improve cognitive functioning in this population, the job is now to fill the gaps in knowledge that this thesis has exposed and make amendments where necessary so that an intervention is designed and delivered that is for purpose.

Chapter Eight

General Discussion

Stroke is the most common cause of severe adult disability with stroke survivors experiencing a significant impact on their physical and psychological health. To date, most research has focused on the rehabilitation of mobility whilst neglecting rehabilitation of psychological health, particularly memory and attention functions. This is concerning as up to 50% and 92% of stroke survivors experience memory and attention problems, respectively (Nys et al., 2005; Hyndman et al., 2008).

Despite a significant proportion of stroke survivors suffering from memory and attention deficits, knowledge of how best to rehabilitate these cognitive functions is limited. Both physical activity and cognitive rehabilitation have the potential to improve cognitive functioning but the problem is it is unknown how to assist stroke survivors to increase their physical activity levels. Additionally, there are no recommendations available, for physical activity and cognitive rehabilitation on the type of activity they should be doing, how long they should be doing it for and how frequent.

As well as overlooking the effects of a stroke on cognitive functioning, the existing research has been slow to investigate the influence of other psychological and behavioural factors on cognition. These factors can be within-person characteristics of the stroke survivors or between-person characteristics of stroke survivors and caregivers. Lastly, studying groups of stroke survivors has taken precedence over studying the individual stroke survivor which is problematic due to heterogeneity.

Aims of Thesis. The present thesis aimed to use an individual-based methodology to investigate memory and attention profiles in long-term stroke survivors, to assess temporal associations between memory and attention, and mood, anxiety and sleep quality in stroke survivors, to assess temporally associated dyadic relationships between stroke survivors' memory and attention and caregivers' mood, anxiety and sleep quality, determine which of the behavioural and psychological factors predict stroke survivors' memory and attention and examine the feasibility of a combined walking and cognitive training programme to improve memory and attention in stroke. Two systematic reviews were also carried out as part of this thesis

Summary of Results. The systematic review of previous research presented in Chapter Three concluded that there was some evidence for memory and attention training improving memory and attention functioning in stroke survivors. Compensatory and mnemonic strategies were beneficial for memory and computerized and attention process training was beneficial for attention. However, the methodological quality of the studies was below average. Problem areas included the lack of sufficient baseline and treatment phase measurements, relying solely on descriptive statistics, the absence of inter-rater reliability checks, independent assessors and the non-support to generalize beyond the main outcome(s).

Chapter Four presented a systematic review of previous research on interventions to increase physical activity and mobility outcomes in stroke survivors concluding that research is needed that evaluates the effectiveness of physical activity interventions to increase overall levels of physical activity in stroke survivors as it unknown how best to do so. All of the studies included in the review aimed to improve mobility outcomes using methods such as treadmill training, cycling,

functional electrical stimulation and robotics and these had relative effectiveness; not all stroke survivors benefitted from the interventions. Consistent with the findings from Chapter Three, the methodological quality of the studies was poor.

A study investigating memory and attention profiles in long-term stroke survivors and explored the temporal associations between memory and attention, and mood, anxiety and sleep quality was presented in Chapter Five. It was found that the stroke survivors performed poorly on the neuropsychological memory and attention tests and self-reported memory and attention problems. However, performance on the neuropsychological tests, in particular, fluctuated across time indicating that performance on these tests is likely influenced by other factors which should be taken into consideration. The study also showed that memory and attention was temporally associated and predicted by mood, anxiety and sleep quality but the patterns of associations and the effects of the predictors differed across stroke survivors highlighting the usefulness of IATP.

Dyadic relationships between stroke survivor and caregiver behavioural and psychological outcomes were presented in Chapter Six. Specifically, the study explored the effect of caregivers' perception of the stroke survivors' memory and attention and caregiver mood, anxiety and sleep quality on stroke survivors' memory and attention. The study showed that half of the stroke survivors recruited experienced low mood, anxiety and were poor sleepers. The findings also showed that stroke survivors' memory and attention was temporally associated with caregivers' perception of the stroke survivors' memory and attention, and caregiver mood, anxiety and sleep quality but, like the findings in Chapter Five, the associations were different for each stroke survivor and caregiver dyad. Despite the

associations, the addition of the caregiver variables did not explain significantly more of the variance in the stroke survivors' memory and attention

The final study was presented in Chapter Seven, which assessed the feasibility of a combined walking and cognitive training intervention to improve memory and attention in long-term stroke survivors. It was concluded that the study was not feasible in its current form. An iterative process of testing subsequent feasibility studies that evaluated amendments made would need to ensue.

Methodological issues such as eligibility, recruitment, blinding, adherence to and acceptability of the intervention and financial and time costs were some of the issues that would need immediate attention. Results also showed that some participants were able to increase their walking and all were able to engage with the cognitive games, and that mood, anxiety, sleep quality and walking predicted memory, attention and walking behaviour but the effects were different across participants. Furthermore, fluctuation of performance on the neuropsychological tests were observed making it difficult to determine the effectiveness of the intervention on memory and attention functioning. Together, these findings resonate with the results obtained in Chapter Five.

Memory and Attention Deficits Post-Stroke. Previous research has shown that stroke survivors experience verbal memory (Duffin et al., 2012), working memory (Sachdev et al., 2004), episodic (Viscogliosi et al., 2011, prospective and retrospective memory deficits (Kim et al., 2009), and problems with sustained, selective and divided attention (Hyndman & Ashburn, 2003; Hyndman et al., 2008). The findings from the studies in this thesis are therefore in line with research in the current literature as many of the stroke survivors also displayed poor performance in

areas such as verbal memory, prospective memory, sustained attention and attentional switching. However, the studies in this thesis advance previous research by investigating memory and attention functions in long-term stroke survivors rather than in the short term, and use batteries of neuropsychological tests instead of focusing on one particular sub-domain. This allows for a more comprehensive grasp of the nature and extent of memory and attention difficulties experienced by stroke survivor who are more than six months post-stroke.

Relationships between Memory, Attention, Mood, Anxiety and Sleep

Quality. The findings from the present thesis also support previous research showing that mood (Dotson et al., 2008; Kauhanen et al., 1999), anxiety (Elliman et al., 1997) and sleep quality (Bloomfield et al., 2010; Kuriyama et al., 2008; Siccoli et al., 2008) affect cognitive processes in stroke survivors, in individuals with TBI and in healthy older adults. However, the findings in this thesis also inform us that the memory and attention processes are separable but related processes, and that influences from the other variables do not uniformly affect memory and attention functions in stroke survivors in the same way. Knowing this is important as memory may be affected by low mood, or memory may be poor as a result of poor attentional abilities, for example. An intervention to improve mood state or attention would therefore be more appropriate than an intervention to improve the memory function, per se.

Cognitive Rehabilitation and Physical Activity Post-Stroke. Typically cognitive rehabilitation studies have been group-based and have focused more on other cognitive functions such as language, perception and spatial neglect than memory and attention (see Cicerone et al., 2000, 2005, 2011; Rohling et al., 2009). Two Cochrane reviews on cognitive rehabilitation for memory and attention in stroke

concluded that there was insufficient evidence to support or refute the effectiveness on rehabilitation for these cognitive functions, thus highlighting the need for more research. Studies adopting an individual method in cognitive rehabilitation studies for memory and attention stroke survivors inform us that certain types of rehabilitation can have a positive effect on these cognitive functions (e.g., Boman et al., 2010; Gauggel et al., 1996; Vallat et al., 2005; Weber, 1990; Wilson, 1982). The effect of cognitive training on memory and attention functions in the present thesis cannot be determined due to not evaluating the effects of the games on their own and problems with the methodology. Thus, it cannot be concluded as to whether the results support previous research or not. In addition, the memory and attention games, although restitution in nature, are very different from the types of cognitive training employed elsewhere. Thus, it would be worthwhile to evaluate the effectiveness of such games in subsequent research studies.

Findings on the relationship between physical activity and cognitive functioning in stroke survivors have been mixed with some studies showing support for the relationship (Pyun et al., 2009; Rand et al., 2010) and others not (Ploughman et al., 2008; Quaney et al., 2009). A meta-analysis reported a small but significant effect of this relationship (Cumming et al., 2012) but most of the studies in this meta-analysis assessed global cognitive function which limits the ability to determine if physical activity affects cognitive domains and their sub-domains differently. This thesis aimed to capture the possibility that physical activity might affect memory and attention differently by administering batteries of neuropsychological memory and attention tests, but for reasons noted above on the issues with the neuropsychological tests, it is unknown if the intervention, which involved increasing walking behaviour,

has had a positive effect on memory and attention in the stroke survivors within this thesis.

Similarly, in the current literature it is not clear if physical activity and cognitive training carried out sequentially improves memory and attention in stroke survivors as the research studies have assessed global cognition or used a composite score for memory, and positive effects were found for treatments delivered on their own (Fabre et al., 1999; Oswald et al., 2006; Pyun et al., 2009). However, simultaneously combining physical activity with cognitive tasks produced a beneficial effect on a verbal task in stroke survivors (Evans et al., 2009). The participants in the Evans and colleagues' (2009) study walked for only two minutes each day over a period of five weeks and positive effects were found on a verbal task. Again, due to methodological limitations it cannot be concluded if the results of the combined walking and cognitive training study in the present thesis support or contradict the findings from previous research.

Strengths, Limitations and Future Directions. Strengths of the present thesis consist of the inclusion of stroke survivors only rather than having participants with mixed aetiology of brain injury, the inclusion of long-term community-based stroke survivors when a lot of emphasis has previously been on stroke survivors in the acute phase of recovery, the inclusion of caregivers alongside stroke survivors as research studies typically focus on either the stroke survivor or the carer, and the delivery of a complex intervention that was designed with the aim of improving memory and attention functions.

Another strength is the use of both objective and subjective measures of memory and attention in long-term stroke survivors. Capturing self-reports of memory and attention in stroke survivors and mood, anxiety and sleep quality in both stroke survivors and caregivers has shown that for some stroke survivors' memory and attention is temporally associated with and predicted by these constructs within-person and in dyadic relationships between stroke survivors and caregivers. Consequently, the findings have important implications for clinical practice in the rehabilitation of memory and attention functioning following a stroke event. In the first instance it would be beneficial for a clinician to assess mood state, anxiety levels and sleep quality of both stroke survivors and caregivers, then determine the possible effects of each on the stroke survivors' memory and attention functions and then provide suitable and appropriate therapies to both stroke survivors and their caregivers if required.

The use of objective tests of memory and attention at the individual level is also a strength within the thesis. Chapters Five and Seven showed that performance on the neuropsychological tests fluctuated which might be the result of a number of factors; one of which is the instability of memory and attention functioning. This finding has important research and clinical implications. In terms of research, with the use of such tests it becomes difficult to assess memory and attention performance accurately, and the impact of this means that the design, implementation and evaluation of the effectiveness of interventions becomes problematic. The outcome may be that erroneous conclusions are made that will have an effect on knowledge and understanding of memory and attention functioning in long-term stroke survivors.

and a continuing lack of knowledge of how best to remediate deficits in these cognitive domains.

The finding that performance fluctuates over time on objective tests also has significant clinical implications. The RBMT-3, in particular, is routinely used by clinicians to assess memory performance, thus evidence that there is variability in performance will likely impact upon the role of the clinician which will have consequences for stroke survivors' recovery. We currently do not know the best way to remediate memory and attention problems in stroke survivors and knowing that memory and attention performance fluctuates over time poses further challenges for the clinician. For example, there may be issues with identifying the nature and extent of cognitive problems meaning that it would be particularly difficult in offering the most suitable treatment option(s). For the stroke survivor, this may hinder recovery and possibly exacerbate other post-stroke sequale such as distress for both stroke survivor and caregiver further adding to the multitude of problems stroke survivors and their families already experience. Additionally, fluctuation in performance could have an effect on other issues such as whether an individual has the cognitive capacity to return to work and fulfil job requirements, to continue driving, to deal with financial affairs and/or whether they qualify for state benefits such as Disability Living Allowance. Given the many implications of the outcomes of cognitive assessments, it is imperative that attention is paid to such issues.

In terms of limitations, shortcomings of the present thesis have been presented throughout, and in particular the feasibility study highlighted a number of shortcomings of the methodology that would need to be improved in future research. A couple of other points are worth noting. First, a combined intervention was

delivered to the stroke survivors therefore the study does not permit the teasing out of potential effects of each part of the intervention. To do this using an individual-based method would require a A-B-A-C-A-D-A-E-A design where the physical activity consultation, walking sessions and cognitive training is delivered individually and then a combined intervention is delivered with all four treatments compared to baseline conditions. This type of design would likely be too complex to implement, the length of the study overall would be significantly long and there would be carry-over effects from one phase to the next.

Secondly, it could be argued that a limitation of the walking study is the use of the neuropsychological memory and attention tests in the feasibility study when it was known that there is fluctuation in performance over time which would make it difficult to determine the effectiveness of an intervention. However, the study in Chapter Five was the first study that has administered the RBMT-3 and TEA individually and found noticeable fluctuation. Therefore, JC felt that it would be important to include the same tests to be consistent and to assess for replication of the results.

Future directions have also been noted throughout, and again the feasibility study highlighted avenues for future research by indicating the aspects of the study that would need to be amended. As well as this, future research could focus on examining the effects of combined physical activity and cognitive training on underlying brain mechanisms rather than relying on neuropsychological test performance and self-report. Previous research has shown that cognitive rehabilitation improves brain function (Olesen, Westerberg, & Klingberg, 2004) and dopamine receptor density (Klingberg, 2010), and physical activity promotes brain

neuroplasticity (Prakash et al., 2007), is associated with an increase in brain derived neurotrophic factor, improved synaptic structure and strength (Cotman, Berchtold, & Christie, 2007), cerebral circulation and overall brain volume (Colcombe et al., 2006).

The argument is that training is associated with an improvement in a wide range of functions and that this improved performance is associated with neuronal changes from the intracellular level to functional organization of the cortex (Buonomano & Merzenich, 1998). However, most of the research studies have been conducted with healthy adult samples and, as yet, there are no studies investigating the effect of combined treatments on underlying mechanisms for memory and attention functions in stroke.

Concluding Remarks. In conclusion the present thesis has demonstrated an individual-based methodology is appropriate and a viable alternative to the group-based design in studies on memory and attention in stroke survivors. The thesis also shows the inherent difficulties in delivering complex interventions which are often overlooked in group designs. Given the difficulties, there is a need for researchers to consult the MRC (2008) framework that provides guidance on the importance of piloting multifaceted interventions. Efforts must be made to rectify the pitfalls to advance the feasibility study. The thesis also demonstrates that stroke survivors in the long-term phase of recovery have memory and attention problems, and for some stroke survivors, these cognitive functions are affected by other psychological and behavioural factors such as mood, anxiety, sleep quality and walking behaviour which adds to the existing literature.

It is clear that further research is required to aid understanding of memory and attention deficits and of the influences on these cognitive functions and how the deficits can be remediated in stroke survivors. Recommendations in terms of the dose cognitive rehabilitation and physical activity sessions should be are non-existent. Efforts should be made to provide such guidance as this will benefit the design and delivery of interventions in subsequent research studies and in clinical practice.

9. References

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Appendix I

Stroke Survivor's Daily Diary

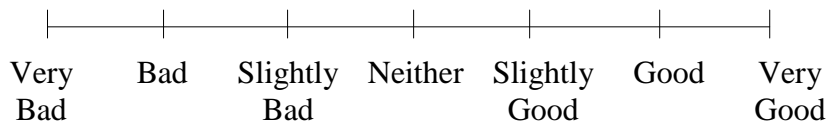


Diary
Booklet
(Stroke Survivor)

Investigating Memory and Attention in
Individuals with Long-Term Stroke

This is your diary that you are asked to complete on a daily basis; once during the day and once during the evening. At the top of each page you are asked to enter the date and/or the time in which you have filled in the responses.

The diary contains rating scales in relation to your sleep quality, anxiety, mood, memory and attention. Below is an example of the rating scale. You are asked to indicate by making a mark somewhere on the horizontal line how you feel in relation to the constructs being measured. You can either circle one of the vertical lines that are already there or you can make a mark between two verbal descriptors. For example, a mark could be placed somewhere between 'slightly good' and 'good'.



There is also space provided below the rating scales if you would like to record any information that you think might be important in relation to the constructs being measured. For example, if you experienced some memory difficulties when you were outside the home environment you can write this information down.

Advice is provided below as to how you would provide a rating for each of the measures.

Sleep: You are asked to indicate how well you slept the night before. If you fell asleep with no difficulty, you awoke feeling refreshed and had an undisturbed sleep a mark would be placed somewhere between 'slightly good' and 'very good'. If it took a while for you to fall asleep, you awoke still feeling tired and had a disturbed sleep a mark would be placed somewhere between 'slightly bad' and 'very bad'.

Anxiety: You are asked to indicate how you have felt during the day/evening with regards to levels of anxiety. If you have felt calm and relaxed a mark would be placed somewhere between 'slightly good' and 'very good'. If you have felt nervous or worried a mark would be placed somewhere between 'slightly bad' and 'very bad'.

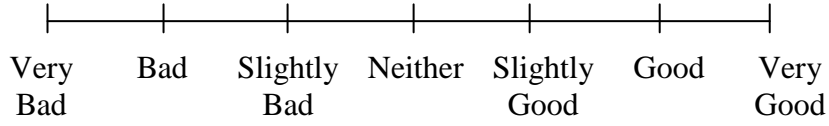
Mood: You are asked to indicate how you have felt during the day/evening. If you have felt happy or cheerful a mark would be placed somewhere between 'slightly good' and 'very good'. If you felt sad or angry a mark would be placed somewhere between 'slightly bad' and 'very bad'.

Memory: You are asked to indicate how your memory has been during the day/evening. If you have experienced little or no memory problems a mark would be placed somewhere between 'slightly good' and 'very good'. If you have experienced several memory difficulties a mark would be placed somewhere between 'slightly bad' and 'very bad'.

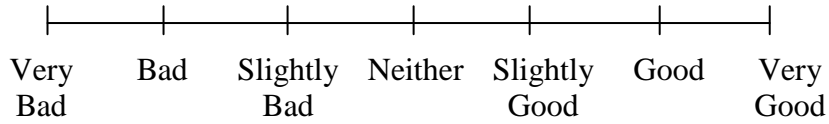
Attention: You are asked to indicate how your attention has been during the day/evening. If you have experienced little or no problems with your attention a mark would be placed somewhere between 'slightly good' and 'very good'. If you have experienced several attentional difficulties a mark would be placed somewhere between 'slightly bad' and 'very bad'.

Daytime: Date and time _____

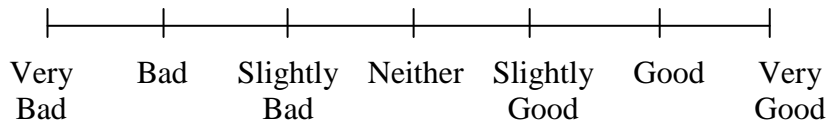
Sleep:



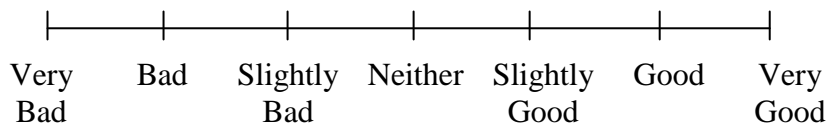
Anxiety:



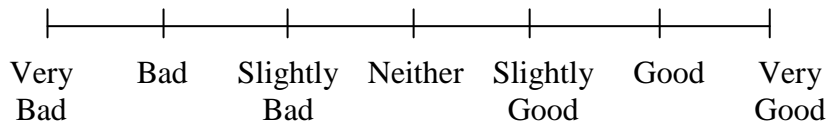
Mood:



Memory:

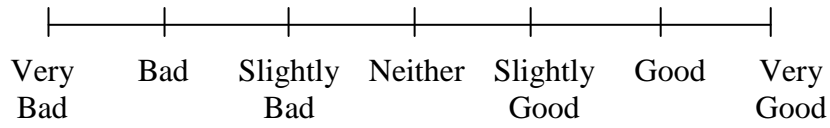


Attention:

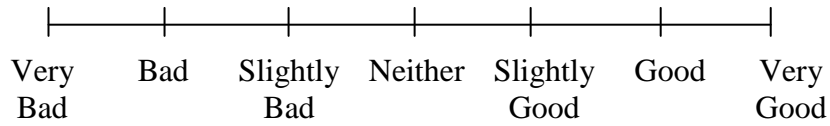


Evening: Time _____

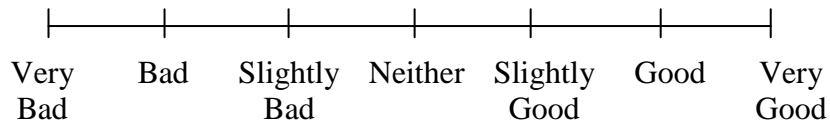
Anxiety:



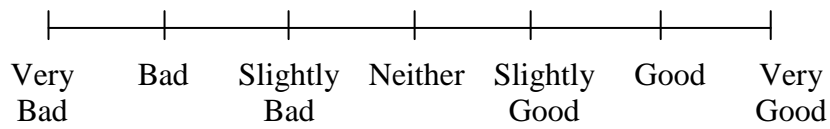
Mood:



Memory:



Attention:




Additional Information:

Appendix II

Ethics Application Form – Chapter Five and Six

AA



**APPLICATION FORM FOR
UNIVERSITY ETHICS COMMITTEE
AND
DEPARTMENTAL ETHICS COMMITTEES**

PLEASE COMPLETE THE FORM IN BOLD TYPE FACE

Checklist of	Document	Enclosed	N/A
enclosed	Participant information sheet(s)	✓	<input type="checkbox"/>
Documents	Consent form(s)	✓	<input type="checkbox"/>
	Sample questionnaire(s)	✓	<input type="checkbox"/>
	Sample interview format(s)	✓	<input type="checkbox"/>
	Sample advertisement(s)	✓	<input type="checkbox"/>
	Any other documents (please specify below)		
	Diary Booklet for both the stroke survivor and caregiver	✓	<input type="checkbox"/>
	Personal information questionnaire for both the stroke survivor and caregiver	✓	<input type="checkbox"/>
	Image of the Actigraph	✓	<input type="checkbox"/>

1.

Chief Investigator
(Ordinance 16 member of staff only)

Name: Madeleine Grealy

Status:

Professor	✓
Reader	<input type="checkbox"/>
Senior Lecturer	<input type="checkbox"/>
Lecturer	<input type="checkbox"/>

Department: School of Psychological Sciences and Health

Contact
Details: Telephone: 0141 548 4885

E-mail: m.grealy@strath.ac.uk

2.

**Other
Strathclyde
Investigator(s)**

Name(s): Joanne Cummings

Status (e.g. lecturer, post-/undergraduate): Post-graduate (PhD researcher).

Department(s): School of Psychological Sciences and Health

If student(s), name of supervisor: Professor Madeleine Grealy

Contact
Details: Telephone: 0141 548 4239

E-mail: joanne.cummings@strath.ac.uk

Details for all investigators involved in the study: Professor Nanette Mutrie. Department: School of Psychological Sciences and Health. Telephone: 0141 950 3371. Email: nanette.mutrie@strath.ac.uk

3.

**Non-Strathclyde
collaborating
investigator(s)**

Name(s):

Status:

Department/Institution:

If student(s), name of supervisor:

Contact
Details: Telephone:

E-mail:

Please provide details for all investigators involved in the study:

4.

Name(s):

**Overseas
Supervisor(s)**

Status:

Department/Institution:

Contact
Details:

Telephone:

E-mail:

I can confirm that the local supervisor has
obtained a copy of the Code of Practice:

Yes

No

Please provide details for all supervisors involved in the study

5.

**Title of the
Investigation:**

Investigating Memory and Attention in Individuals with Long-Term Stroke.

6.

**Where will the
investigation be
conducted:**

Participants will be those who are residing in Glasgow. Investigations will be carried out within the participants' home environment. One of the researchers (Joanne Cummings) will travel to the participant's home to carry out the pre and post-study assessments and will visit on a fortnightly basis to provide a recharged physical movement monitor.

7.

**Duration of the
Investigation
(years/months)**

(Expected) start date: On receiving ethical approval.

(Expected) completion date: Two years after study inception.

8.

Sponsor

(please refer to Section C and Annex 3 of the Code of Practice):

The University of Strathclyde.

9.

Funding Body (if applicable)

Status of proposal – if seeking funding (please click appropriate box):

In preparation **Submitted** **Accepted**

Date of Submission of proposal: / /

Date of start of funding: / /

10.

Objectives of investigation

(including the academic rationale and justification for the investigation)

This project has two aims: first to investigate memory and attention in individuals who are in the chronic phase of stroke recovery, and second to determine if the case study approach is feasible to use with a stroke population and their caregivers. The recent figures from the Institute of Public Health (2008) indicate that there are over one million people in the UK who have had a stroke and about half of this population have residual disabilities as a consequence of the stroke. Individuals who have suffered a stroke often experience impairments in physical ability. However, it is not uncommon for stroke survivors to experience deficits in cognitive functioning also (Zinn, Bosworth, Hoenig, & Swartzwelder, 2007). Despite this, most of the research studies have focused on functional outcomes particularly within the acute phase of stroke recovery, with less attention being paid to the recovery and/or improvement of cognitive outcomes in long-term stroke. In addition to the limited research focusing on cognitive functioning, a recent assessment of stroke survivors at six months post-stroke found that individuals reported issues to do with memory and attention as unmet needs (National Institute

for Health Research, 2010), suggesting that stroke survivors are aware that they have problems associated with their cognitive functioning but these difficulties are not being addressed.

Due to a lack of quality research in this area, our understanding of memory and attentional processes post-stroke is poor and the researchers who have focused on the effectiveness of cognitive rehabilitation programmes following stroke have reported mixed findings. For example, some researchers have found that cognitive functioning is improved post-rehabilitation, whilst others have not (for reviews see Bowen & Lincoln, 2008; das Nair & Lincoln, 2008). As well as cognitive rehabilitation programmes, researchers have begun to focus on the effects of physical activity on cognitive functioning in stroke survivors, reporting that an active lifestyle can improve some aspects of cognition (Quaney, Boyd, McDowd, Zahner, He, Mayo, & Macko, 2009; Rand, Eng, Liu-Ambrose, Tawasy, 2010). However, what is not known is if, or how, memory and attention changes over time when the person is in the chronic phase of stroke recovery and not undergoing a specific physical activity or cognitive rehabilitation programme.

Given the lack of knowledge and understanding of memory and attention in individuals with long-term stroke, it is difficult to inform caregivers about cognitive functioning post-stroke. Many stroke survivors depend on their partners/carers throughout their recovery. However, carers have reported that they view the stroke survivor's cognitive impairments as challenging and distressing, and would value input to help them cope better with such demands (Bulley, Shiels, Wilkie, & Salisbury, 2010). Consequently, caring for a stroke survivor can have an effect on the carers themselves. However, it is currently unknown if factors associated with the carer's behaviour and psychological wellbeing influences the stroke survivor's level of functioning. As this is so, including both the stroke survivor and their caregiver in research studies may enhance our understanding of the factors that have an impact upon memory and attention post-stroke.

A series of case studies will be carried out. The first aim of this study is to investigate changes in stroke survivors' memory and attention over a period of time and to explore factors that may influence these cognitive functions on a daily basis. Stroke survivors in the chronic stage of recovery and their partners/caregivers will be asked to complete a daily diary that records memory and attention, anxiety, mood and sleep quality, and will also be asked to wear a physical movement monitor.

The second aim of the study is to obtain feedback from a stroke population and their caregivers about the suitability of using the case study approach to investigate possible cognitive interventions. The case study approach involves taking repeated assessments of the constructs of interest over a period of time with the same individual. Assessments are taken throughout the study, that is, from baseline to follow-up which index measurement of the factors under investigation. An in-depth study of this manner can allow for monitoring and tracking of an individual's progress (or lack of) over a period time.

There are reasons why this methodology would be useful from a research perspective. For example, there is wide variation in relation to stroke occurrence (e.g. the location, time since stroke onset, stroke severity, and number of strokes) and the effect of stroke on cognitive functioning afterwards. As a result of the variability, group studies are not pragmatic. The case study method can allow for interventions to be tailored based on the needs of an individual. However, this method is time consuming as it involves the completion of measures continually, which may or may not be wholly appropriate for individuals who have suffered a stroke and their carers. It may be that some aspects of the method may need to be adapted dependent on an individual's circumstance. Therefore, determining the suitability of using this methodology from a participant perspective will be useful in the development of future studies. Indeed, the feedback and results of this study will inform a subsequent study that is in the planning stages and will focus on a combined cognitive and physical activity intervention to improve memory and attention post-stroke.

11.

Nature of the participants:

Are any of the categories mentioned in Section B1(b) (participant considerations) applicable in this investigation?

Yes No

If 'yes' please detail:

Participants will be adult stroke survivors who will be in the chronic phase of stroke recovery, that is, 6 months or more post-stroke and who report problems with their memory and attention.

Number: 20 (ten participants will be stroke survivors and ten will be caregivers. Age (range): Adults not exceeding 80 years.

Please also include information on: recruitment methods (see section B4 of the Code of Practice); inclusion/exclusion criteria; and any further screening procedure to be used

The aim is to recruit participants using a number of strategies. First, flyers advertising the study will be posted on websites of stroke organisations such as the Stroke Association and Chest, Heart and Stroke Scotland (CHSS). In addition, an advertisement in the form of a poster will be distributed to the thirteen non-NHS affiliated stroke groups of the stroke organisation CHSS that are located within Glasgow. Stroke organisations such as the Scottish Stroke Research Network (SSRN) offer assistance in the recruitment of stroke survivors into research studies. Individuals who want to take part in the study will be asked to express an interest by contacting the researcher by email or phone.

The inclusion criteria for stroke survivors will be (1) adults between 18 and 80 years old: (2) who have sustained a stroke (ischaemic/haemorrhage) at least 6 months prior to the study commencing; (3) have impaired memory and attention measured by the standardised tests assessing memory and attention (4) are community dwelling residents within Glasgow and (5) reside with a caregiver. The exclusion criteria will be individuals who (1) have visual or hearing impairments that are not corrected with visual and hearing devices, (2) have inadequate English language ability that would prevent understanding of the test instructions/study requirements and (3) suffer from dementia. Vascular dementia will be assessed using the Montreal Cognitive Assessment questionnaire (MoCA; Nasreddine, Phillips, Bédirian, Charbonneau, Whitehead, Collin, Cummings, & Chertkow, 2005). Based on normative data an average score of 16 is indicative of Alzheimer's disease. Therefore, individuals who obtain a score of 16 or below will be excluded from the study (please see section 12 below on informed consent).

The inclusion criteria for caregivers will be (1) residing with and caring for an individual who has suffered a stroke. Exclusion criteria will be (1) inadequate English ability that would prevent understanding of the study requirements.



12.

What consents will be sought and how?

The information sheets and consent forms to be used should be attached to this form.

Written consent will be obtained (see attached forms). Before informed consent is sought from the participants the researcher carrying out the investigations (Joanne Cummings) will explain in detail the nature of the study to both the stroke survivor and their carer. Participants will then be asked to summarize back to the researcher what their involvement in the study will be. This will allow the researcher to determine the participant's level of understanding of their involvement and what it is they are consenting to.

If the researcher is satisfied that participants have understood what is expected of them they will then be informed that they can have some time to reflect as to whether they would like to participate in the study. A minimum of three days will be given for reflection after which the researcher will contact the participants to determine if they would like to participate. If and when participants express that they would like to proceed they will be asked to provide consent and will then be asked to complete the MoCA. As mentioned, if participants have an average score of 16 or less on the MoCA they will be excluded from taking part in the study.

13.

Methodology:

Are any of the categories mentioned in the Code of Practice Section B1(a) (project considerations) applicable in this investigation? Yes No

If 'yes' please detail:

The current study will seek to obtain personal information from individuals who have suffered a stroke and their carer. Participants will be asked to provide information relating to any medications they are taking as well as complete tasks, questionnaires and daily diaries that assess memory, attention, anxiety, mood and sleep. Low scores on the standardised tests of memory and attention are indicative of impairment. In

contrast, higher scores on the questionnaire measuring levels of anxiety and depression will be used in the study indicate more reported difficulties.

To provide duty of care, participants will be informed at the start of the study that if they wish the researcher (Joanne Cummings or Prof Grealy if they prefer) will write a letter to their GP informing him/her that the participant is taking part in the study. The letter will detail the aims of the study, the participant's involvement, and if they wish the scores they achieved on the baseline psychological tests. Irrespective of whether a participant has expressed that they would like their GP to be informed of their involvement in the study, those who show signs of difficulties in relation to any of the factors that are under investigation (e.g., a high score on the anxiety and depression questionnaire) will be informed to seek advice from their GP and/or stroke liaison nurse.

Design: what kind of design/research method(s) is/are to be used in the investigation?

The research design involves a continuous assessment of the constructs over a three-month period that is separated by assessment phases. The first assessment phase is baseline testing. The cognitive tests/questionnaires will be administered during this phase. The second phase, which lasts 12 weeks, will involve the completion of the daily diaries and the wearing of the physical movement monitor. Immediately after this 12-week period, the third and final assessment phase will be carried out in which the cognitive tests/questionnaires will be administered again.

A series of case studies will be carried out. The case study methodology was chosen as it is unknown how long-term stroke survivors' memory and attention change over time in response to self-monitoring therefore this method may be a suitable approach to use to gain more of an understanding of these processes. In addition, this methodology was chosen as there is wide variability concerning stroke and its effect on cognitive functioning. Consequently, group-based designs are unlikely to capture this variation, which prevents the tailoring of interventions to suit individual needs. Finally, feedback can be obtained from the participants about their experience of completing the measures on a frequent basis, which will be useful in the design and development of future research studies.

Techniques: what specific techniques will be employed and what exactly is required of participants?

At baseline, stroke survivors will be asked to provide their date of birth, height, weight, sex, number of years of formal education, employment status/previous employment, and the type of medication that they take. Participants will also be asked for permission for their height and weight to be taken as this information needs to be programmed into the physical movement monitor. Stroke survivors will also be asked to provide stroke specific information such as type and location of stroke (if this is known), time since stroke onset, duration of rehabilitation period and number of stroke incidents. They will then be asked to complete the following measures:

- The Rivermead Behavioural Memory Test – Third Edition (RBMT-3; Wilson, Cockburn, & Baddeley, 2008). The RBMT-3 is a standardised test battery that can detect impairment of everyday memory function in individuals who have acquired neurological damage. The battery contains 11 subtests that measure immediate and delayed recall, prospective memory and orientation.
- The Test of Everyday Attention (TEA; Robertson, Ward, Ridgeway, & Nimmo-Smith, 1996). The TEA is a standardised test battery that measures attentional processes using eight subtests that focus on divided, selective, sustained attention and attentional switching.
- The Everyday Memory Questionnaire (EMQ; Royle & Lincoln, 2008).
- The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).
- The Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman, Kupfer, 1988).
- The International Physical Activity Questionnaire (IPAQ; Booth, 2000).
- The Line-Bisection Test (Schenkenberg, Bradford, & Ajax, 1980). This measure detects the presence of unilateral spatial neglect. Individuals are asked to mark with a pencil the centre of a series of horizontal lines.

After baseline testing, stroke survivors will be asked to complete a daily diary for a period of 12 weeks that will ask about their memory and attention as well as factors that have an effect on cognition such as anxiety, mood and sleep quality. In addition, participants will be asked to wear an accelerometer (GT3X Tri-Axis Actigraph Monitor) during this time. This monitor is a lightweight compact device (27g, 3.8cm x 3.7cm x 1.8cm) that can be worn around the waist, the arm, wrist or ankle. The

monitor stores information relating to physical activity measurements including steps taken, energy expenditure, intensity of activity and body positioning (standing, supine). The monitor will be pre-programmed before it is given to the participant. The device has sufficient memory to sustain the duration of the study. However, battery life is 20 days therefore participants will be provided with an alternate monitor every two weeks. Immediately after the 12-week study period, stroke survivors will be asked to complete the standardised tests and the questionnaires again (i.e. the RBMT, TEA, EMQ, HADS, PSQI and the IPAQ).

Concerning carer involvement, the caregiver of the stroke survivor will be asked to provide their date of birth, height and weight. At baseline, carers will be asked to complete the HADS, the PSQI and the IPAQ. After baseline testing the carer will also be asked to complete a daily diary and wear the physical movement monitor for three months (i.e. at the same time as the stroke survivor). The carer's diary will involve two aspects: the first is that they will be asked to rate the stroke survivor's memory and attention and the second is that they will be asked to complete items relating to their own anxiety, mood and sleep quality. The carer will then be asked to complete the questionnaires at 12 weeks post-study.

Finally, participants (both the stroke survivor and their caregiver) will be asked if they would be willing to take part in a semi-structured interview at the end of the study to provide feedback on the nature of the study. They will be asked to provide an account of their experience of completing the assessments, the diaries and the suitability of wearing the accelerometer. Participants will be informed that the interviews will be audio recorded and will only be carried out if consent is given.

Investigations governed by the Code of Practice that involve any of the types of projects listed in B1(a) must be submitted to the University Ethics Committee for prior approval.

Has this methodology been subject to independent scrutiny? Yes No

Please provide the name and contact details of the independent reviewer

Where an independent reviewer is not used, then the UEC/ DEC reserves the right to scrutinise the methodology.

14.

Data collection, storage and security:

Explain how data are handled, specifying whether it will be fully anonymised, pseudo-anonymised, or just confidential, and whether it will be securely destroyed after use.

The data will be pseudo-anonymised. Participants will be allocated a number that will be used when storing data in relation to the sensitive constructs that will be measured.

Explain how and where it will be stored, who has access to it, and how long it will be stored.

The data will be stored in a locked filing cabinet and stored on a computer that is password protected within a locked room at the University of Strathclyde. The data will be stored until completion of post-graduate study.

Will anyone other than the named investigators have access to the data?

If 'yes' please explain.

No one other than the named investigators will have access to the data.

15.

Potential risks or hazards:

The total time to complete the standardised tasks and the questionnaires is approximately 2 hours. Therefore, the participants (stroke survivors) may experience cognitive fatigue as a consequence. However, before the testing phase begins participants will be informed that they can have a break between the tests and questionnaires if they wish. In addition, the completion of the daily diaries may place too much of a demand on the stroke survivor and their carer. However, participants will be informed that they can stop filling in the diaries and remove the accelerometer at any time if they would like to cease participation in the study.

Regarding the physical movement monitor, the participants will be asked to wear the monitor on a continuous basis only to be removed during bathing/showering if possible. Participants will be provided with information on how the monitor should be worn i.e. if worn around the wrist they will be informed that it should be

close fitting but not overly tight. If participants forget to take the monitor off during bathing/showering the monitor will be damaged as it is only water-resistant. However, it is unlikely that the participant will suffer any harm from doing so.

Given that the aim is to carry out the assessments within the participants' home environment, issues in relation to the researcher's welfare may be raised. The researcher carrying out the assessments has had previous experience of conducting research that involved travelling to participants' homes to conduct the assessment. However, this has been with non-clinical populations. Concerning stroke, the researcher is aware that stroke survivors who have suffered a stroke within the frontal area of the brain may be more likely to display aggressive behaviours. Given this, the researcher will arrange to carry out the assessments when the carer is present and will be thoughtful and sensitive to the stroke survivor's circumstance. Other precautionary measures such as travelling by car, having access to a mobile phone and informing the Chief Investigator (Professor Madeleine Grealy) of the researcher's whereabouts will also be carried out.

16.

Ethical issues:

As participants will be asked to provide personal information and complete measures that assess a range of psychological constructs (e.g., memory, attention, anxiety and depression) ethical issues arise. Regarding personal information, participants will be informed that data will be pseudo-anonymised and under no circumstance will anyone other than the named investigators have access to the data.

With regards to the psychological constructs under investigation, participants' scores may indicate that they are experiencing some difficulties. Furthermore, filling in the diaries may exacerbate the participant's condition if it reflects back to them that their memory and attention is not improving or that they have persistent low mood. Participants will have the option of withdrawing from the study if they experience distress as a result of completing the diaries. Irrespective of whether they withdraw from the study or not, participants in this circumstance might need additional support. Similarly, participants who request feedback at the end of the study of their performance may also experience negative effects if their memory and attention has unaltered or deteriorated. As mentioned participants can request that a letter is

sent to their GP. Irrespective of whether a letter is sent, where there is cause for concern in relation to the ethical issues mentioned participants would be advised to seek assistance from their GP/stroke liaison nurse. In addition, participants will be provided with contact details of stroke organisations such as the Stroke Association and CHSS and support literature from these organisations will also be made available.

17.

Any payment to be made:

No payment will be offered to the participants.

18.

What debriefing, if any, will be given to participants?

Joanne Cummings will carry out a debriefing session at the end of the 3 months. Participants will be asked if they would prefer a debriefing session when they are both present or on an individual basis. In either case, the session will involve providing the participants with some background information about stroke and its effect on memory and attention. The reasons why the study was carried out and why certain tasks and questionnaires were chosen will also be explained to the participants. For example, participants will be informed that one reason for carrying out this study was to further our understanding of memory and attention in individuals with long-term stroke. Basic information about the need for research studies to focus on these aspects of cognition and to assess factors that may have an effect will be relayed back. Participants will also be informed that an additional aim of the study was to evaluate the process in which the data was collected. Again, some general information about why the diary method that incorporated repeated assessments was chosen will be provided. Afterwards, participants will be given the opportunity to ask questions or to express their views/concerns in relation to any aspect of the study.

Participants will be informed that the data will be examined to determine if there were any changes of their memory and attention throughout the lifespan of the study and to assess whether other factors that were included in the study such as

mood, sleep quality and physical movement were associated with these aspects of cognition. They will be asked if they would like to know of the results in relation to their own performance. If a participant expresses that they want to be informed of the outcomes the researcher (Joanne Cummings) will arrange a suitable time to visit the home environment after the data has been analysed. During this feedback session a recap of the participant's involvement will be provided. Thereafter, the participant will be informed of the results and an interpretation of what the results mean will be offered. Participants will then have the chance to ask questions about the outcome. If concern or worry is expressed by either the stroke survivor or their carer they will be advised to seek support from their GP, stroke liaison nurse or stroke organisations.

Participants will be reminded of the researcher's contact details and will be informed that they can make contact if they have any further questions/queries or would like to ask a question/s that were not considered during the debriefing session. Finally, participants will be thanked for their participation in the study.

19.

How will the outcomes of the study be disseminated? Will you seek to publish the results?

The research findings will be disseminated in the form of poster and/or oral presentations at relevant conferences and a paper will be submitted for publication.

20.

Nominated person (and contact details) to whom participants' concerns/questions should be

Questions and/or queries can be answered by:

Joanne Cummings (joanne.cummings@strath.ac.uk) or by:

Professor Madeleine Grealy (m.grealy@strath.ac.uk).

**directed
before, during
or after the
investigation**

**21.
Previous
experience of
the
investigator(s)
with the
procedures
involved.**

The researcher conducting the assessments (Joanne Cummings) has had some experience of administering cognitive tasks during her Masters' training. Ms Cummings will also undergo training before the onset of the study to allow practice in administering the tasks chosen for this study. The Chief Investigator (Professor Grealy) has extensive experience in running projects similar to this.

22.

Chief Investigator and Head of Department Declaration

I have read the University's Code of Practice on Investigations involving Human Beings and have completed this application accordingly.

Signature of Chief Investigator




Please also type name here

Professor Madeleine Grealy

I confirm I have read and approved this application.

Signature of Head of Department



Please also type name here

23.

Only for University sponsored projects under the remit of the DEC, with no external funding and no NHS involvement.

Head of Department statement on Sponsorship

This application requires the University to sponsor the investigation. This is done by the Head of Department for all DEC applications with exception of those that are externally funded and those which are connected to the NHS (those exceptions should be submitted to R&KES). I am aware of the implications of University sponsorship of the investigation and have assessed this investigation with respect to sponsorship and management risk. As this particular investigation is within the remit of the DEC and has no external funding and no NHS involvement, I agree on behalf of the University that the University is the appropriate sponsor of the investigation and there are no management risks posed by the investigation.

If not applicable, click here

Signature of Head of Department



Please also type name here

Date:

/ /

Appendix III

Ethics Approval Letter – Chapter Five and Six

ETHICAL APPROVAL

UEC1011/24 “Investigating Memory and Attention in Individuals with Long-Term Stroke”

I can confirm that the University Ethics Committee has approved this protocol and appropriate insurance cover and sponsorship have now also been confirmed.

I would remind you that the Committee must be informed of any changes that are made to the research project, so that they have the opportunity to consider them. The Committee would also expect you to report back on the progress and outcome of your project, with an account of anything which may prompt ethical questions for any similar future project and with anything else that you feel the Committee should know.

On behalf of the Committee, I wish you success with this project.

Kind regards

Louise.

Louise McKean LLM NP

Contracts Manager

Research & Knowledge Exchange Services
University of Strathclyde
50 George St
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G1 1QE

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T +44 (0)141 548 4364

F + 44 (0)141 552 4409

<http://www.strath.ac.uk/ri/>



Name of department: School of Psychological Sciences and Health.

Title of the study: Investigating Memory and Attention in Individuals with Long-Term Stroke.

Introduction

My name is Joanne Cummings; I am a PhD student at the University of Strathclyde where I will be carrying out research investigating memory and attention in stroke survivors. The research study will form part of my doctoral degree.

What is the purpose of this investigation?

The purpose of the study is to investigate memory and attention processes in individuals who are considered to be in the chronic phase of stroke recovery, that is, 6 months or more since having a stroke. An additional aim of the study is to obtain feedback about the experience of taking part in the study. Research studies that focus on cognitive functioning such as memory and attention are limited therefore this study aims to understand more about these processes after an individual has suffered a stroke. In addition, the study aims to understand more about how best to collect data from stroke survivors.

Do you have to take part?

No. It is up to you to decide whether or not to take part. Participation is voluntary no payment will be offered for taking part in the study. If you do decide to take part you will be given this information sheet to keep and you will be required to provide written consent. You do not have to answer any questions that you do not want to. Also, if you do decide to take part you are still free to withdraw at any time without giving a reason. This will not affect you in any way. You can contact me and I will disregard any data relevant to you. Finally, refusing to take part or withdrawing from

the study will not affect the support/ services that you may receive from stroke organisations.

What will you do in the project?

The duration of the study will last 12 weeks and the assessments will be carried out at a place convenient for you. If you do decide to take part you will be asked to complete a short cognitive test that assesses the presence of vascular dementia. If the test scores indicate that you may be suffering from dementia you will be excluded from taking part in the study. Both you and your caregiver will be informed and will be advised to seek advice from your GP and/or stroke liaison nurse. If the test scores do not indicate the presence of dementia the study will begin. You will be asked to provide some personal information including sex, date of birth, education, occupation, any medication that is taken and stroke specific information such as time since stroke onset and location of stroke. It will take approximately 10 minutes to answer these questions. You will then be asked to complete a number of tasks and questionnaires. The tasks measure memory and attention and the questionnaires will measure some aspects of memory, anxiety, depression and sleep quality. It will take a couple of hours to complete the tasks and questionnaires.

Thereafter, you will be asked complete a daily diary for a period of 12 weeks. The diary contains questions about memory, attention, anxiety, mood and sleep quality. It should take no more than five minutes to complete the diary each day. You will also be asked to wear a lightweight physical movement monitor for 7 days at the start of the study, at week 6 and at week 11. A picture of the monitor is below. At the end of the 12 weeks you will be asked to complete the tasks and questionnaires again and take part in an interview that will be audio recorded. The interview will focus on your experience of taking part in the study.



Figure 1: The physical movement monitor.

Why have you been invited to take part?

You have been invited to take part because the research study is specifically interested in individuals who have sustained a stroke and have trouble with their memory and attention since having the stroke.

To take part you must have sustained a stroke at least 6 months prior to the study commencing, aged between 18 and 80 years old, have impairment of memory and attention, are community dwelling residents living within Scotland and reside with a caregiver. This study will not be suitable for you if you have visual or hearing impairments that are not corrected with visual and hearing devices, or if you have inadequate English language ability that would prevent understanding of the test instructions/study requirements, or if you suffer from dementia. If you have questions about whether you would be suitable to participate in this study please contact Joanne Cummings (details are given below).

What are the potential risks to you in taking part?

It will take a couple of hours to complete the tasks therefore it is possible that you may experience some fatigue during the testing sessions. However, you can have rest periods between the tasks if necessary.

In addition, your test, questionnaire or diary results may indicate that you are experiencing some difficulty in relation to memory, attention, sleep quality, level of anxiety and/or mood. If the results indicate that you may be experiencing some difficulty you will be advised to speak to your GP/stroke liaison nurse. If you wish a letter can be sent to your GP at the beginning of the study to inform him/her that you are taking part in the research study.

What happens to the information in the project?

You will be provided with a participant number which will be used to store information relating to you. No information that would identify you will be included in any written documents or shared with anyone other than my supervisor. Any data that is collected from you will be stored within a locked filing cabinet and on a password protected computer that only my supervisor and I can access. The data will be retained until I have completed my research degree and will form part of my thesis. The results may also be published. However, as mentioned under no

circumstances will you be identified within any document. Thereafter, the data will be securely destroyed.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?

If you agree to take part I will arrange a meeting with you and I will go over in detail what the study involves. If you are satisfied with what is expected of you and are still willing to take part you will be asked to fill out a consent form before the study begins. Thereafter, we will arrange a start date for the first assessment period. If you decide not to take part then I am grateful that you have shown an interest in the study.

This investigation was granted ethical approval by the University of Strathclyde ethics committee.

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G1 1QE
Telephone: 0141 548 3707. Email: ethics@strath.ac.uk

Researcher Contact Details:

For further information please contact:

Joanne Cummings
PhD Researcher
The University of Strathclyde
School of Psychological Sciences and Health

Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 4239
Email: joanne.cummings@strath.ac.uk

Chief Investigator Details:

Professor Madeleine Greal
The University of Strathclyde
School of Psychological Sciences and Health
Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 4885
Email: m.greal@strath.ac.uk

Appendix V

Consent Form - Chapter Five



Name of department: Psychology (School of Psychological Sciences and Health).

Title of the study: Investigating Memory and Attention in Individuals with Long-Term Stroke.

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.

- I consent to being a participant in the project.
- I consent to being audio recorded as part of the project Yes/ No

I hereby agree to take part in the above project:

PRINT NAME : _____

Signature of Participant : _____

Date: _____

Appendix VI
Caregiver's Daily Diary

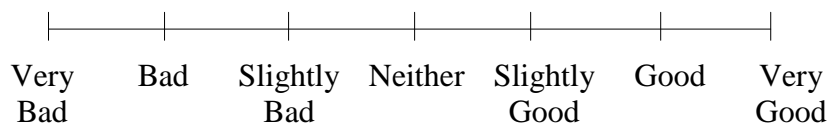


Diary
Booklet
(Caregiver)

Investigating Memory and Attention in
Individuals with Long-Term Stroke

This is your diary that you are asked to complete on a daily basis; once during the day and once during the evening. At the top of each page you are asked to enter the date and/or the time in which you have filled in the responses.

The diary contains rating scales in relation to your sleep quality, anxiety and mood, and the stroke survivor's memory and attention. Below is an example of the rating scale. What you are asked to do is indicate by making a mark somewhere on the horizontal line how you feel in relation to your sleep quality, anxiety and mood and how you think the stroke survivor's memory and attention has been. You can either circle one of the vertical lines that are already there or you can make a mark between two verbal descriptors. For example, a mark could be placed somewhere between 'slightly good' and 'good'.



There is also space provided below the rating scales if you would like to record any information that you think might be important in relation to the constructs being measured. For example, if you experienced some memory difficulties when you were outside the home environment you can write this information down.

Advice is provided below as to how you would provide a rating for each of the measures.

Sleep: You are asked to indicate how well you slept the night before. If you fell asleep with no difficulty, you awoke feeling refreshed and had an undisturbed sleep a mark would be placed somewhere between 'slightly good' and 'very good'. If it took a while for you to fall asleep, you awoke still feeling tired and had a disturbed sleep a mark would be placed somewhere between 'slightly bad' and 'very bad'.

Anxiety: You are asked to indicate how you have felt during the day/evening with regards to levels of anxiety. If you have felt calm and relaxed a mark would be placed somewhere between 'slightly good' and 'very good'. If you have felt nervous or worried a mark would be placed somewhere between 'slightly bad' and 'very bad'.

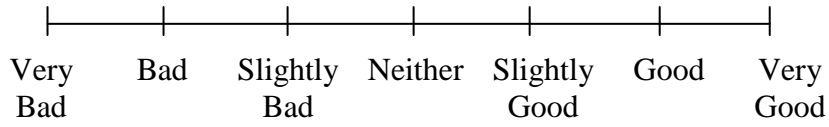
Mood: You are asked to indicate how you have felt during the day/evening. If you have felt happy or cheerful a mark would be placed somewhere between 'slightly good' and 'very good'. If you felt sad or angry a mark would be placed somewhere between 'slightly bad' and 'very bad'.

Memory: Please indicate how the stroke survivor's memory has been during the day/evening. If you think they have experienced little or no memory problems a mark would be placed somewhere between 'slightly good' and 'very good'. If you think they have experienced several memory difficulties a mark would be placed somewhere between 'slightly bad' and 'very bad'.

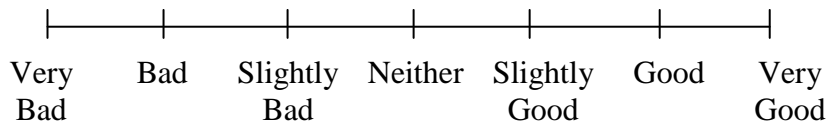
Attention: Please indicate how the stroke survivor's attention has been during the day/evening. If you think they have experienced little or no problems with attention a mark would be placed somewhere between 'slightly good' and 'very good'. If you think they have experienced several attentional difficulties a mark would be placed somewhere between 'slightly bad' and 'very bad'. A mark can be placed somewhere in the middle if the stroke survivor's attention has been neither good nor bad.

Daytime: Date and time _____

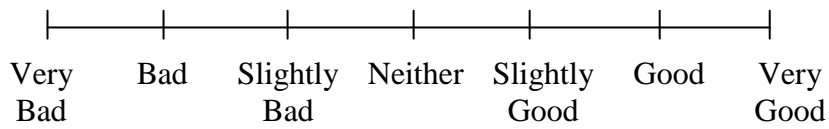
Sleep:



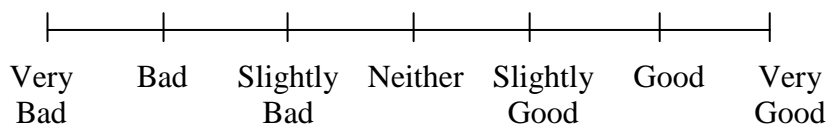
Anxiety:



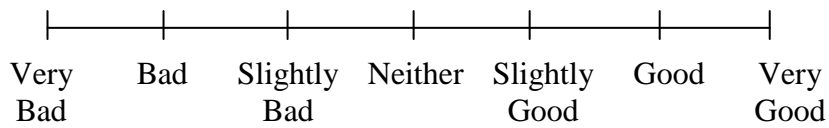
Mood:



Memory (stroke survivor):

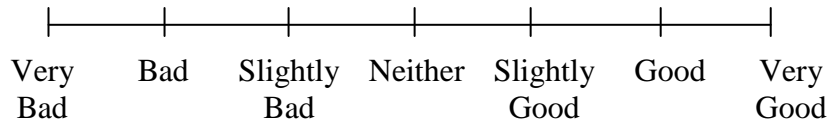


Attention (stroke survivor):

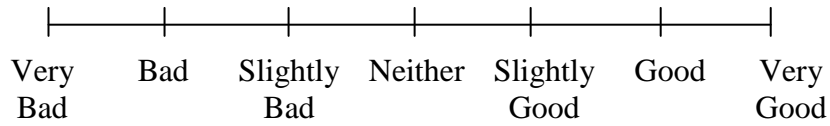


Evening: Time _____

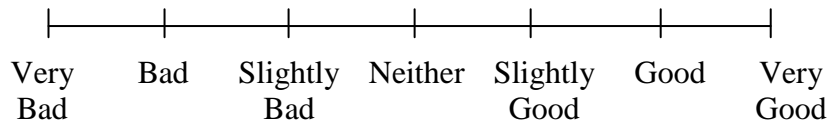
Anxiety:



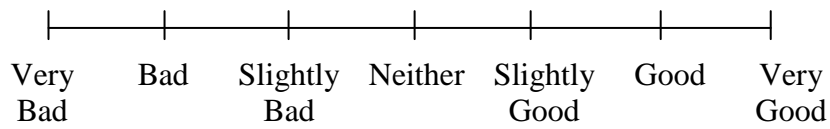
Mood:



Memory (stroke survivor):



Attention (stroke survivor):



Additional Information:



Name of department: School of Psychological Sciences and Health.

Title of the study: Investigating Memory and Attention in Individuals with Long-Term Stroke.

Introduction

My name is Joanne Cummings; I am a PhD student at the University of Strathclyde where I will be carrying out research investigating memory and attention in stroke survivors. The research study will form part of my doctoral degree.

What is the purpose of this investigation?

The purpose of the study is to investigate memory and attention in individuals who are considered to be in the chronic phase of stroke recovery, that is, 6 months or more since having a stroke. An additional aim of the study is to obtain feedback about the experience of completing the tasks that are involved in the study. Research studies that focus on cognitive functioning such as memory and attention are limited therefore this study aims to understand more about these cognitive functions after an individual has suffered a stroke. In addition, the study aims to understand more about how best to collect data from stroke survivors and their caregivers. Therefore, we are interested in recruiting stroke survivors and their caregivers as a pair.

Do you have to take part?

No. It is up to you to decide whether or not to take part. Participation is voluntary no payment will be offered for taking part in the study. If you do decide to take part you will be given this information sheet to keep and you will be required to provide

written consent. You do not have to answer any questions that you do not want to. Also, if you do decide to take part you are still free to withdraw at any time without giving a reason. This will not affect you in any way. You can contact me and I will disregard any data relevant to you. Finally, refusing to take part or withdrawing from the study will not affect the support/ services that you may receive from stroke organisations.

What will you do in the project?

The duration of the study will last 12 weeks and the assessments will be carried out at a place convenient for you. If you do decide to take part you will be asked to provide some personal information at the start of the study including sex, date of birth, education, occupation status and any medication that is taken. It will take approximately 10 minutes to answer these questions. You will then be asked to complete questionnaires that measure anxiety, depression and sleep quality. It will take between 30 – 40 minutes to complete the questionnaires. After the person that you care for has completed their assessments you will be asked to complete a daily diary for a period of 12 weeks. There are two aspects involved: you will be asked to answer questions about memory and attention of the stroke survivor as well as fill in responses in relation to your own anxiety, mood and sleep quality. It should take no more than five minutes to complete the diary each day. You will also be asked to wear a lightweight physical movement monitor for 7 days at the start of the study, at week 6 and at week 11. A picture of the monitor is below. At the end of the 12 weeks you will be asked to complete the questionnaires again and take part in an interview that will be audio recorded. The interview will focus on your experience of taking part in the study.



Figure 1: The physical movement monitor.

Why have you been invited to take part?

You have been invited to take part because the research study is specifically interested in caregivers who reside with a stroke survivor to gain a better understanding of factors that may influence the stroke survivor's memory and attention.

To take part you must be aged between 18 and 80 years old, are community dwelling residents living within Scotland and caring for a stroke survivor. This study will not be suitable for you if you have visual or hearing impairments that are not corrected with visual and hearing devices, or if you have inadequate English language ability that would prevent understanding of the study requirements. If you have questions about whether you would be suitable to participate in this study please contact Joanne Cummings (details are given below).

What are the potential risks to you in taking part?

The results from the questionnaires and diary may indicate that you are experiencing some difficulty in relation to sleep quality, level of anxiety and/or mood. If the results indicate that you may be experiencing some difficulty you will be advised to speak to your GP.

What happens to the information in the project?

You will be provided with a participant number which will be used to store information relating to you. No information that would identify you will be included in any written documents or shared with anyone other than my supervisor. Any data that is collected from you will be stored within a locked filing cabinet and on a password protected computer that only my supervisor and I can access. The data will be retained until I have completed my research degree and will form part of my thesis. The results may also be published. However, as mentioned under no circumstances will you be identified within any document. Thereafter, the data will be securely destroyed.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998. Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?

If you agree to take part I will arrange a meeting with you and I will go over in detail what the study involves. If you are satisfied with what is expected of you and are still willing to take part you will be asked to fill out a consent form before the study begins. Thereafter, we will arrange a start date for the stroke survivor to carry out their first assessment and then the daily diaries will start from there on. If you decide not to take part then I am grateful that you have shown an interest in the study.

This investigation was granted ethical approval by the University of Strathclyde ethics committee.

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G1 1QE
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Researcher Contact Details:

For further information please contact:

Joanne Cummings
PhD Researcher
The University of Strathclyde
School of Psychological Sciences and Health
Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 4239
Email: joanne.cummings@strath.ac.uk

Chief Investigator Details:

Professor Madeleine Grealy
The University of Strathclyde
School of Psychological Sciences and Health
Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 4885
Email: m.grealy@strath.ac.uk

Appendix VIII

Consent Form - Chapter Six



Name of department: Psychology (School of Psychological Sciences and Health).

Title of the study: Investigating Memory and Attention in Individuals with Long-Term Stroke.

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.

- I consent to being a participant in the project.
- I consent to being audio recorded as part of the project Yes/ No

I hereby agree to take part in the above project:

PRINT NAME : _____

Signature of Participant : _____

Date: _____

Appendix IX

Stroke Survivor's Daily Diary



Stride for Stroke

Diary

Ratings of Memory, Attention, Mood and Anxiety¹

This is your daily diary. It asks you to rate your sleep quality, memory, attention, mood, anxiety and record step counts.

When rating your sleep quality, memory, attention, mood and anxiety you can fill the diary in when it best suits you. This might be at the end of the day, or you might prefer to fill it in on the following day. It is up to you but it is important to record each day as fully as you can. When recording your step counts we ask that you write this down at the end of each day.

A rating scale is provided at the top of the page, and this ranges from Very Bad (1) to Very Good (10). Simply choose a number between 1 and 10 that reflects best how you feel each item has been for the day in question. For example, if you had a very bad night's sleep on Monday night you would put 1 under Monday night. You do not have to enter a whole number you can enter half numbers too such as 1.5.

SLEEP

(1) Very Bad _____ (10) Very Good

Mon night	Tue night	Wed night	Thu night	Fri night	Sat night	Sun night
1						

¹ Participants completed this part of the diary in weeks 1 - 25

You are asked to rate memory, attention, mood and anxiety in the same way.

When giving a rating for memory please rate how your memory has been for remembering names, faces and objects, remembering to do something that you had planned to do and remembering information that you were previously told or heard.

When giving a rating for attention please rate how well you have been able to concentrate whilst doing activities, doing two things at once such as making tea and chatting and being able to change from one topic or task to another without losing track of what you were doing.

Week 1:

SLEEP

(1) Very Bad _____ (10) Very Good

Mon night	Tue night	Wed night	Thu night	Fri night	Sat night	Sun night

MEMORY, ATTENTION, MOOD, ANXIETY

(1) Very Bad _____ (10) Very Good

	Mon	Tue	Wed	Thu	Fri	Sat	Sun
Remembering names, faces, objects							
Remembering to do things							
Remembering information							
Being able to concentrate							
Being able to do two things at once							
Being able to change topics							
Mood							
Anxiety							

Walking Diary²

This is your diary for step counts. At the end of each day we would like you to record how many steps you achieved that day.

To record your step counts you need to look at your pedometer and record the number of steps that is shown on the screen. For example, if you walked 1000 steps on Monday, the screen would display this number and you would write 1000 in the box for that day.

	Mon day	Tue day	Wed day	Thu day	Fri day	Sat day	Sun day
Steps walked	1000						

There is space for comments if you wish to record any information that you think is important. For example, you may want to write down that you had a poor night's sleep for a particular reason.

² Participants completed this part of the diary in weeks 2 - 9

Week 2:

	Mon day	Tue day	Wed day	Thu day	Fri day	Sat day	Sun day
Steps walked							

Notes/Comments (Optional)

Monday _____

Tuesday _____

Wednesday _____

Thursday _____

Friday _____

Saturday _____

Sunday _____

Walking and Games Diary³

This is your diary on step counts and games. At the top of each page your walking goal for that week is shown. The goal is shown in steps and time. If you find it easier to judge your walk by time rather than steps use a watch as a guide.

As before, at the end of each day we would like you to record how many steps you achieved that day, but we would also like to know if you played the games whilst you walked.

The step counts will be recorded the same way as before. So, if you walked 1500 steps on Monday you would enter this number in the box for that day. If you played some games whilst you walked on this day too, you would enter a 'Y' in the box below.

	Mon day	Tue day	Wed day	Thu day	Fri day	Sat day	Sun day
Steps walked	1500						
Did you play the games whilst you walked (Enter Y or N)	Y						

Again, there is space for comments if you wish to record any information that you think is important. For example, if you could not manage out for a walk because you were feeling unwell you may wish to write this down.

³ Participants completed this part of the diary in weeks 10 - 25

Week 10:

My walking goal for this week is: _____ steps / _____ minutes

Record the number of steps you walked and enter ‘Y’ if you played the games whilst you walked and ‘N’ if you didn’t.

	Mon day	Tue day	Wed day	Thu day	Fri day	Sat day	Sun day
Steps walked							
Did you play the games whilst you walked (Enter Y or N)							

Notes/ Comments (Optional)

Monday _____

Tuesday _____

Wednesday _____

Thursday _____


Friday _____

Saturday _____

Sunday _____

Appendix X

Ethics Application Form – Chapter Seven

<p>APPLICATION FORM FOR UNIVERSITY ETHICS COMMITTEE AND DEPARTMENTAL ETHICS COMMITTEES</p>	
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PLEASE COMPLETE THE FORM IN BOLD TYPE FACE

Checklist of enclosed Documents	Document Enclosed	N/A
	Participant information sheet(s) ✓	<input type="checkbox"/>
	Consent form(s) ✓	<input type="checkbox"/>
	Sample questionnaire(s) ✓	<input type="checkbox"/>
	Sample interview format(s) ✓	<input type="checkbox"/>
	Sample advertisement(s) ✓	<input type="checkbox"/>
	Any other documents (please specify below)	
	Researcher details ✓	
	Recruitment letter ✓	<input type="checkbox"/>
	GP letter ✓	
	Diary - stroke survivor ✓	
	Personal information questionnaire – stroke survivor ✓	<input type="checkbox"/>

Image of the activPAL and pedometer

✓

PA consultation template

✓

Management risk assessment form

✓

1.

Chief Investigator
(Ordinance 16 member of staff only)

Name: Madeleine Grealy

Status:	Professor	✓
	Reader	<input type="checkbox"/>
	Senior Lecturer	<input type="checkbox"/>
	Lecturer	<input type="checkbox"/>

Department: School of Psychological Sciences and Health

Contact Details: Telephone: 0141 548 4885

E-mail: m.grealy@strath.ac.uk

2.

Other Strathclyde Investigator(s)

Name(s): Joanne Cummings

Status (e.g. lecturer, post-/undergraduate): Post-graduate (PhD researcher).

Department(s): School of Psychological Sciences and Health

If student(s), name of supervisor: Professor Madeleine Grealy

Contact Details: Telephone: 0141 548 4239

E-mail: joanne.cummings@strath.ac.uk

Details for all investigators involved in the study:

Professor Nanette Mutrie. Department: School of Psychological Sciences and Health. Telephone: 0141 950 3371. Email: nanette.mutrie@strath.ac.uk

3.
**Non-Strathclyde
collaborating
investigator(s)**

Name(s):
Status:
Department/Institution:
If student(s), name of supervisor:
Contact Telephone:
Details: E-mail:
Please provide details for all investigators involved in the study:

4.
**Overseas
Supervisor(s)**

Name(s):
Status:
Department/Institution:
Contact Telephone:
Details: E-mail:
I can confirm that the local supervisor has obtained a copy of the Code of Practice: Yes No
Please provide details for all supervisors involved in the study

5.
**Title of the
Investigation:**

Stride for Stroke.

6.
Where will the investigation be conducted:

Participants will be those who have suffered a stroke and who are residing in Greater Glasgow and Clyde, and surrounding areas. The testing sessions will be carried out at a location convenient for the participant. This may be the participant's home environment or at their stroke club, for example. One of the researchers (Joanne Cummings) will travel to the location chosen to carry out the assessments and to collect the physical activity monitors. Joanne or other post-graduate research students, who are members of the Physical Activity for Health Group at Strathclyde University and who have led health walks for older adults, will assist participants (if stroke survivors give permission for this) on a walking session each week in the surrounding area of the participant's home address.

The researchers who may assist on some of the walking sessions are not named investigators as their role in the study is minimal. The researchers will only lead some of the walks if (a) the stroke survivor gives approval, and (b) when Joanne Cummings is unavailable to assist on the walk because she is scheduled to assist another stroke survivor on a walk at the same time. In this situation, the researchers will assist a stroke survivor on a walking session and play the memory and attention games with the stroke survivor whilst doing so. Joanne Cummings will brief the researchers prior to the walk about the stroke survivor's physical activity ability and their walking goal for that session. Joanne will also advise the researchers of the memory and attention games to be played and will provide a written document of the games.

The three researchers named have undergone walk leader training provided by Paths for All and have led walks with older adults who had medical conditions (West End Walkers 65+ research study at the University of Strathclyde). The researchers are also part of the Physical Activity for Health group at Strathclyde and have knowledge and awareness of problems that may arise during walks. The researchers will have no access to any of the stored data. They will have to be informed of the stroke survivor's home address but this will only happen if the stroke survivor has agreed for this to happen (see appendix 1 for details of the researchers who may assist on the project).

7.

(Expected) start date: On receiving ethical approval.

Duration of the Investigation
(years/months)

(Expected) completion date: Two years after study inception.

8.

Sponsor

(please refer to Section C and Annex 3 of the Code of Practice):

University of Strathclyde.

9.

Funding Body
(if applicable)

Status of proposal – if seeking funding (please click appropriate box):

In preparation **Submitted** **Accepted**

Date of Submission of proposal: / /

Date of start of funding: / /

10.

Objectives of investigation

(including the academic rationale and justification for the investigation)

This project aims to determine if a combined walking and cognitive intervention can improve memory and attention functions in individuals who have sustained a stroke. The recent figures from the Institute of Public Health (2008) indicate that there are over one million people in the UK who have had a stroke and about half of this population have residual disabilities as a consequence of the stroke. Individuals who have suffered a stroke may experience deficits in cognitive functioning (Zinn, Bosworth, Hoenig, & Swartzwelder, 2007). Despite this, most of the research studies have focused on functional outcomes particularly within the acute phase of stroke recovery, with less attention being paid to the recovery and/or improvement of cognitive outcomes in long-term stroke. Stroke related cognitive deficits can impede recovery (Zinn, Dudley, Bosworth, Hoenig, Duncan, & Horner, 2004) therefore, it is important to examine

interventions that may improve cognitive functioning post-stroke.

Physical activity and cognitive training have the potential to restore and/or improve cognitive functioning post-stroke. Research studies have shown that cognitive rehabilitation can improve cognitive functioning (for reviews see Bowen & Lincoln, 2008; das Nair & Lincoln, 2008; Westerberg, Jacobbeaus, Hirvikoski, Clevberger, Ostensson, Bartfai, & Klingberg, 2007). Concerning physical activity, being physically active can reduce age-related cognitive decline or improve cognition in healthy older adults (Colcombe & Kramer, 2003) and in those who have cognitive impairment (Heyn, Abreu and Ottenbacher, 2004; Quaney, Boyd, McDowd, Zahner, He, Mayo, & Macko, 2009; Rand, Eng, Liu-Ambrose, & Tawashy, 2010). Potential influencing effects include self-efficacy, mood, anxiety and sleep quality (Etnier, 2009).

However, participation in physical activity after stroke is low (Mead, Cunningham, Lewis, Dinan, & Fitzsimons, 2007). Research studies have found that those who suffered a stroke and are living within the community did not meet the minimum physical activity recommendations (Rand, Eng, Tang, Jeng, & Hung, 2009), and that they walked less than their aged-matched counterparts (Moore, Roth, Killian, & Hornby, 2010). Consequently, stroke survivors are missing out on general and specific health benefits that can be gained from leading an active lifestyle during the recovery process. Physical activity interventions with stroke survivors therefore would benefit from delivering a physical activity consultation that aims to promote behaviour change.

The above demonstrates that physical activity interventions and cognitive training interventions can have positive effects on cognitive outcomes. However, very few studies have examined the possible additive effect of a combined cognitive and physical activity intervention on cognitive functioning. Of those who have, healthy older adults have been the focus of attention (e.g., Fabre, Chamari, Mucci, Massé-Biron, & Préfaut, 2002; Oswald, Gunzelmann, Rupperecht, & Hagen, 2006). The findings showed that the combined cognitive and physical activity intervention led to greater improvements in cognitive functioning than either intervention on its own. To date, no study has examined the effect of combining cognitive tasks with physical activity on cognitive functioning in stroke survivors.

To assess this, a series of single-case experimental studies with

stroke survivors and semi-structured interviews with caregivers will be carried out. The case study approach involves taking repeated assessments of the constructs of interest over a period of time with the same individual. Assessments are taken throughout the study, that is, from baseline to follow-up which measure the factors under investigation. An in-depth study of this manner can allow for monitoring and tracking of an individual's progress (or lack of) over a period time. This methodology is appropriate as there is wide variation in relation to stroke occurrence (e.g. the location, time since stroke onset, stroke severity, and number of strokes) and the effect of stroke on cognitive functioning afterwards. The case study method will allow the interventions to be tailored based on the needs of an individual.

An important part of the case study design is the inclusion of social validation from a caregiver. For example, caregivers can report how they think/feel an individual is performing on a particular task. The stroke survivor will be informed that we would like to interview their caregiver at the end of the study to get their opinion on what the stroke survivor's memory, attention, mood, anxiety and sleep quality has been like throughout the study. Permission to ask the caregiver if they would like to take part in the study will be sought from the stroke survivor. If permission is granted a recruitment letter will be provided for the caregiver to read. If the caregiver decides that he/she would like more information or expresses an interest in taking part an information sheet will be provided. The interviews will be audio-taped.

11.

Nature of the participants:

Are any of the categories mentioned in Section B1(b) (participant considerations) applicable in this investigation?

Yes No

If 'yes' please detail:

Participants will be adult stroke survivors who will be in the chronic phase of stroke recovery, that is, 6 months or more post-stroke and who report problems with their memory and attention.

Number: 20

Age (range): Adults not exceeding 80

years.

Please also include information on: recruitment methods (see section B4 of the Code of Practice); inclusion/exclusion criteria; and any further screening procedure to be used

The aim is to recruit participants using a number of strategies. First, information advertising the study will be posted on websites of stroke organisations such as the Stroke Association (SA). Advertisements will also be put on social networking sites such as Facebook. Additionally, a Facebook page has been set up by Joanne Cummings which details information about on-going studies. We will ask stroke organisations to place adverts on their webpages. The information provided will be the same information given on the paper copies of the advertisement. Posters will also be distributed to the non-NHS affiliated stroke groups, and organisations within communities such as churches and community centres. Individuals who want to take part in the study will be asked to express an interest by contacting the researcher by email or phone (see appendix 2 for the advert). If stroke survivors would like more information an information pack will be sent to them via post or email. To make the information more accessible, an information pack that contains the basic information of the study (appendix 3), additional information about the study, e.g., what will be measured, information on the physical activity monitors and information about the walking sessions, (appendix 4) and information on participation, how to withdraw and who to contact (appendix 5) will be provided in separate documents rather than provided as one lengthy document.

The inclusion criteria for stroke survivors will be (1) adults between 18 and 80 years old: (2) who have sustained a stroke (ischaemic/haemorrhage) at least 6 months prior to the study commencing; (3) can walk independently – with or without a walking aid (4) have self-reported memory and attention problems and (5) are community dwelling residents.

The exclusion criteria will be individuals who have:

(1) the presence of dementia. Vascular dementia will be assessed using the Montreal Cognitive Assessment questionnaire (MoCA; Nasreddine, Phillips, Bédirian, Charbonneau, Whitehead, Collin, Cummings, & Chertkow, 2005). Based on normative data an average score of 16 is indicative of Alzheimer's disease. Therefore, individuals who obtain a score of

16 or below will be excluded from the study (please see section 12 below on informed consent). (2) absolute contraindications to physical activity such as unstable heart disease/angina, myocardial infarction, uncontrolled hypertension, arrhythmia and/or diabetes, acute progressive heart failure, acute aortic dissection, acute myocarditis or pericarditis, pulmonary infarction, deep venous thrombosis, extreme obesity (> 159kg), suspected/known aneurysm, acute infections, uncontrolled visual or vestibular disturbances, recent injurious fall without medical assessment. The Physical Activity Readiness Questionnaire (PAR-Q) will be administered to assess possible contraindications to physical activity participation.

(3) recently been hospitalized.

(4) visual or hearing impairments that are not corrected with visual and hearing devices

(5) inadequate English language ability that would prevent understanding of the test instructions/study requirements.

(6) a diagnosis of a mental illness such as major depressive disorder or schizophrenia.

Investigations governed by the Code of Practice that involve any of the types of projects listed in B1(b) must be submitted to the University Ethics Committee for prior approval.

12.

What consents will be sought and how?

The information sheets and consent forms to be used should be attached to this form.

Written consent from stroke survivors will be obtained (appendix 6). Before informed consent is sought from the participants Joanne Cummings will explain in detail the nature of the study to the stroke survivor. Participants will then be asked to summarize back to the researcher what their involvement in the study will be. This will allow the researcher to determine the participant's level of understanding of their involvement and what it is they are consenting to.

If the researcher is satisfied that participants have understood what is expected of them they will be given some time to reflect on whether they would like to participate. A minimum of three

days will be given after which the researcher will contact the participants to determine if they would like to proceed. If they do they will be asked to provide consent and will then be asked to complete the MoCA and PAR-Q. If they score 16 or less on the MoCA or responses on the PAR-Q indicate they are not fit to exercise they will be excluded from taking part in the study. In this case, participants will be provided with information about physical activity recommendations for stroke survivors and the benefits of physical activity for health, and/or information will be provided on strategies that can be used to help with their memory and/or attention impairments, as appropriate.

If interviews are carried out with caregivers they will be given an information sheet and will be asked to give written consent (see appendix 8, 9 and 10 for information sheet, consent form and interview questions, respectively).

13.

Methodology:

Are any of the categories mentioned in the Code of Practice Section B1(a) (project considerations) applicable in this investigation? Yes No

If 'yes' please detail:

The current study will seek to obtain personal information from individuals who have suffered a stroke. Participants will be asked to provide information relating to any medications they are taking as well as complete tasks, questionnaires and daily diaries that assess memory, attention, anxiety, mood and sleep.

To provide duty of care, participants will be informed at the start of the study that the research team will write a letter to their GP informing him/her they are taking part in the study. A standard letter signed by the Chief Investigator will be issued that details the aims of the study and the participant's involvement. A letter will not be sent if the participant expresses otherwise (see appendix 11). Irrespective of whether a participant has expressed that they would like their GP to be informed of their involvement in the study, those who show signs of difficulties in relation to any of the factors that are under investigation (e.g., a high score on the anxiety and depression questionnaire) will be advised to seek advice from their GP and/or stroke liaison nurse.

Design: what kind of design/research method(s) is/are to be used in the investigation?

A series of single-case studies will be carried out. These will involve a continuous self-assessment over a period of time. The duration of the study is 24 weeks. The first 8 weeks can be considered the baseline phase. The second 8 week block is when the intervention will be delivered. Participants will take part in a walking consultation and will be assisted on one walking session each week by a member of the research team. During the final 8 weeks, participants will no longer be assisted on a walking session but will be encouraged to maintain their walking behaviour.

Techniques: what specific techniques will be employed and what exactly is required of participants?

- At the beginning of the study participants will be asked to provide demographic details such as sex, date of birth and type of medication that they take. They will also be asked to provide information such as type and location of stroke, time since stroke and number of stroke incidents (appendix 10). They will then be asked to complete the following measures.
- The Montreal Cognitive Assessment (MoCA; Nasreddine, Phillips, Bédirian, Charbonneau, Whitehead, Collin, Cummings, & Chertkow, 2005).
- The Line-Bisection Test (Schenkenberg, Bradford, & Ajax, 1980). This measure detects the presence of unilateral spatial neglect. Individuals are asked to mark with a pencil the centre of a series of horizontal lines.
- Weschler Abbreviated Scale of Intelligence (WASI; the Psychological Corporation, 1999). This sub-scale will be administered to get an estimate of pre-morbid intellectual ability.
- The Physical Activity Readiness Questionnaire (PAR-Q; the Canadian Society for Exercise Physiology) will be administered to determine eligibility status.

These measures will be completed only once.

Participants will then be asked to complete the questionnaires and the standardised memory and attention tasks listed below. These will be administered at the start of week 1 and at the end of weeks 8, 16 and 24.

- The Everyday Memory Questionnaire (EMQ; Royle & Lincoln, 2008).
- The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).
- The Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman, Kupfer, 1988).
- The Rivermead Behavioural Memory Test – Third Edition (RBMT-3; Wilson, Cockburn, & Baddeley, 2008). A standardised test battery that contains 11 subtests that measure immediate and delayed recall, prospective memory and orientation.
- The Test of Everyday Attention (TEA: Robertson, Ward, Ridgeway, & Nimmo-Smith, 1996). A standardised test battery that measures attentional processes using eight subtests that focus on divided, selective, sustained attention and attentional switching.

Participants will also be asked to wear a physical activity monitor (activPAL) for 7 consecutive days at the start of weeks 1, 8, 16 and 24. The monitor collects data on time spent seated/lying, standing and walking. It is a lightweight (15 grams) small (53x35x7mm) accelerometer and is worn discretely on the mid-line axis of the thigh. It can be worn whilst showering and does not need to be removed. It is widely available and has been validated and used for research purposes and used within rehabilitation centres. The device has been used extensively with vulnerable populations such as the elderly and participants who have conditions such as cardiovascular disease, obesity and have acquired brain injury. The device is CE marked. To obtain a measure of walking behaviour, on the weeks that the activPAL is not worn, participants will be asked to wear a pedometer (NL-1000) that measures step counts. Like the activPAL, the pedometer is a light weight device and is attached to the participant's belt/waistband. Joanne Cummings will demonstrate how the pedometer operates and will provide safety information about its usage. The pedometer has been research validated also

Participants will be asked to complete a daily diary to rate their memory and attention, anxiety, mood and sleep quality, and to record their step counts (appendix 11). After the consultation, participants will be asked to rate the same constructs as before but they will also be asked to write down if they carried out memory and attention games whilst walking (appendix 12)

At the start of week 9, a physical activity consultation focusing specifically on walking behaviour will be delivered (appendix 13).

Joanne Cummings will receive training in delivering the consultation by Professor Nanette Mutrie or Dr Alison Kirk. Both are academics at the University of Strathclyde and have extensive experience in delivering the consultation training. The consultation is semi-structured and centres on identifying the needs of the individual. It is based on the transtheoretical model of behaviour change (Prochaska & Marcus, 1994) and encompasses stage specific strategies for physical activity behaviour, a decision balance table weighing up the pros and cons of physical activity, a discussion of self-efficacy beliefs and the setting of physical activity goals.

During the consultation, particularly surrounding the discussion of physical activity, the graphical output from the activPAL at week-1 and week-8 will be used to show participants their pattern activity. Walking goals will then be discussed and planned accordingly. These will be graduated and loosely based on the Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings. The guidelines specify that stroke survivors should aim to achieve exercise that is cardiovascular in nature occurring three times per week starting with 15 minutes/1500 steps at the beginning with an increase of roughly 3 minutes/300 steps each session each week at a moderate intensity level where possible. Walking goals will be formed and the participant will receive a copy of their walking programme. Joanne Cummings will receive training in delivering the consultation before any sessions are provided to participants.

A member of the research team will assist the participant on one walking session each week and participants will be encouraged to achieve their walking goals by taking part in walking sessions on their own throughout the remainder of each week. During the walks, participants will be asked to carry out cognitive 'games' such as remember the names of a list of flowers/animals. The cognitive games will also be graded starting at a level that can easily be achieved and increasing in difficulty if and when the individual progresses. For example, if a participant has poor short-term memory (i.e. can only recall 4 items) then they will be asked to remember three-item lists and when that level is achieved the list length will be increased. Participants will be provided with a series of games that can be undertaken when walking on their own (appendix 14).

Regarding the location of the walks, ideally these will be carried out in parks/open spaces close to the participant's home. Prior to

the walks, Joanne Cummings will plan and carry out a risk assessment of the route. Joanne and the other post-graduate research students have undertaken a walking course delivered by Paths for All (an organisation which aims to reduce the proportion of those who are inactive), which addresses route planning and potential risk factors. On the sessions that participants will be assisted, the walk will start from the participant's home address. Joanne will discuss with the participants other options for increasing walking behaviour when they are undertaking walking sessions on their own.

Investigations governed by the Code of Practice that involve any of the types of projects listed in B1(a) must be submitted to the University Ethics Committee for prior approval.

Has this methodology been subject to independent scrutiny? Yes No

Please provide the name and contact details of the independent reviewer

Where an independent reviewer is not used, then the UEC/DEC reserves the right to scrutinise the methodology.

14.

Data collection, storage and security:

Explain how data are handled, specifying whether it will be fully anonymised, pseudo-anonymised, or just confidential, and whether it will be securely destroyed after use.

The stroke survivor and caregiver data will be pseudo-anonymised. Participants will be allocated a number that will be used when storing data in relation to the sensitive constructs that will be measured.

Explain how and where it will be stored, who has access to it, and how long it will be stored.

Data from both stroke survivors and caregivers will be stored in a locked filing cabinet and stored on a computer that is password protected within a locked room at the University of Strathclyde. The data will be stored until completion of post-graduate study.

Will anyone other than the named investigators have access to

the data?
If 'yes' please explain.

No one other than the named investigators will have access to the data.

15.
**Potential risks
or hazards:**

A potential risk for stroke survivors undertaking physical activity is falling and fractures. If the individual is unable to walk with or without a walking aid they will be excluded from taking part in the study. To minimise the risk of falling, the pace of the walks will be self-selected and any changes in direction will be done so at a comfortable speed.

In addition to the risk of falling, there is a risk of cardiac events. It is estimated that up to 75% of stroke survivors have co-morbid heart disease (Roth, 1993). However, the overall risk of having a cardiac event as a result of physical activity is low in cardiac rehabilitation programmes where exercise is tailored to minimize risk (Zipes & Wellens, 1998).

In addition, it is possible that participants may experience physical fatigue as a result of increasing their levels of physical activity. To help reduce the possibility of experiencing fatigue the walking programme will be graduated dependent on their baseline level of physical activity. This means that there will be a gradual increase in walking behaviour. The graduated approach is recommended in the Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings (2010).

It is possible that participants may feel unwell whilst out walking. Joanne Cummings will attend an Emergency First Aid course provided by Paths for All. This course will provide Joanne with the knowledge of how to deal with any situation in which the participant becomes unwell. Joanne has also undergone walk leader training provided by Paths for All that covers what to do in a situation where a walker complains of feeling unwell. Generally, in the event of a participant becoming unwell in which the situation does not require medical attention Joanne will assist the stroke survivor back to their home environment and will contact a relative/friend if the stroke survivor requests this. Where medical attention is required but the situation is not an emergency Joanne will assist the stroke survivor to their home and contact NHS 24 for advice. If it is recommended that the stroke survivor should

see a doctor Joanne will assist the stroke survivor to the medical centre if he/she wishes. In the event of a serious situation Joanne will call emergency services immediately.

The other walk leaders (Leslie Peacock, Freya MacMillan and Laura Watts) will be briefed and will follow the same procedures as above. Leslie Peacock is a certified first aider. Freya MacMillan and Laura Watts have undergone walk leader training provided for Paths for All that has covered what to do in the event of a participant becoming unwell.

The other potential risk is cognitive fatigue. The total time to complete the standardised tasks and the questionnaires is approximately 2 hours. Before the testing phase begins participants will be informed that they can have a break between the tests and questionnaires if they wish. In addition, the completion of the daily diaries may place too much of a demand on the stroke survivor. However, participants will be informed that they can stop filling in the diaries and stop wearing the pedometer/activPAL at any time if they would like to cease participation in the study.

Regarding the attachment of the activPAL, Joanne Cummings will demonstrate using her arm how the monitor should be attached and how the covering material should be placed over the device. As the monitor is a small lightweight device it is unlikely that the participant will suffer additional harm if they were to have a fall whilst wearing the device.

As assessments may be carried out within the participants' home environment, issues in relation to the researcher's welfare may be raised. Joanne Cummings has had previous experience of conducting research that involved travelling to participants' homes to conduct the assessment. She is aware that stroke survivors who have suffered a stroke within the frontal lobes may be more likely to display aggressive behaviours. Given this, she will arrange to carry out the assessments when the carer is present (if the stroke survivor has one) and will be thoughtful and sensitive to the stroke survivor's circumstance. Other precautionary measures such as travelling by car, having access to a mobile phone and informing the Chief Investigator (Professor Madeleine Grealy) of the researcher's whereabouts will also be carried out.

16.
Ethical issues:

With regards to the psychological constructs under investigation, participants' scores may indicate that they are experiencing some difficulties. Furthermore, filling in the diaries may exacerbate the participant's condition if it reflects back to them that their memory and attention is not improving or that they have persistent low mood. Participants will have the option of withdrawing from the study if they experience distress as a result of completing the diaries. Irrespective of whether they withdraw from the study or not, participants in this circumstance might need additional support. As mentioned participants can request that a letter is sent to their GP. Irrespective of whether a letter is sent, where there is cause for concern in relation to the ethical issues mentioned participants would be advised to seek assistance from their GP/stroke liaison nurse.

17.
Any payment to be made:

No payment will be offered to the participants, however participants will be given a pedometer to keep at the end of the study.

18.
What debriefing, if any, will be given to participants?

Joanne Cummings will carry out a debriefing session at the end of the 24 weeks. The session will provide participants with some background information about stroke and its effect on memory and attention. The reasons why the study was carried out and why certain tasks and questionnaires were chosen will also be explained. Participants will be informed that the primary reason for carrying out this study was to determine if taking part in the combined cognitive and physical activity intervention improves memory and attention in individuals with long-term stroke. Basic information about the need for research studies to focus on these aspects of cognition and to assess factors that may have an effect will be relayed back. Afterwards, participants will be given the opportunity to ask questions or to express their views/concerns in relation to any aspect of the study.

Participants will be informed that the data will be examined to determine if they experienced changes in their memory and attention during the study and to assess whether mood, anxiety,

sleep quality and physical activity levels were associated with these aspects of cognition. If a participant expresses that they want to be informed of the general outcomes of the study Joanne Cummings will provide this at the end of the study. Participants will have the chance to ask questions about the outcome. If concern or worry is expressed by the stroke survivor they will be advised to seek support from their GP, stroke liaison nurse and/or stroke organisations.

Participants will be reminded of the researcher's contact details and will be informed that they can make contact if they have any further questions/queries Finally, participants will be thanked for their participation in the study.

19.

How will the outcomes of the study be disseminated? Will you seek to publish the results?

The research findings will be disseminated in the form of poster and/or oral presentations at relevant conferences and a paper will be submitted for publication.

20.

Nominated person (and contact details) to whom participants' concerns/questions should be directed before, during or after the investigation.

Questions and/or queries can be answered by:

Joanne Cummings (joanne.cummings@strath.ac.uk) or by:

Professor. Madeleine Grealay (m.grealay@strath.ac.uk)

21.

**Previous
experience of
the
investigator(s)
with the
procedures
involved.**

The researcher conducting the assessments (Joanne Cummings) has had experience of administering the standardised cognitive tasks during her 1st year of her doctoral research programme. The Chief Investigator (Prof Madeleine Grealy) and second supervisor (Prof Nanette Mutrie) has extensive experience in running projects similar to this.

22.

Chief Investigator and Head of Department Declaration

I have read the University's Code of Practice on Investigations involving Human Beings and have completed this application accordingly.

Signature of Chief Investigator

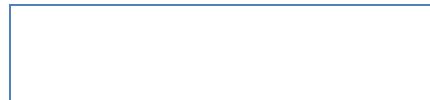


Please also type name here

Professor Madeleine Grealy

I confirm I have read and approved this application.

Signature of Head of Department



Please also type name here

Date:

/ /

23.

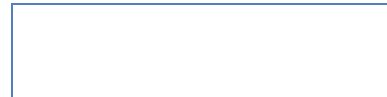
Only for University sponsored projects under the remit of the DEC, with no external funding and no NHS involvement.

Head of Department statement on Sponsorship

This application requires the University to sponsor the investigation. This is done by the Head of Department for all DEC applications with exception of those that are externally funded and those which are connected to the NHS (those exceptions should be submitted to R&KES). I am aware of the implications of University sponsorship of the investigation and have assessed this investigation with respect to sponsorship and management risk. As this particular investigation is within the remit of the DEC and has no external funding and no NHS involvement, I agree on behalf of the University that the University is the appropriate sponsor of the investigation and there are no management risks posed by the investigation.

If not applicable, click here

Signature of Head of Department



Please also type name here

Date:

/ /

Appendix XI

Ethics Approval Letter – Chapter Seven

ETHICAL AND SPONSORSHIP APPROVAL

UEC1011/52 “Stride for Stroke”

I can confirm that the University Ethics Committee has approved this protocol and appropriate insurance cover and sponsorship have now also been confirmed.

I would remind you that the Committee must be informed of any changes that are made to the research project, so that they have the opportunity to consider them. The Committee would also expect you to report back on the progress and outcome of your project, with an account of anything which may prompt ethical questions for any similar future project and with anything else that you feel the Committee should know.

The University agrees to act as sponsor of the abovementioned project subject to the following conditions;

1. That the project obtains/has and continues to have University/Departmental Ethics Committee approval.
2. That the project is carried out according to the project protocol.
3. That the project continues to be covered by the University's insurance cover.
4. That the Director of Research and Knowledge Exchange Services is immediately notified of any change to the project protocol or circumstances which may affect the University's risk assessment of the project.
5. That the project starts within 12 months of the date of this letter.

As sponsor of the project the University has responsibilities under the Scottish Executive's Research Governance Framework for Health and Community Care. You should ensure you are aware of those responsibilities and that the project is carried out according to the Research Governance Framework.

On behalf of the Committee, I wish you success with this project.

Kind regards

Louise McKean LLM NP

Contracts Manager
Research & Knowledge Exchange Services
University of Strathclyde
50 George St
Glasgow, G11QE

Study title: Stride for Stroke

My name is Joanne Cummings and I am a PhD student at the University of Strathclyde. I am carrying out research investigating physical activity, memory and attention in stroke survivors.

What is the purpose of this investigation?

Stroke is the leading cause of adult disability in Scotland. Alongside physical impairments, many stroke survivors also experience problems with their memory and levels of concentration which can affect daily living. It is important that we try to develop better rehabilitation programmes and ways to help improve the lives of those affected by stroke. The purpose of the study is to investigate a new rehabilitation programme which combines physical activity, including walking, and brain training. We want to know if this can help improve fitness, memory and concentration in people who are in the long-term phase of stroke recovery.

What will you do in the project?

The study lasts approximately 24 weeks. You will be asked to do a number of things throughout the study. These are listed below:

- Complete a number of questionnaires and tasks on four occasions
- Wear a physical activity monitor for selected weeks
- Complete a diary checklist
- Take part in a physical activity consultation to help you assess your walking goals
- Participate in walking sessions and playing memory and concentration games

Why have you been invited to take part?

We are interested in individuals who have sustained a stroke and experience some difficulties with their memory and attention.

To take part you must have:

- Sustained a stroke at least 6 months prior to the study commencing
- Aged between 18 and 80 years
- Have the ability to walk independently with or without a walking aid
- Are a community dwelling resident

This study will not be suitable for you if you have:

- Unstable heart disease, uncontrolled hypertension, have had recent falls, or if you have recently been hospitalized
- Visual or hearing impairments that are not corrected with visual and hearing devices
- Dementia
- History of a mental illness
- Inadequate English language ability that would prevent understanding of the study requirements

If you have questions about whether you would be suitable to participate in this study please contact Joanne Cummings (details below).

Tel: 0141 548 4239. Email:joanne.cummings@strath.ac.uk

What are the potential risks to you in taking part?

Falling, a cardiac event and/or physical fatigue are risk factors. Despite these risks, it is recommended that stroke survivors should try and participate in physical activity post-stroke. To minimise these risks, the walking sessions will be based upon your current level of walking ability and you can walk at a pace that you are comfortable with.

Exactly what will I be asked to do?

If you decide to take part you will be asked to complete two short questionnaires to assess whether it is appropriate for you to take part. If your scores indicate that this study is not appropriate for you we will give you information about physical activity and organisations you might be interested in. All assessments will be carried out at a place convenient for you. This can be at your home or a club, for example.

If you do continue the study has three phases.

Phase 1 - we will monitor your normal activity

Phase 2 - we will give you a tailored walking programme with brain training exercises

Phase 3 – we will monitor your activity again.

We will ask you to complete some tasks and questionnaires on four occasions at week 1, 8, 16 and 24. The tasks measure memory and attention. The questionnaires ask for information such as date of birth, and time since stroke onset, as well as your mood, anxiety levels and sleep quality. They take approximately two hours to complete. We will also ask you to fill in a daily diary sheet to rate your memory, attention, mood, anxiety and sleep, and record your step counts. It should take no more than five minutes to complete each day.

You will be asked to wear a physical activity monitor for during weeks 1, 8, 16 and 24. The monitor records movement such as time spent seated, standing and walking. It is worn discretely on the thigh and can be worn whilst showering. In between these weeks you will be asked to wear a pedometer that is worn on your belt/waistband. Pictures of the monitors are shown below.



Figure 1: The physical movement monitor.



Figure 2: The pedometer

At the start of week 9 we will provide you with a physical activity consultation that will help you to set walking goals and identify the pros and cons of taking part in physical activity. After the consultation, a member of the research team will act as a guide and accompany you on one walking session per week for the next 8 weeks. You will be encouraged to stick to your walking goals on your own on the other days of the week. During the walks you will be asked to carry out some memory and attention games. The research team will teach you how to do these.

We would also like to interview your caregiver at the end of the study to get their opinion on how your memory, attention, mood, anxiety has been and how well you have slept at night throughout the study. If you are happy for your caregiver to be involved we will provide a recruitment letter for you caregiver to read and if he/she would like more information or would like to take part an information sheet will be provided.

What happens to the information in the project?

You will be given a participant number and this will be used to store information about you. No information that would identify you will be included in any documents or shared with anyone other than my supervisor. All data will be stored in a locked filing cabinet and on a password protected computer that only my supervisor and I can access. The data will be retained until I have completed my PhD. We hope to publish the results but under no circumstances will you be identified within any document. Thereafter, the data will be destroyed.

Information on participation and how to withdraw

It is up to you to decide whether or not to take part. Participation is voluntary no payment will be offered for taking part in the study, however you will be provided with a pedometer at the end of the study to say thank you for taking part. If you do decide to take part you will be required to provide written consent. You do not have to answer any questions that you do not want to and you are still free to withdraw at any time without giving a reason. You can contact me and I will destroy any data relevant to you. Finally, refusing to take part or withdrawing from the study will not affect services that you may receive from stroke organisations.

If you agree to take part I will go over in detail what the study involves. If you are satisfied with what you will be asked to do, you will be asked to fill out a consent form before the study begins. Thereafter, we will arrange a start date for the first assessment period. If you decide not to take part then I am grateful that you have shown an interest in the study.

Research team contact details

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Who to contact for further information

This investigation was granted ethical approval by the University of Strathclyde ethics committee. If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee, Research & Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50 George Street

Glasgow, G1 1QE, Telephone: 0141 548 3707, Email: ethics@strath.ac.uk

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998. Thank you for reading this information – please ask any questions if you are unsure about what is written here.

Appendix XIII

Consent Form - Chapter Seven



Study title: Stride for Stroke

I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.

- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.

- I consent to being a participant in the project.

I hereby agree to take part in the above project:

PRINT NAME : _____

Signature of Participant : _____

Date: _____

Appendix XIV

An Exemplar of the Memory and Attention Games Played by the Participants

Prospective Memory

- **Intend to Do Game**

In this game, participants were asked at the beginning of the walk to remember to carry out an action either during the walk or at the end of the walk. For example, JC would ask participants at the start of the walk to tell her what they had for breakfast when they returned home. If the participant failed to give the information spontaneously a prompt was given by JC. Participants were informed that if they were walking on their own, they could decide beforehand an action they would carry out when they returned and to write this down, and tick it off when the action had been completed.

Verbal Memory - Names

- **Match the Name Game**

In this game, JC read aloud a list of names (both first name and second name). After a period of time had lapsed (e.g. five minutes) the first name was given by JC and participants were asked to give the surname that matched the first name.

- **First and Second Name Game**

In this game JC and the participant took turns to say names, both the forename and surname. Participants were asked to remember the names that were mentioned previously whilst adding on a new name to the list.

Face Recognition

- **Face Game**

In this game, participants were shown some pictures of faces by JC before the walk. They were asked to pay attention to the features of the face such as the shape of the face, eyebrows, eyes, nose, mouth and cheekbones. At the end of the walk participants were shown some more pictures of faces and they were asked to say whether or not they saw the face at the start of the walk.

Selective Attention

- I Spy Game

In this game, participants were to search for the object that was chosen by JC (or a significant other if they went out walking with stroke survivor). JC (or other) would start the game and say the object began with a letter C, for example. If the participant had difficulty naming the object clues were provided until the object was named. Participants were instructed to look left and right and to consider objects both near and far.

- Vehicle Registration Plate Game

Participants were asked to look for a particular number or letter on registration plates of both moving and stationary vehicles. If and when they spotted the letter/number they were asked to inform JC (or other). If they were walking on their own participants were asked to choose a letter/number that they would look for at the start of the walk.

Sustained Attention

- Object Game

Participants were asked to pay attention to objects in the environment (e.g., dogs, plant pots, horses) and count them throughout the walk and try to remember the total number that they counted at the end of their walk.

- Colour and Object Game

In this game, participants were asked to pay attention to objects in the environment (e.g. vehicles, flowers). Their task was to count how many there were of a particular colour and tell JC (or other) how many they counted at the end of the walk. If walking on their own, participants were asked to try and hold 'in their head' how many they counted in total by the time they reached the end of the walk.

- Serial Name Games

Lists of names of famous people, animals, and food items were read out by JC. Participants were asked to acknowledge when they heard a name in which the first name and second name began with the same letter or an animal name that

began with a specific letter or the food items required to make a particular sandwich and drink.

Divided Attention

- **Food Price Game**

Lists of food items and prices were read out by JC. Participants were asked to count the number of times prices were mentioned whilst ignoring items of a particular price. For example, a list might include, bread 75p, yoghurt 45p, milk 99p, banana 30p, coleslaw 99p, grapes 90p. With this particular list, the task was to count how many times a price was mentioned excluding those mentioned at 99p.

Attentional Switching

- **Alternating Number and Letter Game**

Participants were asked to count numbers and letters in an alternate fashion, e.g. 1, A, 2, B, 3, C, 4, D and so on. Participants could play this game on their own or when assisted on a walk.

- **Alternating Letter and Name Game**

Participants were asked to start at letter A and give a girl's name and then give a boy's name with the letter B and continue switching between girl and boy names as they moved through the alphabet (e.g., A Andrea, B Brian, C Caroline, D Derek). Participants could play this game on their own or when assisted on a walk.

- **Alternating Colour and Object Game**

In this game participants were asked to look for a specific object with a particular colour (e.g. vehicles, house doors). Their task was to count the number of times the object was seen. If however they made a left or right turn they were asked to hold 'in their head' how many they counted and then start counting another object. If they made another left or right turn they were asked to go back to the first object they were counting and add on from the number they previously had. Participants could play this game on their own or when assisted on a walk.