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Stroke, self, identity and post-stroke psychological distress.

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

Abstract

Stroke is associated with high rates of post-stroke depression, anxiety and apathy. While research currently suggests that these issues are of bio-psycho-social origin, at this time, the literature lacks a specific psychological account that makes an explanatory contribution to such a bio-psycho-social model. Moreover, there is also little evidence supporting the use of psychotherapeutic treatment approaches for these post-stroke issues. On this basis, this thesis makes two main arguments. First, there is the need to develop and test stroke-specific psychological hypotheses that may make a specific explanatory contribution to this bio-psycho-social model. Second, there is the need to develop and test psychotherapeutic interventions that are specifically designed and tailored to the needs of stroke survivors. From these arguments, two primary objectives of this thesis emerge.

The first half of this thesis proposes, develops and investigates a specific psychological account of post-stroke psychological distress. Given the sudden nature of stroke, in combination with the onset of almost instantaneous (and lasting), physical, cognitive and functional consequences, it is hypothesised that perceived loss or change to self or identity following stroke may be a psychological factor that mediates affective responses to the stroke experience. In order to explore this possibility, this thesis first outlines the existing stroke, self and identity literature, in addition to providing a theoretically informed framework of self and identity. Utilising a community-based sample of 24 stroke-survivors, this thesis then describes an exploratory quantitative investigation of how stroke affects self and identity. Findings indicate that stroke contributes to considerable changes to both the content and continuity of self and identity, and also the emotional meaning that is attached to that content. This was followed by an investigation
of the proposed link between self and identity change, and post-stroke psychological distress. Results indicate that perceived self-knowledge change is associated with depression and anxiety, while temporal discontinuity is possibly associated with apathy symptoms. Preliminary evidence also indicates that stroke-survivors with higher levels of depression symptomology may display a pattern of biased self-referential information retrieval that is of an abstract or over-general nature. Such a bias is notably consistent with that of non-stroke affective disordered populations and may be an important maintaining factor in post-stroke depression.

Using the same sample of community-based stroke survivors, the second half of this thesis takes a mixed-method approach aimed at determining the effectiveness of a novel, group-based, visual art therapy programme (VATP) for post-stroke psychological distress. Importantly, several of the modules within the VATP are focused upon exploring and processing post-stroke identity change. Findings of this exploratory study indicate that the VATP contributed towards an improvement in psychological wellbeing within the domains of anxiety, apathy, mood and quality of life. Moreover, a complementary thematic analysis of semi-structured interview data outlined a number of possible mechanisms of treatment which were then linked to the existing psychotherapeutic theoretical literature. This analysis allowed for a treatment model of the VATP to be derived, in which it was noted that identity-related therapeutic processes were one of the potentially important aspects of their experience of the VATP.

Overall, this thesis is concerned with addressing two gaps that exist within the literature that pertain to (1) the lack of psychological theory that makes an explanatory contribution to these prevalent post-stroke psychological issues, and (2) the current lack of psychotherapeutic treatment options that exist at the current time. It is considered that the findings presented within this thesis may provide a way for both researchers and
clinicians to link together concepts of self, identity and post-stroke psychological distress in a manner that connects theory, aetiology and treatment in a manner that retains a sense of meaningfulness and relevance stroke-survivors.
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Like all things, this thesis is the product of the efforts of a collective. I would foremost like to acknowledge the social, political and historical context in which this thesis occurred. I feel extremely blessed and lucky to be born within a country that not only understands and values the importance of higher education, but also takes great strides to ensure that barriers to such education are kept (relatively speaking) to a minimum. In this context, I would like to thank the politicians, policy makers and people of New Zealand who continue to ensure that this country retains a higher education system that is both accessible and of an extremely high quality.

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Contribution to the Work

Simon Walker, with guidance and support from his primary supervisor (Associate Professor Lynette Tippett), designed the studies contained within this thesis. Simon Walker was responsible for managing recruitment of participants, liaised with Marpura Studios, organised independent coders and completed all assessments with the exception of the National Institute of Health Stroke Scale (NIHSS). Simon Walker collated, scored and analysed all data, including the thematic analysis contained within Chapter Six, and prepared the manuscript.

Associate Professor Lynette Tippett provided guidance, oversight and support across all elements of this work. Lynette also provided specific advice in regards to the design of the study, measures used, and means of quantitative analysis. She also reviewed draft versions of the manuscript.

Associate Professor Kerry Gibson provided support and advice in regards to the qualitative (thematic analysis) outlined in Chapter 6.

Associate Professor Cathy Stinear and Dr Suzanne Ackerley administered and scored the NIHSS.
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Chapter One: Overview of Stroke

Stroke, or cerebrovascular accident, is defined by the World Health Organisation as a clinical syndrome consisting of rapidly developing clinical signs of focal (or global in case of coma) disturbance of cerebral function that lasts more than 24 hours or leads to death, with no apparent cause other than that of vascular origin (Hatano, 1976). There are two broad subtypes of stroke, ischemic stroke and haemorrhagic stroke.

Ischemic Stroke

Ischemic strokes account for approximately 80% of total strokes (Warlow, Sudlow, Dennis, Wardlaw, & Sandercock, 2003). These occur as a result of disruption of the blood supply to the brain, resulting in an area of necrotic tissue, otherwise known as a cerebral infarct (Adams et al., 1993; Lezak, 2004). During an ischemic event, a blockage within a blood vessel reduces blood supply to localised brain regions resulting in a state of hypoperfusion to approximately 20% of normal blood flow (Sims & Muyderman, 2010). This causes a reduction or loss in availability of nutrients, glucose and oxygen to neurons within these regions resulting in an infarct (Ropper, Adams, Brown, & Victor, 2005). Specifically, the loss of glucose and oxygen from the decreased blood supply results in the inability of neurons to both metabolise energy and synthesise adenosine triphosphatase (ATP) (Iadecola & Anrather, 2011; Moskowitz, Lo, & Iadecola, 2010). Failure of ATP synthesis results in a dysfunctional sodium-potassium pump, causing a build-up of extracellular potassium and intracellular sodium and calcium. This leads to swelling, loss of cell integrity and ultimately cell death (Back, Hemmen, & Schüler, 2004; Lipton, 1999). Whilst neurological dysfunction as a result of an ischemic stroke typically develops within seconds or minutes of blood vessel occlusion, the full extent of
an ischemic injury evolves over an extended period of minutes, hours and even days (Moskowitz et al., 2010).

**Haemorrhagic Stroke**

Haemorrhagic strokes account for approximately 20% of total strokes (Warlow et al., 2003). These are broadly divisible into intracerebral and subarachnoid subtypes. *Intracerebral haemorrhage* occurs when blood vessels within the brain rupture, resulting in an efflux of blood into surrounding areas which damages brain tissue resulting in death or neurological impairment (Lezak, 2004; Schoenberg & Scott, 2011). Blood vessel rupture is commonly the result of sustained hypertension which damages blood vessel walls over time (Xi, Keep, & Hoff, 2006) and typically occurs at or near small artery bifurcation sites that branch from the basilar, anterior, middle, posterior or cerebral arteries (Takebayashi & Kaneko, 1983). Deep brain structures such as the caudate, putamen and thalamus are commonly affected, followed by the cerebellum (Lezak, 2004). Other causes of intracerebral haemorrhage include aneurysm, cerebral amyloid angiopathy, brain tumours and arteriovenous malformations (Qureshi, Mendelow, & Hanley, 2009).

If the volume of blood loss during intracerebral haemorrhage does not exceed approximately 150 mls then the affected individual is considered likely to survive (Xi et al., 2006). However, hematoma and odema are common, either of which have the potential to cause severe injury or death even if the initial stroke event is survived (Lezak, 2004). In this context, mechanisms of injury may include increased intracranial pressure, decreased intracerebral blood pressure, midline shift, herniation, cell degradation and membrane depolarisation (Lezak, 2004; Qureshi et al., 2009; Xi et al., 2006).
Subarachnoid haemorrhage accounts for approximately 3-5% of all strokes, and occurs outside of the brain, but within the subarachnoid space between the arachnoid and pia layers of the meninges (van Gijn & Rinkel, 2001). The most common cause of a subarachnoid haemorrhage is a ruptured aneurysm (a localised, and balloon like bulge that occurs within a weakened blood vessel wall), with the majority of such aneurysms occurring at or near junctions within the circle of Willis (Lezak, 2004; van Gijn, Kerr, & Rinkel, 2007). Less common causes include arteriovenous malformation (an abnormally developed blood vessel) and brain tumour (Barker-Collo & Feigin, 2006; Cervoni, Franco, Celli, & Fortuna, 1995).

Mechanisms of injury following subarachnoid haemorrhage include increased intracranial pressure due to the accumulation of blood within the subarachnoid space (Nornes, 1978), resulting in tissue shift, herniation and disruption to cerebrospinal fluid (Lezak, 2004; Sehba & Bederson, 2006). Due to haemorrhage there is an associated decrease of intracerebral blood pressure which may result in secondary acute ischemic strokes at other brain regions (Cahill, Calvert, & Zhang, 2006). There is also the risk of further ischemic complications due to cerebral vasospasm (narrowing of cerebral blood vessels), causing a reduction in distal blood flow in the days following haemorrhage (Dumont et al., 2003; Macdonald, Pluta, & Zhang, 2007).

Epidemiology
Worldwide, stroke causes approximately 6.2 million deaths annually, is the second most common cause of death (approximately 11% of total) and is a leading cause of disability (Mukherjee & Patil, 2011; WHO, 2012). Feigin et al. (2014) examined the prevalence and incidence of global stroke within the year 2010. They report that 16.9 million people experienced a first stroke, resulting in 5.9 million deaths, contributing to a total of 33 million stroke survivors and 102 million lost disability adjusted life years (DALY’s).
DALY’s being a measure of disease burden that includes years lost due to ill-health, disability and early death. It is expected that global prevalence rates of stroke will increase due to aging populations and by 2020 it is expected that stroke-related mortality will have almost doubled (Warlow et al., 2003). Between 1990 and 2010 the incidence of stroke decreased in high-income countries by 12% and increased by 12% in low-middle income countries (Feigin et al., 2014). Although the economic cost of stroke is difficult to quantify, it is estimated that in the United States the cost of stroke is expected to reach above $2 trillion dollars between 2005-2050 for ischemic stroke alone (in 2005 dollars) (Brown et al., 2006).

A systematic review of 56 population-based studies from around the world found that between 2000-2008, early case fatality following first stroke ranged from 17% to 30% in high-income countries, with differing survival rates across type of stroke (13–23% ischemic, 25–35% intracerebral haemorrhage, 25–35% for subarachnoid haemorrhage) (Feigin, Lawes, Bennett, Barker-Collo, & Parag, 2009). A Canadian study that included 26,676 ischemic stroke patients found that 5.7% (aged <59), 8.6% (aged 60 to 69), 13.4% (aged 70 to 79), and 24.2% (aged ≥80) died prior to discharge, indicating that older age at time of stroke increases risk of early case fatality (Saposnik et al., 2008). Longitudinal research demonstrates that stroke is associated with a 5-fold increased risk of death between one month and one year of ictus and a 2-fold increased risk of death up until 5 years beyond ictus (Brønnum-Hansen, Davidsen, & Thorvaldsen, 2001).

In Aotearoa-New Zealand, stroke is the third leading cause of death with approximately 7000 New Zealanders suffering a stroke annually, contributing to a total of 45,000 stroke survivors (Dyall, Feigin, Brown, & Roberts, 2008; Tobias, Cheung, Carter, Anderson, & Feigin, 2007). It is also estimated that stroke-related hospital and rehabilitation costs reach $450 million annually within Aotearoa-New Zealand (Child et al., 2011). Over the
last 20 years, the incidence of stroke has declined within Pakeha populations, but
remained high or increased within Maori and Pacifica populations (Carter et al., 2006).
On average, Maori and Pacifica peoples experience initial stroke onset at a significantly
younger age (62 and 64 years respectively) relative to their European counterparts (75
years) and age-adjusted rates of stroke were approximately 1.5-2.7 times greater in
Pacifica, Maori and Asian groups when compared to Pakeha (Feigin et al., 2006).
Following stroke, non-European survivors have been found to have significantly lower
functional independence, lower physical functioning and lower vitality (McNaughton,

**Psychological Consequences of Stroke**

Stroke contributes to a number of psychological consequences, however this thesis will
focus upon common, and clinically identifiable indicators of psychological distress
including post-stroke depression, anxiety and apathy.

**Post Stroke Depression**

The DSM-5 defines depression as a collection of clinically significant ego-dystonic
symptoms predominantly characterised by low mood, present for at least 2 weeks and
representing a change from previous functioning (APA, 2013). Although prevalence rates
vary between studies, there is a general consensus amongst the literature indicating that
approximately 20-25% of stroke patients will be affected by major post-stroke depression
(PSD) (Barker-Collo, 2007; Cassidy, O'Connor, & O'Keane, 2004; Robinson, 1997) and
approximately 30-50% will be affected with minor/moderate PSD (which is defined as
depressed mood with at least two, but not greater than four symptoms of major
depression) (Robinson, Starr, Kubos, & Price, 1983; Saxena & Suman, 2015; Shimoda &
Robinson, 1999). Feigin et al. (2010) report that approximately 30% of stroke survivors
retain depressive symptoms 5 years post-stroke. It is noted that the prevalence of depression in stroke populations is higher than that of non-stroke populations (approximately 5.5-9%) (Bromet et al., 2011; Kessler & Bromet, 2013) and similarly aged elderly populations (8-14%) (Jongenelis et al., 2004), indicating that stroke is linked to an increased risk of depression. At this time, PSD is regarded as the most common psychiatric consequence of stroke (Lezak, 2004; Saxena & Suman, 2015).

PSD is associated with poorer outcomes relative to stroke survivors without PSD. These include increased post-stroke mortality (House, Knapp, Bamford, & Vail, 2001; Morris, Robinson, Andrzejewski, Samuels, & Price, 1993; Williams, Ghose, & Swindle, 2004), worse long term functional outcomes (Pohjasvaara, Vataja, Leppävuori, Kaste, & Erkinjuntti, 2001), and lower rates of participation in rehabilitation (Gillen, Tennen, McKee, Gernert-Dott, & Affleck, 2001; Turner-Stokes & Hassan, 2002). Moreover, research indicates that remission of PSD is associated with an improvement in activities of daily living (Chemerinski, Robinson, Arndt, & Kosier, 2001; Chemerinski, Robinson, & Kosier, 2001), cognitive functioning (Narushima, Chan, Kosier, & Robinson, 2014) and functional recovery (Bilge, Kocer, Kocer, & Turk Boru, 2008).

In terms of factors that may underlie or contribute towards high prevalence rates of depression within post-stroke populations, biological theories postulate that ischemic infarcts specific to left-anterior or basal ganglia regions may disrupt noradrenergic striato-frontal circuits that are implicated in the regulation of mood (Lezak, 2004; Singh et al., 2000). Indeed, early research by Robinson et al. (1983) found support for the view that left-anterior lesions are significantly associated with PSD, reporting that lesion proximity to the left frontal pole is significantly correlated with PSD severity. However this view is not supported by more recent and larger scale meta-analyses which have reported no significant relationship between PSD and either lesion location or left-anterior lesions (or
indeed left hemisphere lesions whatsoever) when quality of study, PSD diagnosis, presence of aphasia, subject recruitment or time since stroke were considered (e.g. Carson et al., 2000; Gainotti, Azzoni, & Marra, 1999; Wei et al., 2015). It is acknowledged, however, that proponents of left-hemisphere hypotheses argue that the null findings borne out in such larger scale work may be due to the heterogeneity inherent to such aggregated means of data analysis (Robinson & Jorge, 2015).

Intuitively, if PSD was a consequence of a physical disruption to mood-related circuitry following stroke, it may be expected that the time course of PSD would be characterised by onset at, or very near ictus. However, research by Gainotti et al. (1999) found no relationship between PSD, lesion location and time since stroke. Instead, they report that the severity and incidence of PSD increases with time since stroke, with incidence rates at the acute (<2 months), post-acute (2-4 months) and chronic (>4 months) stages increasing from 29% to 32% and 60% respectively. While the authors argue that these data are more consistent with psychological rather than biological explanations of PSD (Gainotti et al., 1999), these findings potentially indicate that approximately 50% of cases arise at or very near ictus and are therefore possibly more related to biological factors, with the remaining 50% arising sometime after the initial stroke event, and therefore a likely consequence of interacting and multifactorial (i.e bio-psycho-social) origins. Consistent with this view, Whyte & Mulsant (2002) conducted a systematic review of 14 studies and found that peak PSD prevalence occurs approximately 3-6 months after stroke. Taken together, these research findings indicate that PSD may be characterised by later onset than would be expected if there was a specific ictus-related biological disruption to the mood circuitry of the brain. Instead, the characteristic onset and peak prevalence of PSD suggests that alternate factors, possibly of a psychological or psychosocial nature, may contribute to the onset of PSD in a considerable proportion of cases.
PSD has been associated with a number of other stroke-related outcomes. These include severity of stroke as indexed by functional measures, but not severity of stroke as indexed by lesion volume (Johnson, Minarik, Nyström, Bautista, & Gorman, 2006). Moreover, cognitive impairment (Barker-Collo, 2007; Kauhanen et al., 1999; Downhill, & Robinson, 1994), impaired physical functioning (Hosking, Marsh, & Friedman, 2000), anxiety (Ayerbe, Ayis, Wolfe, & Rudd, 2013) and diminished social networks (Andersen, Vestergaard, Ingemann-Nielsen, & Lauritzen, 1995; Robinson, & Jorge, 2015) are found to be associated with PSD. There is also an association between diminished activities of daily living (Ramasubbu, Robinson, Flint, Kosier, & Price, 1998); however it has been noted that this variable explains a small proportion (approximately 10%) of the variance in PSD (Robinson, & Jorge, 2015). Finally, there is reasonable consensus in the literature that PSD is not associated with gender (Hosking et al., 2000) or age (Chemerinski, et al., 2001; Kutlubaev, & Hacket, 2014; Robinson, & Jorge, 2015).

**Post Stroke Anxiety**

Post stroke anxiety (PSA) is a broad construct that captures several distinct anxiety disorders. These include generalised anxiety disorder, panic disorder, social phobia and post-traumatic stress disorder (APA, 2013; Lezak, 2004). Similar to PSD, PSA is prevalent within stroke populations, and is estimated to occur in approximately 21-28% of stroke-survivors (Åström, 1996; Barker-Collo, 2007; Castillo, Starkstein, Fedoroff, Price, & Robinson, 1993). Longitudinal research indicates that approximately 29-31% of stroke survivors will retain symptoms of anxiety 5-years post stroke (Lincoln et al., 2013; Wilkinson et al., 1997). Like PSD, prevalence rates for anxiety within post-stroke populations are higher than what is observed in the general population (approximately 11%) (Somers, Goldner, Waraich, & Hsu, (2006) and similarly aged, elderly populations.
(Flint, 1994; Flint, 2005), suggesting that like PSD, stroke is likely a unique risk factor for the onset of anxiety.

The presence of PSA has been found to be independently associated with increased impairment in activities of daily living (Åström, 1996; Schultz, Castillo, Rosier, & Robinson, 1997) and diminished social functioning (Shimoda & Robinson, 1998). PSA often co-occurs with PSD, with the presence of PSA being found to be independently associated with both relatively worse depressive symptoms and an increase in depression-related risk factors (Åström, 1996; Barker-Collo, 2007; Sagen et al., 2009; Shimoda & Robinson, 1998).

The onset and time course of PSA is heterogeneous, although to a lesser extent than PSD. Research indicates that PSA occurs in approximately 20% of cases directly after stroke, increasing slightly to approximately 24% between one and six months post stroke (Campbell Burton et al., 2013). Longitudinal research by Åström (1996) found that one-year post-stroke, only 23% of stroke survivors with PSA had experienced remission, with the remainder retaining PSA symptoms up to three years post stroke. PSA is considered less prone to spontaneous remission compared to PSD (D’Aniello et al., 2014).

Relative to PSD, there are considerably fewer studies investigating the possible causes or factors that are associated with PSA. Early research found support for biological antecedents, with findings indicating that right hemisphere lesions were over-represented in PSA populations relative to non-PSA populations (Castillo, et al., 1993). More recently, Tang et al. (2012) reported on research involving a cohort of 693 stroke survivors that were three-months beyond stroke. The results of this study indicate that those with PSA symptoms (≥8 Hospital Anxiety and Depression Scale-Anxiety subscale) were more likely to have acute right frontal infarcts than survivors who did not present
with PSA symptoms. It is noted that these findings contrast with the findings of an earlier longitudinal study conducted by Åström (1996). This longitudinal study followed 80 ischemic stroke survivors for three years. At the acute stage (<3 months from index stroke) Generalised Anxiety Disorder (GAD) (according to DSM-III-R criteria) was significantly associated with right hemisphere lesions, however at three months post-stroke, the association between GAD and hemisphere of lesion was no longer significant and this lack of association remained non-significant for the duration of the study.

In terms of the contribution or association with other factors, the literature is largely characterised by inconsistency. Some findings indicate that cognitive performance explains high proportions of the variance (38.5%) in post-stroke anxiety (Barker-Collo, 2007), whilst other researchers report no association (Castillo, Schultz, & Robinson, 1995; Vataja & Kaste, 2013). It is noted, however, that these divergent findings may, in part, reflect differences in methodological approaches, for example, differences in the cognitive assessments used, or the domains of cognitive functioning that were assessed. Finally, early research found a negative association between age and post-stroke anxiety and a positive association between functional impairment and post-stroke anxiety (Schultz, et al., 1997), however, more recently, Morrison, Johnston, & Walter (2000) found no association between age, self-reported disability, neurological impairment and post-stroke anxiety.

In terms of psychosocial factors Åström (1996) found that at time of hospitalisation, survivors who were living alone were more likely to develop PSA than survivors who lived with another person. Moreover, limited social engagement was the only variable that was consistently associated with PSA for the entire duration of this three-year longitudinal study (Åström, 1996). As Åström noted, these findings indicate a probable psychosocial influence whereby survivors with limited social networks are either at
greater risk of developing PSA or alternatively, the presence of PSA inhibits the development and maintenance of social networks. This psychosocial view is further supported by the work of Morrison et al. (2000) who reported that satisfaction with treatment and confidence in likelihood of recovery at one month post-stroke was associated with PSA at six months post-stroke. Interestingly, these authors found that neither self-report disability, nor neurological impairment were significantly correlated with anxiety outcomes. In terms of other stroke-specific factors, there is no support from research to date for the view that PSA is associated with functional recovery (Lincoln et al., 2013), aphasia or severity of stroke (Vataja & Kaste, 2013).

**Post-Stroke Apathy**

Apathy is principally conceptualised as a problem of motivation that may manifest across three domains. (1) Cognitive: A loss of interest in new experiences, a lack of plans or goals, and a lack of regard or concern for one’s problems. (2) Behavioural: A lack of effort, initiative and productivity, and an increasing reliance upon others to structure activities. (3) Affect: A flat affect that is characterised by a lack of response to both positive, and negative life events, and emotional indifference (Caeiro, Ferro, & Costa, 2013; Marin, Firinciogullari, & Biedrzycki, 1994; Starkstein, Fedoroff, Price, Leiguarda, & Robinson, 1993; Starkstein, & Leentjens, 2008). Whilst diagnostic classification systems do not make explicit reference to apathy as a distinct diagnostic construct (APA, 2013; WHO, 1993), it is increasingly recognised that apathy may be a syndrome that is both distinct and dissociable from depression. Qualitatively it seems the distinction between apathy and depression is clear. That is, apathy is characterised by an overall lack of feeling, whereas depression is characterised by the presence of overwhelming negative emotional states (Mayo, Fellows, Scott, Cameron, & Wood-Dauphinee, 2009; Richard, 2006).
The distinction between depression and apathy is supported by the neuropsychological literature. Early research from Marin et al. (1994) found that elevated apathy scores were not correlated with depression scores in groups of patients with either Alzheimer’s disease or right hemisphere stroke. Similarly, Levy et al. (1998) found that across five neuropsychiatric populations (Alzheimer’s disease, Parkinson’s disease, Huntington’s Disease frontotemporal-dementia, progressive supra nuclear palsy) apathy and depression were only weakly correlated in one case (Parkinson’s disease) and not correlated in all other cases. Similarly, Kirsch-Darrow, Fernandez, Marsiske, Okun & Bowers (2006), who assessed 80 Parkinson’s disease patients for apathy and depression, found that although 51% of the sample presented with apathy, the majority of these patients did not have depression.

Although there is a scarcity of studies, findings to date appear consistent with the view that depression and apathy are also dissociable within stroke populations. An investigation into the clinical correlates of apathy within 274 institutionalised stroke patients found that although apathy was prevalent (28% of patients) it was not associated with the occurrence of depressive mood symptoms (Van Almenkerk, Smalbrugge, Depla, Eefsting, & Hertogh, 2015). Similarly, Brodaty et al. (2005) investigated the clinical correlates of apathy within 167 ischemic stroke patients. The authors report that there was a significant but weak correlation between apathy and self-reported depression, but not clinician-rated depression. They note that of the 35 patients with apathy (score ≥ 37 on the informant rated Apathy Evaluation Scale), only 17.2% were depressed according to the DSM-IV major/minor depression criteria. Taken together it appears that within the context of stroke, apathy may be viewed as a qualitatively distinct syndrome that presents alongside depression in a minority of cases. In this context, it is worth noting that the extent to which these constructs overlap may be in part due to the depression measures
themselves, which often contain items that index apathy related symptoms (e.g. DSM-IV, DSM-5, Hamilton Depression Rating Scale, Beck Depression Inventory).

Prevalence rates of post-stroke apathy vary considerably between studies which likely reflects both the heterogeneity of the populations studied and the research methods employed. Prevalence rates range from 22.5% (Starkstein et al., 1993) to 50% (Okada, Kobayashi, Yamagata, Takahashi, & Yamaguchi, 1997) to 71% (Jarzewska, 2007). A recent meta-analysis involving 19 studies and 2,221 participants reported a pooled prevalence rate of 36.3% (95% CI: 30.3-42.8) (Caeiro et al., 2013). In a longitudinal study Mayo et al., (2009) found that one third of apathetic stroke patients in the acute phase of recovery retain clinical levels of apathy one-year post stroke. Although apathy is not significantly related to stroke severity, stroke volume or number of strokes, rates of apathy observed in stroke populations are considerably higher than those observed in healthy age-matched populations (Brodaty et al., 2005).

Research findings indicate that individuals with post-stroke apathy are at increased risk of experiencing worse outcomes relative to non-apathy affected survivors. Apathy predicts poorer functional recovery (Hama et al., 2007) and is associated with less independence in activities of daily living, longer hospital stays, disengagement from rehabilitation services, reduction in both physical and psychosocial recovery (Brodaty et al., 2005; Starkstein et al., 1993), greater cognitive impairment, increased dependency (van Almenkerk, et al., 2015) and lower health-related quality of life (Tang, Lau, Mok, Ungvari, & Wong, 2014). Within neurologic populations, apathy is also associated with increased caregiver burden and conflict within relationships (Landes, Sperry, Strauss, & Geldmacher, 2001).
Within stroke populations, apathy is thought to be associated with internal capsule and subcortical lesions (including the basal ganglia) in addition to the dysfunction of fronto-subcortical systems. This view converges with neuroimaging findings demonstrating that apathetic stroke patients have significantly increased levels of white matter disease in the right hemisphere affecting white matter frontal-subcortical circuits (Brodaty et al., 2005; Jorge, Starkstein, & Robinson, 2010; Okada et al., 1997). These findings are also congruent with the neuropsychological literature, which finds patterns of cognitive performance that are consistent with frontal impairments. For example, Brodaty et al. (2005) report that stroke-related apathy is associated with a reduction in processing speed, attention, concentration, working memory, reasoning, and poor verbal fluency. Similarly, there is evidence that apathy in stroke is associated with cognitive impairment and dependency in activities of daily living (van Almenkerk et al., 2015). To date, there is an overall lack of research that investigates the possible role of psychological or social factors that may be related to post-stroke apathy.

In summary, the preceding discussion considers research findings which indicate that stroke is a common and debilitating experience that results in a number of negative consequences. Of these, this thesis is primarily concerned with the high rates of depression, anxiety and apathy that characterise stroke populations. In this context, the presence of these issues is linked to a number of relatively worse outcomes including, but not limited to, impairment in daily activities, diminished social functioning, lower rates of participation in rehabilitation, and higher post-stroke mortality. In terms of aetiological factors that may account for the high prevalence of these issues, research provides support for a multi-factorial bio-psycho-social view. At this time, however, it is noted that the literature currently lacks a clear psychological hypothesis that aims to account for the very high prevalence of these issues.
Treatment of Post-Stroke Psychological Distress

Psychotherapeutic Approaches
In regards to treatment approaches for post-stroke psychological distress (i.e. depression, anxiety and apathy), there is minimal research that specifically investigates the effectiveness of psychotherapeutic approaches for these issues. Lincoln, Flannaghan, Sutcliffe and Rother (1997) conducted an exploratory, within-subject, baseline versus treatment study of cognitive behavioural therapy (CBT) with 19 stroke survivors. Participants received an average of 8 CBT sessions delivered by a psychiatric nurse or assistant psychologist. The authors reported reduced depression in 8 of 19 participants, and argued that further evaluation of CBT is warranted. A more methodologically robust study of 123 depressed stroke survivors subsequently occurred (Lincoln & Flannaghan, 2003). This study featured a randomised control design with the CBT intervention group (n=39) contrasted against both a no intervention group (n=41) and a psycho-placebo (attention) group (n=43). Outcome measures were completed at 3 and 6 months following recruitment, however there was no significant difference between the three groups on any outcome measure. The authors concluded that this study provided no support for the use of CBT for the treatment of PSD, however they noted that the small sample size may have contributed to these null findings. To date, these are the only known trials of CBT for any post-stroke psychological issue.

Motivational interviewing (MI) for the treatment of PSD has also been investigated as a psychotherapeutic intervention for low post-stroke mood. Watkins et al. (2007/2011) conducted a Randomised Controlled Trial (RCT) with 411 stroke patients comparing motivational interviewing to treatment as usual. Patients within the treatment group received up to four MI sessions (between 30-60 minutes in length) from a recently trained MI therapist. Treatment benefit was based on proportions of participants within
dichotomous low versus normal mood on the General Health Questionnaire- 28 item (GHQ). Authors reported a significant benefit of MI over usual care for mood at 3 and 12 month follow-ups, and depression (as measured by the single answer Yale test) at 3 but not 12 months. While these findings are promising, there are drawbacks to this study. These include: the unclear relationship between dose and response (i.e. only 71% of participants received the maximum of 4 sessions of MI), and the use of change in frequency in dichotomous (low vs. high mood) groups, instead of within and between group changes on dependent variables without explanation.

With the exception of a single case study that examined Acceptance Commitment Therapy (ACT), there are no published evaluations investigating psychotherapeutic interventions for PSA. In this single case, the authors report considerable improvement in anxiety as measured by the Depression, Anxiety and Stress Scale over the 9 weeks of therapy for a young adult male who was experiencing PSA and associated symptoms such as chest pain and dizziness (Graham, Gillanders, Stuart, & Gouick, 2015). At the two month follow-up, the client self-reported benefit of treatment and no continuing problems with mood. Unfortunately, objective measures of anxiety were not re-administered at follow up, limiting conclusions from this case study.

At this time, there is a total lack of published evaluations regarding psychotherapeutic treatments for post-stroke apathy. Therapeutic approaches such as behavioural activation, problem solving, motivational interviewing may have face validity, however, at this time, no such published evaluations exist. There is some evidence that motivational interviewing has been effective in reducing apathy in patients with traumatic brain injury (Lane-Brown & Tate, 2010), however, studies utilizing these approaches are yet to be conducted within stroke populations.
Overall, the current literature does not provide an evidence-base that supports the use of psychotherapy in post-stroke populations. This view is exemplified by the most recent Cochrane review of psychotherapies for post-stroke depression which found no effect of treatment for any of the outcomes measured (Hackett, Anderson, House, & Xia, 2008). Due to the extremely low volume of research it is important to characterise this as an absence of evidence for effectiveness, rather than an evidence of absence of effectiveness. Given that the aetiological literature indicates that these issues are bio-psycho-social in origin (Whyte, & Mulsant, 2002), it is considered that the lack of support for the effectiveness of psychotherapy is somewhat unexpected.

One explanation for the lack of evidence for the efficacy of psychotherapy is due to the possible inconsistency between the theoretical basis of some psychotherapeutic models and either, the lived experience of stroke, or the as yet unknown psychological causes of such issues. CBT for example, frames psychological distress as a construct that is driven by erroneous and subjectively-mediated thinking processes that are often related to maladaptive or dysfunctional core beliefs/schemas that are typically considered to be of developmental origin (Beck, 1979). This explanation of psychological distress, while fitting with non-stroke psychological disorders, may be inconsistent with what is known of the post-stroke experience. That is, stroke is an objectively harrowing occurrence that carries the realistic expectation of continuing existential threat. Moreover, many stroke survivors experience ‘objective’ change across physical, functional, cognitive & social domains which, in many case contributes to a fracturing of the pre and post-stroke identity (e.g. Ellis-Hill, Payne, & Ward, 2000; Hole, Stubbs, Roskell, & Soundy, 2014; Pallesen, 2014). Accordingly, it is possible that CBT may unhelpfully cast stroke-survivor distress as a somehow inappropriate or subjectively-mediated thinking error; however such a view would be objectively false.
As discussed post-stroke psychological distress is often characterised by high levels of co-morbidity, particularly within the context of post-stroke depression and anxiety. This co-morbidity may be a further reason why the literature has been unable to demonstrate substantive support for evidence-based treatments of post-stroke psychological issues. That is, if such co-morbidity is additive (i.e. symptoms are interrelated) rather than random (i.e. people just happen to have multiple disorders) then the commitment to single-disorder treatment models may be inconsistent with the true nature of such post-stroke issues. Accordingly, this may provide one further explanation for why there is a lack of support for such single-disorder treatment approaches (i.e. CBT for post-stroke depression).

In sum, the lack of treatment efficacy for psychotherapies such as CBT may be due to the lack of psychological accounts/explanations of post-stroke psychological distress, irrelevance to the lived experience of stroke and possibly, their single-disorder construction, in addition to the low volume of research. Therefore, despite the current lack of evidence for psychotherapy, it may be expected that future research that accounts for these issues could reveal psychotherapy to be an effective treatment option. Recently, awareness of these issues has given rise to an interest in ‘adapted’ CBT approaches, which include elements of motivational interviewing, grief resolution, and psycho-education (Broomfield et al., 2011; Kootker et al., 2015). Although such approaches are currently untested, such work highlights the importance of therapeutic approaches that account for the relative uniqueness of the stroke experience. Moreover, aetiological explanations of post-stroke psychological distress that are informed by psychological theory may also contribute towards the development of new aetiologically consistent psychotherapeutic alternatives. However, to date there is an absence of such a psychologically-informed view.
Pharmacological Approaches

There is an overall absence of evidence that supports the use of pharmacological approaches for the treatment of post-stroke psychological distress, although it is noted that at this time there is more support for such approaches compared to psychotherapeutic alternatives. A meta-analysis of post-stroke depression treatments that included 12 Randomised Controlled Trials (RCT) found a significant but small effect of anti-depressant use in the reduction and remission of depression symptoms. The authors conclude that there is tentative support for the use of such approaches; however they also caution that pharmacological treatments were associated with an increase in adverse events, including confusion, sedation, tremor and gastrointestinal effects (Hackett, Anderson, House, & Xia, 2008). For post-stroke depression, there is also some promising support for combined psychotherapeutic (behaviourally based) and pharmacological approaches. A randomised controlled trial included 101 clinically depressed, ischemic stroke participants, within 4-months of index stroke who were randomly assigned to either an anti-depressant/8-week behaviourally-based intervention group. At 12-months following entry to the study, the authors reported that participants within the combined intervention group experienced a significantly greater reduction and remission of symptoms compared to the usual care group (Mitchell, et al., 2009).

In terms of PSA, a Cochrane analysis highlights the only two known trials into pharmacological treatments (Campbell Burton et al., 2011). The authors report that pharmacological approaches reduced anxiety symptoms, however, the authors noted the poor quality of the studies, and remarked that on the basis of existing literature, there is insufficient evidence to provide guidance for the use of pharmacological approaches within post-stroke anxiety. Similar to PSD work, the authors also noted common side-
effects including nausea, vomiting or dizziness (Campbell Burton et al., 2011). Finally, within the context of apathy, there is a limited body of research with published treatment studies consisting of a small number of single case reports outlining the possible benefits of dopaminergic agonists and other stimulant medications (Kohno et al., 2010; Martin, DeLeon, Gaviria, Pavel, & Trepashko, 1995).

As is emphasised throughout this research, the tentative support for pharmacological approaches occurs within a context of possible adverse treatment risks. In addition, these risks may be elevated within stroke populations. For example, anti-depressants have been associated with an increased risk of falls, stroke/transient ischemic attack and seizure in older people (Coupland et al., 2011). Epidemiological studies have similarly found that anti-depressant use is associated with an increased risk of stroke (Hackam, & Mrkobrada, 2012; Smoller et al., 2009). Moreover, there is an increased risk of bleeding events as a consequence of drug-drug interactions between stroke-preventative pharmacological agents (e.g. Warfarin) and anti-depressants such as selective serotonin reuptake inhibitors (Cochran, Cavallari, Shapiro, & Bishop, 2011; Wallerstedt, Gleerup, Sundström, Stigendal, & Ny, 2009).

In summary, at this time, the literature lends more support for the use of pharmacological approaches in the treatment of post-stroke psychological distress than psychotherapeutic interventions. However, in both cases the evidence-base is broadly characterised by an overall absence of evidence indicating that more research is required. Additionally, although there is more support for pharmacological approaches, this occurs within a context of potentially heightened treatment risks for stroke populations. When taken together, these factors provide the rationale and impetus for the pursuit of psychotherapeutic treatment alternatives for these highly prevalent post-stroke problems.
Conclusions

This chapter provides an overview of the literature relevant to this thesis. This included a discussion of stroke-relevant epidemiological research, common psychological consequences (consisting of post-stroke depression, anxiety and apathy), aetiological accounts of these consequences and evidence for differing treatment approaches.

This overview has established that stroke is a leading cause of death and disability, and contributes to a broad spectrum of negative physical, cognitive, and functional impairments. Post-stroke psychological issues such as depression, anxiety, and apathy are also highly prevalent, and each is associated with a number of poor outcomes, relative to non-affected stroke survivors. In terms of aetiological pathways, like many non-stroke psychological disorders, evidence suggests that a considerable proportion of cases likely arise out of interacting biological, psychological and social factors (Robinson, & Jorge, 2015; Whyte, & Mulsant, 2002; Vataja, & Kaste, 2013). Of course, this does not mean that any particular stroke survivor cannot have a post-stroke issue that is purely biological or psychological in origin, but it is likely that in the majority of cases, interacting and reciprocal factors contribute to the onset and maintenance of these issues. It is noted however, that to date, the literature lacks any specific psychological hypothesis that may account for the high prevalence of these issues in stroke populations. Moreover, at this time, psychotherapeutic treatment approaches that are well supported in the non-stroke literature (e.g. CBT) have failed to demonstrate effectiveness within the context of stroke. It is considered possible, if not probable, that such psychotherapeutic findings may relate to the lack of psychologically-informed aetiological accounts of these issues. That is, it is difficult to meaningfully assess, formulate and treat a psychological problem, from a psychological standpoint, in the absence of a psychologically-derived explanation for such a problem. Although there is tentative support for pharmacological approaches, this
support needs to be balanced against adverse issues such as side-effects, and drug-drug interactions.

Accordingly, a central argument of this thesis is that the lack of specific psychologically-informed aetiological accounts of post-stroke psychological distress has likely hindered the development of aetologically-congruent psychotherapeutic treatment approaches. Furthermore, the lack of efficacy of ‘gold-standard’ psychotherapeutic approaches (i.e. CBT), may suggest that classic cognitive theories (i.e. core belief/schema, erroneous thinking processes) that underlie these interventions may be inconsistent with the psychological origins of these specific post-stroke issues. Of course, this is not to say that cognitive-behavioural psychotherapeutic approaches may not be useful in future. It is likely however, that such approaches may need to reflect cognitive-behavioural explanations of psychological distress that are specific and unique to stroke populations.

**The current thesis**

This chapter has provided the foundation for much of the remainder of this thesis by identifying two gaps that exist in the relevant stroke literature. First, there is a lack of a psychological account of post-stroke psychological distress and second, there is a lack of support for the psychotherapeutic treatment of these issues. Accordingly, this thesis has two principal objectives. First, this thesis is concerned with an attempt to explore and develop a psychologically informed account of post-stroke psychological distress. Second, this thesis aims to conduct an exploratory evaluation of the efficacy of a novel group-based psychotherapeutic treatment approach that has been specifically developed with stroke-populations in mind.

Within the context of the first objective, given the nature of stroke, with its sudden onset and instantaneous and lasting consequences, it is proposed that stroke may contribute
towards a substantial change or disruption in sense of self or identity. In turn, the perceived extent of this change is proposed to be an important psychological factor that either contributes towards or mediates the onset of post-stroke psychological distress.

Before such a hypothesis can be tested, it is first important to establish whether stroke does in fact, contribute towards a measurable change to self or identity. Accordingly, Chapter Two contains a review of the predominantly qualitative literature that relates to impact of stroke upon self and identity. Chapter Two also outlines a theoretically coherent (but useable) framework of self and identity. This is done with a view towards providing a theoretical basis from which to explore the nature of post-stroke self and identity change using empirically informed quantitative approaches.
Chapter Two: Stroke, Self and Identity

As outlined in Chapter One, stroke is a leading cause of disability and often results in a range of negative consequences for affected individuals, including high rates of post-stroke depression, anxiety and apathy. Although research indicates that these issues are of probable bio-psycho-social origin, at this time there is an absence of a specific psychological theory that makes an explanatory contribution to this model. Accordingly, the first aim of this thesis is to develop and explore a psychologically informed theoretical account of post-stroke psychological distress. This account posits that perceived self and identity change resulting from stroke contributes towards, or mediates the onset of post-stroke psychological distress. The following chapter provides the foundation for this aim. First, by providing a review of the existing stroke research as it pertains to constructs such as self and identity and second, by outlining a theoretically coherent framework of self and identity.

The Problem of Definition

Before conducting this review, it is important to discuss some of the definitional issues that characterise research into self and identity. Commentators note that although these concepts have been the subject of decades of research, they remain definitionally opaque (Addis & Tippett, 2004; Klein, 2010; Prebble, Addis, & Tippett, 2013). Identity for example, often acts as a term that encompasses any one or a number of ‘identities’ including personal, social, gender, sexual, cultural, ethnic, ego identity (and so on) (Klein, 2014; Reid & Deaux, 1996). As Klein notes “…identity is more akin to a complex fractal set than a well-formed taxonomy…” (pp.1, 2014). Moreover, the complexity induced by such definitional problems is increased by the often related or interactive nature of these
identities (Ellemers, Spears, & Doosje, 2002). For example, there a reciprocal relationship may exist between a person’s sense of personal and social identity. Where, for example, an element of personal identity gives rise to specific group-based membership, which reinforces this personal identity and so on (Breakwell, 1986).

Similarly, terms ‘self’ and ‘identity’ are often used interchangeably, and at various times, the term ‘identity’ is often used as a proxy for many aspects of the self, including self-image, self-definition, self-categorisation, me-self, self-knowledge, self-concept, ideal self and actual self (e.g. Biderman, Daniels-Zide, Reyes, & Marks, 2006; Brewer & Gardner, 1996; Ellis-Hill, & Horn, 2000; Klein, 2014; Kuenemund, Zwick, Rief, & Exner, 2014; Medved, & Brockmeier, 2008).

It’s important to acknowledge that in part, such definitional issues arise from the complexity of this topic. Concepts such as ‘self’ and ‘identity’ stand near the intersection of philosophy and psychology and are therefore less amenable to tightly bound definitions that suit exacting and empirical methods of inquiry (Baars, Ramsøy, & Laureys, 2003; Martin, 2005). Furthermore, self and identity are topics of interest for many disciplines (e.g. psychology, philosophy, sociology) as well as many sub-disciplines of psychology (e.g. social, clinical, cognitive, and neuropsychological) (Conway & Pleydell-Pearce, 2000). Often each area of inquiry conceptualises self and identity in different ways, further contributing to the development and maintenance of such definitional problems. Commentators have also noted that in many cases this complexity in meaning has perhaps led researchers to avoid making explicit and exact use of definitions, and instead there may be the tendency to rely on unstated and implicit common-sense understandings of these terms (Klein, 2010; Prebble et al., 2013). However, it is possible that this may, in part, reflect the reluctance of researchers to self-impose definitions upon these concepts.

Given the omnipresent nature of self and identity, this is understandable, as applying a
limiting or narrow definition risks creating a kind of circularity, where the very act of defining these concepts acts to constrain research efforts in accordance with those very definitions.

It is important to note that these definitional issues certainly extend to the stroke literature. That is, there is a lack of clear consistency in use of terminology, both within the stroke literature itself, but also between the stroke literature and the extant theoretical literature. This issue is further complicated by the lack of stroke research which sets out to define the terminology contained within studies. In this context, there is only one example (as far as the writer is aware) whereby scholars set out to clearly state the definitional properties of their study (Kitzmüller, Häggström, & Asplund, 2013).

**The Self, Identity and Stroke**

Before moving to review the relevant stroke literature, it is important to provide a brief overview of the background and context in which such research has occurred. To date, many investigations into the relationship between the self, identity and stroke appear to be concerned with redressing what is perceived as the predominant influence of medical models and functional rehabilitative perspectives in stroke research. For example Guise, McKinlay and Widdicombe (2010), argue that stroke research is predominantly focused on identifying and measuring indicators of physical ability, to the possible detriment of other areas of concern. Salter, Hellings, Foley and Teasell (2008) also posed a critique of the power structures that they perceive as existing within stroke research, arguing that these act to frame health-care professionals, rather than stroke-survivors as ‘experts’ in stroke. They argue that this results in an abundance of research that is concerned with functional outcomes, while the meaning that stroke survivors apply to these outcomes is less understood (Salter et al., 2008). Other commentators note that what is meaningful for stroke survivors may differ from what is perceived as meaningful by those that provide
care, and as such, the presence of ‘researcher imposed frameworks’ are argued to determine outcomes of importance, rather than stroke-survivors themselves (Doolittle, 1991; Secrest & Zeller, 2003).

Accordingly, published research that focuses on stroke, self and identity seems to primarily function as a means of countering these perceived limitations, by providing a research approach that aims to treat stroke-survivors as experts in their own experience (Murray & Harrison, 2004). In this regard, the use of concepts such as self and identity largely function as units of stroke-survivor meaning. While this provides extremely valuable and important insight into both the worldview and experiences of stroke survivors, one result is that the extant literature is not explicitly tied to a coherent definitional or theoretical framework of self and identity.

One of the most consistent findings is that stroke contributes to a considerable change (either loss or deterioration) to self-knowledge. Self-knowledge refers to self-referential information such as self-perceptions, self-identifications, traits, self-esteem, strengths and limitations, in addition to descriptions of the physical self and information about social relationships and groups (Addis & Tippett, 2008; Conway, Singer, & Tagini, 2004). A study by Dowswell et al., (2000) found that between 13-16 months post-stroke, participants experienced a deterioration of their social lives, which contributed to a perceived loss of roles, and a change in status from that of a ‘doer’ to a ‘receiver’. In this study, participants accounted for these changes in three main ways: the physical consequences of stroke, the sense that they had experienced personality changes, and feelings of shame due to their awareness of change (Dowswell et al., 2000).

Findings indicate that stroke survivors experience a perceived change to their self-knowledge in terms of roles, responsibilities, occupation, family and finances, in addition
to both a loss of social control and social position (Anderson & Whitfield, 2013; Becker, 1993; Burton, 2000; Doolittle, 1991). Research by Pallesen (2014) indicates that these perceived changes persist up to 5-years post-stroke, with participants describing their perception that social roles, particularly within the context of employment remain diminished. It is also noted that perceived changes often occur along gendered lines, for example, male stroke survivors whose pre-stroke self-knowledge reflected ‘provider’ roles, experience their post-stroke dependency as emasculating (Murray & Harrison, 2004). Similarly, female stroke-survivors who had a pre-stroke self-knowledge structured around their role as a home-keeper, experienced psychological difficulty when they were no longer able to maintain these roles (Kvine, Kirkevold, & Gjengedal, 2004). Similarly, other research indicates post-stroke changes to perceived skills and abilities (Murray & Harrison, 2004) which can be represented in evaluative statements (Guise et al., 2010) and goal states (Ellis-Hill et al., 2000).

Overall, there is little research that aims to investigate changing self-knowledge since stroke using quantitative methods. One exception to this is the work of Ellis-Hill and Horn (2000), who conducted a quantitative study that aimed to assess the extent of self-knowledge change since stroke using a constrained measure of self-knowledge, the Head Injury Semantic Differential Scale (HISDS) (note: the authors use the term self-concept in their research). In this study, 26 community-based stroke survivors were asked to rate their perceived pre and post stroke self-knowledge across 20 contrasting semantic trait items on the HISDS (e.g. friendly vs. unfriendly, withdrawn vs. talkative). Participants were first time stroke survivors with no severe communication, cognitive or perceptual difficulties. Results indicated that participants perceived themselves as significantly less interested, capable, independent, in control, satisfied and active. Findings also indicated that participants continued to perceive themselves as friendly, calm, caring, hopeful and
talkative. Although these findings provide empirical support that converges with the qualitative literature, this study was characterised by a number of limitations. For example, the study utilised only a single measure (i.e. the HISDS) that indexed self-knowledge in a prescriptive manner. That is, the measure constrained self-knowledge to 20 specific trait-items, which may mean that the important changes in self-knowledge experienced by stroke survivors were not indexed in this study. Moreover, the sample comprised participants with no severe communication, cognitive or perceptual difficulties, limiting the generalizability of the findings to the wider stroke population. Finally, the authors conducted a high number of analyses (i.e. 21) without any family-wise error rate correction (personal communication, February 2016), which would have inflated the type-one error rate, making it difficult to meaningfully interpret the findings of this study. Accordingly, although these researchers provided an important first step in attempting to apply a quantitative approach to the question of self-knowledge change since stroke, these limitations indicate that further work, and possibly, an attempt to repeat this approach is required.

Within the context of the relationship between the physical consequences of stroke and self and identity, research findings indicate that this can contribute to the sense that one is no longer the same person as they were prior to stroke. Ellis-Hill, Payne, & Ward, (2000) conducted life narrative interviews with eight stroke-survivors at three time-points (in hospital, 6-months and 1-year post-discharge). Participants reportedly experienced a fundamental change that was predominantly focused around a splitting between their sense of self and their physical body, which persisted up to the conclusion of the study. This splitting was described by the authors as ‘...a change that could be likened to entering a new foreign world’. (pg. 727, Ellis-Hill et al., 2000). When discussing this, the authors highlighted that the phenomenological experience of self is partly derived via
bodily interactions with the environment. Following stroke, the unreliable and unfamiliar nature of the body seemed to contribute to a state where the body takes the form of an object that is, in many ways, distinct or separate from the self. The authors elaborate on this by arguing that a healthy or unencumbered body largely functions in a ‘silent’ manner, and is accordingly, a taken for granted/unnamed base through which interactions with the environment occur. The authors posit that following stroke, the body no longer functioned in this silent manner and is instead, repeatedly brought into conscious awareness, contributing to a sense of separation between the body and the self (Ellis-Hill et al., 2000).

These findings converge with the work of Kitzmüller et al. (2013) who conducted narrative interviews with 23 stroke survivors. The authors report that following stroke, individuals perceive their bodies as unfamiliar and fragile, and tend to objectify them, rather than see them as intrinsic to the self. Furthermore, this altered body is seen as demanding of attention, which often means that stroke-survivors are pre-occupied with testing and determining the boundaries of its functioning, resulting in a decreased focus on the external world (Kitzmüller et al., 2013). Other researchers also note that prior to stroke, the body had been experienced as a unified ‘whole’, however following stroke, aspects of the body seem separate or alien (Pound, Gompertz, & Ebrahim, 1998). Research findings that this sense of self-body split can persist until at least 5-years post-stroke (Pallesen, 2014).

In regards to stroke contributing to a disruption or disconnection to continuity of self and identity across time, a body of qualitative research indicates that the experience of stroke contributes to a sense of pre vs. post stroke discontinuity. Dowswell et al. (2000) conducted a qualitative study with 30 stroke survivors reporting that participants experienced a considerable sense of discontinuity, noting that stroke-survivors invariably
determined the impact of stroke via comparison with their pre-stroke lives. Similar findings were reported within a qualitative meta-synthesis conducted by Salter et al. (2008), which examined and compared nine qualitative studies published between 1980 and 2007. A major theme observed across a number of these studies related to stroke contributing to a state of change, transition and transformation that is experienced as a profound disruption, a sense of discontinuity and perceived estrangement from the person they were prior to stroke (Salter et al., 2008). Similarly, Murray and Harrison (2004) conducted interviews with 10 stroke survivors, finding that participants often experienced their stroke with a sense of disrupted embodiment and a loss of self, that was described as a “loss of me” (pg. 811).

Conversely, Guise et al. (2010) utilised a social constructionist informed, discourse analytic methodology in the interpretation of data derived from focus-groups from 12 relatively young (<55 years of age) stroke survivors. They report that participants do not necessarily describe their stroke experience as contributing to a disrupted sense of self, noting that instead participants seemed to sensitively navigate their sense of a ‘damaged’ self (Guise et al., 2010). Other findings also indicate that whilst stroke-survivors do experience considerable change to their identity, they do not view themselves as being fundamentally different (Pallesen, 2014). This suggests that while stroke may contribute toward a sense of change to the objective self, the sense of one’s subjective self remains largely intact. It was also noted that stroke survivors report changes to the self that occur in an ever evolving manner, and are subject to a continual process of adjustment that never completely stabilises (Pallesen, 2014). This view is consistent with work by Becker (1993), who conducted interviews with 100 stroke survivors. This study found that stroke contributed to a crisis in meaning, which, in order to be reconciled, required survivors to firstly confront their experiences of loss and secondly, attempt to find ways to link
themselves to their past lives (Becker, 1993). That is, stroke was found to contribute to a sense of discontinuity that, in order to be managed, required survivors to actively work to identify links between their pre and post-stroke selves.

One attempt has been made to develop ways to empirically investigate the experience of continuity or discontinuity since stroke. Secrest and Zeller (2003) devised and tested a ‘Continuity of Self-Scale’ based on the findings of an earlier conducted existential phenomenological qualitative study of 14 stroke survivors (Secrest, & Thomas, 1999). This qualitative study found that the experience of continuity since stroke was related to three factors: control, independence and connections with others (Secrest, & Thomas, 1999; Secrest & Zeller, 2003). Using these data, the authors developed a 45-item scale which aimed to index the extent to which stroke-survivors experienced a sense of continuity and discontinuity since their stroke. Study participants included 55 stroke survivors, recruited from rehabilitation hospitals and the community who were administered the continuity scale, in addition to quality of life and functional ability measures. Findings indicated that participants experienced both a sense of continuity and discontinuity following stroke. Continuity was associated with higher levels of functional ability, higher self-reported quality of life and male gender, and while discontinuity was associated with lower quality of life, there was no association with functional ability (Secrest & Zeller, 2003).

Similar to the work of Secrest and Zeller (2003), other research indicates that the experience of discontinuity to self is not necessarily a ubiquitous aspect of the post-stroke experience. A qualitative study involving 57 European, African-American and Hispanic stroke survivors involved interviews at one month, six months and 12 months after being discharged from hospital (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004). The authors posited that following stroke, an individual’s sense of continuity or discontinuity
may be related to the differences in meaning that they attach to their experience. Accordingly, the authors found that although stroke caused significant and immediate physical disruption to the body, this was not always understood by participants as contributing to a sense of disruption to their life story. That is, some participants were seemingly able to maintain a sense of coherence between the pre and post-stroke self. The authors note that potentially, being able to contextualise stroke as a normal part of the aging experience allowed participants to weave the experience of stroke into the narrative of their lives (Faircloth et al., 2004). Similarly, research indicates that some stroke-survivors may work towards a sense of continuity by prioritising activities that are most salient to their pre-stroke identity (Becker, 1993; Clarke & Black, 2005).

Interestingly, Gillen (2005) also found that a majority of stroke survivors are able to describe positive consequences of their stroke, including improved social relationships, increased awareness of health, changing spirituality, personal growth, and altruism. This has led to further efforts at exploring the co-existence of positively and negatively-valenced identity changes in stroke. For example, Kuenemund, et al. (2014) investigated the possible presence of post-traumatic growth within stroke. Post-traumatic growth is an established concept within trauma research, and is defined as the experience of positive psychological change as a consequence of experiencing a disrupting and distressing event (Calhoun, & Tedeschi, 2014; Kuenemund et al., 2014). Central to post-traumatic growth is the concept of event-centrality which refers to the extent to which an aversive or distressing event is successfully incorporated into a person’s identity or life-story (Berntsen, & Rubin, 2006; Schuettler, & Boals, 2011). Kuenemund et al. took a mixed-methods approach with 42 stroke-survivors, 26 of which were subject to the qualitative component of the study. They found that although 20% of participants reported both a loss of self and self-knowledge, all participants reported at least one positive change (e.g.
closer relationships, increased gratitude & awareness of health). Relative to a control group that had no severe physical illness, but had experienced a salient and highly stressful life within the preceding two years, stroke survivors showed significantly higher levels of post-traumatic growth. Importantly the authors found that enhanced post-traumatic growth was associated with the magnitude of event-centrality of stroke. This indicates that self-reported positive identity change was not simply an avoidance related coping process, but reflected the extent to which the experience of stroke was successfully woven into the life-story of the person (Kuenemund et al., 2014).

In summary, research investigating the impact of stroke upon self and identity has made a meaningful contribution to the understanding of the post-stroke experience. To date, this research appears primarily concerned with providing a means of redressing what is perceived as the predominant influence of medical models and functional rehabilitation perspectives in stroke research. However, rather than being tied to a coherent definitional or theoretical framework, research efforts to date have seemingly focused on the use of concepts such as self and identity as units of stroke-survivor meaning, rather than as being tied to a coherent definitional or theoretical framework. Accordingly, while research clearly indicates that stroke-survivors perceive a sense of change to self and identity, it is unclear, in a theoretical sense, of what these changes may be. Moreover, because research to date is predominantly of a qualitative nature, it is difficult to determine whether the changes reported in the current literature are able to be indexed using quantitative means. With regards to the first objective of this thesis, in order to test the proposed association between stroke-related self and identity change and post-stroke psychological distress, it is firstly important to attempt to understand how, in a definitionally and theoretically clear manner, stroke affects self and identity. Secondly, it is important to determine whether any such changes are able to be measured using
quantitative methods. In order to approach these questions the remainder of this chapter provides an overview and simplified framework of the self and identity theoretical literature, in addition to outlining the important contribution of autobiographical memory systems. This is done with a view towards enhancing the definitional clarity of the field, in addition to providing a theoretical basis from which empirically informed investigations into post-stroke self and identity change may occur.

**An Overview and Framework of Self and Identity**

It is important to firstly distinguish between common terms such as self and identity, as it is noted that the relationship that exists between these concepts is seldom addressed directly. In the following framework, the self is conceptualised as the mental processes that provide a person with a sense of self-aware existence as a singular, coherent and individual being that has existed across time (Prebble et al., 2013). Integral (yet not sufficient) to this is the sense of self-reflective consciousness (the ability to direct consciousness inwardly), the sense that one is distinct from the environment and that one is capable of autonomously engaging with and learning from that environment (Damasio, 2003; Gallagher, 2000). Conversely, identity captures self-referent traits, characteristics and knowledge in addition to both the abstracted story of one’s life, and the autonoetic and subjective experience of oneself having existed across time. While it is acknowledged that it is not possible to completely disentangle these constructs, however in this discussion and in accordance with Addis and Tippett (2008), these concepts are viewed as related but distinguishable, with identity being a component part of the broader concept of self.

The ontogeny of both self and identity is thought to reflect a circular, interactive and emergent process whereby agentic individuals, within their own biological and sociocultural context, pursue activities and interactions that are congruent with their own
ever-evolving values, ideals and meanings (Biderman et al., 2006; Erikson, 1959). This is articulated by Martin (2005):

“...the psychological person starting from a basic, pre-conceptual, embodied first person perspective develops self-consciousness, conceptual self-understanding, deliberative agency and a personal identity defined by commitments and concerns associated with his or her particular existence and activity in the world” (pg. 218).

As this excerpt highlights, the capacity for self-awareness begins to emerge early in childhood (Lewis, 2000; Rochat, 2003) and consists of; the ability to direct consciousness inwardly, the realisation that one has private thoughts and feelings, and the ability to focus attention on one’s own subjective experience of the world (Leary & Tangney, 2011). Furthermore, due to continually altering developmental and sociocultural contingencies that occur across the lifespan, aspects of identity are subject to considerable change, yet despite this, identity is overwhelmingly characterised by a sense of coherent sameness and temporal continuity (Erikson, 1963; Chandler & Lalonde, 1995). This indicates that identity potentially reflects two related, but independent parts. First, identity consists of a core set of schema’s and traits that an individual considers to be representative of their person, termed self-knowledge. Second, identity is characterised by a sense of temporal continuity. That is, despite the individual experiencing considerable qualitative change to identity over time, they perceive themselves as existing as the same person over time. Accordingly, the framework within this chapter defines identity as a superordinate term that is comprised of two subcomponents; self-knowledge (oftentimes referred to as self-concept), and temporal continuity (often times referred to as self-continuity) (Prebble et al., 2013).
Chapter Two

**Self-Knowledge**

As described earlier, self-knowledge describes self-referential information such as self-perceptions, self-identifications, traits, self-esteem, strengths and limitations (Addis & Tippett, 2008; Conway et al., 2004; Klein & Loftus, 1993). Self-knowledge also captures affective and emotional judgements about the self, in addition to descriptions of the physical self and information about social relationships and groups (Prebble et al., 2013). Self-knowledge may be regarded as the scaffold through which an individual qualitatively associates or differentiates him/herself with/from others (individually or collectively), giving rise to a unique, subjective and idiosyncratic sense of self-understanding (e.g. I am hard working, I am timid, I am a Dad, I am a surfer). Within the current framework, self-knowledge is considered to be conceptually analogous with self-concept (Ellis-Hill, & Horn, 2000; Kihlstrom & Klein, 1997; Prebble et al., 2013), self-schemas (Cross, & Markus, 1994) and self-image (Rosenberg, 1965).

**Temporal Continuity**

Argued to be an essential characteristic of identity and the self, temporal continuity provides a person with a sense of coherent permanence, linking their experience of their past, to their experience of the present, to their expected experience of the future (Addis & Tippett, 2008; Chandler, & Lalonde, 1995). Temporal continuity is thought to arise from an individual’s ability to capture, bind and unify temporally-extended information and knowledge derived from the diversity of events and experiences across an individual’s lifespan, combining it into a coherent and complete temporally extended whole (Addis & Tippett, 2004; Klein & Nichols, 2012; McAdams, 2001; Prebble et al., 2013). In accordance with differences in the character of this information, temporal continuity is thought to be divisible into two subcomponents. *Phenomenological continuity* describes the subjective experience of selfhood and captures the vivid and
conscious re-experiencing of the self through time, providing an autonoetic link between the past, present and future (Addis & Tippett, 2008; Prebble et al., 2013; Tulving, 1985; Klein & Nichols, 2012). Semantic continuity refers to the various ways in which the self is represented across time and largely consists of generalised and abstracted self-referential information, which unlike phenomenological continuity, lacks any vivid or autonoetic character (Conway, & Pleydell-Pearce, 2000; Klein, & Gangi, 2010; Prebble et al., 2013). An important aspect of temporal continuity is narrative continuity, which refers to the process in which an individual creates, integrates and reconstructs life experiences into an ever evolving, coherent and meaningful life story (Ellis-Hill & Horn, 2000; McAdams, & McLean, 2013; Prebble et al., 2013; Singer, 2004). This creative and narrative process is thought to contextualise and consolidate the often disparate experiences and memories from across the lifespan into a single story that provides a sense of unitary wholeness. The creation of such narratives is thought to provide a sense of unified coherence in two ways: The first involves integrating disparate features of self-knowledge (traits, attributes, personal evaluations etc.) into a present moment conception of self that is stable and whole. The second involves linking together the disparate ‘identities’ that have existed across time by the creation of a continuous and understandable story, contributing towards a sense of temporally continuous identity (McAdams, 2001; Prebble et al., 2013). That is, the story telling or narrative process provides the means by which the disparate experiences and ‘identities’ are weaved together to create a sense of coherent temporal continuity.

**The Role of Autobiographical Memory**

The autobiographical memory system is a component of the declarative memory system and allows an individual to recollect events, experiences from their life, as well as facts and knowledge that pertain to the self (Cohen, & Conway, 2007; Robinson, 1986).
Autobiographical memory is comprised of personal episodic and personal semantic memory systems, with neuropsychological research indicating that these episodic and semantic memory systems are dissociable (Klein, Loftus, & Kihlstrom, 2002; Rosenbaum et al., 2005). Dominant theories of self and identity consider that these autobiographical memory systems are important for both a person’s sense of temporal continuity, self-knowledge and narrative identity (Conway, & Pleydell-Pearce, 2000; Gallagher, 2000; McAdams & McLean, 2013; Prebble et al., 2013).

**Personal Episodic Memory**

Personal episodic memories are memories for events and experiences of an individual’s life that are characterised by rich contextual, temporal and sensory detail (Suddendorf, Addis, & Corballis, 2009; Tulving, 1986). Personal episodic memories also contain a ‘tag’ or record of the time and space in which the remembered event was originally experienced, which in combination with the high level of sensory and affective detail, means that they are experienced as a virtual and vivid re-experiencing of the original event (Klein & Nichols, 2012; Tulving, 1986). Personal episodic memories are therefore considered to underpin the phenomena known as autonoetic consciousness or mental time travel (Tulving, 2002). Accordingly, episodic memory systems contribute to phenomenological sense of having existed across time (Tulving, 2005; Prebble et al., 2013; Vandekerckhove, 2009).

**Personal Semantic Memory**

By contrast, personal semantic memories consist of abstract, generic information, facts or knowledge about an individual or their life which, unlike episodic memories are devoid of any sensory or contextual information (Addis & Tippett, 2008; Klein & Nichols, 2012; Tulving, 1986). By providing both content and structure to an individual’s life story,
personal semantic memories are proposed to contribute to an individual’s sense of temporal continuity (Prebble et al., 2013). Conway and Pleydell-Pearce (2000) argue that abstracted personal semantic memories are contained within a hierarchical autobiographical memory system that is structured in a manner of increasing abstraction. It is important to note that conceptually, Conway and Pleydell-Pearce (2000), do not consider that the concept of semantic memory perfectly maps onto their conceptual system. Instead they consider such memories to be of an overall declarative nature, and contained within a general purpose, long-term knowledge base. However, for the purpose of this discussion, and in accordance with Prebble et al. (2013), forms of autobiographical memory that are abstracted from time and place are referred to herein as semanticized memories.

In order from highest levels of abstraction these hierarchical semantic structures consist of life-story schema, lifetime periods and general events (Conway, et al., 2004; Conway & Pleydell-Pearce, 2000). *Life-story schema* consist of highly abstracted semantic categories that arc across a great proportion of an individual’s life. *Lifetime periods* are less abstracted and contain semantic knowledge that captures the important characteristics of a defined period of time within a person’s life. Lifetime periods also contain generic thematic knowledge that describes common characteristics of that time (e.g. I was happy then, that was a busy time, things were hard financially etc.). *General events* are more specific than lifetime periods. General events may consist of repeated events (e.g. our yearly camping trip to the beach) and specific events (e.g. our trip to France). General event memories retain their semantic character and consist of conceptual representations of an event that are accompanied by the feeling of de-contextual familiarity, rather than the experience of reliving or recollecting an event (often termed ‘gist’ memories).
Conway and Pleydell-Pearce, (2000) contend that in healthy individuals, activation of the autobiographical memory system involves a process of hierarchically mediated retrieval, with ever increasing levels of specificity. For example, knowledge stored at the level of life-story schema can index information within a lifetime period which then indexes a general event. The hierarchically organised nature of this information is thought to allow for a stable, consistent and coherent pattern of self and identity to exist and persist, both within the present moment and across time, thereby contributing to temporal continuity.

A summary model of the relationship between autobiographical memory systems and their contribution to temporal continuity is outlined in Figure 1 (adapted from: Addis & Tippett, 2008; Conway et al., 2004; Conway, 2005; Conway, & Pleydell-Pearce, 2000; Prebble et al., 2013).

![Figure 1: Autobiographical Memory and relative contributions to the temporal continuity of identity and self.](image)

**The Contribution to Self-Knowledge**

Autobiographical semantic memory systems are also understood to provide a storehouse for generic, factual knowledge about the self, including traits, schemas and other
examples of abstracted, context-less information (Conway, 2005; Klein & Nichols, 2012). Termed self-knowledge within this thesis, this semantic storehouse provides an easily accessible database, which is able to deliver summaries of self-knowledge which are based on behaviours and dispositions displayed in and throughout earlier life (Klein & Gangi, 2010; Klein & Loftus, 1993). This is an important function as the contextualisation of self-knowledge with reference to certain lifetime periods or repeated events allows for the individual to make behavioural, cognitive and affective predictions about the self, given differing future contexts. It is noted that although such self-knowledge is crucial to the development and maintenance of an individual’s sense of identity, it is not thought to contribute to temporal continuity (Klein, German, Cosmides, & Gabriel, 2004).

Although the majority of self-knowledge is derived from autobiographical semantic networks, it has been proposed that episodic autobiographical memory systems may contribute to self-knowledge, albeit in a relatively minor way. This contribution of episodic memory may occur via the conscious retrieval of specific episodic events when individuals attempt to make trait judgments about themselves (e.g. if an individual was asked to consider whether they were an aggressive person, they may retrieve relevant episodic memories that help inform that judgement) (Bower, & Gilligan, 1979; Addis & Tippett, 2008).

**Overview of Self and Identity**
This overview started by attempting to partially disentangle the concept of the self from that of identity. The self and identity were framed as related but distinguishable concepts, with identity being a component part of the broader concept of self. Conceptually, the self was framed as arising from a number of mental processes that provide a sense of self-aware existence as a coherent and singular being. This includes the ability to direct
consciousness inwardly (reflective self-awareness), the awareness that one’s body was distinct from the environment and that one is capable of autonomously engaging with the environment. It is noted that the concept of self, whilst conceptually distinguishable from that of identity, is integrated with, rather than distinct from, identity. In this context, identity was framed as the mental representation that one has of oneself, and is comprised of semantic self-knowledge, in addition to the sense of temporal continuity. Temporal continuity, in turn, is derived from phenomenological continuity (i.e. the autonoetic re-experiencing of the self over time) and semantic continuity (i.e. the ways in which the self is abstractly represented across time). It is also noted that this includes the temporally extended sense of self, which is maintained by a creative, integrative and constructive process of narrative continuity.

Existing theories that outline the contribution of autobiographical memory to self and identity were also discussed. It is thought that the autobiographical memory system provides the raw materials by which an individual condenses and integrates the experiences and knowledge from their life into a coherent and continuous sense of self. Episodic memories, in conjunction with the phenomena of autonoetic consciousness contribute towards the sense of phenomenological continuity. Semantic memories, through the creation of a coherent life-story, comprised of abstracted schema, periods and events contribute to a sense of semantic continuity and are creatively combined in a process of narrative continuity, in addition to providing a storehouse of semantic self-knowledge. The conceptual relationship between autobiographical memory systems, identity and the self as described in this chapter are outlined in Figure 2.
Overall Summary

The existing body of stroke-related research has made an extremely valuable contribution to the understanding of the experience of stroke by focusing on the use of self and identity as units of stroke-survivor meaning. Overall, the literature supports the view that survivors experience change to their sense of self and identity, particularly through the perception of negative change to self-knowledge. Moreover it is indicated that this change occurs across a number of important domains, including physical functioning, social roles and responsibilities, attributes, goal states and possibly, self-referential evaluative statements. Findings also indicate that physical change that is experienced following stroke, contributes to a sense of a body-self split, which may contribute towards a specific disruption to the sense of self, irrespective of any identity change.

What is less clear is whether stroke survivors experience a sense of discontinuity between their pre and post-stroke selves. A body of qualitative research does indeed report such a
pattern; however the literature is by no means characterised by a clear consensus. Instead, research indicates that discontinuity is a contingent phenomenon, possibly related to contextual factors and the extent to which the individual is able to weave this experience into the biography or narrative of their lives. Moreover, it is noted that, with the exception of one study, which reported that survivors do not experience themselves as being ‘fundamentally’ different, there is an absence of research that contrasts the subjective and objective aspects of self and identity as they exist across time.

It is also noted that research to date is almost exclusively of a qualitative nature. Of course, while the use of qualitative approaches provides an importantly ideographic and contextually rich account of survivor experiences, the lack of quantitative methods means that it is difficult to both generalise the existing findings beyond the samples studied and link findings to the theoretical literature. Moreover, while the existing literature clearly indicates that change to self and identity occurs, it is not, in of itself, sufficient to justify an investigation into a proposed link between stroke-related self and identity change, and post-stroke psychological distress. That is, it remains unclear whether the stroke-survivor accounts reported in the qualitative literature would be borne out in more empirically informed investigations into this research question. In this regard, the second half of this chapter outlined a theoretical framework of self and identity. This was done with a view to providing some definitional and theoretical clarity to the field, which in turn, may support a more empirical approach to the question of how the experience of stroke impacts self and identity. In this context, the current chapter, by providing an overview of the current stroke, self and identity literature, in addition to a theoretical framework of self and identity has laid the foundation for the first objective of this thesis.

Chapter Three now moves to describe the methods and participants that comprise the current thesis. Chapter Four then outlines an initial quantitative investigation which aims
to determine some of the ways in which stroke affects perceptions of self and identity. Chapter Four also describes the study that is related to the first objective of this thesis. This study involves an initial investigation into whether perceived self and identity change following stroke is a psychological factor that is associated with post-stroke psychological distress. The second objective of this thesis is then addressed within Chapters Five and Six. These chapters describe a further exploratory study that takes a mixed-method approach for the purposes of examining the effectiveness and possible treatment mechanisms of a novel, group-based, visual art therapy programme (VATP) for post-stroke psychological distress. Finally, Chapter Seven provides an overall discussion and summation of the work contained within the current thesis.
Chapter Three: General Method

Participants
Two cohorts (n (cohort one) = 12 and n (cohort two) = 12), separated by one year, were initially recruited. Both cohorts comprised community-based stroke survivors who were experiencing psychological or psychosocial difficulties and/or maladjustment since stroke as determined by their Stroke Foundation stroke-advisor (a trained nurse). Independent samples t-tests found no significant difference between the cohorts for age (t(22)=0.123, p=0.903), years of education (t(22)=1.055, p=0.303), number of strokes (t(22)=0.871, p=0.393), or time since most recent stroke (t(22)=0.563, p=0.579). Pearson’s chi-square tests found no difference between cohorts for frequency of hemisphere of stroke ($\chi^2_{(1,n=24)}=0.686$, p=.408), gender ($\chi^2_{(1,n=24)}=0.00$, p=1) and frequency of self-reported post-stroke psychiatric problems ($\chi^2_{(1,n=24)}=0.00$, p=1). Because no differences were found on any of these demographic variables, for the purpose of increased statistical power, for the majority of analyses the two cohorts were combined to create a single sample of 24 participants. Descriptive statistics for demographic variables are presented in Table 1.

Table 1: Descriptive statistics for demographic variables of cohort one and two.

<table>
<thead>
<tr>
<th></th>
<th>Cohort One (n=12)</th>
<th>Cohort Two (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age: Mean (SD)</td>
<td>58.58 (7.29)</td>
<td>59.17 (14.71)</td>
</tr>
<tr>
<td>Gender: Male %</td>
<td>58%</td>
<td>58%</td>
</tr>
<tr>
<td>Ethnicity¹</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maori</td>
<td>2 (17%)</td>
<td>2 (17%)</td>
</tr>
<tr>
<td>European²</td>
<td>9 (75%)</td>
<td>7 (58%)</td>
</tr>
<tr>
<td>Pacifica</td>
<td>-</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (8%)</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>Indian</td>
<td>-</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>Years of Education: Mean (SD)</td>
<td>13 (1.71)</td>
<td>12.33 (1.37)</td>
</tr>
<tr>
<td>Number of strokes: Mean (SD)</td>
<td>1.33 (0.89)</td>
<td>1.67 (0.99)</td>
</tr>
<tr>
<td>Time since most recent stroke (years)³: Mean (SD)</td>
<td>3.21 (3.67)</td>
<td>4.20 (4.89)</td>
</tr>
<tr>
<td>Hemisphere of stroke: Left (%)</td>
<td>4 (33%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>Self-reported post-stroke psychiatric difficulties: Yes (%)</td>
<td>6 (50%)</td>
<td>6 (50%)</td>
</tr>
</tbody>
</table>

Note: ¹= Self-identified. ²= Includes those that identify as being of Pakeha, New Zealand European, Scottish, Dutch-South African, Celtic, Australian and Georgian descent. ³= In the case of multiple strokes, this describes time since most recent stroke. ⁴= Self-reported depression, anxiety, low mood, emotional dysregulation and suicidal ideation.
The combined community-based sample (n=24) comprised 14 males and 10 females between the ages of 23 and 77 years (M=58.88, SD=11.36). All participants had experienced at least one stroke, with time since most recent stroke ranging from 6 weeks to 16 years (M(years)=3.70, SD(years)=4.26). Sixty-three percent of participant’s experienced their most recent stroke within 3 years. Ten (42%) participants had left hemisphere stroke. Twelve participants (50%) self-reported such post-stroke adjustment difficulties including low mood, anxiety, emotional dysregulation, impulsivity, anger and suicidal ideation. Demographic and clinical characteristics of the total sample are presented in Table 2.

**Table 2:** Descriptive statistics for demographic, clinical and cognitive variables for the combined cohort.

<table>
<thead>
<tr>
<th>Total sample (n=24)</th>
<th>Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
</tr>
<tr>
<td>Age: Mean (SD)</td>
<td>58.88 years (11.36)</td>
</tr>
<tr>
<td>Education: Mean( SD)</td>
<td>12.67 years (1.55)</td>
</tr>
<tr>
<td>Handedness: Right (%)</td>
<td>22 (92%)</td>
</tr>
<tr>
<td><strong>Clinical Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Hemisphere of Stroke: Left (%)</td>
<td>10 (42%)</td>
</tr>
<tr>
<td>Time since most recent stroke</td>
<td></td>
</tr>
<tr>
<td>&lt; 6 months (%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>6 months-1 year (%)</td>
<td>5 (21%)</td>
</tr>
<tr>
<td>1-3 years (%)</td>
<td>6 (25%)</td>
</tr>
<tr>
<td>3-6 years (%)</td>
<td>7 (29%)</td>
</tr>
<tr>
<td>&gt;6 years (%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td><strong>Cognitive Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>ACE-III¹ total score: Mean (SD)</td>
<td>83.29 (12.87)</td>
</tr>
<tr>
<td>Block Design²: Mean (SD)</td>
<td>9.13 (2.96)</td>
</tr>
<tr>
<td>Matrix Reasoning²: Mean (SD)</td>
<td>10.70 (3.01)</td>
</tr>
<tr>
<td>Guilfords Alternative Uses Task: Fluency: Mean (SD)</td>
<td>19.95 (9.67)</td>
</tr>
<tr>
<td>Guilfords Alternative Uses Task: Flexibility: Mean (SD)</td>
<td>11.95 (4.71)</td>
</tr>
<tr>
<td><strong>Other Variables</strong></td>
<td></td>
</tr>
<tr>
<td>Self-reported post-stroke psychiatric difficulties³: n (%)</td>
<td>12 (50%)</td>
</tr>
<tr>
<td>Proportion with HADS-D scores ≥8: n (%)</td>
<td>12 (50%)</td>
</tr>
<tr>
<td>Proportion with HADS-A scores ≥8: n (%)</td>
<td>11 (46%)</td>
</tr>
<tr>
<td>Co-morbidity⁴: n (%)</td>
<td>9 (38%)</td>
</tr>
<tr>
<td>Modified Rankin Scale: Mean (SD)</td>
<td>2.17 (0.87)</td>
</tr>
<tr>
<td>Social Networks Scale: Mean (SD)</td>
<td>6.25 (1.89)</td>
</tr>
<tr>
<td>NIHSS⁵: Mean (SD)</td>
<td>2.57 (2.21)</td>
</tr>
</tbody>
</table>

**Note:** 1=Addenbrookes Cognitive Exam-III. 2= Scaled Scores (M=10, SD=3). 3=Includes depression, anxiety, low mood, emotional dysregulation and suicidal ideation. 4=Both HADS-D & HADS-A ≥8, 5= National Institute of Health Stroke Scale.
Chapter Three

Participant Discontinuation/Exclusion

One participant (participant 20) decided to not continue onto the VATP after completion of the initial assessment due to scheduling issues. Two participants (participants 16 & 21), started but did not complete the VATP (note: these two participants are discussed more fully in Chapter Five). Accordingly, data from these three participants were used in Chapter 4 only. One participant (participant 5) completed assessments and undertook the VATP however; all data for this participant were excluded. During the pre-VATP assessment this participant’s responses were judged to provide an inaccurate estimation of his current level of physical and psychological functioning. For example, on all items that rely on self-report (across both psychological and physical domains) his scores reflected a total absence of distress or impairment. That is, he scored the ‘best’ possible score on all these measures. However his pattern of responding was inconsistent with his presentation during the assessments, in that the participant was noted to have some difficulty walking and presented with behavioural indicators of anxiety (agitation, fast-speaking, hand shaking, nervousness etc.). Additionally, at the time of the initial assessment, this participant reported being in the midst of an employment dispute, possibly related to stroke, and subsequent to the assessment he requested that the results be made available to aid in this dispute. This raised the possibility that he was externally motivated to under-represent any psychological distress or physical impairment that he was experiencing. On the basis of the assessment, however, it was not possible to determine whether the nature of this participant’s response was due to intentional wrong responding, anosognosia or a stroke-related deficit in self-awareness. On this basis, the study outlined in Chapter Four retained a total number of 23 participants, while Chapters Five and Six retained a total number of 20 participants.
**Materials**

The majority of measures that are used within this thesis are described in the current chapter. However, measures that are exclusive to Chapter Four are described therein.

*Addenbrookes Cognitive Exam-III (ACE-III)* (Hsieh, Schubert, Hoon, Mioshi & Hodges, 2013): The ACE-III is a brief screening tool of global cognitive function that assesses 5 domains (attention, memory, fluency, language & visuospatial ability). It is commonly used as a screen for dementia in clinical and research contexts (Dudas, Berrios, & Hodges, 2005). The maximum score on the ACE-III is 100 with a higher score indicating better cognitive functioning. The ACE-III has shown to have high internal reliability with a Cronbach’s $\alpha$ of 0.88 (Hsieh et al., 2013).

*Block Design (WAIS-III)*: Block Design is a timed task that requires the examinee to use their hands to rearrange patterned blocks into specific designs of increasing difficulty. Performance on Block Design relies upon non-verbal abstract conceptualisation, visuospatial ability and motor skill. Raw scores are calculated based on accuracy of designs produced by the examinee and completion times. Raw scores are then transformed into age-corrected scaled scores with a mean of 10 and a standard deviation of 3. The Block Design subtest has shown high reliability across age ranges ($r=0.86$) and correlates well with the WAIS-R ($r=0.77$) and WAIS-IV ($r=0.80$) Block Design subtest.

*Matrix Reasoning (WAIS-III)*: Matrix Reasoning is an untimed task that requires the examinee to view an incomplete matrix pattern and accurately select the missing component from a plate of response options. Performance on the Matrix Reasoning subtest relies upon non-verbal abstract conceptualisation, problem solving and inductive/spatial reasoning. Raw scores are calculated based on accuracy of an examinee’s response. Raw scores are then transformed into age-corrected scaled scores with a mean of 10 and a standard deviation of 3. Matrix Reasoning has shown high...
reliability across age ranges \((r=0.90)\), it correlates highly the Standard Progressive Matrices \((r=0.81)\) and the WAIS-IV \((r=.70)\) Matrix Reasoning subtest.

Within this sample, there was a significant, high and positive correlation between scores on Block Design \((M=9.13, SD=2.96, \text{Range}= 2-14)\) and Matrix Reasoning \((M=10.70, SD=3.01, \text{Range}= 5-16)\) subtest scaled scores \((r=.771, p<.001)\), therefore for the purpose of this study, Block Design and Matrix Reasoning scaled scores were combined to provide an aggregate measure of visual reasoning and constructional ability (note, due to these subtest scale scores having the same mean and standard deviation, they were simply averaged for each participant).

*Guilford’s Test of Alternative Uses (Guilford, 1967):* The Guilford’s Test of alternative uses (henceforth referred to as alternative uses task) provides an index of divergent, creative thinking ability. During three trials, participants are required to generate as many alternative uses as possible for an everyday object. Three objects were used (brick, paperclip and automobile tyre). Each trial was two minutes in duration. Participant responses were recorded and scored in two ways. *Fluency* involved totalling the number of valid responses (repeat responses were removed) for each object. For each participant these were then summed to provide a total score. *Flexibility* involved coding the responses into the number of distinct semantic categories using a prescribed coding method (see appendix I). For example, on the trial *paperclip*, responses ‘to make earrings’, ‘to make a necklace’ would be grouped in one semantic category (i.e. jewellery), whereas responses ‘clean fingernails’, ‘unblock sink’, would be grouped in another category (i.e. attribute of paperclip: size). Due to the subjectivity involved in this coding procedure, coding was undertaken by an independent coder.

The coder was a post-graduate clinical psychology student who was blind to any hypotheses and the coding procedure was as follows. The coder was provided with the
coding manual (see appendix I) and a small amount of sham data for the purpose of practice. This sham data was also coded by the writer and any major differences between the codes, or any major deviations from the coding manual were discussed until a good level of consistency was obtained. At this time the entire data set was coded by the coder. For each participant, total flexibility scores were derived by summing the number of semantic categories used for each object. The writer then coded 50% of the sample (n=12) for the purpose of determining inter-rater reliability. Inter-rater reliability was determined using the intra-class correlation co-efficient (ICC) (Shrout, & Fleiss, 1979). The ICC was used to determine the extent of concordance between the ordinal data applied by the coder and the writer, therefore providing an indication of the consistency to which the primary coder applied the coding scheme. Settings for these inter-rater reliability analyses consisted of a two-way mixed model for absolute agreement between ratings. In this case, an intraclass correlation revealed high inter-rater reliability with regard to each participants total flexibility score (Cronbach’s α = .992).

It was anticipated that fluency and flexibility scores would be highly correlated and this was confirmed by a preliminary correlational analysis ($r=0.902$, $p<.001$). Accordingly, it was decided to only use data derived from flexibility coding in the analyses within this thesis. Flexibility data was chosen as the ability to cycle through different semantic categories as a generation strategy was considered to provide a better index of divergent, creative thinking ability, relative to fluency.

*Modified Rankin Scale (Rankin, 1957)*: The Modified Rankin Scale (mRS) is a commonly used clinician reported measure of dependence and disability in neurologically impaired individuals (Sulter, Steen, & De Keyser, 1999). Responders answer a series of questions that relate to pre/post stroke activities of daily living in order to determine the extent of stroke-affected change. Questions are delivered verbally and ordered from most severe
(e.g. ‘Does the patient require constant care?’) to least severe (e.g. ‘Does the patient have any symptoms resulting from stroke?’). Each question maps onto one of six categories ranging from 5 (severe disability) to 0 (no disability). When a patient first answers in the affirmative (i.e. confirms that stroke has negatively affected this domain of living) they are scored in accordance with the appropriate category of impairment.

**National Institute of Health Stroke Scale (Brott et al., 1989):** The National Institute of Health Stroke Scale (NIHSS) provides a quantitative assessment of stroke-related neurological deficit and has been widely used in both clinical and research contexts. The NIHSS is comprised of a 15-item neurologic examination which assesses levels of consciousness, language, neglect, visual-field loss, extraocular movement, motor strength, ataxia, dysarthria and sensory loss. Each item is allocated a score (which range between 0-2 & 0-4) with higher scores indicating greater levels of impairment. Individual scores from each item are summed in order to calculate a patient’s total NIHSS score (range: 0-42). The NIHSS has demonstrated good inter-rater reliability ($r=.95$) (Hinkle, 2014).

**Social Network Measure (Cohen, Underwood, & Gottlieb, 2000):** The Social Network Measure provides an index of the types of social relationships that an individual has. This measure consists of 14-items, each of which describes a different social relationship (e.g. spouse, parent, workmate). Responders indicate (Yes/No) whether they have spoken to a person, either in person or on the phone, within that particular relationship in the past two-weeks. During scoring, all yes responses are summed, providing a single, continuous outcome variable with higher scores indicating a greater number of social networks.

**Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983):** The Hospital Anxiety and Depression Scale is a self-report questionnaire which is used within research and clinical contexts where responders may have underlying physical or cognitive impairments that may overlap with symptoms of depression or anxiety (e.g. fatigue,
physical impairment, insomnia). The HADS contains 14 statements (e.g. ‘I feel tense and wound up’), seven of which each relate to anxiety and depression. The HADS features two subscales, which are scored separately; anxiety (HADS-A) and depression (HADS-D). The responder is presented with four Likert responses (numbered 0-3) for each statement and is asked to select the response which best describes how he/she has been feeling in the past week, including today. A systematic review by (Bjelland, Dahl, Haug, & Neckelmann, 2002) found that the mean optimal cut-off score for the HADS-A and HADS-D in patients was ≥8 with a mean sensitivity of 0.90 and 0.83 and specificity of 0.78 and 0.79 (respectively). Internal consistency was also reported in 15 studies with the HADS-A and HADS-D having a mean Cronbach’s co-efficient of 0.83 and 0.82 (respectively) (Bjelland et al., 2002). Retest reliability for both the HADS-A and HADS-D is high within two weeks (0.84 and 0.85 respectively) decreasing at 2-6 weeks (0.73 and 0.76 respectively) and >6 weeks (0.70 in both cases) (Herrmann, 1997).

*Stroke Impact Scale version 3.0, Mood and Participation subtests (Duncan et al., 1999):* The Stroke Impact Scale (SIS) is a stroke specific, self-report measure. It provides a multidimensional health status assessment across 8 domains of functioning including; strength, mood, participation, memory, communication, activities of daily living, mobility and hand function. In this thesis, two subtests were used: SIS (mood) and SIS (participation). SIS (mood) contains nine items that relate to feelings of sadness, hope for the future, self-blame and enjoyment of life. SIS (participation) contains eight items that index the extent to which people feel that they have been limited in the meaningful aspects of life, including work, recreation, social interactions, and social roles. Broadly speaking, the SIS (participation) subtest provides an index of impact of stroke on quality of life status. Participants respond to items by either pointing or replying verbally to a five-point Likert scale which expresses the continuum of difficulty/impairment in mood and participation in daily life.
activities that the patient experiences. It is noted that SIS (mood) items relate to how the participant is feeling over the preceding week, whereas SIS (participation) relates to experiences over the preceding four-weeks. Raw scores are calculated for each domain of functioning and transformed using the following formula: 

\[
\text{Transformed Scale} = \frac{(\text{Raw Score} - \text{Lowest Possible Raw score})}{\text{Highest Possible Score}} \times 100
\]

Internal consistency of the SIS is excellent (Cronbach’s alpha ≥0.89 except for mood α= 0.76) (Duncan et al., 2005). The SIS has been demonstrated to have good pre-post treatment concurrent validity when compared to the Fugal-Meyer Assessment, Motor Activity Log, Functional Independence Measure, Frenchay Activities Index and Nottingham Extended Activities of Daily Living Scale (Lin et al., 2010). The SIS demonstrates good/excellent test-retest reliability (r≥ 0.75) on all measures except for mood (r=0.68) (Duncan et al., 2005).

**Apathy Evaluation Scale-self rated (Marin, Biedrzycki, & Firinciogullari, 1991):** The Apathy Evaluation Scale (AES) is a self-report measure that provides an assessment of apathy across cognitive, emotional and behavioural domains (Marin et al., 1991). The AES contains 18 items which responders answer according to a 4-point Likert scale featuring categories; *not at all true, slightly true, somewhat true* and *very true*. Responders may respond to the items by pointing, verbalising or circling (with pen) their preferred response. The AES features 3 items (numbers 6, 10 & 11) which are reverse scored. Total scores for all items are summed, providing a single, continuous dependent variable. Higher scores indicate greater self-reported apathy. The self-reported version of the AES has good internal consistency (Cronbach’s alpha, α= .86) and test re-test reliability (r=0.76) (Marin et al., 1991). The AES has been used in Parkinson’s Disease (Remy, Doder, Lees, Turjanski, & Brooks, 2005) Multiple Sclerosis (Raimo et al., 2014), geriatric (Resnick, Zimmerman, Magaziner, & Adelman, 1998) and stroke (Marin et al., 1991) research.
Quality of Life Scale (Flanagan, 1982): This scale provides a quantitative index of quality of life. It is comprised of 16-items that map onto the constructs of (1) material/physical wellbeing, (2) relationships with others, (3) social activities, (4) personal development and (5) recreation (Burckhardt & Anderson, 2003). Participants are asked to rate how satisfied they are at that time with each item. Participants score their responses using a seven point Likert scale that ranges from ‘1’ (terrible) to ‘7’ (delighted). The 16-item scores are summed to provide a total score (range 16-112) with higher scores indicating a higher quality of life. The Quality of Life Scale has demonstrated internal consistency reliability (α=.82 at Time 1 and .88 at Time 2) and good test-retest reliability (r = .84 for a 4-week interval) (Burckhardt & Anderson, 2003; Burckhardt, Archenholtz, & Bjelle, 1992).

Generalised Self-efficacy Scale (Schwarzer & Jerusalem, 1995): The generalised self-efficacy scale (hereafter referred to as the self-efficacy scale) is a self-reported measure of self-efficacy. This scale was created to assess perceived self-efficacy with a focus on coping with daily life, adaption and problem solving abilities in response to life events. The self-efficacy scale contains 10-items, which responders answer according to a 4-point Likert scale featuring categories; not at all true, hardly true, moderately true and exactly true. Responders may respond to the items by pointing, verbalising or circling (with pen) their preferred response. During scoring all responses are summed, providing a single, continuous dependent variable. Scores range from 10-40, with higher scores indicating greater self-reported efficacy. The scale has good internal consistency (Cronbach’s alpha ranging from, α=.75-.90) (Schwarzer & Jerusalem, 1995).

Procedure
Ethics approval was acquired from the University of Auckland Human Subjects Ethics Committee prior to the commencement of the study. Potential participants were initially
provided information about the study and the associated Visual Arts Therapy Program (VATP) by their community-based stroke advisor. If potential participants demonstrated interest in the study they were provided a copy of the participant information sheet (see Appendices A & B). If they demonstrated continued interest they were told that a researcher would contact them within 7 days to explain the study, answer any questions and set up an initial appointment. If, after further discussion of the scope, intent and purpose of the study, the participant wished to continue, an appointment was made in which informed consent would be obtained and the first assessment conducted. All participants were required to be able to provide informed consent and be fluent in English. Written informed consent was acquired in all cases.

All participants were recruited through the Stroke Foundation of New Zealand, Auckland region. All participants (total n=24) had experienced at least one stroke, were living in the community and were drawn from the Auckland area. Exclusion criteria were purposely kept to a minimum. Exclusion criteria consisted of (a) previous experience of a post-stroke art therapy course (b) inability to provide informed consent (c) not fluent in English. Assessment sessions began with the gathering of background demographic information (see Appendix E), followed by the administration of assessment measures. During the assessments, participants were encouraged to go at their own pace, to take breaks, and if necessary adjournment was offered. Participants did not pay to participate in the VATP and at each assessment point they were provided a koha ($20 voucher). All assessments and measures were conducted and administered by the writer with the exception of the National Institutes of Health Stroke Scale (NIHSS) which was administered by other researchers that are experienced in its use. The first cohort completed the VATP in 2014 and the second in 2015.
All participants undertook assessments at three time-points: within two weeks prior to the VATP (pre-VATP assessment), within two weeks of VATP conclusion (post-VATP assessment) and approximately 6-months post-VATP conclusion (follow-up assessment) (see Figure 3). However, in order to provide a waitlist non-active control condition, the second cohort undertook an additional assessment which took place approximately 6 weeks prior to the pre-VATP assessment (henceforth referred to as baseline assessment). It is noted that this earlier assessment was originally planned to occur 10-12 weeks prior to the start of the VATP (see appendix B), however recruitment issues prohibited this.

The duration of assessments for stroke participants across these time points varied across participants. Neuropsychological assessments were delivered directly after the collection of demographic information to minimise the possibility that fatigue may affect test performances. Measures that were expected to be more emotionally challenging were delivered towards the end of the assessments, to allow for the development of rapport. Initial assessments took between 2-5 hours and the post-VATP and follow-up assessments took between 1-3 hours. An overview of the study is provided in Figure 3.

Design overview

In general, this thesis featured a within-subjects design; however, on occasion, between-subject analyses were conducted. This design was chosen because of the increased statistical power that is gained due to the use of each subject as their own control.

Epistemological rationale

Overall, this thesis takes a positivist epistemological stance and for the most part makes use of quantitative means of inquiry. However, Chapter Six, which outlines a qualitative analysis of participant experiences of a group-based Visual Art Therapy Programme is an exception to this. This epistemological departure from the positivist tradition is discussed more fully at the outset of Chapter Six.
Data Analysis

Statistical Analyses

All analyses were performed with SPSS for windows (version 22) or JASP (Version 7.1.12).

Scoring and Data Entry

All measures and tests were scored by the writer with the exception of the NIHSS and those that were subject to independent coding. All scores were entered into an excel spreadsheet and double checked for accuracy of entry at two, separated time points. Minimum and maximum values were inspected for plausibility and data was visually examined in a scatter plot, allowing for re-checking of outliers. When transferred between excel spreadsheets and SPSS, minimum and maximum values, in addition to measures of central tendency were cross checked to ensure consistency between data sets. JASP allows for direct access to excel files so no cross-checking is required. Semi-structured interviews were transcribed by a confidential professional transcription service.

Effect Size Calculations

For the purpose of providing an index of effect strength, effect sizes are reported for both parametric and non-parametric analyses. Effect size estimation for all parametric analyses utilises the partial eta squared (\( \eta^2_p \)) statistic and is calculated using the formula: 

\[
\eta^2_p = \frac{SS_{effect}}{SS_{effect} + SS_{error}}
\]

and interpreted using the following qualitative ranges: small (.01-.06), medium (.06-.14) and large (> .14) (Cohen, 1988). Effect sizes estimation for all non-parametric analyses utilised the effect size \( r \) as proposed by Cohen (1988) and is calculated using the formula 

\[
r = \frac{z}{\sqrt{n}}
\]

where \( z \)= the derived z-score derived from the analysis and \( n \)= the number of participants (Fritz, Morris, & Richler, 2012). These effect sizes are interpreted using the following qualitative ranges: small (.1-.3), medium (.3-.5) and large (> .5) (Fritz, et al., 2012).
Figure 3: Overview of the data collection timeline.
Chapter 4: Exploring the association between stroke, self, identity and post-stroke psychological distress.

Introduction

In Chapter Two the existing stroke, self and identity literature was reviewed and an overall theoretical framework of self and identity was presented. The existing literature suggests that stroke-survivors experience change to their identity, particularly within the context of self-knowledge. Findings also indicate that the physical consequences of stroke may contribute to the sense of a body-self split, which may, in turn, contribute to a specific disruption to the sense of self, over and above any change to self-knowledge. What is less clear is whether stroke survivors experience a sense of temporal discontinuity following stroke. As noted in Chapter Two research efforts have largely focused on the use of self and identity as units of stroke-survivor meaning, rather than as theoretically-derived constructs and there is a paucity of research that uses quantitative methodologies when investigating stroke-related self and identity change. While the use of qualitative approaches undoubtedly provides a contextually rich ideographic account of stroke-survivor experience, the lack of quantitative methods means that it is difficult to conduct research in a theoretically congruent manner for the purpose of obtaining generalizable findings. Furthermore, before investigating the proposed link between stroke-related self and identity change and post-stroke psychological distress it is necessary to first determine that the changes to self and identity that are borne out in the qualitative literature are able to be detected and measured using quantitative means.

In this context, it is considered that the issues outlined in Chapter Two of this thesis highlight the difficult and perhaps divergent requirements of research that investigates the impact of stroke upon self and identity. It is challenging to balance the needs and
constraints imposed by empirical and positivist means of enquiry, with the highly
ideographic, subjective and contextually bound nature of self and identity change since
stroke. In this context, an improved (yet still perhaps imperfect) approach may be to use
quantitative methods that retain flexible responses during data collection.

Within the context of investigating change to self-knowledge following stroke, the
Twenty Statements Test (TST) may provide such an approach. Relative to the HISDS, the
TST provides a more spontaneous and ideographic measure of self-knowledge. The TST
involves asking respondents to spontaneously provide a description of themselves, by
completing a number of ‘I am…’ statements (Kuhn & McPartland, 1954). The TST
features a coding procedure which provides a means of quantitatively assessing different
aspects of self-knowledge including strength of self-knowledge, complexity of self-
knowledge (i.e. physical characteristics, social identities, attributes, evaluations, beliefs,
emotional states, global descriptions and other) and quality of self-knowledge (i.e.
general, abstract and context-less responses vs. specific, contextualised responses) (Addis
& Tippett, 2004; Rhee, Uleman, Lee, & Roman, 1995; Prebble, 2014). The TST
therefore provides a potentially flexible, idiographic and nuanced means of assessing
subjective self-knowledge change, which along with the coding scheme, allows for the
derived data to be analysed quantitatively. The TST has been successfully used to
investigate self-knowledge differences and identity change within the context of
neurologic populations (Addis & Tippett, 2004; Prebble, 2014), in addition to a number
of cross-cultural and gender difference studies (Grace & Cramer, 2002; Watkins, Yau,
Dahlin, & Wondimu, 1997).

Within the context of temporal continuity, an approach developed by Troll and Skaff
(1997) may also provide a means of balancing research needs described above. Troll and
Skaff outlined a simple semi-structured interview that featured two questions: (1) ‘In
what ways do you see yourself as being the same’, and (2) ‘In what ways do you see yourself as being different’. Importantly, the authors attempted to disentangle the temporally continuous subjective vs. objective aspects of self and identity, through the development of a coding scheme that delineates responses according to whether they relate to the fundamental/core ‘I-self’ (i.e. the underlying essence of who the person is) versus responses that related to the objective ‘Me-self’ (i.e. those responses that relate to the attributes, content and qualities that one uses to describe oneself). Hence, this semi-structured interview, in combination with the coding scheme may provide participants with the freedom to respond in accordance with what they perceive as important to their experience, while allowing researchers to interpret their responses in a more theoretically meaningful and potentially generalizable manner.

**Perceived changes to self and identity following stroke**

The first aim of this chapter is to apply quantitative methods to the question of how stroke affects self and identity along the domains of self-knowledge and temporal continuity. This is a required initial step before the first objective of this thesis can be undertaken. This initial aim involved an attempt to repeat and replicate the quantitative approach taken by Ellis-Hill & Horn (2000), before moving to utilise the TST and self-continuity interview (and associated coding procedures). It is hypothesised that in accordance with Ellis-Hill & Horn (2000), the current sample of community-based stroke survivors will display a negative change in self-knowledge following stroke. Within the context of the TST it is hypothesised that participants will report a decrease in both their strength and complexity of self-knowledge following stroke. In terms of temporal continuity, given the existing literature it is difficult to develop a specific hypothesis, however it is anticipated that findings will indicate that participants have experienced a sense of temporal discontinuity following stroke.
Chapter Four

The relationship between stroke, self, identity and post-stroke psychological distress.

The second aim of this chapter sets out to examine whether there is an association between stroke, self, identity and post-stroke psychological distress. As discussed in Chapter One, clinically significant levels of psychological distress, including depression, anxiety and apathy are prevalent following stroke. Like many psychological disorders, evidence suggests that these issues may be a consequence of interacting biological, psychological and social factors, however at this time; the literature lacks a specific psychological hypothesis that may account for the increased prevalence of psychological distress in stroke populations. Accordingly, and as noted in Chapter One, it is considered that there is a pressing need to develop theoretically derived, psychologically informed accounts of these post-stroke phenomena that seek to link theory to aetiology to treatment.

In this chapter, it is proposed that judgements about post-stroke self and identity change may be a psychological factor that contributes to, or is associated with, clinical indicators of post-stroke psychological distress (i.e. depression, anxiety and apathy). More specifically, post-stroke psychological distress may arise as an interaction between the ‘concrete’ consequences of stroke (physical, functional, cognitive & social) and the meaning that the individual assigns to these consequences. This hypothesis, that there is an association between the perceived difference that exists between the pre and post-stroke self/identity and post-stroke psychological distress, will be tested in the following study.

Also of relevance to the nature of this association are findings in non-stroke populations that show affective disorders are associated with an over-general autobiographical memory bias. That is, such individuals display a retrieval preference for abstract, generalised or categorical summaries of autobiographical information (rather than
specific information) relative to non-affective disordered populations (Williams et al., 2007). Consistent with dominant theories of self and autobiographical memory systems (as described in Chapter Two), it is thought that during the retrieval of autobiographical memories, affective disorders disrupt downward hierarchical (i.e. abstract to specific) search processes before the retrieval of more event specific memories can occur (Hitchcock, Werner-Seidler, Blackwell, & Dalgleish, 2016). This over-general memory bias is considered to contribute towards the perpetuation of depressive states via the maintenance of maladaptive or negative self-beliefs. Accordingly, this chapter also seeks to test the hypothesis that stroke-survivors with higher levels of depression symptomology display over-general biases when retrieving self-referent information. Such a bias may be an important maintaining factor in post-stroke depression.

**Method**

**Participants**

Twenty-four participants were initially recruited. Details of the demographic, neuropsychological and stroke characteristics of the sample are described in Chapter Three (General Methods). As previously described one participant’s data was removed due to validity concerns about responses, giving an overall sample of 23 participants that were included in this chapter. One participant did not complete the pre-post conditions of the HISDS or the self-continuity interview due to fatigue issues. A further participant did not complete the Twenty Statements Test or the Self-Continuity Interview as these tasks were too emotionally distressing.

For the final analysis within this chapter, participants were split into higher and lower depression symptom sub-groups using HADS (depression) cut-off scores (i.e. ≥8). On this
basis the lower symptom sub-group contained 11 participants and the higher depression group comprised 12 participants.

**Materials**

*Self and Identity Measures*

*Head Injury Semantic Differential Scale-III (Tyerman, & Humphrey, 1984):* The HISDS, a self-report scale of self-knowledge, consists of 20 paired adjectives (e.g. patient-impatient) which are separated by a 7-point numerical scale (See Appendix F). Responders are told that the numerical scale represents a continuum between the paired adjectives and are asked to choose the number that best represents their sense of self. For alternate items within the scale, the polarity of adjective pairs are reversed. Participants were asked to complete the scale twice, whilst reflecting upon their (1) pre-stroke and (2) current selves. The order in which these versions of the scale were completed (pre-stroke versus post-stroke) was counterbalanced across participants. Note, for those participants with multiple strokes, ‘pre-stroke’ was defined as prior to their first stroke. When scored, counterbalanced items are reversed so that higher scores indicate a more positive self-concept. In accordance with Ellis-Hill & Horn (2000) scores are interpreted within each individual adjective pair, as well as being summed to give a total score ranging from 20-140. The original scale has demonstrated good internal reliability (Cronbach’s α=.88) and has demonstrated sensitivity to changes in self-knowledge following head injury (Ellis-Hill & Horn, 2000; Tyerman, & Humphrey, 1984).

*Twenty Statements Test (Kuhn & McPartland, 1954):* The Twenty Statements test (TST) is a test of spontaneous self-knowledge that requires individuals to provide up to twenty statements that answer the open ended question ‘who am I?’ The TST allows for the assessment of the strength, quality and complexity of self-knowledge (Addis & Tippett, 2004). The original format of the TST requires individuals to reflect on their current self,
however for the present study, participants were asked to complete the task twice and in consideration of two time-points (current self and pre-stroke self). Repeat responses that occurred during the same time point and nonsense responses were discarded. The order of administration of these two time-points was alternated across participants. Responses were recorded verbatim and also audio-recorded for later transcription if required.

For each time point, responses were coded in three ways. First, number of responses were summed, providing a total response score (strength of identity). Second, each response was coded by an independent coder according to a modified version of the coding method set out in Rhee et al. (1995). First, this involved assigned each response to one of eight categories of identity (Physical Descriptions, Social Identities, Attributes, Evaluative Descriptions, Beliefs/Values, Emotional States, Global Descriptions and Other) (see Appendix H) (complexity of identity). Each response was further coded as either specific (i.e. contextually bound) or abstract (quality of identity). Finally, for the current study the coding procedure was amended, with each response also coded for emotional valence (i.e. positive vs. negative).

For responses that contain two parts the following guidance was provided to coders (in accordance with Addis & Tippett, 2004; Prebble, 2014). When statements contain several closely related meanings, they are only coded for the first meaning (e.g. for ‘I am kind and caring’ only ‘I am kind’ is coded). Any statement that contains an evaluative descriptor (e.g. ‘I am a good tennis player’, ‘I am a bad cook’) is coded as an evaluation regardless of the context of that evaluation. Any response that had emotional content to it (i.e. love, hate, anger, worry, anxiety, happy, unhappy etc.) is coded as emotional state regardless of context of the response (e.g. ‘I love rugby’). When a response combines a preference (e.g. like/dislike) with another statement that can be coded within a different (non-attribute) category then that is coded in accordance with the other category.
On this basis the following scores were calculated for each time point (pre and post-stroke): *Strength of identity* was indexed by total number of a) responses and b) total number of responses by positive and negative valence. *Complexity of identity* was indexed by a) the number of categories sampled, b) the number of categories sampled by positively and negatively valenced responses. *Quality of identity* was indexed by a) the proportion of responses coded as abstract and b) the proportion of responses coded as abstract by valence.

For all coding procedures, the writer coded 50% of the sample (n=12) for the purpose of determining inter-rater reliability of the coding procedure (displayed in Table 3). Inter-rater reliability was determined using the intra-class correlation co-efficient (ICC) (Shrout, & Fleiss, 1979). The ICC was used to determine the extent of concordance between the ordinal data applied by the primary coder and the writer, therefore providing an indication of the consistency to which the primary coder applied the coding scheme. Settings for these inter-rater reliability analyses consisted of a two-way mixed model for absolute agreement between ratings. Note, number of responses was not independently coded as there is no subjective element inherent to this scoring procedure. Full coding instructions and overview of categories are set out in Appendix G.

<table>
<thead>
<tr>
<th>TST Variable</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valence²</td>
<td>.997</td>
</tr>
<tr>
<td>Number of categories</td>
<td>.904</td>
</tr>
<tr>
<td>Number of abstract responses²</td>
<td>.958</td>
</tr>
</tbody>
</table>

*Note: 1= Intra-class correlation co-efficient. 2= Both valence and quality are binary variables, therefore inter-rater reliability was only calculated for positively coded responses at each time point.*
Self-continuity interview (Troll & Skaff, 1997): Temporal continuity was assessed using the semi-structured self-continuity interview. This incorporated elements of the procedure used by Troll and Skaff (1997) with the addition of a single perceived continuity question as in Prebble (2014). Perceived Continuity Question: Participants were asked whether they perceive themselves as the same person now, relative to prior to stroke. Responses were coded as: no= 0 and yes=1. I-self and Me-self continuity: This procedure was adapted for the purpose of this study, with the experience of stroke used to temporally contextualise the questions. Participants were asked how they believed they had (1) changed and (2) stayed the same since their stroke. These questions were alternated depending on their response to the perceived continuity question. Because of the nature of the questions, participants often provided answers that overlapped with other questions, therefore, the entire transcript was analysed for each coding procedure described below.

Following a period of training an independent coder read through the transcripts and coded responses that first related to the subjective ‘I-self” (i.e. knowing and experiencing the self, the inner entity, the awareness of the self, and then the objective Me-self (i.e. the content of self, temporally extended semantic self-knowledge). Using two, three-point scales (one for both the I-self and Me-self), the coder then scored each set of responses (see Table 4). This approach assessed perceptions of temporal continuity, with higher scores indicating greater perception of continuity since stroke. A score of ‘1’ indicated a perception of fundamental change, “2” indicated some change, and “3” indicated perceived continuity since stroke. Participant responses that were considered to not be captured by the I-self or Me-self coding procedure were coded as NR (no response).
Table 4: Summary of I-self and Me-self coding procedure.

<table>
<thead>
<tr>
<th>Score</th>
<th>I-self continuity subscale</th>
<th>Me-self continuity subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td><strong>Fundamental change.</strong></td>
<td>Indicates a perception of fundamental change in attributes with details of what has changed</td>
</tr>
<tr>
<td></td>
<td>(e.g., &quot;I have changed in so many ways since my stroke – personality, the way I act, my emotions, my abilities&quot;).</td>
<td>(e.g., &quot;In some ways I’m the same (describes these,) but in other way’s I’m different, (describes these&quot;).</td>
</tr>
<tr>
<td></td>
<td>Indicates a perception of some change in the core self or uncertainty about core continuity</td>
<td>Indicates a perception of some change in attributes with some details of what has changed.</td>
</tr>
<tr>
<td></td>
<td>(e.g., &quot;Not exactly the same person...I’m different but the same – it’s hard to explain&quot;).</td>
<td>(e.g., &quot;In some ways I’m the same (describes these,) but in other way’s I’m different, (describes these&quot;).</td>
</tr>
<tr>
<td>3.</td>
<td><strong>No change.</strong></td>
<td>Indicates a firm perception of stability in attributes with detailed examples of this stability (e.g. “I am exactly the same (describes how)”).</td>
</tr>
<tr>
<td></td>
<td>Indicates a firm perception of continuity in the core self with detailed examples of this stability (e.g. “I feel my essence is the same”).</td>
<td></td>
</tr>
</tbody>
</table>

Note: Coding scheme taking from Prebble (2014) and adapted from Troll and Skaff (1997).

As with the TST, the writer coded 50% of the sample (n=12) and the ICC was used to determine consistency in the use of the self-continuity coding procedure (I-self ICC r=.908 Me-self rating ICC r=.836).

**Measures of post-stroke psychological distress**

In order to test the association between perceived self and identity change and post-stroke psychological distress, three indices were used (HADS (depression), HADS (anxiety), and the Apathy Evaluation Scale). In order to test the hypothesis that post-stroke depression disrupts autobiographical memory retrieval processes, the HADS (depression) scale was utilised. In this case, HADS (depression) cut-off scores (i.e. ≥8) were used to split the sample into higher and lower depression symptom sub-groups (as described within Participants). These three measures are fully described in Chapter Three (General Methods).

**Procedure**

The general procedure for this thesis is set out in Chapter Three (General Methods). For the study described in the current chapter, all data were collected at the pre-VATP (for
cohort one) or baseline and pre-VATP assessment (for cohort two) time points. TST and self-continuity interview responses were recorded with an audio device and transcribed by a professional transcription service.

Data Analyses
All analyses were performed with SPSS for windows (version 22 or 23) or JASP (Version 7.1.12).

Data Screening
Ordinal data were analysed using non-parametric statistical tests. Other variables were subjected to preliminary analyses to investigate the assumption of normality. This included visual inspection of data using histograms, normal Q-Q plots, and Shapiro-Wilk tests. In cases where violations of the normality assumption occurred, non-parametric analyses were conducted.

Statistical Analyses
Perceived Changes to Self and Identity Following Stroke
To test for perceived within-subject self-knowledge changes as indexed by the HISDS, and in accordance with the procedure of Ellis-Hill & Horn (2000) Wilcoxon-Signed Rank Tests were conducted contrasting pre versus post-stroke responses for each item and total HISDS scores. In order to correct for multiple comparisons, these data were subject to the Holm-Bonferonni (sequential) procedure (Holm, 1979). This method involves ordering all p-values from smallest to largest, with each being considered in a sequential fashion. For the smallest p-value \( p_1 \) the alternative hypothesis \( H_1 \) is accepted if \( p_1 < \alpha/n \) (where \( \alpha = .05 \) and \( n = \) number of tests). If \( H_1 \) is accepted, then \( H_2 \) is then considered, however \( H_2 \) is accepted if \( p_2 < \alpha/n-1 \). This sequential procedure continues until a null hypothesis fails to be rejected. At this point all further null hypotheses are considered to have failed to be
rejected. This approach is considered to be slightly less conservative than the Bonferroni correction (Holm, 1979).

In order to determine changes to the strength of identity as indexed by the TST, pre vs post stroke differences in self-knowledge were assessed using a $2 \times 2$ repeated measures ANOVA with variables of time (pre and post) and valence (positive versus negative). For changes to complexity of identity, Chi-square tests for independence were used to determine whether there were changes to the number of categories sampled per participant at each time point in accordance with the procedure set out in Rhee et al. (1995).

For temporal continuity, frequencies of responses for the perceived continuity question are first reported. In order to determine whether the experience of stroke contributed greater perceived change to the continuity of the subjective (I-self) vs. objective (Me-self) self, these data were subject to a Wilcoxon-Signed Rank Test. Finally, to determine whether participants base their judgements of temporal continuity upon their fundamental and subjective sense of self rather than their objective sense of self, point bi-serial correlations were conducted to determine if there is any association between perceived continuity question responses and self-continuity interview I-self versus Me-self ratings.

*The association between perceived self and identity change and post-stroke psychological distress.*

This approach initially involved conducting correlations between measures of self and identity and the three indices of post-stroke psychological distress used within this study. These correlations were uncorrected for multiple comparisons and used to determine which variables to enter into multiple regression analyses. Following this, multiple regressions were conducted to determine whether perceived pre versus post-stroke self
and identity change predicted post-stroke psychological distress in combination with stroke severity (as indexed by the NIHSS).

To test for self-referential retrieval biases, after splitting the cohort into lower and higher depression subgroups, Mann-Whitney U tests for independent samples with Holm-Bonferroni corrections were conducted to determine any differences between high vs. low symptom groups and quality of pre-stroke and post-stroke self-referential retrieval on the TST.

**Results**

**Perceived change to self and identity following stroke**

**Self-Knowledge**

A Wilcoxon-Signed Rank Test was conducted to test whether there had been within-subject changes in self-knowledge as indexed by the HISDS. This revealed a significant difference between total pre-stroke (Mdn=116, IQR= 25) and total-post-stroke (Mdn=90, IQR=37.75) HISDS scores (z=-3.72, p<.001, r=.79). This indicates that overall, participants within this cohort reported more negative ratings in self-knowledge following stroke. Follow-up Wilcoxon-signed rank tests with Holm-Bonferroni correction (α=p≤.0038) revealed that pre and post-stroke self-knowledge differences also reached significance across a number of the trait items contained within the HISDS. Overall, participants in this cohort perceived themselves as less capable, stable, talkative, interested, confident, of value, independent and calm since their stroke. Table 5 presents these pre-post stroke findings across the 20 trait items that comprise the HISDS.

---

1 Indicates the alpha level at which the first failure to reject the null hypothesis occurred.
Table 5: Results of pre-post stroke item analyses for the HISDS.

<table>
<thead>
<tr>
<th>HISDS Item</th>
<th>Pre-stroke median (IQR)</th>
<th>Post-stroke median (IQR)</th>
<th>z-score&lt;sup&gt;1&lt;/sup&gt;</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incapable-Capable</td>
<td>7 (1)</td>
<td>5 (2.25)</td>
<td>-3.78</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Unstable-Stable</td>
<td>7 (1)</td>
<td>5 (2.25)</td>
<td>-3.56</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Withdrawn-Talkative</td>
<td>6 (2)</td>
<td>5 (4.25)</td>
<td>-3.20</td>
<td>.001</td>
</tr>
<tr>
<td>Bored-Interested</td>
<td>7 (1)</td>
<td>4.5 (3.25)</td>
<td>-3.13</td>
<td>.002</td>
</tr>
<tr>
<td>Lacking Confidence-Self-Confident</td>
<td>7 (1.25)</td>
<td>5 (2.50)</td>
<td>-3.10</td>
<td>.002</td>
</tr>
<tr>
<td>Worthless-Of Value</td>
<td>6 (1)</td>
<td>5 (3.25)</td>
<td>-3.00</td>
<td>.003</td>
</tr>
<tr>
<td>Dependent-Independent</td>
<td>7 (0)</td>
<td>6 (3.25)</td>
<td>-3.00</td>
<td>.003</td>
</tr>
<tr>
<td>Irritable-Calm</td>
<td>6 (3)</td>
<td>4 (4)</td>
<td>-2.98</td>
<td>.003</td>
</tr>
<tr>
<td>Helpless-In control</td>
<td>7 (1.25)</td>
<td>4 (4.25)</td>
<td>-2.84</td>
<td>ns</td>
</tr>
<tr>
<td>Unfeeling-Caring</td>
<td>7 (1)</td>
<td>6 (3.25)</td>
<td>-2.40</td>
<td>ns</td>
</tr>
<tr>
<td>Unhappy-Happy</td>
<td>6 (2)</td>
<td>4 (3)</td>
<td>-2.37</td>
<td>ns</td>
</tr>
<tr>
<td>Inactive-Active</td>
<td>6.5 (2.50)</td>
<td>4.5 (3)</td>
<td>-2.23</td>
<td>ns</td>
</tr>
<tr>
<td>Impatient-Patient</td>
<td>6 (3.25)</td>
<td>5 (4)</td>
<td>-2.17</td>
<td>ns</td>
</tr>
<tr>
<td>Unattractive-Attractive</td>
<td>5.5 (1.25)</td>
<td>4 (2.25)</td>
<td>-2.09</td>
<td>ns</td>
</tr>
<tr>
<td>Despondent-Hopeful</td>
<td>6 (2)</td>
<td>5.5 (3)</td>
<td>-2.01</td>
<td>ns</td>
</tr>
<tr>
<td>Un-cooperative-Cooperative</td>
<td>6 (1.25)</td>
<td>6 (2.25)</td>
<td>-2.01</td>
<td>ns</td>
</tr>
<tr>
<td>Unfriendly-Friendly</td>
<td>7 (1)</td>
<td>6 (2)</td>
<td>-1.99</td>
<td>ns</td>
</tr>
<tr>
<td>Dissatisfied-Satisfied</td>
<td>5.5 (2.50)</td>
<td>5 (3)</td>
<td>-1.72</td>
<td>ns</td>
</tr>
<tr>
<td>Worried-Relaxed</td>
<td>6 (3.25)</td>
<td>4.5 (3.25)</td>
<td>-.99</td>
<td>ns</td>
</tr>
<tr>
<td>Unaggressive-Aggressive</td>
<td>6 (4)</td>
<td>5 (3.25)</td>
<td>-.57</td>
<td>ns</td>
</tr>
</tbody>
</table>

Note: Bold typeface = Significant following Holm-Bonferroni correction (a = p<.0038). I = Z-scores derived from Wilcoxon-Signed Rank tests.

The TST was used to assess changes to spontaneous semantic self-knowledge following stroke. The relationship between valence and strength (number of responses) of self-knowledge change since stroke, was examined with a 2x2 repeated measures ANOVA with time (pre and post) and valence (positive and negative) as within subject variables. There was no significant main effect of time (p=.788), however there was a significant main effect of valence ($F_{(1,21)}=20.85, p<.001$) and a significant time × valence interaction ($F_{(1,21)}=28.124, p<.001$).

A simple effects analysis with Bonferroni correction examined the effect of valence within each level of time (see Figure 4). There was a significant difference between the number of positive ($M= 12.90, SD= 5.30$) and negative ($M= 0.773, SD= 1.60$) responses in the pre-stroke condition ($p<.001$), but no significant difference between the number of positive ($M=5.63, SD=4.96$) and negative ($M=6.864, SD=5.24$) responses in the post-stroke condition ($p=.523$). A further simple effects analysis to examine the effect of time.
for each valence type revealed that participants provided significantly fewer positively-valenced responses in the post-stroke ($M=5.63, SD=4.96$) versus pre-stroke ($M=12.90, SD=5.30$) condition ($p<.001$); and significantly more negatively-valenced responses in the post-stroke ($M=6.864, SD=5.24$) versus pre-stroke ($M=0.773, SD=2.56$) condition ($p<.001$). Overall the results indicate that while participants did not, irrespective of valence, experience a decrease in the strength of their self-knowledge following stroke, they did experience a significant change in self-knowledge as indexed by the number of responses when valence was considered. This change was characterised as both a decrease in positively-valenced self-referential statements and an increase in negatively-valenced statements in the post-stroke condition.

![Figure 4: Mean number of positively and negatively valenced responses on the Twenty Statements test between the pre and post-stroke conditions. Error bars denote standard error of the mean.](image)

The complexity of self-knowledge was assessed by examining the number of distinct categories sampled by participant responses on the TST according to the Rhee et al. (1995) coding procedure. The distribution of the number of categories sampled per participant between pre and post-stroke time points is shown in Figure 5.
To test the hypothesis that following stroke, participants would demonstrate lower complexity in their spontaneous self-knowledge, differences in the number of categories sampled per participant between the pre and post-stroke time-points were analysed using a Chi-square test for independence. In order to provide a valid Chi-square, the number of categories sampled per participant was collapsed into those that sampled lower numbers of categories (i.e. 2-4) and those that sampled higher numbers of categories (i.e. 5-7) (Note: because no participants sampled either 1 or 8 categories these were excluded). A Chi-square test indicated that there was no significant difference in the frequency of participants who sampled lower numbers of categories versus those that sampled higher numbers of categories between pre and post-stroke conditions ($\chi^2(1)=.8199, p=.365$).

In order to determine whether this analysis, which did not consider changes to valence of responses, obscured changes to the complexity of self-knowledge following stroke, two further Chi-square tests were conducted for both (1) positively and (2) negatively-valenced responses. Because the inclusion of valence meant that in some cases there was an absence of responses, and hence no categories sampled (i.e. within the pre-stroke negative condition), the way in which categories were collapsed was changed relative to
the prior analysis. In this case, numbers of categories sampled per participant were collapsed into those that sampled between 0-3 categories, and those that sampled between 4-7 categories (note, no participant sampled all eight categories with their responses).

Chi-square tests for independence revealed that between the pre and post-stroke time points there was a significant difference in the frequency of participants that sampled higher and lower numbers of categories for both positively ($\chi^2 (1)=11.02, p<.001$) and negatively ($\chi^2 (1)=11.45, p<.001$) valenced responses (see Figure 6).

**Figure 6:** Frequency of participants who sampled lower and higher number of categories with positively-valenced responses (A) and negatively-valenced responses (B).
Taken together, these findings indicate that although there was no overall change to complexity of self-knowledge following stroke in terms of *absolute* numbers of categories sampled, this finding obscured changes that were evident when valence of responses was considered. These findings indicate that participants experienced a reduction in the complexity of self-knowledge based upon positively-valenced self-referential information, and an increase in complexity in self-knowledge based upon negatively-valenced self-referential information.

It was also considered possible that following stroke, participants would experience a change to the relative ‘weight’ of their self-knowledge as indicated by number of responses within specific categories. For example, in the post-stroke condition, due to potential pre-occupation with physical recovery or change, post-stroke self-knowledge may become characterised by an increase in the number of responses that fall within the physical category. Figure 7 shows the mean frequency of TST responses for each of the eight categories provided by the Rhee et al. (1995) coding procedure, at the two time points, irrespective of valence.

![Figure 7: Mean number of responses falling within each category at the pre and post-stroke conditions.](image)
As can be seen in the graph, some patterns of change seem to have occurred from the pre to the post-stroke time-points. For example, following stroke there appears to be a decrease in the frequency of responses that fall within the social category, and an increase in the frequency of responses that fall within the physical, evaluative and emotional categories. In order to determine whether there was an overall difference in the number of responses per category from the pre to post-stroke condition, Wilcoxon-signed rank tests with Holm-Bonferroni corrections were conducted (α = p < .0071) that assessed pre versus post-stroke differences in the number of responses within each category. Results indicate that there was a significant decrease in the frequency of responses that fell within the social category between the pre (Mdn=3, IQR=3.50) and post-stroke (Mdn=1, IQR=1) condition (p < .001). There was no significant difference for any other category (all p > .021). These findings indicate that overall, participants experienced a decrease to self-knowledge that specifically relates to their social identity, irrespective of valence.

**Temporal continuity**

Of the participants who completed the perceived continuity question, 55% (12/22) did not perceive themselves as being the same person following stroke as they were prior to stroke. For the self-continuity interview response ratings, a Wilcoxon-signed rank test for related samples found a borderline significant difference between the objective (Me-self) ratings (Mdn=2, IQR=1) and (I-self) ratings (Mdn=2, IQR=2, Z=1.890, p = .059) indicating that participants may have perceived greater change to their objective self (i.e. attributes, content and qualities that one uses to describe oneself) rather than their subjective self (i.e. the fundamental underlying essence of who the person is). Figure 8 displays the descriptive data for the self-continuity interview response ratings.
Pearson correlations were then conducted to determine if there is any association between perceived continuity (as indexed by the perceived continuity question) and Me-self and I-self-continuity interview ratings. Interestingly, while correlational analyses found that Me-self and I-self continuity response ratings were highly and significantly correlated ($r_s=.708, p=.001$), point biserial correlations found that responses to the perceived continuity question were significantly correlated with the I-self continuity rating ($r_{pb}=.665, p=.004$), but not the Me-self continuity ($r_{pb}=.364, p=.105$). For illustrative purposes, two participant excerpts detailing I-self (above) and Me-self (below) related responses are outlined below.

"The only way I can describe myself pre-stroke is that I am very different person. I feel the same but I am not the same...I like to feel like I have retained some of the sameness, the same way I was before but if I be honest I don’t, I just have to reinterpret cause I keep saying I am the same, but I am not the same, and if you can make sense of that...well."

-Participant 06: Self-continuity interview excerpt that is relevant to the fundamental, experience of the self (I-self).
“I have lost confidence in my ability to be physical or walk...(but)...I am adventurous I still love my children and my family I still value education and I like smart people and good hearts the same person, I love music, I love the garden, I love sailing and nature.”

-Participant 03: Self-continuity interview excerpt that is relevant to the objective, content of self (Me-self).

**The relationship between stroke, self, identity and post-stroke psychological distress.**

Correlational analyses were conducted to determine if there were any associations between perceived self-knowledge change and clinical indicators of post-stroke psychological distress. There was a significant, moderate and positive association between HISDS (difference) total scores and HADS (depression) scores ($r=.539$, $p=.010$) and a significant, moderate and positive association between HISDS (difference) scores and HADS (anxiety) scores ($r=.506$, $p=.016$). This indicates that perceived magnitude of post-stroke self-knowledge change as indexed by the HISDS was associated with greater depression and anxiety symptoms within this sample. There was no association between HISDS (difference) scores and Apathy Evaluation Scale scores ($r=.219$, $p=.328$).

Two multiple regression analyses were conducted to determine whether stroke-severity (as indexed by the NIHSS) and HISDS (difference) scores influenced HADS (depression) and HADS (anxiety) scores. The regression procedure conducted to see whether NIHSS and HISDS (difference) scores predicted HADS (depression) scores was not significant ($R^2=.270$, $F_{(2,19)}=3.138$, $p=.069$). However, the model examining whether HADS (anxiety) scores were directly influenced by these same variables was significant ($R^2=.307$, $F_{(2,19)}=3.768$, $p=.044$). Individually, within this model HISDS (difference) scores were a significant predictor of HADS (anxiety) scores ($\beta =0.613$, $t_{(21)}=2.742$, $p=.014$), NIHSS scores were not ($p=.213$).
Results of correlational analyses found a significant, moderate and positive association between TST strength (positive) difference scores and HADS (depression) scores ($r=.568$, $p=.007$), and HADS (anxiety) scores ($r=.481$, $p=.027$), but not Apathy Evaluation Scale scores ($r=.243$, $p=.289$). There was also a significant, moderate and negative association between TST strength (negative) difference scores and HADS (depression) scores ($r=-.525$, $p=.015$), and HADS (anxiety) scores ($r=-.520$, $p=.016$), but not Apathy Evaluation Scale scores ($r=-.408$, $p=.066$). This suggests that while higher levels of both depression and anxiety symptomology were associated with a reduction in positively-valenced self-knowledge and an increase in negatively valenced self-knowledge, these patterns were not found for apathy symptoms.

Follow-up multiple regressions were then conducted to determine whether stroke-severity and TST strength (positive) and TST strength (negative) difference scores directly influenced HADS (depression) and HADS (anxiety) scores. The regression procedure conducted to see whether HADS (depression) scores were predicted by these variables was significant, ($R^2=.526$, $F_{(3,19)}=5.909$, $p=.007$). However, while TST strength (positive) difference scores significantly predicted HADS (depression) scores ($\beta=0.585$, $t_{(21)}=2.471$, $p=.025$), neither NIHSS scores ($p=.446$), or TST strength (negative) difference scores ($p=.149$) were significant predictors. In a separate regression analysis, the model predicting HADS (anxiety) scores was significant ($R^2=.385$, $F_{(3,19)}=3.340$, $p=.046$). However, individually neither NIHSS scores ($p=.321$), TST strength (positive) difference scores ($p=.117$), or TST strength (negative) difference scores ($p=.149$) predicted HADS (anxiety) scores.

Finally, correlational analyses were conducted to determine whether there was any association between indices of temporal continuity and post-stroke psychological distress. Point bi-serial correlations found that there was no significant association between
perceived continuity question responses and HADS (depression) ($r_{pb}$=.052, $p$=.823), HADS (anxiety) ($r_{pb}$=-.061, $p$=.791) or Apathy Evaluation Scale scores ($r_{pb}$=.022, $p$=.923). For the self-continuity interview, Spearman correlations indicated that there was a significant association between Me-self scores and Apathy Evaluation Scale scores ($r_s$=-.533, $p$=.016), indicating that greater perceived discontinuity to the objective self was associated with higher levels of apathy. However, a follow-up regression procedure conducted to see whether NIHSS and Me-Self scores predicted Apathy Evaluation Scale scores was not significant ($R^2=.163$, $F_{(2,18)}=1.560$, $p$=.240). There was no significant association between either I-self or Me-self scores and HADS (depression) or HADS (anxiety) scores (all $p's$.36). These findings provide tentative support for the view that disruption to temporal continuity may be associated with post-stroke apathy, however, within the context of PSD and PSA, this hypothesis was not supported.

**Pre-stroke self-referential retrieval biases**

To test for the presence of biased self-referential retrieval within the pre-stroke condition, two Mann-Whitney U tests with Holm-Bonferroni corrections ($\alpha$.025) were conducted to examine any differences in the quality (i.e. abstract vs. specific) of statements made by participants within high ($n=12$) and low ($n=11$) depression sub-groups. Consistent with the hypothesis it was revealed that the higher (depression) group provided significantly more pre-stroke abstract responses ($Mdn$=5, $IQR$=5) than the lower (depression) group ($Mdn$=2.50, $IQR$=3.75) ($Z=2.524$, $p$=.012, $r=.55$). There was no significant difference between groups for the number of pre-stroke specific responses ($p=.375$) (see Figure 9).
**Figure 9:** Median number of TST responses within the pre-stroke condition coded as abstract or specific between the lower and higher depression subgroups.

**Post-stroke self-referential retrieval biases**

Similarly, to test for the presence of biased self-referential retrieval processes within the post-stroke condition, two Mann-Whitney U tests with Holm-Bonferroni correction ($\alpha<.025$) were conducted to determine differences in the quality of statements made by participants within high ($n=12$) and low ($n=11$) depression sub-groups. Contrary to our hypothesis there was no significant difference between either the number of abstracted ($p=.314$) or specific ($p=.605$) statements in the post-stroke condition.

Due to the differences in the valence of responses within the post-stroke condition, further Mann-Whitney U-tests with Holm-Bonferroni correction ($\alpha=.025$) were conducted to determine whether there are any specific differences in the quality of responses within the specific context of negatively valenced post-stroke statements alone (note, this analysis was not conducted within the pre-stroke condition due to the very low numbers of negatively valenced statements within this time point). Negatively valenced responses were specifically selected as it was considered that such responses would be preferentially retrieved by participants with higher levels of depression symptoms. Consistent with our
hypothesis results indicated that the higher (depression) group provided significantly more post-stroke negative abstract responses ($\text{Mdn}=5$, $\text{IQR}=6$) than the lower (depression) group ($\text{Mdn}=0.50$, $\text{IQR}=4$) ($Z=2.288$, $p=.022$, $r=.50$). No significant difference between groups was found for the number of post-stroke negative specific statements ($p=.156$) (see Figure 10).

![Figure 10](image.png)

**Figure 10**: Median number of negatively valenced TST responses within the post-stroke condition coded as abstract or specific between the lower and higher depression subgroups.

**Discussion**

This chapter first outlined an investigation into the nature of perceived post-stroke self and identity change along dimensions of self-knowledge and temporal continuity. Initially this involved repeating the approach taken by Ellis-Hill and Horn (2000), and then progressed to make use of quantitative methods that allowed for flexibility and subjectivity in participant responses. Second, this chapter approached the first objective of this thesis which was to describe and test the hypothesis that perceived change in post-stroke self and identity is associated with post-stroke psychological distress.
Perceived change to self and identity following stroke

The findings of the current chapter support the view that the experience of stroke contributes to considerable change to an individual’s perceived identity and that these changes are discoverable using quantitative methods. In terms of self-knowledge, the use of a constrained/prescriptive measure (HISDS) indicated that this was characterised by an overall negative shift in identity since stroke, with changes occurring to specific trait items: incapable, unstable withdrawn, bored, lacking confidence, worthless, dependent and irritable. A more flexible and spontaneous measure of self-knowledge (TST) revealed that overall, neither strength nor complexity of self-knowledge had changed since stroke, however when the valence of participant responses was considered, it was revealed that these null findings obscured marked changes to identity.

As described earlier, the work of Ellis-Hill and Horn (2000) represents the only attempt to assess post-stroke change to self-knowledge using a quantitative approach. Accordingly, this approach was replicated but with a sample that was characterised by higher levels of variability in physical/cognitive impairment, and greater post-stroke adjustment issues. Overall, findings converged with that of Ellis-Hill and Horn; however our sample perceived a negative change across a relatively greater number of trait items (i.e. 8 vs 6). It is likely however, that the difference between studies is underestimated, as Ellis-Hill and Horn did not correct for multiple comparisons. That is, it is likely that a proportion of their significant trait-item differences were due to an inflated type-I error rate.

The relatively higher number of trait items identified within the current study relative to Ellis-Hill & Horn (2000) may relate to differences in the sample (i.e. differences in physical, cognitive and adjustment issues), suggesting that these issues may influence perceptions of identity change since stroke. In terms of specific trait-item comparisons between the current study and that of Ellis-Hill and Horn, only three trait items (i.e.
incapable, bored, and dependent) converged. However, within the Ellis-Hill& Horn study, these three trait items were the only ones to be endorsed at a more conservative alpha level ($\alpha=p<.001$), which given their probable false discovery rate, indicates that across both studies, there was a convergence of findings indicating that stroke contributes to a negative change to specific trait items ‘incapable’, ‘bored’, and ‘dependent’.

In this context, perceived post-stroke identity change appeared to be related to both a decrease in positively-valenced self-knowledge and an increase in negatively-valenced self-knowledge. Moreover, these changes to valence were linked to changes observed in the complexity of identity, with participant responses indicating a distinct narrowing of the number of identity domains endorsed by positively-valenced self-referential statements, in addition to a considerable expansion in domains associated with negatively-valenced statements following stroke. These findings are important as they indicate that for many stroke-survivors, negatively-valenced aspects of identity are not limited to a few discrete domains affected by the consequences of stroke (i.e. physical or social domains), and include those that are of an attributional or evaluative nature.

Finally, in the post-stroke condition, participants seemed to have experienced a considerable loss of social identity, irrespective of valence.

In accordance with the framework set out in Chapter Two, this chapter also investigated change to perceived temporal continuity since stroke, with an interesting constellation of findings emerging. Results indicate that more than half of participants experienced themselves as no longer being the same as prior to stroke. Moreover, self-continuity interview analyses revealed that participants may have perceived greater change to the objective content of self (Me-self), rather than the subjective experience of self (I-self). This view is also supported with descriptive data which indicated that approximately 95%
of participants experienced at least some change to their sense of ‘Me-self’, whereas for those participants who obtained a score in the ‘I-self’ condition, responses were much more uniform across the three response ratings.

Interestingly, although responses to the perceived continuity question indicated that just over half of sample saw themselves as being different following their stroke, and although Me-self and I-self responses were correlated, judgements about perceived continuity were found to be associated with I-self ratings rather than Me-Self ratings. This suggests that although stroke-survivors may report greater discontinuity to their objective Me-self, when making judgements about their extent of change since stroke, they rely more upon representations of their core, fundamental and subjective sense of who they were and are. Overall, these results are reasonably consistent with the findings reported within the qualitative literature which indicates that while stroke participants do experience change to their identity, they do not necessarily perceive themselves as being fundamentally different (Palleson, 2014).

When considering these findings it is important to keep in mind that the retrieval of self-referential information is mediated by memory processes, and research indicates that these processes are constructive in nature, and therefore, recalled memories that underlie perceptions of pre-stroke self and identity may provide an inaccurate or inexact record of the past (Barclay, & Wellman, 1986; Loftus, 2003; Schacter, 2002). On the basis of the current study it is therefore not possible to determine whether the self-referential information provided by participants accurately reflects both who they were prior to stroke and who they are now. In particular, it is possible that what is remembered and hence described about the pre-stroke self may be unrealistically positive, and similarly what is described about the post-stroke self may be unrealistically negative. Future research could aim to contrast information provided by third parties (e.g. family
members), with the self-report of stroke survivors, in order to provide insight into the extent of concordance/discordance between such accounts. Congruence between third party and stroke-survivor report, would support the view that autobiographical memory retrieval following stroke is a relatively accurate and reliable process, whereas dissonance between accounts may reveal important information about both the presence of retrieval biases and how individuals come to conceptualise themselves following stroke.

It is noted that at the outset of the current study, there was an attempt to recruit family members for the purpose of approaching this question. However, difficulties recruiting family members meant that this approach was discontinued. These recruitment difficulties seemed to be attributable to either (1) stroke-survivors being relatively isolated, and therefore not having family members available, or, (2) for those stroke-survivors that did have family members available, these people generally stated that they were too busy (i.e. working long hours, taking care of children etc.) to participate. Provided that researchers could find a way to effectively work around these recruitment issues, such a research approach would yield important information about how stroke survivors conceptualise themselves.

The current study represents the first time that measures such as the TST and self-continuity interview have been used to investigate post-stroke self and identity change. This approach allows participants to flexibly outline their unique experience of post-stroke change, at the same time as providing the researchers with data that can be interpreted using quantitative means. Although it was considered that relative to the HISDS, the TST provided a richer and potentially a more meaningful account of post-stroke identity change, one limitation in regards to the use of measures such as the TST (relative to more objective measures) remains. The spontaneous and unstructured nature of such tasks may mean that results are confounded by impaired verbal fluency or
generative retrieval abilities. That is, TST performance may be influenced by generative retrieval abilities within the specific domain of semantic self-referential knowledge, in addition to functioning as a measure of identity. This issue may be particularly pronounced within the context of stroke populations, as cognitive impairments may impact upon the ability to generate and retrieve responses. As the current study featured a within-subjects design (with each participant used as his/her own control), this issue was unlikely to impact findings. However, if a study contrasted stroke populations with non-stroke populations then this issue would need to be considered, and analyses would need to account for cognitive impairments that may influence generative retrieval processes.

It is also noted that the framework set out in Chapter Two sets out the relationship between autobiographical memory systems and self and identity. However, the current study did not include any specific autobiographical memory measure, and therefore, there is no way of understanding if stroke populations make use of autobiographical memory systems to facilitate self-referential judgements in a manner that is qualitatively distinct to non-stroke populations. For example, in addition to possible differences in the valence of retrieved self-referential statements, it is possible that, relative to non-stroke populations, stroke survivors may increasingly rely upon a strategy of episodic, rather than semantic memory retrieval. Indeed, it was noted during interviews that participants often made reference to such a strategy, indicating that the retrieval of episodic memories were used to assist in making judgements about who they were prior to stroke. In this context, future research could potentially investigate changes to autobiographic memory retrieval processes in stroke versus non-stroke populations in order to determine how these changes may be associated with differences in perceived self and identity change.

Overall, the results of this study converge with the extant qualitative literature by finding that stroke contributes to a considerable change to identity. However, the current findings
also indicate that stroke-survivors perceive a distinct qualitative change to both the content and continuity of self and identity, but also the emotional meaning that is attached to that content. Therefore, this study not only provides converging evidence that change occurs, but provides further insight into the nature of this change. The successful application of quantitative methods that nonetheless retain some subjective nuance to the question of post-stroke self and identity change may also provide an initial step for the possible emergence of a new literature that may take a more empirically informed, yet contextually bound means of inquiry in this area. This may yield generalizable understanding of the ways in which stroke commonly affects the self and identity. Such research approaches may be particularly suited to studying such intrinsic and theoretically challenging topics such as stroke, self and identity. Most importantly however, these findings provide the pathway for investigating the proposed association between stroke-related self and identity change and post-stroke psychological distress.

**The relationship between stroke, self, identity and post-stroke psychological distress.**

The second aim of this study was concerned with a principal objective of this thesis which was to investigate a proposed link between perceived self and identity change and post-stroke psychological distress. Overall, results found that greater change in perceived self-knowledge following stroke, but not temporal discontinuity, was associated with depression and anxiety symptoms (but not apathy symptoms). Conversely, there was some limited support for the view that perceived discontinuity to the objective content of self (Me-self) was associated with apathy symptoms. Regression models that included an index of stroke severity and indices of self and identity change revealed no clear pattern, however it was noted that within these models, identity change generally predicted depression and anxiety to a greater extent than stroke severity. Finally, an analysis of the quality of responses on the TST supported the hypothesis that those participants with
higher levels of depression symptoms would display self-referential information retrieval biases towards abstracted and over-general information.

Although it is emphasised that further research is required, these results provide support for the view that post-stroke psychological distress may arise as an interaction between the consequences of stroke (i.e. physical, functional, cognitive & social) and a psychologically mediated self and identity related meaning making process. In evaluating this meaning, it is proposed that stroke-survivors undertake a process of reflective self-analysis, comparing their current self to their pre-stroke self, using both their conceptual understanding of their pre-stroke self/identity (‘who they were’) and their pre-stroke autobiographical memories. In this context, the magnitude of pre versus post-stroke difference that the individual perceives is argued to relate to the magnitude of post-stroke psychological distress that they then experience. This indicates that for different people, similar disabilities (or other consequences of stroke) may give rise to quite different psychological responses. That is, pre-stroke conceptions of self and identity may provide the context in which the consequences of stroke play out.

It is noted that this view converges with many aspects of the existing literature. For example, there is a body of qualitative evidence suggesting that for stroke-survivors, self-referential evaluative processes are one of the ways in which the meaning and impact of stroke is determined (Clarke & Black, 2005; Dowswell et al., 2000; Guise et al., 2010). Moreover, such a mediating psychological process may explain why there are such inconsistencies within the literature in regards to findings that attempt to link stroke-related variables (e.g. severity of stroke, cognitive ability, functional impairment and so on) and post-stroke depression and anxiety. Furthermore, with regards to the time course of PSD, it is noted that the delayed onset approximately coincides with the conclusion of the most intensive period of post-stroke physical rehabilitation (Aziz, 2010; Demain,
Wiles, Roberts, & McPherson, 2006; Lee et al., 2015). This period is also noted to be where the greatest proportion of recovery is expected by medical professionals, rehabilitative specialists and potentially, stroke-survivors themselves (Jørgensen et al., 1995; Skilbeck, Wade, Hewer, & Wood, 1983). Moreover, this time course also coincides with when stroke survivors typically return home. This, as noted by Becker (1993), is a time at which stroke survivors return to an environment that is filled with cues that may induce the retrieval of memories that may index post-stroke change. Finally, within the context of traumatic brain injury, which shares some similarities with stroke (i.e. sudden onset and instantaneous change), it has been found that perceived identity change is positively associated with depression and grief, and negatively associated with self-esteem (Carroll, & Coetzer, 2011).

An alternative possibility however, is that affective state of stroke-survivors influences how they perceive themselves. For example, the presence of depression symptomology could give rise to a tendency towards characterising the pre-stroke self and identity in an unrealistically positive manner, and their post-stroke self and identity in an unrealistically negative manner. As described earlier, future studies that contrast third party (i.e. family member) and stroke-survivors accounts, in addition to studies that work to further investigate possible differences in autobiographical memory retrieval processes may yield important information in relation to the mechanisms by which stroke survivors construct an understanding of who they were prior to and following stroke.

One important limitation of this study is that both the HISDS and TST may act as proxy measures of depression or anxiety, and accordingly, using such measures to explore the current hypothesis is potentially tautological. In the case of the HISDS, it is noted that a number of items may index symptoms of post-stroke psychological distress (e.g. happiness, despondence & worry). Similarly, responses on the TST were confounded by
valence and although it was noted that post-stroke depression and anxiety symptoms were associated with both a reduction in positively valenced responses and an increase in negatively valenced items, it is possible that this measure was simply indexing the emotional states of participants.

This limitation highlights the difficulty in exploring relationships between post-stroke identity change and post-stroke psychological distress. That is, significant perceived affective change as a consequence of stroke, can be, in of itself, a type of post-stroke self or identity change. With regards to the HISDS, this limitation is somewhat tempered as it is noted that within the whole sample, trait-items such as happy, despondent and worry did not significantly change post-stroke. In terms of the TST, it is still considered that the current findings make an important contribution as there are a number of possible differences in the regards to how such an association may be configured. For example, post-stroke depression or anxiety could potentially be (1) not associated with self and identity change, or associated with (2) loss (i.e. absence) of identity, (3) qualitative change to identity that is not related to valence, (4) an absence of positively valenced trait items, alongside the presence of negatively valenced trait items, or (5) a decrease in positively valenced traits with a commensurate increase in negatively valenced traits. Within the current sample, the fourth configuration was supported, which has potentially important implications for the treatment of such individuals.

As hypothesised, the current findings suggest that participants with higher levels of depression symptoms display a pattern of retrieval that seems to be biased towards abstracted self-referential information. Although sample size was small and findings were limited to the TST (i.e. further research is clearly required), these results are consistent with the non-stroke literature (e.g. Williams et al., 2007). It is emphasised that at this time, it is unknown whether such cognitive biases are causally related to the onset of
affective disorders. However, research from Brittlebank, Scott, Williams, & Ferrier, (1993) highlights the possibility that such an over-general bias is a trait rather than state marker. That is, such biases reflect a relatively invariant cognitive style that increases vulnerability to depression, as opposed to developing as a consequence of depression. If the findings of the current study are confirmed, then it is possible that assessing for the presence of such abstracted or over-general memory biases within the acute recovery stage may provide a means of identifying those stroke-survivors that are possibly at increased risk of developing post-stroke depression. Similarly, Brittlebank and colleagues also found that over-general recall on an autobiographical memory test was highly correlated with failure to recover from depression and predicted a high proportion of the variance (33%) in depression symptoms during a follow-up assessment, indicating that these cognitive biases are a significant maintaining factor. This research, taken together with the findings of the current chapter, supports the view that autobiographically memory retrieval may be a viable and important psychotherapeutic treatment target in post-stroke depression.

The identification of stroke-related self and identity change as a factor that may mediate post-stroke depression and anxiety may provide clinicians with a novel and meaningful means of assessing and formulating stroke clients. As argued in Chapter One, one explanation for the lack of evidence for the efficacy of psychotherapy is possibly due to the incongruence between the theoretical basis of such psychotherapeutic models and both the lived experience of stroke, and the stroke-specific aetiological origins of these issues. Accordingly, the identification of the link between perceived self and identity change may provide clinicians with a meaningful way to assess and formulate instances of post-stroke psychological distress, which may, in turn, lead to the identification of important treatment targets. For example, the identification of areas of identity loss versus
stability, in addition to those identity domains that have become dominated by negatively-valenced self-referential information may assist the development of treatment targets that are both meaningful and relevant to the client. In this context, it is argued that pre-stroke identity is not about specific behaviours per se, but the meaning that is attached to those behaviours. Therefore, it is suggested that it is the engagement in behaviours that are consistent with the meaning attached to pre-stroke identity that is important, rather than behaviours themselves.

Finally, when working with stroke-survivors, some clinicians may be inclined to support clients to ‘move on’ from their pre-stroke identity, and develop a ‘new’ identity in accordance with the newly imposed constraints of stroke. The current findings indicate that this would not be the most appropriate way forward, and instead, supporting clients to live in line/engage with behaviours that are the most congruent with their pre-stroke identity (within the constraints imposed by stroke) may be likely to lead to better outcomes. Overall, it is possible that such a self and identity focused approach may be more experientially meaningful to stroke-survivors, relative to traditional CBT type approaches, which have thus far have failed to demonstrate effectiveness within stroke populations.

In conclusion, the current study found some support for the view that stroke contributes to a change in self and identity, and that this magnitude of change, may be associated with post-stroke psychological distress. Accordingly, this chapter addresses the first objective of this thesis by providing a psychologically informed account of post-stroke psychological distress. Moreover, this chapter has provided a possible means of assessing and possibly understanding the ways in which stroke-survivors assign meaning to their experience of stroke. Accordingly, this work may go some way towards providing clinical psychologists (and researchers) with a way of further conceptualising post-stroke
psychological distress that is meaningful and relevant to stroke-survivors, which in turn, may assist in the formulation, assessment and treatment of such issues. In this latter context, and in light of the current absence of evidence-based treatment approaches for post-stroke psychological distress, the remainder of this thesis will move towards the second objective of this thesis, which is focused upon the evaluation of a novel, group-based visual art therapy programme for community-based stroke survivors.
Chapter Five: An exploratory study of group-based visual arts therapy as a psychotherapeutic intervention for the psychological and psychosocial consequences of stroke

Introduction

As noted in Chapter One, there is an absence of evidence that supports the use of psychotherapeutic approaches in the treatment of post-stroke psychological distress. Although there is tentative support for the use of pharmacological interventions, it is noted that these approaches carry additional risks (i.e. side effects and drug-drug interactions) that may be pronounced within stroke populations. It is considered that these factors provide the rationale and impetus for the second objective of this thesis, which is to examine a new and novel treatment approach that is specifically developed for stroke populations. Accordingly, this chapter describes an exploratory study that examines the efficacy of a novel group-based visual arts therapy programme.

A role for Visual Arts Interventions?

There is an emerging evidence base that provides tentative support for the use of creative arts therapies in the improvement in mental health, psychosocial functioning and wellbeing for a variety of chronic conditions. A RCT involving 39 participants found that 4 one-hour (individual) sessions of art-therapy significantly decreased negative emotional states and increased positive emotional states in women living with breast cancer (Puig, Lee, Goodwin, & Sherrard, 2006). Similarly, a national evaluation study of 22 participatory art programs in England involving participants with a range of mental health issues (including depression, anxiety and schizophrenia) found significant post-intervention improvement for empowerment, mental health and social inclusion (Hacking, Secker, Spandler, Kent, & Shenton, 2008). Research has also shown that
creative arts interventions are effective in the treatment of depression in prison populations (Gussak, 2007), and improve the wellbeing of individuals with dementia (Rusted, Sheppard, & Waller, 2006) and diabetes (Stuckey & Tisdell, 2010).

**What is Visual Arts Therapy for stroke?**

Visual arts therapy (VAT) is a creative, group-based, strengths-focused intervention comprising cognitive, non-verbal, verbal, physical, and kinaesthetic sensory features (Gussak, 2007). VAT is primarily a psychological intervention which provides a platform for the creative and experiential expression of the unique consequences of stroke as experienced by individuals, in addition to providing a forum for the acquisition of new skills and creative endeavours (Eum & Yim, 2015). The creative and metaphoric practice inherent to VAT is thought to allow survivors to contact, process and express aspects of their stroke that they may have otherwise suppressed, avoided or disengaged from (Gonen & Soroker, 2000; Lusebring, 1990; Reynolds, 2012). VAT’s primary purpose is to facilitate emotional and psychological wellbeing by allowing the individual to begin to process, adapt, adjust and make sense of the turbulent change that commonly occurs following stroke (Reynolds, 2012).

Proposed mechanisms of improvement include the opportunity to both discover and divulge feelings about the change and loss individuals have experienced since their stroke in a safe supportive environment, thereby gaining insight and reducing distress (Morris et al., 2014; McNiff, 1992). VAT also encourages autonomous creative decision making by emphasising strengths (rather than deficits) and aims to actively dilute submissive patient roles (Reynolds, 2012). When delivered in a group format, VAT may use each artwork as a catalyst and conduit for discussion. Although session content differs according to the themes set out by the arts therapists/facilitators, the artworks are used as a means of
unravelling both the idiosyncratic and shared experiences of stroke within a safe group-based context (Gonen & Soroker, 2000).

Before engaging in a discussion of art-therapy for stroke, it is important to highlight an important distinction that arises from the arts-intervention literature. There is a distinction between those interventions that are intended as arts-based therapies, versus those that use art-making as a practice. It is noted that researchers do not always make this distinction clear when describing the interventions upon which their study was based, and there are no specific criteria that exist in the literature. Accordingly, the writer has attempted to distinguish between arts-based practices and therapies. Practice based interventions typically focus on the technical and skill based aspects of art making, and these interventions are facilitated by arts practitioners or teachers. This contrasts with those that use art making as a therapeutic modality, which are typically facilitated by trained arts therapists. In the latter context the greatest emphasis is placed on using art as an expressive therapeutic practice that specifically aims to work with, and through, the survivor’s experience of stroke. Therefore, although skills and techniques may be taught, these are used to facilitate therapeutic expression.

**Current status of Visual Art Interventions for stroke**

An overview of all known visual art interventions for stroke is presented in Table 6. As can be seen the volume of research investigating VAT and stroke is reasonably small. Overall, research generally consists of individual case work and qualitative studies typically characterised by small samples. Although such research provides valuable insight into possible mechanisms and processes that may contribute to change, it is not possible to make generalizable inferences about treatment efficacy on the basis of such studies alone. Table 6 also highlights the importance of differentiating between arts interventions that are practice versus arts therapy based. With this demarcation in mind,
to date, only two studies involve the assessment of group arts therapy. One of these consisted of a very small number (n=6) of participants (Ali, Gammidge, & Waller, 2014) and the other used a single, self-designed and un-validated outcome measure (Kim & Kang, 2013).

There are other limitations to the existing research base. Overall, there are a lack of studies that take an empirically informed methodological approach. Such an approach may allow for a more reliable and generalizable determination of any clinical benefit bestowed by visual arts interventions. Additionally, in some cases, the method of qualitative analysis employed within studies has been unspecified, and future research would do well to provide transparency in this regard. Furthermore, no attempt has been made to characterise the stroke cohorts with regards to factors that may be expected to impact response to a complex psychotherapeutic intervention such as VAT. For example, cognitive deficits, physical impairment and social support are all variables that have been demonstrated to affect outcomes in stroke interventions (Cumming, Marshall, & Lazar, 2013; Galski, Bruno, Zorowitz, & Walker, 1993; Schmid et al., 2012). Moreover, it may be expected that the ability to think creatively would exert an influence upon the efficacy of arts-based therapy. Finally, to date, no research has included follow up assessments to determine whether any benefit was maintained over longer periods of time.
### Table 6: Published research on visual arts therapy to date

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Therapy vs. Practice¹</th>
<th>Length</th>
<th>Sample (n)</th>
<th>Methodology</th>
<th>Inclusion (exclusion) criteria</th>
<th>Reported benefit</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morris et al. (2016)</td>
<td>Combination of individual and group practice.</td>
<td>Up to 8 sessions (40 min one on one; 90 min group)</td>
<td>11</td>
<td>Qualitative (framework approach)</td>
<td>Nil</td>
<td>Facilitation of social interaction, enjoyment, distraction, identity growth. Increase in confidence and self-efficacy. Improvement in subjective mood.</td>
<td>Concomitant interventions.</td>
</tr>
<tr>
<td>Kim &amp; Kang (2013)</td>
<td>Group colour therapy</td>
<td>1 × 120 mins p/week for 16 weeks</td>
<td>Community (28)</td>
<td>Quantitative (Arts therapy vs. TAU)</td>
<td>&gt;6 months from stroke. No psychiatric history. (Serious cognitive dysfunction/physical disability)</td>
<td>Significant improvement on Purpose in Life (PIL) questionnaire.</td>
<td>Outcome measure designed by researchers therefore validity and reliability not known. No follow-up assessment.</td>
</tr>
<tr>
<td>Beesley et al. (2011)</td>
<td>Group arts practice</td>
<td>1 × 2 hrs p/week for 8 weeks</td>
<td>Community (16)</td>
<td>Qualitative-grounded theory</td>
<td>(Moderate/severe receptive aphasia or significant cognitive impairment)</td>
<td>Improved confidence, self-efficacy, community participation and quality of life.</td>
<td>No baseline or follow up interviews.</td>
</tr>
<tr>
<td>Michaels (2010)</td>
<td>Individual arts therapy</td>
<td>Up to 27 sessions over 6 months</td>
<td>Community (1)</td>
<td>Single Case</td>
<td>Adjustment difficulties</td>
<td>Not reported. Author reflects upon psychodynamic processes of therapy</td>
<td>Author also lead therapist.</td>
</tr>
<tr>
<td>Gonen &amp; Soroker (2000)</td>
<td>Individual therapy</td>
<td>2 × 1.5 hr p/week for 10 weeks</td>
<td>In-patient (6-8)</td>
<td>Qualitative/single illustrative case</td>
<td>Stable clinical condition.</td>
<td>Facilitated discussion for participants. Author’s state intervention was appropriate and effective.</td>
<td>Concomitant interventions</td>
</tr>
</tbody>
</table>

Note: ¹Visual Arts Therapy must involve at least one trained arts therapist. This is differentiated from arts practice which may include arts practitioners or tutors but no arts therapist. ²= Fugl-Meyer and Functional Independence Measure.
The Present Study
Currently, there is a lack of empirically supported psychotherapies for the treatment of post-stroke psychological distress, however there is an emergent evidence base that supports the use of visual arts therapies in both stroke and non-stroke populations. As a group-based, strengths-focused intervention that comprises cognitive, non-verbal, verbal, physical, and kinaesthetic features, visual art therapy may be a treatment approach that fits well with the needs of stroke survivors. Accordingly, visual-arts therapy appears to be a good candidate intervention for these post-stroke issues, worthy of further investigation.

While the research to date has highlighted the possible value, benefit and feasibility of arts-based stroke interventions, the question of whether VAT is therapeutically effective with regards to post-stroke psychosocial and psychological distress remains to be determined. Accordingly, Chapters Five and Six describe an exploratory study of the effectiveness of a manualised 10-week group-based visual arts therapy programme (VATP) developed by Marpura Studios (Auckland, New Zealand), that combines quantitative (current chapter) and qualitative (Chapter Six) research approaches. Accordingly, the current chapter aims to determine whether such an arts-based intervention is therapeutically beneficial to a cohort of community-based stroke survivors.

Method
Participants
As described in Chapter Three (General Methods), 24 participants were initially recruited, however one participant decided to not continue with the VATP after undertaking the initial assessment, two participants discontinued during the VATP, and one participants’ data was excluded due to the probable invalidity of his self-report (described in Chapter...
Three). This provides a total post-VATP cohort of 20 (cohort one=11; cohort two =9).

See Table 2 in Chapter Three for an overview of demographic information for this cohort.

**Participant discontinuation during the VATP**

As described, two participants withdrew from VATP after it had commenced (participants 16 & 21). These two participants and the reason for their withdrawal are briefly discussed both below and in the discussion section of the current chapter.

Participant 16 was a 61 year old male who suffered four right hemisphere strokes, the most recent occurring 5-months prior to his baseline assessment. This participant reported a psychiatric history that included major depression, bi-polar depression, alcohol misuse and a history of suicidal ideation. He also expressed suicidal intent at the initial assessment, and it was noted that at that time he appeared subject to housing stress with low levels of social support (Social Networks Measure score of 2). He also reported being an amateur visual artist prior to stroke. In spite of his presenting issues however, he reported being excited to begin the VATP.

Since his stroke, participant 16 reported considerable vision problems. During the pre-VATP assessment, likely bilateral lower right quadrant hemianopia was noted due to characteristics of his performance on certain cognitive tasks (particularly on a test of visuo-spatial constructional ability). According to the facilitators of the programme, this sensory issue seemed to prevent this participant from participating fully in the programme, and it is possible that this difficulty caused him to feel distressed. The facilitators also noted that he began to become disruptive and oppositional and arrived to the third session in an intoxicated state. At this point, it was mutually agreed by facilitators and the participant that he would discontinue the programme.
Participant 21 received a terminal diagnosis during the second week of the programme and subsequently discontinued.

**Materials**

**Intervention**

The intervention was originally developed by Marpura Studios (formally Spark) (Auckland, New Zealand). It was designed by a qualified arts therapist and is conceptualised as a stroke-specific arts-based psychotherapeutic programme. The VATP is a manualised 10-week program for up to 12 participants and is facilitated by at least two trained arts therapists and arts practitioners. Each session is 3 hours in length, and sessions occur weekly for 10 successive weeks. This program utilises the process of art making as an expressive, metaphoric and therapeutic device that places emphasis on the experience and consequences of stroke, self-efficacy, consolidation of post-stroke identity change and acceptance. Art making is guided by different weekly themes, and the art is then used to inform and guide group-based discussions. An overview of the VATP that was provided to both cohorts within this study is presented in Table 7.

**Visual Art Therapy Programme Attendance**

The mean attendance for participants who completed the VATP for Cohort One (n=12) was 9.08 (SD=0.79), with a range of 8 to 10 sessions. Mean attendance for participants who completed the VATP for Cohort Two (n=9) was 9.78 (SD=0.44), with a range of 9 to 10 sessions. The mean attendance for all participants that completed the VATP (n=21) was 9.38 sessions (SD=0.74). Because of this high attendance rate and low variance, no dose-treatment response effect was calculated.
<table>
<thead>
<tr>
<th>Session Number</th>
<th>Theme of session</th>
<th>Art Making</th>
<th>Art Materials</th>
<th>Group Inquiry</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Intro and Induction</td>
<td>Where are you now? Expectations of the VATP.</td>
<td>Pastels Paper</td>
<td>Expectations of the programme? How do you see yourself in the future?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>Expression through Colour Self-Reflection Art vocabulary</td>
<td>Mood painting and incorporation of words to express emotion.</td>
<td>A3 paper and paint</td>
<td>Predominant mood and tone.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>Connecting with internal experiences (thoughts &amp; feelings)</td>
<td>Impact (of stroke) on you.</td>
<td>A3 paper and paint</td>
<td>What is the opposite of the painted emotion?</td>
</tr>
<tr>
<td></td>
<td>Self-reflection and group relationship Building</td>
<td></td>
<td></td>
<td>Moments of significance.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>What did you experience?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>How did you respond?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Impact on you?</td>
</tr>
<tr>
<td>Four</td>
<td>Self-Reflection Emotional Intelligence</td>
<td>Tints &amp; Tones &amp; Monotones Self-Portrait (how you see yourself vs. how others see you).</td>
<td>A3 paper and paint</td>
<td>Emotional Intelligence.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>How negative and positive inform each other.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Self-portraiture.</td>
</tr>
<tr>
<td>Five</td>
<td>Self-Identity Spiritual Intelligence To Belong Elements that Anchor in Life</td>
<td>To Belong Body Spiritual Mental Physical</td>
<td>A3 paper and Collage</td>
<td>Spiritual Intelligence – What is it?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>To Belong (warm up to collage) To Belong Identity – story of place/memories/places of significance.</td>
</tr>
<tr>
<td>Six</td>
<td>Identity Who we have been? Who are we now? Who we are becoming?</td>
<td>Conversation and Imagination Who have we been? Who we are now? Who we are becoming?</td>
<td>Clay Pastels</td>
<td>Self-Identity. Comfort in making it visible. Symbols and exemplars.</td>
</tr>
<tr>
<td>Seven</td>
<td>Self-Expression</td>
<td>Explore mark-making as a visual language. Colour – Polarieties/meaning e.g. Happy /Sad</td>
<td>A3 paper and paint</td>
<td>Relationship to emotion. Communication of art making through art-making and colour.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Nine</td>
<td>Resilience What sustains us? Self-efficacy</td>
<td>Group work at tables Create visual map of inner and outer using symbols/images that visually express the extent of your resource both inner and outer. Consider how inner resources interface with outer resources.</td>
<td>Own choice</td>
<td>Self-Identity. “You are becoming…” Inequalities (pre &amp; post stroke) Identify qualities before and after stroke. Outer resources and systems in life</td>
</tr>
<tr>
<td>Ten</td>
<td>Review and Conclusion Your journey through the programme</td>
<td>Create a symbol/image that embodies all you have experienced as a result of this process. Spread out and review all artwork Take time to fully review – Sharing and processing of works – Create closure. Where to from Here?</td>
<td>Card for symbols Own choice of all mediums</td>
<td>Review Key learnings. Experience vs. insight. What have you been touched by? What have you seen/valueed in others? What has grown/developed in yourself?</td>
</tr>
</tbody>
</table>
Measures

Measures included in this study can be broadly categorised as either predictor variables (i.e. those variables that are possibly associated with treatment benefit) or outcome variables. These are outlined Table 8 and Table 9 respectively. Full descriptions of the measures are provided in Chapter Three (General Methods).

Table 8: Predictor variables, their domain of functioning and underlying factors.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Domain of functioning</th>
<th>Underlying factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE-III&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Cognitive</td>
<td>General cognitive ability: Attention, memory, fluency, language &amp; visuospatial ability.</td>
</tr>
<tr>
<td>Visual Reasoning and Constructional Ability&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Cognitive</td>
<td>Non-verbal abstract conceptualisation, problem solving, visuospatial ability, motor skill.</td>
</tr>
<tr>
<td>Alternative Uses Task&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Cognitive</td>
<td>Divergent, creative thinking.</td>
</tr>
<tr>
<td>NIHSS&lt;sup&gt;4&lt;/sup&gt;</td>
<td>Neurological</td>
<td>Language, neglect, visual-field loss, extraocular movement, motor strength, ataxia, dysarthria and sensory loss.</td>
</tr>
<tr>
<td>SIS&lt;sup&gt;5&lt;/sup&gt;-Communication</td>
<td>Language ability</td>
<td>Self-reported verbal language ability.</td>
</tr>
<tr>
<td>Social Networks Measure</td>
<td>Psychosocial</td>
<td>Social engagement</td>
</tr>
<tr>
<td>Time Since Stroke&lt;sup&gt;6&lt;/sup&gt;</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: 1= Addenbrookes Cognitive Exam-III Raw Scores. 2= For this measure Block Design and Matrix Reasoning (WAIS-III) Scale Scores were combined to provide a composite score of visual reasoning and constructional ability. 3= Guilfords Alternative Uses Flexibility Coding. 4= National Institute of Health Stroke Scale. 5= Stroke Impact Scale. 6= Time since most recent stroke.

Table 9: Outcome variables and their domain of functioning

<table>
<thead>
<tr>
<th>Variable</th>
<th>Domain of functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Psychological</td>
</tr>
<tr>
<td>Apathy Evaluation Scale</td>
<td>Psychological</td>
</tr>
<tr>
<td>SIS&lt;sup&gt;2&lt;/sup&gt; Mood subscale</td>
<td>Psychological</td>
</tr>
<tr>
<td>SIS&lt;sup&gt;2&lt;/sup&gt; Participation subscale</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>Quality of Life Scale</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>General Self-efficacy scale</td>
<td>Psychological</td>
</tr>
</tbody>
</table>

Note: 1= Hospital Anxiety and Depression Scale. 2= Stroke Impact scale
Procedure

All participants undertook assessments at three time-points: within two weeks prior to the VATP (pre-VATP assessment), within two weeks of VATP conclusion (post-VATP assessment) and approximately 6-months post-VATP conclusion (follow-up assessment). The second cohort undertook an additional assessment which took place approximately 6 weeks prior to the pre-VATP assessment (henceforth referred to as baseline assessment). One participant within the second cohort did not complete the additional baseline assessment due to assessment scheduling issues. The purpose of this extra assessment was to provide a waitlist control condition, during which time participants were not subject to any intervention. Initial assessments took between 2-5 hours and the post-VATP and follow-up assessments took between 1-3 hours. The first cohort completed the VATP in 2014 and the second in 2015. An overview of the study is provided in Figure 11.

Figure 11: Schematic providing an overview of the current study including assessment time points and intervening periods.

Data Analyses

All analyses were performed with SPSS for windows (version 22) or JASP (Version 7.1.12).

Missing Data

Of the 20 participants who completed the post-VATP assessment, one participant (Cohort One) did not complete the 6 month follow-up assessment due to bereavement at the time of the assessment. Little’s Missing Completely at Random Tests (Little, 1988) was conducted to test whether these data were missing completely at random. The results
revealed that for all variables, data were completely randomly missing (see Table 10).

These findings indicate that it is appropriate to impute this single data point for all dependent variables (using SPSS) in order to preserve sample size. Accordingly, for all variables, 6-month follow-up data includes one imputed data point.

Table 10: Table displaying Little’s Missing Completely at Random test-statistic for the dependent variables contained within this study.

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Chi-Square statistic</th>
<th>Degrees of freedom</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS (depression)</td>
<td>2.759</td>
<td>2</td>
<td>.252</td>
</tr>
<tr>
<td>HADS (anxiety)</td>
<td>1.387</td>
<td>2</td>
<td>.500</td>
</tr>
<tr>
<td>SIS (mood)</td>
<td>.939</td>
<td>2</td>
<td>.625</td>
</tr>
<tr>
<td>SIS (participation)</td>
<td>3.117</td>
<td>2</td>
<td>.204</td>
</tr>
<tr>
<td>Apathy Evaluation Scale</td>
<td>.866</td>
<td>2</td>
<td>.649</td>
</tr>
<tr>
<td>General Self-Efficacy Scale</td>
<td>1.736</td>
<td>2</td>
<td>.420</td>
</tr>
<tr>
<td>Quality of Life Scale</td>
<td>1.876</td>
<td>2</td>
<td>.391</td>
</tr>
</tbody>
</table>

Note: 1 = Hospital Anxiety and Depression Scale. 2 = Stroke Impact Scale.

Statistical Analyses

To test for changes in dependent measures following a period of non-intervention (non-active control), within-subject Wilcoxon-signed rank tests were initially conducted on participants within cohort two, contrasting baseline scores with pre-VATP scores. A preliminary analysis was then conducted that directly contrasted the effect of the VATP intervention with this non-active control condition. This involved comparing the pre and post-VATP difference scores of Cohort One to the to the waitlist/ non-active control condition (baseline vs. pre-VATP) difference scores of that of Cohort Two. Due to small samples size (11 versus 10) non parametric analyses were used. Difference scores were calculated by subtracting the scores obtained at the second time-point to the scores obtained at the earlier time point. These difference scores were then subjected to Mann-Whitney U tests for independent samples. Finally, to assess the presence of any specific cohort effects, pre versus post VATP difference scores for cohorts one and two were
subject to Mann-Whitney U tests of independent samples. For all analyses the alpha level set at $p<.05$.

For all primary analyses of the VATP, pre-VATP, post-VATP and follow-up VATP intervention data of the two cohorts were combined. Outcome variables were initially subjected to preliminary analyses to investigate the assumption of normality. This included visual inspection of data using histograms, normal Q-Q plots, and Shapiro-Wilk tests. These indicated that data for Apathy Evaluation Scale-post, HADS-D-post, HADS-D-follow-up, General Self-Efficacy Scale -follow-up and SIS-Mood-pre were non-normal. Accordingly, these data were subjected to non-parametric statistical tests (Friedman’s). For all significant main effects post-hoc, non-parametric pair-wise analyses were conducted using three Wilcoxon signed-rank tests: 1) pre VATP and post-VATP, 2) pre-VATP and follow-up, and 3) Post-VATP and follow-up. In order to correct for the family-wise error rate for these pair-wise tests, the alpha level was set at $p<.017$, based upon the Bonferroni’s inequality test ($\alpha=.05 / \text{number of comparisons}$). Variables that met the assumptions of normality (HADS-A, SIS-Participation & Quality of Life Scale) were subject to one-way repeated-measure ANOVA’s. No data violated Mauchly’s Test of Sphericity. In order to correct for the family-wise error rate, Bonferroni corrections were used for all parametric pair-wise tests with an alpha level set at $p\leq.05$.

For those variables that indicated an improvement at the post-VATP time point, secondary analyses using Pearson’s correlations tested for associations between the magnitude of this improvement and predictor variables. For any significant correlations, multiple regressions were then conducted with regression models seeking to provide insight into the influence of these variables over and above the influence of stroke severity (as indexed by the NIHSS) and visual reasoning and constructional ability.
Data Visualisation

Within-subject Brinley plots (Brinley, 1965) were used to provide a more idiographic approach to data analysis for all dependent variables. Within-subject Brinley plots are scatter plots with axes that are of the same origin and scale. Individual pre-VATP data is presented on the X-axis, and individual post-VATP data is presented on the Y-axis. Paired-data points that fall on or very near the overlaid 45° diagonal indicate a lack of change. Differences between pre and post VATP scores will be indicated by a deviation from the diagonal line of no change. Trendlines (based upon Pearson correlations) are superimposed which also provide a visual index of the magnitude of improvement. Mean pre-post scores are also contained on the plots and are indicated by a filled diamond data series. Note, repeat data (i.e. matching pre-post participant data) are included in the plots and therefore contribute towards the derived trendline, however these data are not jittered. These data are instead represented by a modified asterisk-like data series.

Results

Preliminary Analyses: Non-active control Condition (Cohort Two)

To test for changes in dependent measures following a period of non-intervention (non-active control), Cohort Two undertook an additional baseline assessment approximately six weeks prior (M = 6.17, SD=1.5) to the pre-VATP assessment. Wilcoxon signed rank tests revealed no significant difference (all p>.17) for any outcome measure between the baseline and pre-VATP assessments (see Table 11).
Table 11: Cohort Two median scores and interquartile range (IQR) on outcome measures following a non-active control period.

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>Baseline Median (IQR)</th>
<th>Pre-VATP Median (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIS^1-Mood</td>
<td>10</td>
<td>57.77 (13.89)</td>
<td>61.11 (15.56)</td>
</tr>
<tr>
<td>SIS-Participation</td>
<td>10</td>
<td>53.75 (41.25)</td>
<td>51.25 (30.63)</td>
</tr>
<tr>
<td>HADS-D^2</td>
<td>10</td>
<td>8 (6.25)</td>
<td>5.5 (6)</td>
</tr>
<tr>
<td>HADS-A^3</td>
<td>10</td>
<td>7.5 (6.25)</td>
<td>9 (3.5)</td>
</tr>
<tr>
<td>Apathy Evaluation Scale</td>
<td>10</td>
<td>34.50 (8.5)</td>
<td>32 (15.50)</td>
</tr>
<tr>
<td>General Self-Efficacy Scale</td>
<td>10</td>
<td>30.50 (8.75)</td>
<td>30.75 (3.25)</td>
</tr>
<tr>
<td>Quality of Life Scale</td>
<td>10</td>
<td>77.50 (33)</td>
<td>77 (32.75)</td>
</tr>
</tbody>
</table>

Note: 1= Stroke Impact Scale; 2= Hospital Anxiety and Depression Scale-Depression subscale; 3= Hospital Anxiety and Depression Scale—Anxiety subscale.

Preliminary Analysis: Contrasting post-VATP treatment outcomes with a non-active waitlist-control.

To test whether there was a difference in the amount of change following the VATP intervention compared to the non-active control condition, a series of Mann-Whitney U tests were conducted comparing the difference scores of cohort one (pre vs. post-VATP) and cohort two, waitlist control (baseline vs. pre-VATP). Despite the small number of participants in each group, there was a significant difference between groups for SIS (Participation) \( z=-2.189, \ p=.029 \), indicating that the VATP group had a greater increase in participation than the non-active waitlist control group. There was no significant difference for any other variable although both HADS-A and the Quality of Life Scale approached significance (indicated in bold, see Table 12).
Table 12: Median scores and interquartile range (IQR) for between-group analyses comparing pre-post VATP difference scores (Cohort One) to a non-active control condition (Cohort Two).

<table>
<thead>
<tr>
<th>Measure</th>
<th>VATP¹ Median (IQR)</th>
<th>Non-Active Control¹ Median (IQR)</th>
<th>z-score</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIS-Mood</td>
<td>13.33 (22.23)</td>
<td>3.33 (7.78)</td>
<td>1.623</td>
<td>.105</td>
</tr>
<tr>
<td>SIS -Participation</td>
<td>12.50 (12.50)</td>
<td>0 (16.25)</td>
<td>2.189</td>
<td>.029</td>
</tr>
<tr>
<td>HADS-D</td>
<td>1 (4)</td>
<td>.5 (4.25)</td>
<td>1.069</td>
<td>.285</td>
</tr>
<tr>
<td>HADS-A</td>
<td>0 (8)</td>
<td>-1 (4.50)</td>
<td>1.810</td>
<td>.070</td>
</tr>
<tr>
<td>Apathy Evaluation Scale</td>
<td>2 (10)</td>
<td>1.5 (7.25)</td>
<td>0.389</td>
<td>.698</td>
</tr>
<tr>
<td>General Self-Efficacy Scale</td>
<td>2 (4)</td>
<td>.50 (4.75)</td>
<td>0.460</td>
<td>.646</td>
</tr>
<tr>
<td>Quality of Life Scale</td>
<td>12 (24)</td>
<td>-2.50 (10.13)</td>
<td>1.833</td>
<td>.067</td>
</tr>
</tbody>
</table>

Note: ¹ For ease of interpretation, scores for Stroke Impact Scale, General Self-Efficacy Scale and Quality of Life Scale have been reversed so that for all measures, positive difference scores indicate improvement.

Preliminary Analysis: Contrasting post-VATP treatment effects between the two cohorts.

Between cohort analyses were also conducted in order to determine whether there were any differences in the magnitude of pre vs. post-VATP change between the two cohorts. Difference scores were calculated by subtracting post-VATP scores from pre-VATP scores for both cohorts. A series of Mann-Whitney U tests were then conducted comparing the difference scores of the two cohorts on each dependent variable. Although the sample sizes were small, with corresponding reduced statistical power, it was considered important to run these analyses in order to test for the possibility of any cohort differences. These analyses revealed no significant difference between magnitude of post-VATP change on any dependent variable (all p>.11).

Primary Analyses: Testing the effects of VATP on outcome measures

Within-subject parametric analyses

One-way repeated measures ANOVAS were utilised to test for differences in HADS (anxiety) SIS (participation) and Quality of Life Scale scores, with time as the within subject factor (pre-VATP, post-VATP and follow-up). Figure 12 displays mean scores at the three time-points for these three dependent variables.
There was a significant main effect of time on HADS (anxiety) scores, $F(2, 38) = 6.373, p = .004, \eta^2 = .251$. Bonferroni pairwise comparisons found significant differences between pre-VATP and post-VATP HADS (anxiety) scores ($p = .019$); and pre-VATP and follow-up HADS (anxiety) scores ($p = .044$). No significant difference was found between post-VATP and follow-up HADS (anxiety) scores ($p = 1$). These findings indicate that overall, participants experienced an improvement in anxiety symptoms as measured by the HADS immediately following completion of the VATP and that this improvement was maintained 6-months following VATP completion.

A repeated measures ANOVA also showed a significant main effect of time on SIS (Participation) scores ($F(2, 38) = 5.636, p = .007, \eta^2 = .229$). Bonferroni pairwise comparisons revealed a significant difference between pre-VATP and follow up SIS (Participation) scores ($p = .015$). However, no significant difference was found between pre-VATP and post-VATP SIS (Participation) scores ($p = .068$); and post-VATP and follow-up SIS (Participation) scores ($p = 1$). These findings indicate that overall, participants did not experience an improvement in participation in activities that they find meaningful and purposeful immediately following the VATP, however they did experience an improvement 6-months following VATP completion.

A repeated measures ANOVA showed a significant main effect of time on Quality of Life Scale scores ($F(2, 38) = 11.42, p < .001, \eta^2 = .375$). Pair-wise Bonferroni comparisons found significant differences between both pre-VATP and post-VATP ($p = .005$); and pre-VATP and follow-up ($p = .002$) Quality of Life Scale scores. No significant difference was found between post-VATP and follow-up Quality of Life Scale scores ($p = 1$). These findings indicate that overall, participants experienced an improvement in Quality of Life as measured by the Quality of Life Scale immediately following completion of the VATP and that overall, this improvement was maintained at the 6-month assessment point.
Figure 12: Mean scores and standard error bars for HADS-Anxiety (top), SIS-Participation (middle) and Quality of Life Scale (bottom). Pairwise comparisons producing a Bonferroni corrected p value < .05, denoted by *. Note: Decreasing scores indicate improvement on the HADS, while increasing scores indicate improvement for SIS and Quality of Life Scale.
Within-subject non-parametric analyses

Friedman’s tests were utilised to determine whether there were significant differences in measures completed at the three time-points for SIS\textsubscript{(mood)}, HADS\textsubscript{(depression)}, Apathy Evaluation Scale and General Self-Efficacy Scale measures (see Table 13).

The Friedman’s test of differences was significant for SIS\textsubscript{(mood)} scores \(\chi^2(2)=11.47, p=.003\). Post-hoc pairwise Wilcoxon signed-rank tests revealed a significant difference between pre-VATP and post-VATP \(Z=2.56, p=.010, r=.57\); and pre-VATP and follow-up \(Z=3.08, p=.002, r=.69\) SIS\textsubscript{(mood)} scores. No significant difference was found between post-VATP and follow-up SIS\textsubscript{(mood)} scores \(Z=.078, p=.938, r=.02\). These findings indicate that overall, participants experienced an improvement in mood symptoms as measured by the SIS\textsubscript{(mood)} subtest immediately following completion of the VATP and that this improvement was maintained 6-months following VATP completion.

The Friedman’s test of differences was also significant for HADS\textsubscript{(depression)} scores \(\chi^2(2)=7.314, p=.026\). Pair wise post-hoc Wilcoxon signed-rank tests revealed a significant difference between pre-VATP and follow-up HADS\textsubscript{(depression)} scores \(Z=2.84, p=.004, r=.64\). No significant differences were found between pre-VATP and post-VATP \(Z=1.75, p=.080, r=.39\); or post-VATP and follow-up \(Z=.66, p=.509, r=.15\) HADS\textsubscript{(depression)} scores. These findings indicate that overall, participants did not experience an improvement in participation in depression symptoms immediately following the VATP, however they did experience an improvement 6-months following VATP completion.

For the Apathy Evaluation Scale scores the Friedman’s test was also significant \(\chi^2(2)=16.55, p<.001\). Pairwise Wilcoxon signed-rank tests found significant differences between both pre-VATP and post-VATP Apathy Evaluation Scale scores \(Z=2.41, p=.015\).
$p=.016, r=.54$) and pre-VATP and follow-up Apathy Evaluation Scale scores ($Z=3.16, p=.002, r=.71$). No significant difference was found between post-VATP and follow-up Apathy Evaluation Scale scores ($Z=.28, p=.777, r=.06$). Overall, participants experienced an improvement in Apathy symptoms immediately following completion of the VATP and that this improvement was maintained 6-months following VATP completion. Finally, no significant difference between the Self-efficacy scale scores at the three time-points was found ($\chi^2(2)=2.62, p=.270$).

**Table 13**: Medians and inter-quartile range (IQR) between pre-VATP, post-VATP and 6-month follow-up time points for outcome measures subject to non-parametric analyses.

<table>
<thead>
<tr>
<th></th>
<th>Pre-VATP Median (IQR)</th>
<th>Post-VATP Median (IQR)</th>
<th>Follow-Up Median (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIS$^1$ (Mood)</td>
<td>62.22(18.89)</td>
<td>67.78(10)$^*$</td>
<td>68.89 (8.90)$^{**}$</td>
</tr>
<tr>
<td>HADS$^2$ (Depression)</td>
<td>5 (4)</td>
<td>5(3)</td>
<td>5(4.66)$^{**}$</td>
</tr>
<tr>
<td>Apathy Evaluation Scale</td>
<td>32 (9)</td>
<td>28 (11.63)$^*$</td>
<td>27.5 (12)$^{**}$</td>
</tr>
<tr>
<td>Self-Efficacy Scale</td>
<td>31(3.75)</td>
<td>32 (5.5)</td>
<td>32.50 (6.75)</td>
</tr>
</tbody>
</table>

*Note: 1=Stroke Impact Scale. 2= Hospital Anxiety and Depression Scale. All $p$-value indicators are relative to pre-VATP scores. $^* p<.05; ^{**} p<.01$. For the HADS and Apathy Evaluation Scale decreasing scores indicate improvement. For the SIS and Self-Efficacy Scale, increasing scores indicate improvement.*

Because the HADS provides dichotomous cut-off (≥8) for both depression and anxiety sub-scales, changes in the proportions of participants who fell in the abnormal range following the VATP were analysed. McNemar tests revealed that significantly fewer participants fell above cut-off for HADS (anxiety) following VATP completion (n=3, 15%) relative to pre-VATP (n=11, 55%, $p=.021$). Consistent with the within-subjects analyses, McNemar tests found no significant difference between the number of participants who fell above cut-off on the HADS (depression) scale following VATP completion (n=2, 10%) relative to pre-VATP (n=6, 30%, $p=.219$). Note, chi-square statistics are not reported due to SPSS utilising binomial distribution for the McNemar test, due to small sample size.
Primary Analyses: Visual Analysis of within-subject data.

Participant pre-post scores for all seven outcome measures are displayed in Figure 13. Inspection of these plots indicates that 12 (60%) participants reported improved HADS (anxiety) scores; 15 (75%) participants reported improved SIS (Participation) scores; 11 (55%) participants reported improved HADS (depression) scores; 16 (80%) participants reported improved SIS (Mood) scores; 16 (80%) participants reported improved Apathy Evaluation Scale scores; 12 (60%) participants reported improved SES scores and 14 (70%) participants reported improved Quality of Life Scale scores following the VATP. It is noted that in the majority of cases, superimposed trendlines (based upon Pearson correlations) indicate that those participants with pre-VATP scores that indicated poorer levels of psychological or psychosocial wellbeing, generally presented with the greatest amount of improvement. Exceptions to this appears to be SIS (mood) and SIS (participation) where it is noted that some participants experienced a decrease in wellbeing following VATP. It is also noted that superimposed trendlines for HADS (Depression) and SES indicate little deviation from the line of no change, which is consistent with the inferential analyses described earlier. Note that no substantive inference on the basis of these data is intended; instead these visual plots are intended to provide an alternative means representing the data, in addition to data transparency.
Figure 13: Within-subjects Brinley plots displaying individual pre-post scores for the seven outcome measures within this study with superimposed Pearson correlation coefficients.
Secondary Analyses: Exploring the association between factors that may affect VATP efficacy.

Participant factors such as cognitive ability, neurological impairment, language ability and social context may impact upon VATP efficacy. For example, lower levels of general or specific cognitive abilities induced by stroke may impact treatment effects due to difficulties with, for example, understanding and reasoning. Similarly, those participants with poorer self-reported communication abilities may struggle with the verbal, group-based nature of the programme, or alternatively, may experience anxiety as a consequence of this. Alternatively, given that many stroke survivors experience an increase in social isolation following their stroke, it is possible that treatment effects were driven by an increase in social engagement for those participants that experience isolation within their communities. Finally, given the diverse verbal, visual, and physical components that comprise the VATP, those participants who experienced greater levels of neurological impairment may be subject to less benefit from the programme.

To investigate whether efficacy of the VATP was influenced by such factors, uncorrected Pearson correlations were conducted using pre-VATP and post-VATP difference scores for the four outcome measures that indicated an improvement at the post-VATP time-point (HADS-A, Quality of Life Scale, SIS-Mood &Apathy Evaluation Scale) and the predictor variables outlined in Table 8. Following this, multiple regressions were conducted to determine whether magnitude of change was influenced by any significantly associated predictor variable. Each hierarchical regression analysis sought to initially control for stroke severity (as indexed by the NIHSS) and visual reasoning and constructional ability (as indexed by aggregate Block Design and Matrix Reasoning scores).
There were no significant correlations between general cognitive ability (as measured by
the ACE-III) and HADS-A (difference) scores, Quality of Life Scale (difference) scores, SIS-
Mood (difference) scores or Apathy Evaluation Scale (difference) scores (all p’s > .16). Similarly,
there were no significant associations between visual reasoning and constructional ability
and any of these outcomes (all p > .20). There was a significant, positive correlation
between Alternative Uses (flexibility) scores and HADS-A (difference) scores (r = 0.486, p = .041),
indicating that those participants who displayed greater divergent and creative thinking
ability, displayed a greater reduction in anxiety symptoms. There was no association
found between Alternative Uses (flexibility) and Quality of Life Scale (difference) scores, SIS-
Mood (difference) scores and Apathy Evaluation Scale (difference) scores (all p’s > .24).

There were no significant correlations between neurological impairment (as indexed by
the NIHSS), self-reported language ability (as indexed by the SIS-communication
subtest), social networks or time since stroke and any of the four outcome variables that
demonstrated a significant improvement following the VATP intervention (HADS-A
(difference), Quality of Life Scale (difference), SIS-Mood (difference) and Apathy Evaluation Scale
(difference)), all p-values > .18.

Because a significant association was found between Alternative Uses (flexibility) scores and
HADS-A (difference) scores, a hierarchical regression was conducted in order to determine
whether divergent thinking ability predicted anxiety symptom reduction beyond any
effect of stroke severity and non-verbal cognitive ability. Stroke severity (as indexed by
the NIHSS) and visual reasoning and constructional ability (as indexed by aggregate
Block Design and Matrix Reasoning scores) were entered in the first block, and divergent
thinking ability (as indexed by the Alternative Uses flexibility scoring) was entered in the
second block. Although these variables were not associated with HADS-A (difference) scores
in the current sample, they are indicated in the literature and it was considered that the
combined effect of stroke severity and cognitive impairment may influence VATP outcomes. The hierarchical multiple regression revealed that at block one, stroke severity and visual reasoning and constructional ability did not contribute significantly to the regression model ($R^2_{(change)} = .065, F_{(2, 17)} = 0.521, p=.604$). It was found that while divergent thinking alone significantly predicted HADS-A (difference) scores ($\beta = .608, t_{(17)}=2.538, p=.024$), the addition of divergent thinking ability did not contribute towards an overall significant regression model ($R^2_{(change)} = .295, F_{(3, 17)} = 2.620, p=.092$).

In summary, for the four outcomes that demonstrated significant improvement immediately following the completion of the VATP, there were no significant associations with neurological impairment, self-reported verbal language ability or extent of social networks. There was an association found between divergent thinking ability and HADS-Anxiety (difference) scores indicating that those participants with greater divergent thinking ability tended to demonstrate a greater magnitude of reduction in anxiety symptoms. However, a follow-up hierarchical regression that also included stroke severity and visual reasoning and constructional ability did not produce a significant model predicting HADS (anxiety) scores, even though divergent thinking ability was a significant predictor.

**Discussion**

This chapter reports the findings of an exploratory evaluation of a 10-week, group-based visual arts psychotherapeutic intervention for the common psychological consequences of stroke. Two-cohorts, separated by one year undertook Marpura studios visual arts therapy programme (VATP). All participants completed a number of self-report measures at three time-points (pre-VATP, post-VATP, & 6-months following VATP completion), which provided an index of within-subject change across a number of psychological and
psychosocial domains. The second cohort also undertook a non-active control waitlist condition. This discussion will feature a summary and evaluation of the findings of this study, with emphasis placed on strengths, limitations and future directions.

The findings of this study indicate that participants’ experienced a significant improvement on self-reported measures of anxiety, apathy, mood and quality of life immediately following completion of the VATP. For these four outcomes, this improvement was maintained at the 6-month time-point. Conversely, following completion of the VATP, there was no significant improvement on self-reported measures of depression and a stroke-specific measure of quality of life, however, for both these domains a significant improvement was found at the 6-month time point. On a self-reported measure of self-efficacy, no significant improvement at any time point was observed. These findings were supported by a comparison between post-VATP scores (for cohort one) and a waitlist control condition (cohort two). These analyses found a significant improvement in life participation and an improvement in anxiety, mood, life participation and quality of life that approached significance. However, there was no demonstrable difference in depression, apathy or self-efficacy scores. These findings were also consistent the significant reduction in the number of participants who fell above the HADS cut-off for anxiety (i.e. 55%-15%) after completion of the VATP, but not depression (i.e. 30%-10%).

These results are consistent with, and support, the small number of previous qualitative studies investigating the benefit of an arts-based intervention. However, this study differs from much of this research as it provides an assessment of a specific arts-based psychotherapeutic programme, rather than a practice based art programme. It is considered that this exploratory study represents an important addition to the stroke-related psychotherapeutic literature as at this time, it is the first study that has attempted
to determine the efficacy of an arts-based intervention for stroke using quantitative methods.

For the outcomes that demonstrated a significant improvement immediately following completion of the VATP (anxiety, apathy, mood and quality of life), pre-post VATP effect size estimates fell within the medium or large ranges. Given the current lack of evidence that supports the use of psychotherapy for stroke, it is not possible to compare these effect estimates to findings within the stroke-specific literature. However, the effect estimates of the current study are broadly consistent with the treatment effects reported in meta-analyses for a number of psychotherapeutic interventions for non-stroke psychological problems. These include CBT for depression (Cuijpers, Smit, Bohlmeijer, Hollon, & Andersson, 2010), behavioural activation for depression (Cuijpers, Van Straten, & Warmerdam, 2007), CBT for anxiety (Hofmann, & Smits, 2008), CBT for adolescent depression (Klein, Jacobs, & Reinecke, 2007) and Acceptance Commitment Therapy for a range of outcomes (Powers, Zum Vörde Sive Vörding, & Emmelkamp, 2009).

The importance of this study lies in the provision of a pragmatic initial exploration of the benefit of a novel psychotherapeutic programme for stroke survivors. Moreover, this study is noted to occur within the context of a population that experiences high levels of psychological distress, yet, at this time, there is a lack of evidence for psychotherapeutic approaches for stroke and only tentative support for the use of pharmacological treatments. Moreover, and as discussed, the use of pharmacological treatments may contribute towards adverse consequences due to drug-drug interactions or side-effects which may be more pronounced in stroke populations (Campbell Burton et al., 2011; Hackett, Anderson, House, & Xia, 2004/2008). With this in mind, this study takes an important and necessary first step by providing initial quantitative support for therapeutic
potential of a novel group-based psychotherapy for a population that experiences high levels or of psychological distress, for which currently, there are minimal treatment options.

**Strengths of the study**

This study had several strengths that are important to note. The design of this study included a 6-month follow-up assessment which provided important insight into whether the changes noted immediately following VATP completion were maintained. Given the nature of visual arts therapy, this follow-up assessment is important as it may be expected that participants report improvement in psychological wellbeing immediately after completion purely due to the programme providing a form of social interaction and enjoyment. It is noted that this is the first investigation of a VATP to include a follow-up assessment.

Another strength of the study was the inclusion of a high number of outcome variables. When taken together, these captured much of the complex diversity that defines the psychological and psychosocial experience of stroke survivors. Moreover, this approach is both consistent with research indicating that co-morbidity of psychological issues is a reasonably prevalent phenomena within stroke populations (e.g. Åström, 1996), in addition to the view that generally, psychological co-morbidity is unlikely to occur randomly and is instead considered to reflect symptomology that is additive, interacting and overlapping (e.g. behaviours associated with anxiety such as avoidance, may be expected to increase depression symptoms) (Westen, Novotny, & Thompson-Brenner, 2004). Accordingly, the inclusion of multiple outcome variables meant that it was possible to determine that, in general the VATP acted as a broad psychotherapeutic intervention. That is, there was noted improvement across a number of outcomes.
Furthermore, the methodology of this study attempted to take account of the heterogeneity that characterises community-stroke populations. First this was represented in the diversity of the sample which captured an excellent range of ethnic, gender and other demographic differences. Minimal exclusion criteria also meant that the sample was characterised by a high degree of stroke-related variability (e.g. time since stroke, hemisphere of stroke etc.). These factors ensured that the study retained a good level of ecological validity. Second, a number of ‘predictor’ variables were included that provide an index of cognitive, neurological, social functioning, divergent (creative) thinking, in addition to other factors such as time since stroke and self-reported communication ability. This allowed for a consideration of how these factors may be associated with VATP outcomes. Overall, these findings support the view that the VATP appropriately accounts for the diverse cognitive, social and physical needs of stroke survivors, in addition to the high levels of psychological co-morbidity that characterises this population.

**Therapist Variables**

Another strength of this study was that although the first cohort was led by the visual art therapist that designed the programme, the second cohort was led by an alternate therapist. Importantly, between-cohort analyses revealed no significant difference in pre/post difference scores for any outcome. It is important to note that given the small sample size, the ability to reliably detect a difference between the cohorts was limited; however these finding provide cautious support for the view that the VATP delivers benefit to participants irrespective of any therapist effects contained within the current study.
Discontinuation and Attendance

Two participants discontinued the VATP. Such participant discontinuation may contribute towards bias in this study as those who discontinue may simply be more difficult to treat, or alternatively, it may suggest that the programme was unsuitable for some participants. In one case, this discontinuation appeared to be related to a medical issue and therefore, no further conclusion need be drawn. However, in the second case, the discontinuation appeared to be at least partially due to the specific art-making content of the programme. It is therefore possible that for this participant, his pre-stroke engagement with art-making, in combination with his sensory deficit, and the art-making content of the programme potentially exacerbated his sense of loss or change since his stroke. In this case it seems that the VATP exerted a negative effect on the psychological state of this participant. Facilitators reported that he arrived intoxicated to the third session, and over time, became increasingly oppositional and agitated. Accordingly, he was subsequently exited from the programme. It is possible, therefore, that visual art therapy is contraindicated in individuals who had a pre-stroke art-making ability that has been subsequently affected by stroke. It is noted that only two participants (9% of total) that started the programme did not complete, which reflects favourably given the literature indicating that drop-out rates of 30-40% may be typically expected within group-therapy (Yalom & Leszcz, 2005).

Overall, VATP attendance rates were excellent. This indicates that with the exception of the participant described above, the programme was well tolerated and provided for an appropriate level of engagement which ensured high therapeutic dose. This is a particularly important consideration as many stroke-survivors experience financial or other difficulties which can act as a considerable barrier to treatment attendance.
Secondary Analyses

The results of correlational and regression analyses provided no evidence of any associations between significant outcomes and neurological impairment, self-reported verbal language ability or extent of social networks. Of course, it is expected that there would be a point at which neurological or language impairments would prohibit successful engagement with such a programme, however these findings indicate that the content of the VATP appropriately accounted for the diversity of treatment responsivity needs that characterised this particular community-based stroke sample. It was noted that greater divergent/creative thinking ability and less time since stroke was associated with greater improvement in anxiety and apathy symptoms (respectively). However, while divergent/creative thinking ability predicted anxiety outcomes, time since stroke did not.

Divergent thinking relates to the ability to generate multiple solutions to a given problem in a non-linear and free flowing manner (Razoumnikova, 2000). Divergent thinking also reflects the ability to derive novel concepts and solutions through the flexible combination of components, concepts or ideas that are distant in semantic relatedness (Guilford, 1967; Howard-Jones, Blakemore, Samuel, Summers, & Claxton, 2005). Although not considered to be synonymous with creativity, it is considered by some that being creative relies in part, on divergent thinking ability (McCrae, 1987; Runco, 1991). Therefore, one obvious explanation for the finding that divergent thinking predicts anxiety symptom reduction is that participants with greater divergent thinking ability were able to benefit more from the programme due to its inherently creative character. That is, such participants were simply more able to fully explore, examine and express the consequences and experiences of their stroke using an arts-based/creative medium.

Alternatively, it is possible that regardless of the arts-based content, those participants with greater divergent thinking ability were better able to flexibly combine the knowledge
and skills gained within the programme, in order to imagine, develop and enact an alternative view of their future. This explanation is consistent with recent research indicating that greater divergent thinking ability is associated with greater episodic detail when individuals engage in constructive future thinking tasks (Addis, Pan, Musicaro, & Schacter, 2016). In this context, the alternative uses task may have indexed the ability of participants to reconsider and flexibly reconceptualise the possibilities available to them within their post-stroke life as a consequence of VATP. Interestingly, although recent research has begun to identify psychological inflexibility as related to a number of mental health outcomes (Kashdan, & Rottenberg, 2010; Masuda, & Tully, 2012), little research investigates the role of cognitive flexibility as a predictor of psychotherapeutic treatment response. In this context, the findings of the current study indicate that cognitive flexibility may be an important predictor of treatment outcome in stroke populations, and perhaps, non-stroke populations. This view is however tempered somewhat, as no consistent pattern of association was found between divergent/creative thinking and outcomes. However, within this may be an important area of future research.

**Limitations of the study**

There are a number of limitations to this current study which are important to consider. The primary limitation of this study is the small sample size, which limits the ability to generalise these findings to the wider stroke population. It is recognised that studies with small samples sizes tend to overestimate effect sizes (Cuijpers, van Straten, Bohlmeijer, Hollon, & Andersson, 2010; Durlak, 2009; Lakens, 2013). Moreover, due to low statistical power, the ability to detect group differences was limited, which may mean that ‘true’ between-group effects were not detected (for example, those that reflect therapist differences or cohort effects). However, the decision to limit the cohorts to 12 participants
is defensible given the literature which indicates that the maximum recommended size for group psychotherapy is approximately 12 participants (e.g. Gladding, 1994; Weis, 2003). The lack of a non-randomised control group and non-blinded assessor may also contribute to an over-estimation of treatment effect. In the former case, the addition of a baseline assessment added an important between-groups condition. Although the small sample size would have limited the ability to find an effect, it is encouraging that one significant finding was found, in addition to others that were trending towards significance. Nevertheless, the lack of a fully powered between-subjects design means that it is difficult to determine whether treatment effects were due to visual arts therapy, or other factors such as regression to the mean, placebo or expectancy effects (or a combination of these). Thus whilst the effect estimates within this study ought to be interpreted in a conservative manner, these findings provide a strong justification for the undertaking of a fully-powered study in the future.

While one strength of this study, relates to the use of a high number of dependent variables it is also a limitation. The use of seven outcome variables in this study increases the probability of a type-I error to approximately 30% \((1-.95^7 \times 100\%)\). This probability of error can (and ought to) be corrected for, typically by the use of a Bonferroni correction (i.e. \(\alpha/7\)), however, given the small sample size of this study, such an approach would grossly inflate the probability of a type-II error. In this regard, it is noted that of the six outcome variables that displayed a significant main effect of time, only HADS (depression) scores would have been non-significant given an adjusted \(p\)-value of <.0071 (i.e. \(\alpha=.05/7\)). Accordingly, the pattern of results (i.e. four variables demonstrating improvement post-VATP, and all variables except generalised self-efficacy, demonstrating improvement at 6-month follow up) gives some confidence that the
findings within this chapter are not simply due to this inflated Type-I error rate. However, this ought to be confirmed by further research.

Another limitation of this study was that it was subject to sampling bias. Given that the VATP is a group-based program, it was a requirement that participants would be able to travel to sessions. This likely meant that only those participants that were sufficiently well resourced (either financially or socially), and able to travel were included in this study. Similarly, participants were informed of the art-making content of the programme at the outset, which may have resulted in a self-selection bias, whereby only those participants who anticipated enjoying the art-making process continued into the programme and study. Although it is noted that that all community-based psychotherapeutic interventions require some form of travel (particularly group-based interventions) and it is difficult to envisage a psychotherapy that is not subject to some level of self-selection bias, these factors may limit the extent to which the findings of the current study can be generalised to the wider community population.

**Future directions**

The findings within this exploratory study suggest that a more substantive trial of Marpura studios VATP is warranted. This is considered particularly important in light of the current lack of evidence-based psychotherapeutic treatments for such post-stroke issues. Based on the present findings, a randomised-controlled trial featuring a between-subjects design with a two-sided alpha of .05 and 80% power to detect a moderate effect-size ($d=.70$) would require a sample size of 68 (34 in each group). From time of recruitment to post-VATP assessment, the current study retained 20/24 participants which provides an overall discontinuation rate of 17%. In accordance with these discontinuation rates, for a fully powered between-subjects design, future studies would therefore be required to recruit a total of 82 participants.
It is possible that the social aspects of the VATP contributed towards improvement in outcomes. Therefore it is important for future studies to disentangle the importance of the art-making vs. socially interactive nature of the VATP. Accordingly, a future trial ought to include three conditions that contrast visual art therapy with facilitated social support group with a usual care condition. It is also recommended that future studies retain the use of cognitive and divergent thinking measures in order to confirm/disconfirm the findings of the current study. Moreover, in order to better protect against inflated type-I error rates it is also recommended that future studies consider the use of a reduced number of outcome measures. However this needs to be carefully considered in light of the co-morbidity that characterises stroke populations, in addition to the fact that the VATP was not specifically designed for any one psychological disorder.

One strength of this study was that exclusion criteria was kept to a minimum, however this meant that in some cases participants entered the programme with a minimal level of post-stroke distress. This may have meant that floor effects contributed to some of the null findings. Given the group-based nature of the programme however, it is possible that the inclusion of relatively well-functioning participants provided for a therapeutic process of normalisation, where the possibility of living a meaningful life, despite the experience of stroke, was realised through interacting with further recovered, or less affected stroke survivors. Although participant accounts (Chapter Six) are likely to reveal any such processes, it may be beneficial for future studies to ensure that such high functioning participants only comprise a minority of any future sample (i.e. approximately 10%).

Finally, findings indicate a relationship between cognitive flexibility and treatment response. Given the uniquely creative character of the VATP, it is not possible to conclude whether these findings were due to cognitively flexible participants being able to better engage with the creative aspects of the programme or whether such individuals
generally respond to psychotherapeutic treatment responses more readily. It is noted that at this time there is a lack of research that investigates the relationship between cognitive flexibility and treatment response. Accordingly, future research, within both stroke and non-stroke contexts would do well to further explore this question.

**Summary**

This exploratory study is the first to use a quantitative methodology with a 6-month follow-up condition which attempted to determine the efficacy of a visual arts based treatment for stroke populations. The findings of this study suggest that visual arts therapy is a good candidate psychotherapeutic treatment for a number of post-stroke issues with effect-size estimates that are congruent with a number of widely used evidence-based psychotherapies. Moreover, VATP appears to appropriately account for the diverse cognitive, social and physical needs of stroke survivors, in addition to the high levels of psychological co-morbidity that characterises this population. The importance of this study is best highlighted by the literature which demonstrates that at this time, there is an overall lack of psychotherapeutic treatment options for this population, and only tentative evidence for the use of pharmacological treatments. Finally, whilst a strength of the current study was that it was the first to apply quantitative research methods to the question of VATP efficacy, this design did not feature a randomised control group which makes it difficult to understand the unique contribution (if any) that the process of art-making made to the observed treatment effects. Accordingly, the next chapter (Chapter Six) takes a qualitative research approach in order to uncover participant experiences of the programme, which may, in turn, provide insight into such mechanisms of change.
Chapter Six: Experiences of participation in a group-based Visual Art Therapy Programme for stroke survivors

Introduction

The current chapter follows on from Chapter Five by using a qualitative research method to provide insight into participant experiences of the VATP. It is noted that using a qualitative approach represents a departure from the epistemological foundation that underlies the preceding chapters of this thesis. Therefore, it is important to introduce this chapter by briefly discussing and outlining the nature of this departure, in addition to providing an understanding of why such an approach was taken.

Commentators have noted that certain research questions or phenomena may be more or less suited to quantitative or qualitative means of inquiry (Sale, Lohfeld, & Brazil, 2002). As described in Chapter Three (General Methods), the majority of this thesis utilises quantitative methods, which are founded upon a positivist epistemology. This epistemic view is related to an underlying ontological position which argues that there is objective reality or truth that exists independently of human perception (Furlong, & Marsh, 2010; Sale et al., 2002; Tuli, 2011). Quantitative methods are therefore implemented with the aim of understanding and gaining knowledge about this external reality or truth, and are accordingly concerned with establishing causal relationships between variables. Qualitative research by contrast, is founded upon an interpretative or constructionist epistemology. This relates to an ontological position which considers that there is no discoverable external or objective truth that exists ‘out there’ (Sale et al., 2002). Instead, reality is considered to be emergent, and is created or constructed within the context of subjective human experiences (Furlong, & Marsh, 2010; Schwandt, 1994). In this context, it is considered that multiple truths exist and these are largely derived on the basis of how one constructs and interacts with reality (Furlong, &
Qualitative research is therefore, primarily concerned with the meaning and processes that give rise to, and arise out of, this constructed reality.

It is considered that both quantitative and qualitative approaches may have utility in regards to research that aims to understand the benefit of an intervention such as visual arts therapy, albeit in differing ways. Quantitative methods (as in Chapter Five) may be most appropriate for understanding if the VATP resulted in improved psychological wellbeing across a number of clinically relevant domains. Qualitative methods by contrast, may be suited to understanding participants’ experiences of the VATP, which in turn, may provide understanding as to how the programme resulted in improved psychological wellbeing. Some commentators argue however, that due to irreconcilable differences in their ontological and epistemological foundations, it may be inappropriate to attempt to combine such differing methodological paradigms as they are seen as incompatible or irreconcilable (Furlong, & Marsh, 2010). That is, some consider that because these approaches arise out of entirely different assumptions about the underlying nature of reality, they cannot be combined for the purposes of research (e.g. Guba, 1987).

It is considered that this argument is logically valid in cases where researchers blend differing methodological approaches to study the same phenomena or approach the same research question. However, commentators argue that this view does not apply as long as researchers attempt to answer or understand different research questions or phenomena (Sale et al., 2002). That is, while it may be inappropriate to combine methods within a single study for the purpose of cross-validation/triangulation, it is possible to combine methods in a complementary manner, provided that the phenomena under study are both well-defined and distinct (Sale et al., 2002). Other views are based upon the philosophy of pragmatism, which is concerned with finding the middle ground between philosophical or epistemological dogma and scepticism (Johnson, & Onwuegbuzie, 2004). This view argues that the research question
or phenomena of interest should be of central concern, irrespective of the particular ontological or epistemological foundations of a given method or the particular ontological or epistemological beliefs of the researcher (Bryman, 1984; Doyle, Brady, & Byrne, 2009; Morgan & Smircich, 1980).

On this basis, the writer argues that while the current chapter represents a methodological (and hence epistemological/ontological) departure from the rest of this thesis, it is considered justified as the current chapter is concerned with phenomena that are distinct from Chapter Five. That is, while Chapter Five was concerned with whether the VATP contributed to improved psychological wellbeing as indexed by a number of outcome variables, Chapter Six is concerned with the meaning and experiences that were important to participants. While these aims are complementary they are not analogous. Furthermore, just as a qualitative approach is not suited to the research question that underlies Chapter Five, neither is a quantitative approach suited to the research question that has inspired the current chapter. Accordingly, the writer also appeals to the philosophy of pragmatism, and irrespective of his own ontological or epistemological beliefs, seeks to apply a method that is most suited to the question at hand.

The present study

By adopting a qualitative research approach, the current chapter aims to complement the findings of Chapter Five by providing understanding of the factors that were important to their experience of the VATP. It is hoped that this approach will provide insight into the processes that drove the treatment effects observed within Chapter Five.
Methods

Data gathering
Participants who completed the VATP (n=20) undertook a one on-one interview at the post-VATP time point which was conducted by the writer. All interviews occurred at the end of an assessment session that involved the administration of outcome measures (as described in Chapter Five). Interviews aimed to provide participants with the opportunity to describe their experiences of the VATP, including any aspects of the programme that they found meaningful or unhelpful. Interviews were conducted in an open ended, semi-structured style and were loosely based around the following prompts and questions: (1) Can you please talk about your experience of the VATP? (2) Have you noticed any change in yourself following your involvement in the VATP? (3) In your view, what were the important aspects of the VATP? (4) Is there anything else you’d like to say about the VATP? A semi-structured interview process was taken as this provided a flexible means of data collection that nonetheless, structured questions around the specific research aim. Interviews were carried out in a conversational style, and participants were encouraged to provide as much detail as possible through prompts such as ‘can you speak more about that’, ‘what was that like for you’ and so on. Interview questions were delivered in a flexible manner, in accordance with needs of each participant. Finally, for participants who had retained their art works, these were often viewed and discussed as the interview progressed. Mean interview length was approximately 28 mins (SD= 16 mins, Range=10-60 mins).

Data Analysis
The data was analysed using thematic analysis (TA), using guidelines set out in Braun and Clarke (2006). TA involves identifying meaningful patterns across the dataset in an inductive and flexible manner. TA acknowledges the researcher as an active participant in
the analysis as stated by Braun and Clarke ‘...researchers cannot free themselves from their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum’ (pg. 84, 2006). This requires researchers to state their theoretical position prior to the analysis, and be explicit in how this position may affect the way in which the data was interpreted. Accordingly, the writer was primarily interested in the way that participants understood their experience of the VATP, and in particular, their understanding of the unique processes that may have contributed to any improvement in psychological and psychosocial wellbeing. The writer also recognises that the interpretation of the data are, at least in part, shaped by his own understanding of psychological therapies and theories, in addition to his experiences and relationships with the participants across the duration of the study. Due to the writers own psychotherapeutic training largely occurring within the context of third-wave behavioural approaches (i.e. cognitive behavioural therapy and acceptance commitment therapy), it is acknowledged that the analysis of data is likely to be constrained in accordance with this.

Data were analysed by the writer using the six step TA guide provided by Braun and Clarke (2006). These include (1) familiarisation with the data, (2) generation of initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6), writing up the findings. The writer conducted all interviews and was therefore familiar with the data prior to transcription and coding. Anonymised audio-recordings of the interviews were transcribed by a professional transcriber. Following this, the writer undertook a systematic thematic analysis of the data in accordance with the steps outlined above. Initially, this consisted of reading and re-reading the data, which was followed by the identification of a large number of discrete and specific codes which aimed to represent the content of the data. These codes were then collated, sorted and grouped together and assigned a theme, which aimed to capture the shared meaning contained
within these clusters of codes. This procedure was repeated with a process of coding and re-coding themes, to ensure that the themes provided an honest, coherent and fair representation of the underlying data (Williams & Morrow, 2009). In order to ensure that this analysis was rigorous, the writer sought advice and oversight from a qualitative researcher who has specific experience with thematic analysis. The writer provided this person with an overview of the methods, codes, initial themes and a draft manuscript. Following feedback, a small number of themes were consolidated, and the manuscript was revised. This revised manuscript, including the findings and was then provided to this person for final review. In general, when conducting this analysis, greater weight was given to those ideas that were widely expressed across participants, but in some cases (particularly in regards to perceived weaknesses of the programme) weight was given to views that were expressed across a minority of participants.

**Findings**

The following section outlines the characteristics of VATP that participants identified as being important to their experience of the programme. Five major themes were identified in the data: (1) *something interesting and meaningful to do*, (2) *being with others and noticing the similar*, (3) *communicating and processing the experience of stroke through art*, (4) *who was I, who am I and who will I be?* (5) *it wasn’t all easy or enjoyable.* Findings are set out in accordance with these major themes, with each briefly explained and supported by explanatory quotes. Where appropriate, and in cases where verbal consent was provided, images of participant artwork that was relevant to a theme are also presented.
**Theme One: Something interesting and meaningful to do**

This theme captures the most rudimentary function of the VATP in that participants found that they were provided with the opportunity and simple joy of partaking in an enjoyable activity that provided respite from the perceived predictability of their post-stroke lives. For example, when describing what he enjoyed about the programme, the following participant simply acknowledged that the programme provided a break from his everyday life which since his stroke, had consisted of living in a supported care environment.

“It’s got me out of this environment, it gave me something to do and it made me find my own way there and back”

Another participant expanded on this by speaking about how the VATP provided a sense of structure and purpose to her day. She notes that the day of the programme became one that was set aside for her own self-care and joy.

“I take myself out for a nice lunch and then I’d go to art therapy and I’d have my cake packed in the back of the car, tramp in with it and we would all begin... I kind of kept my energy by having a proper lunch and I found a Vietnamese café and I would go and I just worked my way through the menu, go and have something different and it was wonderful, a favourite day of the week.”

Accordingly, this theme captured the role that the VATP may have played in providing a feeling of meaningful engagement with the world, in addition to the sense of difference in structure that the VATP provided to the lives of participants.

**Theme Two: Being with others and noticing the similar.**

The social context of the VATP was consistently acknowledged as one of the most important features of the VATP. It seemed that the social nature of the programme was one of the major features that contributed to participants’ perceptions of enjoyment and
therapeutic benefit. In this context, it appeared important that the social environment of the VATP group was characterised by a sense of solidarity, inclusion and togetherness.

“I think being with like-minded people was really important, like to be amongst people that could identify with what I was saying... particularly by the end of it you felt like you had gotten to know a group of people that were the same or there was just some really strong sort of connection there.”

For many participants, the VATP was the first time that they had met, engaged and interacted with a group of stroke survivors over an extended period of time. It seemed that this process provided participants with an opportunity to contextualise the adverse stroke-related consequences that they had faced within the experience of others. The following participant for example, describes her initial resistance to the group due to her beliefs in regard to disability and how this was overcome through her interactions with other group members.

“...and while I resisted the idea of joining the group because I thought I’m not crook, I’m not going to go and hang out with people who can’t do stuff...what I found was actually I found a bunch of people like me...I was meeting people who had similar experiences. They actually got me. They understood me...these people they’re using the same language as me. I had a bunch of people that I resonated with because my whole experience was I can’t work, I can’t go sailing, I can barely walk up a small hill...”

It seemed that the VATP also provided a platform where they could reflect upon their own stroke, using other participants as a kind of comparative template.

“I was talking to (participant name) and the fact that we see her now to what she was, she was saying that she was basically paralysed. She couldn’t talk, she couldn’t do and yet she’s now very capable and so it was just listening to all these stories and you sort of realise that yours wasn’t bad but it still rocked your world.”
In some cases, this self-reflective process seemed to allow participants to identify those areas of their own recovery where perhaps, more possibilities and capacities for improvement may be realised. The following participant, for example, discusses his experience of noticing that other survivors who appeared more affected by their strokes had seemed able to accept the consequences and had, in some ways, taken more steps to move on with their lives, in spite of the immense change that they had experienced.

“What I enjoyed most of all I think was listening to other people and how they tackled their problems. You know quite a few of them were worse off physically than me. The main thing I learnt was I’m not unique, everyone else had their problems too. And they accepted it more I think and all of them had moved on in their lives. I think this is my major problem at the moment.”

Similarly, the social context provided a safe, accepting and non-judgemental space for participants to tell and hear the story of stroke, as the following participant describes.

“...one of them, his first painting showed the inside of his house and his wife was in bed and there was a small child and there was a pet and you could just feel his angst about not being able to provide for his family and during the course of the programme he got the opportunity to go back, because he lost his business and he got the opportunity to go back to where he used to work in a warehouse as a computer geek and man you know the pride in him, quiet pride but it was just wonderful to see...”

Overall, this theme captured the importance of the group-based context of the VATP. It seemed that the social aspect of the programme allowed for processes of normalisation and reflection to occur, in addition to the materialisation of a sense of solidarity and togetherness within the group.

**Theme Three: Communicating and processing the experience of stroke through art.**

The majority of participants spoke about the important contribution that the process of art-making made to the therapeutic benefit of the programme. Many participants
spoke about using art-making as a means to process the experiences and consequences of their stroke. The following participant for example, explained how initially, it was difficult for her to talk to the group about the feelings that she had experienced since her stroke, and it was only after she had expressed these via the process of art-making, that she was able to verbally convey her experience with others.

“We talk about things at the beginning and I kept hiding. Second week I didn’t say anything. Third week it’s like we draw the thing and I sat there and drew the feeling that I had. And after that I shared in front of everyone. And that’s how it changed my life. It’s like I locked in the closet. I come home from the hospital and wait to die. Stay home and wait to die. ...I joined the programme; I come out from the closet”

Moreover, this same participant went on to describe how she had been unable to be honest with her family about how she was feeling about her stroke. However, it seemed that by learning to express herself, she gained the strength and confidence to tell her family how she was feeling. As a consequence, this participant seemed to become more open with her family.

“It’s like I hided inside and never talked to anyone. And I pretend to my kids I am happy but I am not. I am not happy. When I started the programme it’s like that everything came out...and I tell my kids that I was pretending before, I said my feeling. I pretend to my kids I’m happy but I’m sad, angry, you know and now it’s like I feel light, my life, and it’s like I feel happy, alive.”

Similarly, participants described how they used the art-making process as a means to express the physical consequences of stroke and how these consequences affected them emotionally. It seemed that some participants found the art-making to be a rather cathartic process. This is evident in the following excerpt as a participant
describes an art-work that dealt with his loss of vision and his interactions with health professionals during this time (see Figure 14).

“7% it’s dead you will never drive again. Suck it up. The thing they diagnosed me having with my eyes, said I only had 7% chance of recovering any sight in that eye. And of course they were wrong. But as you can see I was a bit annoyed when they said suck it up. Your eye’s dead. You’re fucked. Well it was really profound. I really let go (describing the art-making process). But afterwards I ripped it (the art-work) in half and was going to quarter it and 16th it and whatever after, but they grabbed it off me and said you can’t do that. And I said I can do whatever I like. It’s my art. Well I felt much better ripping it up and venting it and saying okay, if I’m here to express my anger at what happened to me then I will do exactly that and I will express my anger and follow through...”

Figure 14: Image of an art-work created by a participant (04) referencing the loss of vision that he was told to expect following his stroke.

As these excerpts suggest, for many participants, the art-making process seemed to provide a medium that allowed them to express things that they otherwise may have struggled to discuss. Participant responses indicated that art-making provided them with an abstract and almost metaphoric means of conveying and communicating their experience of stroke. In particular, this process seemed to allow participants to
convey those aspects of their stroke that were not easily captured and conveyed in
conventional language. As one participant described:

“...the process of the art allowed me to express concepts which to a certain extent are beyond words and there was the movement of doing it, the focus of doing it, like what colour and texture and form, they all added dimensions in terms of it and yeah absolutely...this actually opened a world for me, of expression”

Similarly, participants often spoke about the sense that art-making provided them with the ability to engage with their stroke experience in a slow, controlled and potentially deeper manner. Art-making seemed to perform an almost intermediary function by bridging the gap between the lived experience of stroke, and the verbal expression of that lived experience.

“It’s in a safe way and because you are almost abstract from verbalising it. Verbalisation is maybe a bit too honest whereas the art is kind of a safety mechanism between that and being totally open”.

A core feature of VATP pertaining to the process of art-making involves the use of the derived art-work as a tool for discussion with the group. This is a process that requires a number of steps. These include: consideration of what to express, consideration of the mode of expression (colour, texture, technique, image etc.), the creation of the work, consideration of whether the work adequately captures the intent, consideration of what to verbalise to the group, speaking to the group and finally, receiving feedback from others.

It is noted that this process involves extended periods of engagement with the subject matter, which, in turn, for some participants, seemed to provide an opportunity for reflection and the development of new insights.

“...when we had to, you know, speak about our picture I was feeling really embarrassed and like I almost didn’t want to talk about it. But in the end I got what it was about the picture and why I had done that and through the talking
about it I got to understand something that if I was just internally thinking about it I wouldn’t have come to the same conclusion...sometimes I would create something and not even understand it, and then I think the process of listening or just being with the picture and then it kind of would almost speak to you. And then when you had to kind of speak aloud what it was that you were thinking and it all sort of became clear....”

However, it is important to note that for a minority of participants, the process of art-making seemed to inhibit expression. In particular, these few participants found it difficult engage with and understand the art-making process, as an abstracted and metaphorical practice. This is exemplified in the following excerpt, which also highlights a feeling of needing to express something emotional, perhaps in order to meet the expectations of the facilitators or the group in general.

“Well they would come in and look at some of my paintings and they’d say oh I see you’re painting here and I see your emotion and I see your love here and I thought shit it’s just paint you know. I don’t know if I was supposed to put in those sort of feelings or not, I don’t know. I found it a bit of a struggle to draw something that was acceptable. I don’t think I got what I supposedly should have...I found a lot of times I would draw something to shut them up and then I would make up a story to what I painted.”

This excerpt also provides insight into an important distinction that emerged in the overall data. Regardless of their previous experience of art or creative practice, it seemed that for participants to perceive a benefit or sense of enjoyment from the art-making aspect of the programme, they had to come to the realisation that it was the emotional content and intent of the work that was important rather than aesthetics (see Figure 15).
Figure 15: Image of an art-work created by participant (10) demonstrating the abstracted and metaphoric approach to art-making that seemed important for participants to be able to understand.

“So I now get the emotion that goes into a painting sometimes rather than a tranquil countryside with a little mill sort of thing which is more of a photograph really. I kind of understood before but I understand more now. Actually (participant name) probably summed it up quite well at the end of it on the last day. He said I now understand that a single line on a piece of paper can actually be artistic.”

In summary, this theme captures participants' views of the importance of the art-making process within the VATP. In particular, this theme captures the idea that art-making provided a way for participants to slowly, safely and metaphorically engage with the experience of stroke. Although some participants found this a challenging and perhaps confusing process, this theme suggests that the art-making component of the programme was important to their experience.

**Theme Four: Who was I, who am I and who will I be.**

For some participants, the VATP provided a means of processing and exploring how their sense of who they were had changed as a consequence of stroke. One participant for
example, remarked about how he had been undertaking a process of self-analysis in an attempt to try to understand both who he was prior to his stroke and who he is now and he remarked that the VATP provide a unique means of exploring and understanding this change.

“I’ve been going through this internal self-diagnosis. I’m trying to get back to who I was before my stroke. But so much has changed, not just physically but mentally. Who I was before my stroke I’m not entirely 100% sure, but I am self-analysing all the time. I found that working with the different regions in the art class helped me to re-explore some of those things but instead of doing it internally I was able to put it on paper.”

This same participant expands on this idea as he describes an art-work that he created using the medium of clay which expresses, in a very visceral manner, the affect that stroke had on his identity as a tradesman (see Figure 16).

“This is pre-stroke and this is post-stroke (describing the work). That’s how I feel about it. Hand has been amputated sort of thing. What I intend to do is I intend to paint it now and put it on, mount it on something and yeah put stroke pre, post, and I’ll put two hands up. That is basically what it means. I guess being a tradesman as well, that is kind of what it means to me. Fingers have been cut off...”

Figure 16: Image of an art-work created by participant (08).

Interestingly, other participants remarked that the VATP caused them to recall or revisit aspects and experiences from their very early life, and particularly their childhood. Maori participants tended to refer to this as their papakainga (a nurturing place to return to).
“It was mainly to do with, as one other Maori lady that came, she said something about your papakainga which is where you are from, that’s how I see it, where you are from, your home base. But as she put it, papakainga can be anywhere you want to be, which is quite true, wherever you want to build your life. And a lot of my artwork went back to when I was a child.”

While many participants noted that they spent time in the programme examining who they were, others described using the programme to examine who they are and who they may be in the future. The following participant for example, describes VATP as providing a means of understand his new, more emotional self that has emerged since his stroke.

“It was an outlet, a creative outlet if you like. Part of my therapy was seeing a psychologist and a psychiatrist at one stage because part of my brain that got damaged was also to do with my emotional side, so I had big anger issues, also like laughter and tears uncontrolled. So I was seeing a psychiatrist and psychologist who kind of put it back into place, put a lid on it. But this was great for exploring the avenues that had been unleashed.”

Similarly, the following participant felt that his pre-stroke self was so dissimilar to his post-stroke self that he referred to his pre-stroke self in the third-person, and even went so far as to adopt the use of a new name since his stroke. However, based on this this participants’ report, it seems that following the VATP, there are some early (and tentative) indications that he is slowly beginning to reconnect with aspects of his pre-stroke me. Note, although this participant also refers to the importance of his ‘tradesman’ type identity, this excerpt is from a different participant to the previous.

“He’s gone. He was a very articulate building type (referring to his pre-stroke self). I’ve only just started building again. You’ll see my first attempt at building since I first had my stroke, outside there, a fence and a hanging garden. I thought anyone can do a garden on the ground. Let’s do one in the sky and see how we go. So I built a garden in the sky because the wife wanted a garden. So I said well I can manage that now. So I built a garden. And it’s growing things.”
As a consequence of the VATP, some participants began to consider new possibilities for their future that involved the creative arts. For some participants, this resulted in them engaging in art-making processes in their own time.

“... I was enjoying it more and more, to the point where I went and bought some little paint brushes and things. But I really need to get proper paint because that thing I got from the two dollar shop is not really any good.”

“So my creativity has increased tenfold. I have too many ideas inside my head to create art that works. And I want to get them all started and have 20 unfinished paintings.”

Similarly, other participants remarked that they intended to continue with some form of art-class or creative pursuit. One participant not only described an interest in continuing with art-making, but also spoke about attending art-galleries and possibly attempting to sell his art-works (see Figure 17).

Figure 17: Image of an art-work created by participant (04).

“I am quite comfortable with going into an advanced group and working on my own because I think I can already see where I would like my art to go. Everyone liked this one. I don’t particularly like it, but everyone liked this one, the yin and yang, and everyone liked that one. And that is probably how I would go. I’m not into painting fields with a rock in it and flowerpots... so I went and had a look in there (at a gallery) and although they probably give a 50% charge for some of their art, at least I can walk through there and have an opinion as to whether I thought it was good art...”
or bad art, what they were actually expressing and emotion...I wouldn’t mind making some money doing some art. That would be an incredibly enjoyable job.”

This theme broadly captured the identity related processes that participants engaged with during the programme. As described, many participants spent time understanding, grappling with and in some cases, reconceptualising who they were prior to their stroke, who they were after their stroke, in addition to the possibilities for who they might be in the future.

**Theme Five: It wasn’t all easy or enjoyable.**

This theme captures those aspects of the programme that participants perceived as either challenging or as a limitation of the programme. The following participant, for example, describes some of the physical difficulties that he encountered as he began to engage in the art-making process.

“Well I had to think about where I am from and perhaps where I am going and even the component of moving a brush I felt I was very tight and I think that helped me loosen me up.”

Other participants commented on the psychological aspects of the programme, with some participants reporting a sense of exhaustion.

“For me it was psychologically exhausting. I found that the artwork was brutally honest because you can’t hide in art. Well I can’t anyway, whereas I’ve had a lot of psychological sessions. You can avoid stuff that you don’t want to talk about. But with the art (the facilitators) are very good at getting it out of you, stuff that you might take somebody three or four sessions to get out of you. And you put it down and I was quite surprised by my honesty within the art. Sometimes neurologically I could sleep all day Saturday just processing all these rehashed thoughts that the art brought out.”

Others noted that early on in the programme, they felt a sense of fear or trepidation.

In this context, it seemed that the group-based context of the programme, which
involved meeting a number of new people and speaking publicly, was anxiety
provoking.

“The first week was quite dynamic because we started and within the first five
minutes you were worrying about what you were going to say, how confident you
were with everybody else. But then listening to others it just made you feel a lot of the
things that had happened to you… I’m opening up to all these strangers and all of a
sudden I laid my soul and you know that was scary… I mean it didn’t wear off till
about 9.30 that night so it was an exhausting day.”

In general, participants reported that they found the VATP enjoyable, they were glad that
they did it and they perceived that it benefited them in some way. However, in some
cases, participants remarked on the aspects of the programme that they considered to be a
drawback or limitation. In this context, the most consistent criticism of the programme
noted by participants was that they felt that it was too short.

“... I think we probably needed another two to four weeks. It became a bit rushed at
the end. We were doing enormous things that could have been extended just slightly
to really get the value, thinking about opposites for example.”

Another participant echoed this concern, but also noted that the brevity of the VATP may
have been such that potentially some harm was done.

“... all of a sudden you’d start and you’re getting to understand it, you’re just
starting and all of a sudden it’s gone...because it’s, first four or five weeks was just,
yeah sort of learning...we’ve seen a few emails (afterwards), people saying that they
feel as though their bubble has burst. So my concern is that, have you, you know,
you’ve created something, have you broken something in the process?”

Similarly, a small minority of participants expressed a sense of confusion as to the
purpose of the programme. It seemed to these participants that the facilitators had not
clearly clarified the purpose, intent and process of the VATP at the outset.
“...a lot of us would sit there and think what the hell are we talking about, what are we trying to achieve and some days you’d sit there and look at a blank piece of paper, what is he trying to get me to say...and still, I mean, as I say, on the ninth session, I question the trainers and that, is to, what are you actually trying to achieve? There was times, a lot of times, I’m like, what am I doing?”

**Overall Summary**

These five themes capture and describe the experiences and features of the VATP that participants perceived as being important. In general, the first four themes capture the features of the programme that participants found particularly meaningful or important. The fifth theme depicted those aspects of the programme that participants perceived as either challenging or as a limitation of the programme.

**Discussion**

This chapter aimed to provide insight into participant experiences of a group-based VATP, which in turn, may be used to develop understanding of the mechanisms of change that possibly contributed to the treatment effects observed within Chapter Five. Accordingly, the following discussion will place emphasis on the first four themes identified within the data. The main purpose of this discussion is to connect these participant accounts to the existing theoretical or psychotherapeutic literature. In turn, this will contribute to the development of a theoretically informed hypothetical model of the psychological mechanisms of Marupura studios VATP, providing a link between the data and themes contained within this chapter, to the outcomes reported in Chapter Five.

**The Behavioural Component (Theme: Something interesting and meaningful to do).**

Many stroke survivors are isolated within their communities and may have lives that are characterised by boredom, monotony and a lack of meaningful activities (Lai, Studenski,
Duncan, & Perera, 2002; Pound, Gompertz, & Ebrahim, 1998; Teasdale, & Engberg, 2005).

Consistent with this, almost all participants that undertook the VATP had anecdotally reported a decrease in pursuit of meaningful activities and a commensurate increase in a sense of tediousness and in some cases, loneliness within their lives. The first theme (‘something interesting and meaningful to do’) captured participant views of the role that the VATP played in providing them with a feeling of re-engagement with the world. Accordingly, theme one captured the mechanisms of treatment that are considered to fit within a behaviourally based psychotherapeutic and theoretical framework.

This theme suggests that some aspects of the VATP may have functioned in a manner that is similar to conventional psychotherapeutic behavioural approaches (often known as Behavioural Activation Therapy). These approaches focus on increasing access to pleasant activities and aim to ensure the positive reinforcement of adaptive behaviours in an attempt to break the patterns of maladaptive behaviours that perpetuate psychological distress (Hopko, Lejuez, Ruggiero, & Eifert, 2003; Jacobson, Martell, & Dimidjian, 2001; Lewinsohn, & Graf, 1973; Lewinsohn, Sullivan, & Grosscup, 1980). Although such behavioural methods were superseded by therapies derived from the cognitive revolution of the late 20\textsuperscript{th} century (e.g. Beck, 1979; Meichenbaum, 1977; Hayes, Strosahl, & Wilson, 1999), recent research indicates that such behavioural approaches are as, if not more effective than these more complex and sophisticated cognitively informed psychotherapeutic approaches (Cuijpers, Van Straten, & Warmerdam, 2007; Dimidjian et al., 2006; Ekers, Richards, McMillan, Bland, & Gilbody, 2011).

Of course it is noted that the VATP did not include explicit features of Behavioural Activation Therapy, such as diary keeping, pleasant activity scheduling, problem-solving and skill training. However, it was likely that the programme implicitly provided for
some of the therapeutic components of behaviourally based approaches, which were then reflected in participant accounts. Factors such as attending the VATP, experiencing a change in environment, facing the challenges of transport and fatigue, positive social and emotional reinforcement, in addition to the simple enjoyment of an art-making experience, may have contributed to a disruption in the existing cycles of maladaptive behaviours and negative reinforcement that had possibly contributed towards an onset and maintenance of psychological distress in participants.

The Social Environment (Theme: ‘Being with others and noticing the similar’).

This theme highlighted the importance that participants placed on the group-based and social context of the VATP. Moreover, the data indicated that the importance of this social context was not limited to the enjoyment that this brought to participants. Instead, therapeutic effects seemed to occur as a consequence of working both alongside and with other stroke survivors. In this context, it appeared that witnessing the consequences of stroke (in others), in addition to the challenges faced by other participants, in addition to relative impressions of deficit and recovery, seemed to allow for normalising, self-reflective and re-framing processes to take place. It is noted that these processes are broadly consistent with some of the group-based therapeutic factors identified within the influential group-based theoretical work of Yalom and Leszcz (2005). This includes universality, which speaks to the therapeutic process that occurs when individuals realise that they are not alone in their struggles or difficulties and altruism, which highlights the unique aspect of a group-based therapy in that it allows participants to both give and receive advice and assistance, which is thought to challenge the belief that they are a burden or have little to offer.

The data also indicated that these effects occurred within a social environment that was defined by the sense of community, solidarity, inclusion and empathy. This highlights the
important role that both participants and facilitators played in creating an environment in which such socially mediated therapeutic effects may occur. This finding is consistent with group-based psychotherapeutic research which highlights that the creation of such a social environment is of primary importance as it allows for a space in which participants can safely risk exposure and disclosure of emotionally meaningful events and ideas (Klein, & Schermer, 2000; Robertson, Rushton, Bartrum, & Ray, 2004). Moreover, it is possible that the development of this sense of community and solidarity, through the process of a collective ‘buy-in’ to the programme contributed to both the high levels of attendance and the behavioural component of the programme discussed previously.

**Art making processes (Theme: ‘communicating and process the experience of stroke through art’).**

The third theme reflected the importance that participants placed upon the role of art-making within the VATP. Similar to social processes, the benefit of art-making seemed to extend beyond the simple enjoyment that this brings and in particular, the data indicated that the art-making underlined two important psychotherapeutic processes that may have contributed to outcomes; *exposure* and *externalisation*.

*Exposure:* The art-making process seemed to provide a metaphoric yet meaningful method for participants to engage with their experience of stroke. As stated earlier, the process of conceiving and creating an art-work is time intensive, and ensures that participants remain connected to their experience of stroke (whether it be the emotional, physical or social consequences) for extended periods of time. In this context, findings suggests that the art-making process may have contributed towards an exposure like psychotherapeutic function that is similar to what is seen within trauma or anxiety-focused therapies.
Chapter Six

Trauma theorists have long argued that in order for individuals to successfully process and recover from a traumatic experience, emotional engagement with that experience is required (Jaycox, Foa, & Morral, 1998). Similarly, experiential avoidance, which is defined as attempts by individuals to avoid or suppress negative thoughts, feelings and memories, is thought to contribute to states of psychological distress and/or delay recovery from traumatic experiences (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996; Jaycox et al., 1998; Reddy, Pickett, & Orcutt, 2006). It is therefore considered that psychotherapy, in part, functions as providing a setting in which the safe engagement and confrontation with aversive or traumatic events and their associated internal experiences can occur (Foa, & Kozak, 1986). Within the context of stroke, such engagement may function in a manner that is similar to therapeutic approaches for anxiety or phobias, however, instead of the aversive stimulus existing in the outer world (e.g. a fear of public spaces); it exists within the inner world (e.g. memory of stroke, its consequences or associated negative emotional states). Therefore, the use of the experience of stroke, as the ‘material’ for a creative art-making endeavour, may have led participants to experience something akin to an exposure/desensitisation process, whereby, through extended and repeated engagement with the experience of stroke in art, negative thoughts and emotions that were associated with that experience were diminished.

Similarly, it is possible that the art-making process performed a function similar to an exposure hierarchy. Participant responses indicate that art-making provided a means of engagement with the experience of stroke in a non-verbal, abstracted, metaphorical and safe form. With time, this seemed to lead to the more confronting verbal expression of the experience of stroke to other group members. This process, combined with the encouragement and modelling of disclosure by facilitators and group-members, may have contributed towards anxiety reducing sensitisation.
effects. This then allowed for a gradual hierarchy of exposure, from the art-work to the group, and in some cases, to family members.

Externalisation: The use of the experience of stroke (whether it be the physical, emotional, social or other aspects of this experience) as the material in a creative art-making process seemed to provide participants with an opportunity to externalise, or place their experience of stroke momentarily beyond the self. This externalising process of externalisation is a feature of both Narrative and Acceptance Commitment Therapies (Carey, & Russell, 2002; Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Weber, Davis, & McPhie, 2006) and involves the creation of a sense of separation or linguistic space between the person and their problem (Weber et al., 2006). This externalising process may have allowed for participants to evaluate the meaning ascribed to stroke, in addition to how their beliefs and ideas about their stroke have influenced this meaning. As described by White and Epston (1989) ‘...a person gains a reflective perspective on their life, and new options become available to them in challenging the truths that they experience as specifying them...’ (p.33). As described in Chapter Four, the experience of stroke may contribute to negative psychological outcomes in two related yet, distinct ways. First, the ‘concrete’ consequences of stroke, (such as physical, cognitive or social impairment or other change) and second, the meaning that the person attaches to these consequences. Accordingly, the process of externalisation of the stroke experience in art may have been an important mechanism of treatment whereby the meaning that is attached to stroke is able to be examined and perhaps reconsidered.

Identity (theme: ‘who was I, who am I and who will I be’).

The fourth theme was the last that was considered to provide insight into treatment mechanisms of VATP. This theme indicated that some participants undertook a process of
examination and re-conceptualisation of pre and post-stroke identity during the programme. As discussed in Chapters Two and Four, there is support for the view that stroke may contribute to the perception of a significant change to a person’s sense of identity and self. Moreover, Chapter Four found a positive association between the magnitude of perceived identity change and depression, anxiety and apathy symptomology. Taken together, these findings indicate that identity may be a viable and meaningful psychotherapeutic treatment target in stroke populations, in that targeting the perceived schism between pre and post stroke identity, may contribute towards improved psychological wellbeing. While the VATP is not conceptualised as an identity specific intervention, the programme places emphasis on exploring identity related constructs and features (see Table 7).

It appeared that the VATP encouraged an exploration of identity change/stability since stroke. For some participants this contributed to the development of a new aspect of identity related to creativity or art-making. For other participants this seemed to lead to a sense of partial reconciliation of pre and post stroke identity. Notably, this finding converges with the qualitative research of Baumann, Peck, Collins, & Eades (2013), who found that engagement in an arts programme provided a means of reconnection with the pre-stroke self, in addition to providing a link to possible future selves. While it is neither appropriate nor possible to make any substantive inference on the basis of the findings of the current chapter, given the findings of Chapter Four, it is plausible that a reduction in the perceived magnitude of identity change since stroke, could contribute towards improved psychological wellbeing. Another idea that emerged from these data was that the VATP may have supported participants to explore how, in spite of stroke, they could possibly strive to live in accordance with their pre-stroke identity. Finally, some participants expressed an interest in continuing to develop their interest in creative
practices, which may, over time, lead to the development of new features of identity. A model of Marpura studios VATP, which links the findings of the current chapter to plausible mechanisms of treatment and outcomes is outlined in Figure 18.

**Figure 18:** Model of proposed treatment mechanisms and outcomes for Marpura Studios VATP linking the findings of Chapters Five and Six.

**Challenges and limitations**

The sixth and final theme (‘it wasn’t all easy or enjoyable’) captured the challenges and limitations that participants reported as a part of their experience of the VATP. These
ranged from factors that may be expected to occur given the nature of the VATP. For example, the physical challenge that is inherent to art-therapy or the anxiety provoking prospect of having to speak to a group. Conversely, it is possible that some of the challenges faced by participants (e.g. that the programme was exhausting) would be expected given the therapeutic nature of the programme. That is, psychotherapy aims to provide for a context in which personal growth can occur, and in particular, negative events or emotional states are often a focus, therefore, aspects of psychotherapy would be expectedly experienced as daunting, confronting, challenging and at times, unpleasant (Göstas, Wiberg, Neander, & Kjellin, 2013).

It is also noted that in some cases, the process of art-making seemed to inhibit expression, and, in particular, it seemed that some participants felt that they were required to ‘perform’ in a certain manner (i.e. express themselves emotionally through art), in order to meet the expectations of the facilitators, or perhaps others in the group. Finally, a considerable minority of participants consistently reported their impression that the VATP was too short. This is an important issue and relates to the arc of therapy. Early in treatment, clients need to be sufficiently supported in order to allow them to enter a meaningful and transformative state of therapeutic change. This often requires the development of trust and rapport which then allows for states of openness and emotional vulnerability to occur. However, in time-limited therapy (as in the VATP), these processes need to occur rapidly to ensure that participants are returned to a state where they can reconcile their experience of treatment with a sense of closure and be safely exited from the programme. Given the brief, 10-week nature of the VATP, it is not unexpected that some participants would take some time to enter into this therapeutic state, and it is possible that for them, the programme was completed before any closure or
reconciliation could occur. This is an important limitation of the programme, as it is likely that this was experienced as very distressing by some participants.

**Summary and limitations of the current chapter**

The current chapter aimed to provide insight into participant experiences of Marpura studios VATP. A thematic analysis of semi-structured interview data provided insight into these experiences, which were then linked to existing psychotherapeutic or psychological theory, allowing for the development of a hypothetical model which detailed proposed mechanisms of treatment. One limitation of this model is that although it is strongly linked to the existing psychological literature, its origins lie with participant accounts and experiences. This caveat does not seek to diminish the importance of participant accounts; however, deriving a model on the basis of participant accounts alone runs the risk of conflating the *meaning* that participants attach to a therapeutic experience with the *factors* that drive therapeutic change. That is, it is possible that the aspects of the programme that the participants perceived as important and meaningful were not the same aspects that drove treatment effects. However, it is important that this chapter be included in this thesis as research suggests that many of the difficulties faced by stroke-survivors are not captured by standardized outcome measures (Pound et al., 1998) and there can exist a difference between what professionals and stroke-survivors perceive as important to stroke recovery (Bendz, 2003).

On the basis of the current findings, it is not possible to reliably determine the unique contribution that the art-making process made to treatment effects. Although theme three was entirely related to the art-making experience, and elements of themes one and four appeared meaningfully connected to art-making, it is possible that treatment effects were purely driven by behavioural, social, and identity related mechanisms irrespective of the art-making components. Accordingly, on the basis of the current data, weight of evidence
indicates that the art-making was important, especially in regards to the behavioural (enjoyment), exposure and externalisation processes that this introduced, for this to be fully determined, a trial that contrasts a VATP with a group-based psychotherapeutic programme that features all the elements set out in the above model (Figure 18) with the exception of the art-making processes will need to be conducted. It is noted that this highlights the importance of this model as it provides a possible ‘blueprint’ of those mechanisms that were important to participants and could possibly be used to develop a novel psychotherapeutic approach for stroke which could then be contrasted with the VATP.
Chapter Seven: General Discussion

Stroke is a common and debilitating experience that results in a number of negative consequences including high rates of post-stroke depression, anxiety and apathy. Moreover, the presence of these issues are linked to a number of relatively worse outcomes including, but not limited to, impairment in daily activities, diminished social functioning, lower rates of participation in rehabilitation, and higher post-stroke mortality. Although research supports the view that these post-stroke issues are of biopsychosocial origin, the literature currently lacks a specific psychological account that may contribute towards an explanation of the very high prevalence of these issues. Furthermore, at this time, there is a lack of research that supports the use of psychotherapeutic treatments for these post-stroke problems. Although it is acknowledged that pharmacological treatments are tentatively supported, this is tempered by the risk of secondary adverse consequences, of which stroke populations may be particularly vulnerable.

This thesis is underpinned by a central argument that links together these issues. It is considered that the lack of a psychologically informed account of post-stroke psychological distress may have prohibited the development of aetiologically congruent psychotherapeutic treatment approaches. This in turn, is argued to relate to the lack of evidence for psychotherapeutic treatments (whether conventional or novel) that are currently available for stroke populations. To state this issue pithily, it is difficult to assess, formulate and treat a post-stroke problem (such as post-stroke depression) from a psychological standpoint, in the absence of a psychological explanation of such a problem.
Accordingly, these issues gave rise to the two principal objectives of this thesis. First, it was considered that there is the need to develop psychological explanations that may account for the high prevalence of post-stroke psychological distress. The first half of this thesis was therefore concerned with an attempt to develop and find support for such a psychological account. Given the nature of stroke, it was considered that perceived loss or change to self or identity may be a mediating psychological factor that bridges the gap between the ‘concrete’ consequences of stroke and clinically identifiable instances of post-stroke psychological distress. Second, given the lack of support for ‘gold-standard’ psychotherapeutic approaches (e.g. CBT) it was considered that there is a pressing need to develop and test the effectiveness of novel psychotherapeutic treatment approaches that are specifically designed within stroke-populations in mind. The second half of this thesis was therefore concerned with examining the effectiveness of a novel, group-based, visual art therapy programme for community-based stroke survivors.

As described, the first principal objective of this thesis related to a proposed psychological explanation of post-stroke psychological distress that focused on the impact of stroke upon sense of self and identity. However, before such an explanation could be investigated it was important to first understand the ways in which stroke contributes towards a sense of change to self and/or identity. To initially achieve this, a review of the existing stroke, self and identity literature was conducted. Although this review clearly indicates that stroke-survivors do perceive a change to self and identity, the nature of this change was somewhat unclear. Moreover, it was noted that within this predominantly qualitative literature, concepts such as self and identity were oftentimes used in a definitionally opaque manner, and seemingly functioned as units of stroke-survivor meaning, rather than as specific theoretically derived constructs. This made it difficult to come to a clear conclusion regarding the current state of knowledge with regards to post-
stroke self and identity change. Moreover, it was considered that in order to test the proposed association between perceived self and identity change and post-stroke psychological distress, quantitative methods would necessarily be employed. Accordingly, before the first objective of this thesis could be approached, it was important to determine whether the changes to self and identity that were identified within the extant qualitative literature would be observable and measurable when such quantitative measures were employed. Therefore, before this principal objective could be achieved further groundwork was required.

This first involved summarising and outlining the self and identity theoretical literature, including the contribution of autobiographical memory systems. This provided a framework through which quantitative methods could be utilised to determine how the experience of stroke does affect self and identity. It was also considered that such a framework may make a more general contribution to the field by bringing some definitional and theoretical clarity to this complex area of research. That is, it is possible that framework may support researchers to embark upon a more empirically driven attempt to understand post-stroke self and identity change.

Following this, a quantitative investigation into the nature of change to self and identity following stroke, along specific dimensions of self-knowledge and temporal continuity was undertaken. The work of Ellis-Hill & Horn (2000) was first replicated as this is the only known research that has attempted to understand post-stroke self-knowledge change using a quantitative method. Relative to the findings of Ellis-Hill & Horn, the current sample endorsed post-stroke change in self-knowledge across a higher number of trait-items. This was likely due to the current sample being characterised by higher levels of physical and cognitive impairment and being characterised by greater post-stroke adjustment issues. Interestingly, however, after accounting for Ellis-Hill & Horn’s
probable false discovery rate (due to lack of pair-wise corrections), there was a convergence in findings between the studies indicating that following stroke; individuals experience a negative change to specific trait items, namely ‘incapable’, ‘bored’, and ‘dependent’. It is noted that these specific findings are possibly connected by a sense of loss of agency, and increased reliance upon others following stroke, which may be related to ‘disability’ type roles. These findings indicate that empowering and supporting stroke survivors to develop a sense of agency, autonomy and efficacy may contribute towards improved post-stroke psychological wellbeing.

Further investigations that made use of quantitative measures were then conducted. However, in contrast to the work of Ellis-Hill and Horn (2000), the chosen measures attempted to provide participants with the opportunity to respond in a flexible and unconstrained manner, thereby allowing them to convey their own unique experiences and meanings. Overall, these results indicate that post-stroke changes to identity do not result in generally impoverished strength or complexity, but instead are highly influenced by valence, with both a decrease in positively valenced self-knowledge and an increase in negatively valenced self-knowledge following stroke. Such changes to the valence of identity are linked to a narrowing in the complexity of ‘positive’ aspects of identity, and a commensurate expansion in those domains that are associated with ‘negative’ aspects of identity. Finally, it was noted that following stroke, participants seemed to have experienced a considerable loss within the specific domain of social identity. These findings are important as they indicate that following stroke, self-perceptions become increasingly negative, however, rather than being limited to a few discrete domains that may expectedly be directly affected by the consequences of stroke (i.e. physical consequences), these negative self-perceptions are pervasive, and span a high number identity domains, including those that are of an attributional and evaluative nature.
With regards to perceived temporal continuity, more than half of the current sample indicated that they perceive themselves as no longer being the same as prior to stroke. Results also indicate that following stroke, almost all individuals experience at least some change to their objective content of self, whereas perceived changes to the arguably deeper, intrinsic, fundamental and more subjective aspects of self were much more variable across the sample. There was also tentative support for the view that overall, stroke-survivors experience greater change to the objective rather than the subjective self. Expectedly, while changes to these objective and subjective aspects of self-continuity were strongly correlated, results indicated that perceived continuity judgements were related to representations of their subjective self (i.e. the ‘I-self), but not their objective content of self (i.e. ‘Me-self). Taken together, these findings suggest that despite stroke-survivors reporting more consistent and possibly greater change to the objective aspect of self, when asked to make judgements about their perceived sense of continuity since stroke, these are based on their more fundamental, intrinsic and subjective sense of self-continuity.

In summary, by finding that stroke contributes to a considerable change to identity the results of the current thesis are reasonably consistent with qualitative literature. However, the current findings also indicate that change occurs to the content and continuity of self and identity, and also the emotional meaning that is attached to that content. Within the context of the first objective of this thesis, these findings were important as they empirically confirmed that change to self and identity does indeed occur following stroke and that the nature of these changes are measurable using quantitative methods. Accordingly, the initial findings outlined in Chapter Four, meant that the proposed association between post-stroke self and identity change, and post-stroke psychological distress was able to be examined.
In regard to the first objective of this thesis, findings indicate that the extent of perceived self-knowledge change is associated with depression and anxiety (but not apathy) symptoms. Moreover, results also suggest a possible, albeit tentative association between discontinuity to the objective content of self (i.e. the Me-self) and apathy symptoms. Finally, and consistent with the non-stroke literature (Brittlebank et al., 1993; Hitchcock et al., 2016; Williams et al., 2007) stroke survivors with higher levels of depression symptoms displayed a pattern of retrieval that seems to be biased towards abstracted, rather than specific self-referential information.

Although it is acknowledged that exploring an association between self and identity change and post-stroke psychological distress is methodologically challenging, these preliminary investigations suggest that post-stroke psychological distress may arise as a consequence of an interaction between the ‘concrete’ outcomes of stroke (physical, functional, cognitive & social) and a psychologically mediated self and identity related meaning making process. In this thesis it is argued that that in evaluating this meaning, stroke-survivors engage in a process of reflective self-analysis, comparing their current self to their pre-stroke self, using both their conceptual understanding of ‘who they were’ and their pre-stroke autobiographical memories.

Aspects of the existing stroke literature also provide support for this view. Qualitative findings suggest that self-referential evaluative processes are one of the ways in which the meaning and impact of stroke is determined. Moreover such a mediating psychological factor may explain inconsistent findings that are observed within the literature in regards to the association between stroke-related variables (e.g. severity of stroke, cognitive ability, and functional impairment) and post-stroke psychological distress. Furthermore, such a psychological process fits with the time course of PSD, which is in approximately half of cases is characterised by late onset. The finding that stroke-survivors with higher
levels of depression displayed a bias towards abstracted self-referential information in both the pre and post-stroke conditions, also suggests that differences in cognitive processing may be influencing the aetiology of these post-stroke issues. Taken together, these findings suggest that for different people, similar levels of disability (or other consequences of stroke) may give rise to quite different psychological responses, with this difference being contingent upon the extent to which these consequences affect perceptions of pre-stroke self and identity. That is, pre-stroke self and identity may provide the psychological context in which the affective reactions to the consequences of stroke play out.

The second objective of this thesis addressed the pressing need to develop and test the effectiveness of psychotherapeutic treatment approaches that are specifically designed with stroke-populations in mind. Accordingly, this thesis outlined an exploratory mixed-methods study of a novel group-based, arts intervention for the psychological consequences of stroke. This study provides preliminary evidence that this novel 10-week psychotherapeutic programme contributed towards improved psychological wellbeing in a community-based sample of stroke survivors, as indicated by improvement in a number of important outcomes (specifically anxiety, mood, apathy and quality of life). Importantly treatment effects were maintained up to 6-months post-stroke. Moreover, effect-estimates associated with the VATP were noted to be consistent with that of the non-stroke psychotherapeutic literature. Interestingly improvement following the VATP was not contingent upon participant factors such as cognitive ability, social networks, communication ability, time since stroke and stroke severity, indicating that the VATP was appropriately targeted towards the needs and limitations of community-based stroke survivors. However, it was noted that in one case, performance on a measure of divergent/creative thinking ability may have been associated with treatment response. In
this case, it is possible that this association relates to such individuals obtaining greater benefit from the creative aspects of the VATP, or alternatively, it is possible that such individuals are, in a general sense, better able to flexibly combine the knowledge and skills obtained in psychotherapy in aid of developing and enacting alternative possibilities for their future. In either case, this is an interesting finding, and further research, both in based and non-arts based psychotherapeutic contexts, may be warranted.

A qualitative approach that aimed, in a complementary manner, to gain an understanding of participant perspectives and experiences of the VATP was then utilised to develop a treatment model of the VATP. A thematic analysis of 20 semi-structured interviews indicated that behavioural, group-based, art-making and identity related mechanisms were important to participants. These themes and concepts were then linked to the existing psychotherapeutic theoretical literature in order to derive a treatment model of the VATP. Thus the quantitative findings of the current thesis provided insight into the benefit of the VATP, whilst the qualitative findings, by linking participant accounts to the psychological/psychotherapeutic literature, provided a blueprint for understanding both how and why this benefit occurred.

**Clinical Implications of the current thesis**

The identification of post-stroke self and identity change as a factor that may mediate post-stroke psychological distress fills a gap in the literature and could provide clinicians with a novel means of assessing and formulating stroke clients. When conducting a psychological assessment with individuals who are experiencing post-stroke psychological distress, the identification of important aspects of pre-stroke identity, in addition to domains of loss, change or stability would provide important information for the purpose of both psychological formulation, and treatment planning, in a manner that
is potentially meaningful and relevant to the client. Moreover, because concepts such as self and identity are derived from the *meaning* that is attached to certain behaviours, rather than the behaviours themselves, the concept of identity may be utilised in a manner that is similar to the concept of ‘values’ within Acceptance Commitment Therapy frameworks. That is, conceptions of pre-stroke identity may be used to drive purposeful and meaningful identity-orientated behaviour. In this context, it is the engagement in behaviours that are consistent with the *meaning* attached to pre-stroke identity that is important, rather than behaviours themselves. Thus, such an identity informed approach may provide both stroke-survivors and clinicians with a means of negotiating their way around the lasting consequences and limitations imposed by stroke. This approach may be particularly relevant for those clients who are at the point of recovery where minimal physical or cognitive gains are expected to occur.

Within the current sample, it was noted that higher levels of depression symptoms were associated with a biased self-referential memory retrieval process. Although these findings are limited to the TST, and further research is required, they are notably consistent with the non-stroke literature. Research suggests that such biases may reflect possible invariant trait characteristics and additionally, abstracted or over-general memory retrieval is associated with failure to recover from depression and predicts a high proportion of the variance in later depression symptoms, indicating that these cognitive biases may be a significant maintaining factor (Brittlebank et al., 1993). Within the context of stroke populations, a tendency toward abstract self-referential biases may potentially stifle the complex and realistic understanding of pre and post-stroke self and identity change. Moreover, it is also possible that the presence on an over-general cognitive style may predate the onset of post-stroke psychological distress. Given that the experience of stroke increases vulnerability to depression, it is possible that assessing
such memory biases early in the acute stage of recovery may provide a possible means of identifying those stroke-survivors that are at increased risk of depression. Moreover, in light of the very high prevalence of stroke, in conjunction with evidence that suggests that such retrieval biases are an important maintaining factor in depression, treatment that (in part) takes an autobiographical memory approach may form an important part of novel stroke-specific psychotherapeutic approaches. In this regard, a recent meta-analysis has identified that autobiographical memory based training for the treatment of mood-disorders within non-stroke contexts may show some promise (Hitchcock, Werner-Seidler, Blackwell, & Dalgleish, 2016).

Results provide support for the view that Marpura studios’ VATP contributed to an improvement in post-stroke psychological wellbeing and adjustment, across a number of important domains. These findings are considered important because at this time, there is an overall lack of stroke-related psychotherapeutic treatment options, and while pharmacological approaches are tentatively supported, they carry an increased risk of adverse outcomes. This study is the first to attempt to investigate a group-based VATP using quantitative means and findings suggest that visual arts therapy is a good candidate psychotherapeutic treatment for a number of post-stroke issues. It is also noted that such a broad-based approach (i.e. non-specific to a particular clinical presentation) may be appropriate given the high levels of co-morbidity that characterises these post-stroke issues. Moreover, given the existentially threatening nature of stroke, it seemed that the arts-based framework of the VATP was potentially relevant to the post-stroke experience as it provided a uniquely meaningful way for participants to engage with, and express their experience of stroke in a manner that overcame the limitations of conventional language.
Considerations for future research

The work contained within this thesis offers opportunities for future avenues of research. The framework of self and identity set out in Chapter Two acts to distil a reasonably complex theoretical literature in a way that may allow future stroke researchers to design studies that distinguish between the various subsections of self and identity. By potentially providing for greater definitional consistency and clarity this may provide for a more collaborative research context in which researchers are able to compare findings across studies due to improved definitional clarity. Moreover, by outlining the contribution of autobiographical memory processes to self and identity and finding that the affective states of stroke-survivors may influence autobiographical memory retrieval processes, future research may be able to make use of tools such as the Autobiographical Interview (Levine, Svoboda, Hay, Winocur, & Moscovitch, 2002), or alternatively third-party (i.e. family member) accounts. This may contribute to understanding whether affective disordered stroke-survivors display differences in autobiographical memory retrieval both in comparison to non-stroke populations, and non-affective disordered stroke populations. In this context, it is noted that the current thesis did not provide an index of self-awareness. Accordingly, future work would be well served by the inclusion of this variable. This would allow for a determination of the influence self-awareness impairment on both perceptions of post-stroke self and identity change and psychotherapeutic treatment outcomes. It is also considered that the use of an adapted Autobiographical Interview (as in Addis, Wong, & Schacter, 2008) may yield important knowledge in regards to how affective disordered stroke survivors may differentially utilise autobiographical memories for the purpose of constructing and imaging future events. Such understanding may make an important contribution to understanding factors that influence goal setting, planning and motivation in post-stroke populations.
It is also noted that the methods employed within this thesis seemed to demonstrate the utility of approaches such as the TST and Self-Continuity Interview, relative to a more strictly quantitative measure such as the HISDS. That is, these measures enabled participants to respond flexibly and in an idiosyncratic manner, while still providing a means of inquiry that enabled the application of inferential statistics. This may provide the important first step for the emergence of a new literature that may take a more theoretically informed, yet contextually bound means of inquiry. Such a literature may provide further understanding of how existentially threatening events such as stroke affect complex phenomena such as self and identity.

Findings also indicate that a further and more substantive trial Marpura Studio’s VATP is warranted. As argued throughout this thesis, there is a pressing demand for the development of viable, stroke-specific psychotherapeutic treatment approaches. This issue is perhaps best illustrated by recent review of stroke rehabilitation practice across New Zealand which found that 43% of rehabilitative units did not screen for depression, and only 7% of units screened for depression in >90% of patients (McNaughton, McRae, Green, Abernethy, & Gommans, 2014). Although this is low level of assessment likely relates to a number of factors, such as resource constraints, it is possible that the lack of evidence-based treatments also influences this. Accordingly, two possibilities arise out of the current thesis. First, the current findings provide a defensible rationale for further research into the efficacy of Marpura studios VATP to occur. Second, it is possible that by combining the non-arts related aspects of the treatment model outlined in Chapter Six (i.e. behavioural, emotional exposure and externalising components), with a focus on pre-stroke identity, and an approach that includes autobiographical memory training may lead to the development of a novel psychotherapeutic approach for post-stroke psychological distress.
Chapter Seven

It is noted that findings of the thematic analysis indicate that participants found the programme to be too short. Furthermore, some participants also felt that the purpose of the art-making, and potentially, the entire programme was not adequately explained by facilitators at the outset. In some cases, participants indicated that this led to feelings of confusion, uncertainty or anxiety. For this reason, in the future, it may be appropriate for facilitators to be more explicit and transparent as to the purpose of the VATP, and in particular, make clear what the specific role of art-making may be within the context of that purpose.

Additionally, as would be expected with a psychotherapeutic intervention, the study described in Chapter Six found that the VATP contributed to the onset of distressing emotions that for some participants took many days to process. It is also noted that during pre-VATP assessments, three of the 24 participants expressed some level of suicidal ideation to the writer. For these reasons, if a confirmatory trial of the VATP was to take place (or indeed any post-stroke psychotherapeutic trial or further iterations of the VATP) it would be important that the emotional states of participants are continually monitored, and in particular, that issues of clinical risk are proactively managed during the course of treatment. It is also emphasised that future stroke-related intervention studies ought to include an element of distress tolerance skills or emotional regulation techniques, so that when emotions are raised within the context of treatment, they can be appropriately managed by participants.

Finally, it is considered that the issues of emotional distress and risk to self that were present within the current study highlight a potential ‘grey area’ in intervention trials, and particularly those that are subject to external evaluation by a third-party (as in this thesis). That is, there is the potential for the mismanagement of clinical risk to occur, given that researchers who evaluate trials and the facilitators who conduct interventions are often
operating within differing levels of clinical or ethical responsibility. For this reason it is considered important that future studies (and interventions) give consideration to how issues of clinical risk can be ethically communicated and managed between parties. It is also considered important that at the outset of any future study that all parties come to a clear agreement as to who holds clinical responsibility for risk at the various stages of that study.

**Conclusion**

This thesis has threaded together concepts of self, identity and post-stroke psychological distress in a manner that attempts to connect theory, aetiology, and treatment. This work has arisen out of the awareness that although evidence indicates that post-stroke psychological distress is of likely bio-psycho-social origin, there currently lacks a psychological account of these issues. In turn, it was reasoned that the lack of such an account has contributed to a situation in which there is a lack of psychotherapeutic treatment options available for these post-stroke issues.

Accordingly, this thesis was underlined by two fundamental objectives which were derived from these two concerns. First, this thesis outlined and tested a hypothesis that linked perceived post-stroke identity change to post-stroke psychological distress. Results found some support for this psychological account, in addition to initial evidence that depressed stroke-survivors display memory retrieval biases that is similar to that of non-stroke populations. Second, this thesis found initial support for a novel, group-based psychotherapeutic VATP that was specifically designed and developed for stroke populations. Participant accounts of their experience of the programme were also linked to the extant psychotherapeutic psychological literature, with a view to outlining a model of VATP treatment. Accordingly, by proposing possible mechanisms of treatment, this
model provides context to the findings of the intervention study. That is, this thesis has
not only found that the VATP contributed towards an improvement in post-stroke
psychological wellbeing, but also provided insight in how this improvement may have
occurred.

In summary, it is extremely challenging for both researchers and clinicians to grasp the
magnitude of what it would be like to experience something as sudden and devastating as
a stroke. Similarly, it is very difficult to gain insight into the worldview of people that
have survived a stroke. In this context, the undertaking and construction of this thesis has
only served to remind me that most often, researchers and clinicians are little more than
bystanders hoping catch a glimpse into both the minds of stroke-survivors, but also the
post-stroke world. In this context, it is hoped, if not considered, that this thesis has made a
small, but potentially meaningful contribution to not only furthering understanding of
post-stroke experience, but how clinicians and researchers can work to improve the lives
of those who are affected by stroke.
Appendix A: Participant Information Sheet (Cohort One)

Art therapy and identity: Evaluating the rehabilitative efficacy of Spark’s visual arts therapy program for survivors of stroke.

You are invited to take part in a research project which aims to determine the rehabilitative effectiveness of Spark's visual arts therapy program for long term survivors of stroke. This project is being carried out by Associate Professor Lynette Tippett and Simon Walker, a doctoral student and trainee clinical psychologist within the School of Psychology at the University of Auckland. Please read the below information carefully and feel free to ask any questions. Thank you for taking the time to read this.

What is the purpose of this study?

The overall aim of this project is to evaluate the effectiveness of Spark's visual art therapy programme (VATP) for individuals who are living with the long term effects of stroke.

Why do we need to do this study?

Approximately 7000 New Zealanders experience stroke annually, contributing to a total of 60,000 stroke survivors in New Zealand. In addition to the physical consequences of stroke, many stroke survivors are affected by cognitive (thinking) impairments, depression, anxiety and apathy. It is understood that these outcomes can negatively affect quality of life, post-stroke adjustment and recovery from stroke.

To date there are few rehabilitation methods that attempt to address the long term outcomes of stroke. One exception is a novel therapeutic programme for survivors of stroke developed by Auckland’s Spark Centre of creative development (a community organisation). Spark has developed a 10-week therapeutic programme that aims to facilitate post-stroke adjustment via group centred visual art therapy. The aim of this study is to evaluate this programme with regards to its rehabilitative effectiveness in promoting adjustment, facilitating functional and psychological recovery, improved mood, sense of identity and quality of life in stroke survivors.

Who can participate in this study?

People who have experienced stroke within the last 3 months-5 years and are fluent in English. Participants must be committed to completing Spark's 10 week visual arts stroke programme and have had no previous experience of visual arts therapy following their stroke.

We are also asking participants to nominate a family member or significant other for participation in this research. The involvement of this nominated person would provide researchers with additional information about the effectiveness of Spark's visual arts programme. Please note, you can choose to not nominate a family member without forfeiting your own involvement in this research project. If you do nominate a family member they will not be obliged to participate. Following your nomination, they will be provided information about this study and what their participation may entail. Following this they will have opportunity to freely decide whether they would like to be involved or not.

What is involved?
Because we are interested in determining the long term benefits of Spark's visual arts therapy program we will be assessing participants across four timepoints. The first assessment will occur approximately 2 weeks prior to beginning the program, the third will occur approximately 2 weeks following the completion of the programme and the fourth assessment will occur approximately 6 months following the completion of the program. If you give permission, and if they are willing, we will also be asking questions of family member or significant other (nominated by you) across some of these time points as well. Please note, that if you do not want to nominate a family member or significant other you can still participate in this study.

During the three assessment sessions you will be asked to complete a variety of tasks and questionnaires that aim to assess your cognitive ability, mood, social support and the extent of change that you've noticed following your stroke and involvement in the visual arts programe. Additionally, at the first and third assessments, you will be asked to undergo a brief informal interview. This is designed to allow researchers to get a greater understanding of your own unique experience of stroke and the visual art programe. The first assessment is the longest and will take between approximately 1.5-2 hours. The remaining three sessions will last between 60-90 minutes.

If you choose to nominate a family member or significant other, they will be asked to complete a small number of tasks across at timepoints that approximately coincide with your assessments. These tasks consist of questionairres that aim to give insight into their views of changes that you have experienced following your stroke and since your involvement in Spark's visual arts programe. Each session will last a maximum of 30 minutes.

You can choose whether your would like the assessments to occur in your home, or on premises at the University of Auckland.

What are the expected benefits?

Your participation will contribute to a better understanding of how we can help rehabilitate individuals who are living with the long term effects of stroke. Given that this study aims to assess the effectiveness of Spark's visual arts therapy programme, it is unlikely that you will personally benefit from your involvement in this study. However, it is possible that by your involvement in the VATP that you will experience increased self-esteem, forging a new identity, reduced depression/anxiety symptoms and increased quality of life.

You will be offered a summary of the overall findings when the study is complete. Participation will not cost you anything, and you will receive $20 voucher (either food or petrol voucher) at each assessment timepoint ($60 total).

What are the potential risks and discomforts?

It is not anticipated that you will experience any risks or discomfort, however many of the measures we are using may 'bring to mind' some of the negative consequences that you may have experienced as a result of stroke. Within this context, your reaction to these measures will be closely monitored, and you are freely able to opt out of the study at any time that you choose.

Given that the assessment sessions may reach up to two hours, this may be tiring. We will include as many breaks as you need. If you become fatigued at any time, you are able to adjourn the session, which will be continued at a later date/time.

Your rights as a participant

Your participation in this project is completely voluntarily. If you choose to participate you can change your mind about taking part at any point during the testing process, without giving a reason. There will be no
negative consequences as a result of changing your mind. After your participation is complete, should you change your mind about us using your results, you can request that your data be withdrawn for a period of up to two months. You can keep this document as a reminder.

Confidentiality, Anonymity and Data Storage

Any information which can identify you as a participant will be stored in a secure locked location and used with utmost confidentiality. Your name will only appear on the Consent Form, which will be coded with a unique identification number, assigned by Simon Walker. Only this number will be linked with your data. No information will be shared with any third party, including your nominated family member.

The Consent Form will only be seen by yourself and the investigators. Electronic data will be anonymised as will paper copies of tasks. These will be stored separately from Consent Forms, in a locked location in the University of Auckland Human Sciences Building. Data will be kept for a minimum period of six years to allow for publication and future re-analysis. Research publications and conference presentations based on the study results will not contain any information that can personally identify you. If you agree, your data may be used in future studies.

Research contact details

We appreciate the time you have taken to read this invitation. If you have any queries, please contact Simon Walker by email: swal137@aucklanduni.ac.nz Telephone: (09) 3737599 Ext 83072.

You may also contact the supervisor of the study, Associate Professor Lynette Tippett

School of Psychology, University of Auckland

Private Bag 92019, Auckland 1142

Telephone: (09) 373 7599 extension 88551

Email: ltippett@auckland.ac.nz

Or the Head of the Department of Psychology, Professor William Hayward

Email: w.hayward@auckland.ac.nz

For ethical concerns:

The Chair of the University of Auckland Human Participants Ethics Committee,

Office of the Vice Chancellor, Research Office,

Alfred Nathan House, University of Auckland,

Private Bag 92019, Auckland 1142

Ph: (09) 373 – 7559 ext. 87830

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15th August 2014, FOR A PERIOD OF 3 YEARS. Reference number: 012617
Appendix B: Participant Information Sheet (Cohort Two)

Art therapy and identity: Evaluating the rehabilitative efficacy of Spark’s visual arts therapy program for survivors of stroke.

You are invited to take part in a research project which aims to determine the rehabilitative effectiveness of Spark's visual arts therapy program for long term survivors of stroke. This project is being carried out by Associate Professor Lynette Tippett and Simon Walker, a doctoral student and trainee clinical psychologist within the School of Psychology at the University of Auckland. Please read the below information carefully and feel free to ask any questions. Thank you for taking the time to read this.

What is the purpose of this study?

The overall aim of this project is to evaluate the effectiveness of Spark's visual art therapy programme (VATP) for individuals who are living with the long term effects of stroke.

Why do we need to do this study?

Approximately 7000 New Zealanders experience stroke annually, contributing to a total of 60,000 stroke survivors in New Zealand. In addition to the physical consequences of stroke, many stroke survivors are affected by cognitive (thinking) impairments, depression, anxiety and apathy. It is understood that these outcomes can negatively affect quality of life, post-stroke adjustment and recovery from stroke.

To date there are few rehabilitation methods that attempt to address the long term outcomes of stroke. One exception is a novel therapeutic programme for survivors of stroke developed by Auckland’s Spark Centre of creative development (a community organisation). Spark has developed a 10-week therapeutic programme that aims to facilitate post-stroke adjustment via group centred visual art therapy. The aim of this study is to evaluate this programme with regards to its rehabilitative effectiveness in promoting adjustment, facilitating functional and psychological recovery, improved mood, sense of identity and quality of life in stroke survivors.

Who can participate in this study?

People who have experienced stroke within the last 3 months-5 years and are fluent in English. Participants must be committed to completing Spark’s 10 week visual arts stroke programme and have had no previous experience of visual arts therapy following their stroke.

We are also asking participants to nominate a family member or significant other for participation in this research. The involvement of this nominated person would provide researchers with additional information about the effectiveness of Spark’s visual arts programme. Please note, you can choose to not nominate a family member without forfeiting your own involvement in this research project. If you do nominate a family member they will not be obliged to participate. Following your nomination, they will be provided information about this study and what their participation may entail. Following this they will have opportunity to freely decide whether they would like to be involved or not.

What is involved?

Because we are interested in determining the long term benefits of Spark's visual arts therapy program we will be assessing participants across four timepoints. The first assessment will occur approximately 10-12 weeks prior to the beginning of the programme, the second will occur approximately 2 weeks prior to beginning the program, the third will occur approximately 2 weeks following the completion of the programme and the
fourth assessment will occur approximately 6 months following the completion of the program. If you give permission, and if they are willing, we will also be asking questions of family member or significant other (nominated by you) across some of these time points as well. Please note, that if you do not want to nominate a family member or significant other you can still participate in this study.

During the four assessment sessions you will be asked to complete a variety of tasks and questionnaires that aim to assess your cognitive ability, mood, social support and the extent of change that you’ve noticed following your stroke and involvement in the visual arts program. Additionally, at the first and third assessments, you will be asked to undergo a brief informal interview. This is designed to allow researchers to get a greater understanding of your own unique experience of stroke and the visual art program. The first assessment is the longest and will take between approximately 1.5-2 hours. The remaining three sessions will last between 60-90 minutes.

If you choose to nominate a family member or significant other, they will be asked to complete a small number of tasks across at timepoints that approximately coincide with your assessments. These tasks consist of questionnaires that aim to give insight into their views of changes that you have experienced following your stroke and since your involvement in Spark's visual arts program. Each session will last a maximum of 30 minutes.

You can choose whether your would like the assessments to occur in your home, or on premises at the University of Auckland.

**What are the expected benefits?**

Your participation will contribute to a better understanding of how we can help rehabilitate individuals who are living with the long term effects of stroke. Given that this study aims to assess the effectiveness of Spark's visual arts therapy programme, it is unlikely that you will personally benefit from your involvement in this study. However, it is possible that by your involvement in the VATP that you will experience increased self-esteem, forging a new identity, reduced depression/anxiety symptoms and increased quality of life.

You will be offered a summary of the overall findings when the study is complete. Participation will not cost you anything, and you will receive $20 voucher (either food or petrol voucher) at each assessment timepoint ($80 total) in addition to $50 in either petrol or supermarket vouchers at the second assessment to help with transport costs to and from the arts therapy program.

**What are the potential risks and discomforts?**

It is not anticipated that you will experience any risks or discomfort, however many of the measures we are using may ‘bring to mind’ some of the negative consequences that you may have experienced as a result of stroke. Within this context, your reaction to these measures will be closely monitored, and you are freely able to opt out of the study at any time that you choose.

Given that the assessment sessions may reach up to two hours, this may be tiring. We will include as many breaks as you need. If you become fatigued at any time, you are able to adjourn the session, which will be continued at a later date/time.

**Your rights as a participant**

Your participation in this project is completely voluntarily. If you choose to participate you can change your mind about taking part at any point during the testing process, without giving a reason. There will be no negative consequences as a result of changing your mind. After your participation is complete, should you
change your mind about us using your results, you can request that your data be withdrawn for a period of up to two months. You can keep this document as a reminder.

Confidentiality, Anonymity and Data Storage

Any information which can identify you as a participant will be stored in a secure locked location and used with utmost confidentiality. Your name will only appear on the Consent Form, which will be coded with a unique identification number, assigned by Simon Walker. Only this number will be linked with your data. No information will be shared with any third party, including your nominated family member.

The Consent Form will only be seen by yourself and the investigators. Electronic data will be anonymised as will paper copies of tasks. These will be stored separately from Consent Forms, in a locked location in the University of Auckland Human Sciences Building. Data will be kept for a minimum period of six years to allow for publication and future re-analysis. Research publications and conference presentations based on the study results will not contain any information that can personally identify you. If you agree, your data may be used in future studies.

Research contact details

We appreciate the time you have taken to read this invitation. If you have any queries, please contact Simon Walker by email: swal137@aucklanduni.ac.nz Telephone: (09) 3737599 Ext 83072.

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APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15th August 2014, FOR A PERIOD OF 3 YEARS. Reference number: 012617
Appendix C: CONSENT FORM (Cohort One)

Art therapy and identity: Evaluating the rehabilitative efficacy of Spark’s visual arts therapy program for survivors of stroke

I have read and understood the accompanying Participant Information Sheet, which explains this research project and my role as a participant. I have had the opportunity to ask questions and to use family/whanau support or a friend to help ask questions, and have had them answered satisfactorily. I have had the opportunity understand the study.

- I agree to take part in this research.
- I understand that taking part in the study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future and continuing health care.
- I agree to complete a range of tasks and questionnaires approximately 2 weeks prior to beginning the arts therapy programme, after completing the programme and six months later.
- I understand the tasks and questionnaires at the first session may take about two-three hours to complete and understand that this can be done in one or two sessions, whatever I choose.
- I understand that the following sessions will take up to 70 minutes to complete.
- I understand that I will be given vouchers to the value of $20 at each assessment session.
- I understand that my participation is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that my data will be stored anonymously and securely for a minimum period of 6 years, after which it will be destroyed.
- I know who to contact if I have any problems from taking part in this study.
- I understand that I am not obliged to nominate a family member/spouse/significant other.
- Should I choose to nominate a family member for involvement in this study, I understand that no information will be shared with my nominated family member and vice versa (if applicable).
- I agree that my responses on the interview questions may be recorded. YES/NO
- I choose to nominate a family member/spouse/significant other who is able to answer questions about any changes that may have occurred to me following my stroke and involvement in Spark’s Visual Arts Therapy Program.
  YES/NO

Name of nominated family member/spouse/significant other ____________________________

- I would like to receive a copy of the results of the study YES/NO

I voluntarily agree to take part in this research.

Name of Participant ____________________________

Signature of participant ____________________________ Date: _____________

Principle Investigator ____________________________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15 August 2014 FOR A PERIOD OF 3 YEARS. Reference number: 012617 Contact Simon Walker at the School of Psychology, Building 721 Room 314, The University of Auckland, Private Bag 92019, Auckland (email: swal137@aucklanduni.ac.nz).
Appendix D: CONSENT FORM (Cohort Two)

Art therapy and identity: Evaluating the rehabilitative efficacy of Spark’s visual arts therapy program for survivors of stroke

I have read and understood the accompanying Participant Information Sheet, which explains this research project and my role as a participant. I have had the opportunity to ask questions and to use family/whanau support or a friend to help ask questions, and have had them answered satisfactorily. I have had the opportunity understand the study.

- I agree to take part in this research.
- I understand that taking part in the study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future and continuing health care.
- I agree to complete a range of tasks and questionnaires approximately 6-10 weeks prior to beginning the arts therapy programme, approximately 2 weeks prior to beginning the arts therapy programme, after completing the programme and six months later.
- I understand the tasks and questionnaires at the first session may take about two-three hours to complete and understand that this can be done in one or two sessions, whatever I choose.
- I understand that the following sessions will take up to 70 minutes to complete.
- I understand that I will be given vouchers to the value of $20 at each assessment session and $50 at the second assessment session to assist with transport costs.
- I understand that my participation is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that my data will be stored anonymously and securely for a minimum period of 6 years, after which it will be destroyed.
- I know who to contact if I have any problems from taking part in this study.
- I understand that I am not obliged to nominate a family member/spouse/significant other.
- Should I choose to nominate a family member for involvement in this study, I understand that no information will be shared with my nominated family member and vice versa (if applicable).
- I agree that my responses on the interview questions may be recorded. YES/NO
- I choose to nominate a family member/spouse/significant other who is able to answer questions about any changes that may have occurred to me following my stroke and involvement in Spark’s Visual Arts Therapy Program. YES/NO
- I would like to receive a copy of the results of the study YES/NO

I voluntarily agree to take part in this research.

Name of nominated family member/spouse/significant other ____________________________

Name of Participant ____________________________

Signature of participant ____________________________ Date: ____________

Principle Investigator ____________________________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15 August 2014 FOR A PERIOD OF 3 YEARS. Reference number: 012617 Contact Simon Walker at the School of Psychology, Building 721 Room 314, The University of Auckland, Private Bag 92019, Auckland (email: swal137@aucklanduni.ac.nz).
Appendix E: Demographic Interview

I would like to ask you some brief questions to get to know a bit about you and your background.

1. First, I’d like to ask about your schooling
   a. How old were you when you left school?__________________________________________
   b. What did you do when you left school?__________________________________________
   c. Did you go on to do any other sort of education or classes? (Where, how long).

Now I need to ask you some questions about your lifestyle and medical history. These are standard questions that I ask everyone in this study.

2. How old are you now (Years/DOB)?__________________________________________

3. Are you right or left handed?__________________________________________

4. What is your ethnicity?__________________________________________

5. Do you or have you smoked?__________________________________________

6. Do you have a history of high blood pressure?__________________________________________

7. Do you have diabetes?__________________________________________

8. Do you have a history of high cholesterol?__________________________________________

9. Drug and Alcohol use
   a. Do you drink at all? Y/N
   b. How much alcohol in a typical week?__________________________________________
   c. Were you ever a heavy drinker? Y/N
   d. Has there ever been a time in your life when a prescription/Non-prescription drug has been a problem for you? For example, you may have had difficulty stopping a medication that you were on (e.g. sleeping tablets or valium). Y/N
   Describe ________________________________

10. Past psychiatric history
   a. Have you had a time in your life where you experienced problems with your mental health, for instance depression, anxiety, schizophrenia? Y/N
   Describe ________________________________
   b. Have you ever required treatment for any emotional, nervous or psychiatric illness? Y/N
11. Do you have any history with any of these medical conditions:
   a. Head injuries Y/N__________________________
   b. Major heart problems Y/N____________________
   c. Major surgery Y/N__________________________
   d. Seizure or fits Y/N__________________________
12. What medications are you currently on?
13. How many strokes have you had? ____________
14. When was your most recent stroke?___________
15. Do you remember the month and year of your stroke?__________________________
16. Do you know which side of your brain was affected by stroke?________________________
17. Following your stroke were you weak on one particular side of your body (which side)?
   _______________________________________________________________________
18. Have you ever participated in a stroke related arts therapy programme? Y/N?
Appendix F: Head Injury Semantic Differential Scale

Below you will see pairs of words that people often use to describe themselves. These pairs are separated by the numbers one through seven. I would like you to look at each pair of words and circle the number that you believe best describes your **CURRENT SELF**. Please be sure to look at both pairs of words.

| Bored       | 1 2 3 4 5 6 7 | Interested   |
| Happy       | 1 2 3 4 5 6 7 | Unhappy      |
| Helpless    | 1 2 3 4 5 6 7 | In Control   |
| Relaxed     | 1 2 3 4 5 6 7 | Worried      |
| Dissatisfied| 1 2 3 4 5 6 7 | Satisfied    |
| Attractive  | 1 2 3 4 5 6 7 | Unattractive |
| Despondent  | 1 2 3 4 5 6 7 | Hopeful      |
| Self-confident | 1 2 3 4 5 6 7 | Lacking confidence |
| Unstable    | 1 2 3 4 5 6 7 | Stable       |
| Of value    | 1 2 3 4 5 6 7 | Worthless    |
| Aggressive  | 1 2 3 4 5 6 7 | Unaggressive |
| Calm        | 1 2 3 4 5 6 7 | Irritable    |
| Unfeeling   | 1 2 3 4 5 6 7 | Caring       |
| Capable     | 1 2 3 4 5 6 7 | Incapable    |
| Dependent   | 1 2 3 4 5 6 7 | Independent  |
| Active      | 1 2 3 4 5 6 7 | Inactive     |
| Un-Cooperative | 1 2 3 4 5 6 7 | Cooperative |
| Talkative   | 1 2 3 4 5 6 7 | Withdrawn    |
| Unfriendly  | 1 2 3 4 5 6 7 | Friendly     |
| Patient     | 1 2 3 4 5 6 7 | Impatient    |
Appendix G: Twenty Statements Test Coding Instructions

The twenty statements test involves asking participants to describe themselves using 20 statements. In this study, participants were asked to complete this task with reference to two time-points. 1) Current self and 2) Pre-stroke self.

The derived data is to be coded in a number of ways that will be described below. Broadly, this coding consists of 1) valence of statements, 2) categories and specificity/abstraction of responses. In all cases, a score is provided for each time-point condition. That is, scores are not combined.

Coding Method One: Emotional Valence

Each response is coded according to the perceived emotional valence of that response. Coding consists of binary ‘positive’ or ‘negative’ codes.

This is a subjective coding procedure and it can be difficult to code certain responses. Overall, it is important to remember that you are coding the meaning rather than the content of the response, and all that is required is that if you are unsure, then you make a reasonable inference.

- Straightforward examples of this coding include ‘I am limited’ (negative) and ‘I am happy’ (positive).
- More complicated examples include responses where participants define an aspect of themselves as an absence of something. For example, ‘I am not religious’ would be coded positive. Although the response is negative in content (i.e. the person is defining themselves according to an absence of something), it is reasonable to assume that this participant sees their lack of religious belief as positive in emotional meaning.
- Conversely, ‘I am not interesting’ and ‘I don’t see friends’ would be coded as negative. Although the subject of the response is positive (i.e. ‘interesting’ and ‘friends’) it is reasonable to assume that the participant considers this to be a negative aspect of their identity. Alternatively, if the response is negative in subject but is framed positively (e.g. ‘I prefer to be alone’) then this would be coded positively, as in this case, it is reasonable to assume that this participant does not see this as a negative aspect of their identity.
- For some responses it is unclear whether the emotional meaning for that particular participant is positive or negative, such examples include ‘I am selfish’ and ‘I am cynical’. That is, such responses can be coded as either positive or negative as some individuals may see selfishness as a positive trait while others do not. In this context, the most important thing is consistency.

Please code the emotional valence of all participants before continuing with the other coding procedures.

TST Coding Method Two: Category and quality coding procedure

The table below outlines the criteria for this coding method. This table contains 8 categories (in bold) and 32 subcategories (indented). Please code each statement according to the following method.

1. Code each statement according to the category in which it fits.
2. Code each statement according to whether it fits the criteria of a ‘specific’ or ‘abstract’ statement as outlined below (on the right of the table). You do this by identifying the sub-category. Generally, responses that have a context (e.g. ‘I am happy at home’) are coded as specific, and responses that don’t have a context (e.g. ‘I am happy’) are coded abstract.
3. Due to the administration of the TST with reference to two time points, in the pre-stroke condition, there will be many responses prefaced with ‘I was’, these should be coded as if they are equivalent to ‘I am’ statements. Note that some participants changed their pattern of responding half way through their responses.
4. The most difficult categories to distinguish are Attributes and Evaluative Descriptions; this is particularly due to the nature of this sample. Accordingly, the following general rules apply.

5. **Attributes:** Generally this captures a quality or feature of the participant’s identity that is characteristic or inherent to them. Although, due to the nature of the sample (stroke survivors), in some cases, many qualities or features will not have persisted for a long time, however they still need to be coded as attributes.

6. **Evaluative Descriptions:** Generally this captures statements that include an evaluation, judgement or reflection upon an aspect of the participant’s identity. Responses typically contextualise an aspect of identity using words such as ‘good’, ‘lack’, ‘limited’, ‘less’ and so on. For example in the response ‘I am a hands on father’, this participant is making an evaluation of the fathering aspect of his identity. A further example is ‘I am sporty’ which indicates a preference for sports and an identity that is related to sporting ability (so would be coded attribute), however, this response also has an evaluative quality to it (so could be coded evaluation). In this case it is correct to code this response as an attribute rather than an evaluation. However, if the response was ‘good at sports’, it would be coded as an evaluation. Similar examples include, ‘I was a gardener’ (attribute), ‘I was a good gardener’ (evaluation); ‘I am impulsive’ (attribute), I am too impulsive (evaluation).

7. **Beliefs and Values:** These are statements that indicate priorities and values in life. Occasionally it can be difficult to determine whether a response falls within an attribute (trait) or belief/value category. Generally, if the response indicates a reference to an underlying moral or ethical code that is consistent with the morals and ethics of western or Maori culture, then it is coded as values rather than attributes.

*Please note, when coding for category, you are coding for meaning rather than responses and that each statement is only coded once. Therefore in cases where there are two parts to the statement, the following rules are applied.*

i. When statements contain several closely related meanings, only code the first meaning (e.g. for ‘I am kind and caring’ only ‘I am kind’ is coded).

ii. If one statement was qualified by another from a different category (e.g. ‘elderly lady’), code in relation to the main object of the statement (i.e. ‘lady’), unless a previous statement has already accounted for that aspect of identity, in which case you would code for the other term (i.e. ‘elderly’).

iii. Any statement that contains an evaluative descriptor (e.g. ‘I am a good tennis player’) is coded as an evaluation regardless of what the evaluation was in relation to (e.g. activities, social roles, abilities).

iv. Emotional States: Note, any response that has emotional content to it (i.e. love, hate, anger, worry, anxiety, happy, unhappy etc.) is coded as emotional state regardless of context of the response.

v. When a statement combines a preference (e.g. like/dislike) with another statement that can be coded within a different (non-attribute) category (note: preference falls within the attribute category) (e.g. ‘I like being a mum’) then code the statement in accordance with the other non-attribute category.

vi. Alternatively, when a statement combines a preference with another attribute (e.g. an activity or a personality trait) this is coded as a preference.

vii. Negations (e.g. ‘I am not religious’) were assigned to the same category that would have been used if the same statement was described positively (i.e. in this case: social Identity-religion).
Appendix H: Rhee et al., (1995) TST coding Table

<table>
<thead>
<tr>
<th>1. Physical Characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Descriptive (e.g. short, pretty)</td>
<td>Specific</td>
</tr>
<tr>
<td>2) Age</td>
<td>Specific</td>
</tr>
<tr>
<td>3) Fact about self (e.g. height, weight, eye colour, hair colour)</td>
<td>Specific</td>
</tr>
<tr>
<td>4) Physical condition (e.g. health, sight, losing memory, disability, can’t do as much)</td>
<td>Specific</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Social Identities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5) Role status-roles assigned by society/culture (e.g. student, housewife, taxpayer, citizen etc.). Note: More formal than self-ascribed identities which are a choice.</td>
<td>Specific</td>
</tr>
<tr>
<td>6) Group Membership (e.g. belong to a club, rotary)</td>
<td>Specific</td>
</tr>
<tr>
<td>7) Family Information (e.g. mother, father, sister)</td>
<td>Specific</td>
</tr>
<tr>
<td>8) Self-ascribed identities (e.g. musician, surfer, dancer)</td>
<td>Specific</td>
</tr>
<tr>
<td>9) Religion (i.e. association with religious denomination)</td>
<td>Specific</td>
</tr>
<tr>
<td>10) Occupation</td>
<td>Specific</td>
</tr>
<tr>
<td>11) Origin (e.g. born in Auckland, from China)</td>
<td>Specific</td>
</tr>
<tr>
<td>12) Ethnicity, race, nationality (e.g. Maori, Kiwi, Pakeha, Scottish)</td>
<td>Specific</td>
</tr>
<tr>
<td>13) Gender</td>
<td>Specific</td>
</tr>
<tr>
<td>14) Name</td>
<td>Specific</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Attributes (Activities, preferences, aspirations &amp; traits)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally captures a quality or feature of the participant’s identity that is characteristic or inherent to them.</td>
<td></td>
</tr>
<tr>
<td>15) Activities (e.g. Participates in, habits)</td>
<td>Specific</td>
</tr>
<tr>
<td>16) Preferences (e.g. Includes activities and interests that are prefaced with terms such as ‘enjoys, likes, dislikes fond of’). Note: If a preference prefaces a non-attribute aspect of identity, then it is coded within that non-attribute category.</td>
<td>Specific</td>
</tr>
<tr>
<td>Aspirations (e.g. wishes, hopes, dreams, future orientation, negative predictions).</td>
<td></td>
</tr>
<tr>
<td>17) Specific/contextualised aspirations (e.g. want to be a better cricket player), temporal (used to wish I was richer) or socially bound (hope to spend more time with my family).</td>
<td>Specific</td>
</tr>
<tr>
<td>18) Abstract aspirations (e.g. want to be a better person, want to be happy)</td>
<td>Abstract</td>
</tr>
<tr>
<td>Traits (including personality characteristics)</td>
<td></td>
</tr>
<tr>
<td>19) Specific/qualified traits: (e.g. in certain situations), temporal (e.g. I work hard at rehabilitation, usually, used to be try to be) or social (e.g. with someone, with my family).</td>
<td>Specific</td>
</tr>
<tr>
<td>20) Abstract/pure traits: lacks any specific situational, temporal context (e.g. ‘kind, honest, hard working, social, curious and quiet’).</td>
<td>Abstract</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Evaluative Descriptions (i.e. abilities, evaluations)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally captures judgements or reflections upon an aspect of the participant’s identity.</td>
<td></td>
</tr>
<tr>
<td>21) Specific evaluative descriptions: Contain context (e.g. ‘I am bad at maths, I am a good listener, I have lots of friends, I am a good mother).</td>
<td>Specific</td>
</tr>
<tr>
<td>22) Abstract/reflective evaluative descriptions: Lack any context (e.g. ‘sporty’, ‘good abilities’, ‘good life, ‘decent person’,’slack’, I am lucky’).</td>
<td>Abstract</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Beliefs/values (i.e. statements that indicate someone’s priorities and values in life, as well as statements that suggest an underlying moral or ethical code).</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>23) Specific beliefs and values: Contextualised (e.g. ‘I am generous when there are tragedies) or socially bound (I try to be a good role model to my Grandchildren).</td>
<td>Specific</td>
</tr>
<tr>
<td>24) Abstract beliefs and values: Lack context (e.g. ‘I value honesty, I am kind, I am hardworking, I try to be a good role model).</td>
<td>Abstract</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Emotional States</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>25) Specific emotional states (e.g. happy to be living here, sad about stroke), temporal (e.g. unhappy at the moment, happy some of the time) or social (e.g. in love with partner, I love snooker).</td>
<td>Specific</td>
</tr>
<tr>
<td>26) Abstract Emotional States: Statement lacks context (e.g. I am worried, happy, I am a worrier, angry)</td>
<td>Abstract</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>7. Global Descriptions</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>27) Universal, context-less descriptions (e.g. a human being, earthing, child of god</td>
<td>Abstract</td>
</tr>
<tr>
<td>28) Existential descriptions (e.g. me, myself, a unique creation)</td>
<td>Abstract</td>
</tr>
</tbody>
</table>

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<tr>
<th>8. Other/peripheral information</th>
<th></th>
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<tbody>
<tr>
<td>29) Immediate situations, states (e.g. tired, hungry)</td>
<td>Specific</td>
</tr>
<tr>
<td>30) Present residence (e.g. live at home, in care facility)</td>
<td>Specific</td>
</tr>
</tbody>
</table>
APPENDIX I: ALTERNATE USES TASK: ADMINISTRATION AND SCORING PROCEDURE

Instructions

In this task, you will be given an object word, and you will be asked to write down as many examples of possible uses for that object as you can think of in 2 minutes. For each object, we have provided two examples of the object’s use to give you a starting point.

Write as many uses for this object as you can think of in the next two minutes.

BRICK

CAR TIRE

PAPERCLIP

ALTERNATE USES TASK: SCORING

Prior to coding, responses that were categorised as the same as the object's standard use were excluded. Repeat responses were excluded, and nonsense responses were excluded.

(1) Fluency

This measure refers to the amount of responses generated, and is simply the total number of responses generated by a participant regardless of 'quality' or appropriateness (excluding repetitions).

Coding procedure

Simply total the number of responses for each object/category, and sum these 3 object/category scores for a total score. Repeat responses are not coded.

(2) Flexibility

This measure captures the flexibility of responses by assessing the number of ‘categorically’ or ‘semantically’ distinct responses (i.e., the number of categories the responses can be grouped into). The process of deciding which responses are sufficiently similar or different to constitute being in the same or distinct categories is difficult, so we have generated some guidelines outlining the ways in which responses can be similar:

Please note: coding for flexibility is somewhat subjective and requires you to make a judgement call.

- End products: For instance, using a tyre to ‘make a swing’, and to ‘make play equipment in a park’ are considered one category as they are semantically related. However, if the individual gives more information about the possible use that differentiates it from the other it would be considered as a separate category. For example, if a tyre was used to make ‘a swing over a river to jump off’, or ‘a swing as part of a romantic date’, these uses are unrelated to the swing you may find at a playground. Using a paperclip to make a necklace, to make a ring, and to make a bracelet are all forms of jewellery.
- **Physical actions / processes:** Semantically similar physical actions are grouped together even if the objects they are interacting with are different (e.g., using a paperclip to unclog a pen, unclog a drain; using a paperclip to scratch glass, to scratch windows; to throw a button as far as you can and to skim a button across water) Exception: when the process described is very general (e.g., “to make” – to make a sculpture, to make a table) then the items will only be grouped together if they share an end product (e.g., to make a dinner table, to make a coffee table).

- **Disassembly Use Production:** Using certain physical parts of the object or reassembling them to create a new object to use. These responses can be grouped according to similar kinds of disassembly even if used to make different objects, (e.g., to melt down tyre to make shoes; melt down tyres to make toys), or according to similar kinds of end products even if the disassembly process is different (e.g., cut tyre to make shoes, melt tyre to make shoes)

- **Attributes of the object:** Different uses that rely on the same attribute of the object to the same end (e.g., the heaviness of the object) are grouped together. For example, using a brick as a paperweight or as a door stop, both uses are grouped together as they are using the weight of the brick to stop things moving.

Following this categorisation, there may be items that cannot be grouped with other items according to don’t share any of these attributes with other items (e.g., an impossible use, like making a laser gun from a paperclip). In this case, each response is considered in a category of its own.

*For each participant, tally the number of categories.*

**Tips:** Look for expected uses for the items. E.g., brick = standard forms of construction (e.g., using a brick to build a wall, a pathway, a fireplace etc.) Note that some categories may have two or more expected uses, e.g., button (sewing, something you push).
References


References


Schmid, A. A., Damush, T., Tu, W., Bakas, T., Kroenke, K., Hendrie, H. C., & Williams, L. S. (2012). Depression improvement is related to social role functioning after stroke. *Archives of physical medicine and rehabilitation, 93*(6), 978-982.


