

Self-Discrepancy and Affective Distress after Stroke

Irina Lapadatu

Clinical Supervisor: Professor Reg Morris

Academic Supervisor: Professor Reg Morris

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ABSTRACT

AIMS: To investigate self-discrepancies in stroke survivors and explore associations between discrepancies and distress, drawing on Higgins's (1987) Self-Discrepancy Theory. More specifically, investigate if stroke survivors reported a change in their sense of self following stroke, if this change was related to their reported anxiety and depression, and if this relationship was mediated by their perceived self-esteem. Also, to explore if discrepancies between survivors' post-stroke self and their ideal and ought self, respectively, were associated with depression and anxiety, respectively.

METHOD: A retrospective cross-sectional design was employed. The participants were 67 first-time community-living stroke survivors, with a mean age of 61.6 years and a mean time since stroke of 5.6 years. The measures included the Head Injury Semantic Differential for assessing pre-stroke (retrospectively), post-stroke, ideal and ought selves; the Hospital Anxiety and Depression Scale; the Rosenberg Self-Esteem Scale; the Stroke-Specific Quality of Life Questionnaire (adapted); and the Barthel Index.

RESULTS: Stroke survivors perceived themselves significantly more negatively than prior to their stroke. The discrepancy between pre and post-stroke selves was positively associated with affective distress and negatively associated with self-esteem and quality of life, respectively. The discrepancy between post-stroke self and ideal self, and the discrepancy between post-stroke self and ought self were also positively associated with affective distress. However, these relationships were undifferentiated, as the former was not only related to depression but also to anxiety, and the latter was not only related to anxiety but also to depression. Survivors' perceived self-esteem was a mediator in the relationship between the pre and post-stroke selves discrepancy and affective distress.

CONCLUSIONS: This was the first study to show a perceived change in identity in a large sample of stroke survivors, and it contributed to our understanding of how psychological factors may be involved in emotional adjustment after stroke. This highlighted the importance of considering such changes in informing neurorehabilitation; the clinical implications were discussed. It was also the first study to provide support, albeit partial for Higgins' (1987) self-discrepancy theory in a stroke population. The strengths and limitations of the study were considered and ideas for future research were proposed.

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CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION TO THE STUDY

While stroke represents the focus of this study, stroke is a form of acquired brain injury (ABI) and thus it will be considered in this context. The wider evidence from ABI research, particularly from traumatic brain injury (TBI), will be drawn on as relevant, in order to complement the evidence from stroke research, particularly when this is lacking; and thus enhance understanding of the issues presented. This is based on the argument that regardless of the cause, e.g. stroke or TBI, the resulting neurological damage leads to similar difficulties across physical, cognitive, behavioural, emotional and social functioning (Lezak *et al.*, 2004).

Stroke is a sudden, life changing event, confronting survivors with a wide range of impairments, and it is associated with decreased quality of life (Bays, 2001a). Emotional problems, such as anxiety (Campbell Burton *et al.*, 2013) and depression (Ayerbe *et al.*, 2013), are a common occurrence following stroke. They are not only distressing, but they can interfere with adjustment (Mukherjee, 2006) and rehabilitation (Gillen *et al.*, 2001). These emotional difficulties can be explained by neurological factors and also by psychosocial factors, considering the adjustment required following such a major life event, which involves coming to terms with multiple losses.

The concept of identity change or loss following ABI has been receiving increasing attention in the literature, with support coming mainly from qualitative studies (Segal, 2010; Yeates *et al.*, 2008). Furthermore, changes in self-concept have also been associated with emotional problems after ABI (Cantor *et al.*, 2005; Carroll & Coetzer, 2011). This has been explained by Cantor *et al.* (2005) using Higgins' (1987) self-discrepancy theory which related affective distress to discrepancies between different aspects of self. This model may be useful in understanding emotional disorders after ABI as partly due to a change in survivors' sense of self, between pre and post-injury, with important implications for psychosocial neurorehabilitation.

A systematic review of the studies that investigated survivors' perceived difference in their identity following ABI was carried out. This highlighted a growing area of research, however, with only very few studies involving stroke survivors and quantitative studies using modest samples, thus emphasising the need for further research.

Consequently, the main aim in this study was to investigate, using a larger sample, if stroke survivors perceive themselves as different following stroke, and to explore the relationship between this perceived difference and their reported affective distress.

1.2 CHAPTER OUTLINE

Firstly, an overview of ABI / stroke and their consequences will be provided, focusing on their associated emotional problems and how these have been explained. The impact of ABI / stroke on identity will then be considered; the terminology will be explained and relevant accounts of identity change following ABI / stroke will be outlined using a biopsychosocial framework (Yeates *et al.*, 2008). This will be followed by a brief account of how self-esteem is affected by ABI / stroke. Higgins' (1987) Self-discrepancy theory will then be introduced, as a means of explaining affective distress in relation to discrepancies between different aspects of self. This will be followed by a systematic review of the studies that investigated changes in the sense of self following ABI / stroke. Finally, the rationale, aims and hypotheses of this study will be outlined.

1.3 ACQUIRED BRAIN INJURY AND STROKE

1.3.1 Overview

The World Health Organization (WHO) defines acquired brain injury as “damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial or functional disability or psychosocial maladjustment” (WHO, 1996 cited by Powell River Brain Injury Society, 2014). Stroke is a form of ABI defined by a sudden death of brain cells caused by the interruption of the blood supply to the brain (WHO,

2001). There are two main sub-types of stroke (Intercollegiate Stroke Working Party, 2012): an ischemic stroke is characterised by a blockage in the blood supply to the brain, and this accounts for 69 % of all strokes; a haemorrhagic stroke is caused by a major blood vessel that ruptures and bleeds into the brain, and this accounts for approximately 13% of all strokes (Wolfe *et al.* 2002).

In the UK, there are approximately 152,000 strokes every year, with one in five strokes being fatal, and there are approximately 1.1 million stroke survivors living in Britain (Townsend *et al.*, 2012). Furthermore, approximately 25% of strokes occur in people aged under 65 years (Intercollegiate Stroke Working Party, 2012a).

In what follows, the aim is to provide an outline of the general consequences of stroke, with a focus on the emotional problems experienced after ABI / stroke. More specifically, the incidence, impact and etiology of post-stroke anxiety and depression will be considered.

1.3.2 Consequences of ABI / Stroke

Acquired brain injury is a major cause of disability and is highly idiosyncratic. The consequences of the neurological damage resulting from ABI are well documented and include a range of difficulties across physical, cognitive, behavioural, emotional, and social functioning. The symptoms range in severity depending on the extent and location of injury, age, premorbid personality, and individual social circumstances (e.g. family support, access to rehabilitation services, etc.) (Lezak *et al.*, 2004).

In stroke, the most prominent effects are motor and sensory deficits, aphasia and visual field problems (Bogousslavsky & Caplan, 2001). The individuals may also experience a broad range of higher cognitive deficits (Lezak *et al.*, 2004) and impaired social functioning (Sjogren,1981). Stroke is the main cause of severe disability in the UK (Adamson *et al.*, 2004). This is understood both in terms of loss of ability to carry out activities of daily living, required for being independent at home, and reduced participation in wider roles (work, leisure, socialising) (Lincoln *et al.*, 2012). More than half of all stroke survivors are left dependent on others for everyday activities (Intercollegiate Stroke Working Party, 2012).

1.3.2.1 Emotional problems after ABI / stroke

Stroke can be an extremely challenging and frightening event, involving a sudden transition from being able-bodied to disabled, confronting survivors with a wide range of physical, psychological, social and sexual impairments (Delmar *et al.*, 2005; Hjelmlink & Holmstrom, 2006; Teasell *et al.*, 2011). It is a life-changing condition, associated with decreased quality of life, even in the case of little visible functional impairment (Carlsson *et al.*, 2003; Edwards *et al.*, 2006; Muus *et al.*, 2010) and successful rehabilitation (Hopman & Verner, 2003; Kim *et al.*, 1999; Seacrest & Thomas, 1999). Within six months of discharge from inpatient rehabilitation, over half of stroke survivors report reduced participation in meaningful activities (Mayo *et al.*, 2009; Rittman *et al.*, 2007; Roth & Lovell, 2007) and many report increased isolation, with 25% housebound (Belanger *et al.*, 1988; Mayo *et al.*, 2009; Rittman *et al.*, 2007), or in contact only with immediate family members (Green & King, 2009; Hommel *et al.*, 2009; Hopman & Verner, 2003).

Consequently, given the life changes and the sense of loss they often experience, it is not surprising that, generally, ABI survivors are typically at heightened risk of developing emotional disorders (Williams & Evans, 2003). Moreover, these seem to be irrespective of the level of severity of brain injury (Lishman, 1987), and can be present at various stages of recovery (Wright & Telford, 1996).

Depression is the most widely reported mood disturbance following ABI, although anxiety is also common (Harris & Barraclough, 1997; Williams, 2003). On average, anxiety and depression rates after stroke are about 33%, but some studies report over 70% (Altieri *et al.*, 2011; Hackett *et al.*, 2009; Salter *et al.*, 2010).

1.3.2.1.1 Incidence of depression and anxiety after stroke

Post-stroke depression rates are high (Brodaty *et al.*, 2007). At any one time, depression is present in approximately one third of community-living stroke survivors (Hackett *et al.*, 2005), and around 55% of survivors experience depression at some stage after stroke, as shown by a 15 year longitudinal study (Ayerbe *et al.*, 2013). Relatives of stroke survivors reported depression associated with stroke as most prominent during the acute stage of recovery, but this may become more widespread

and more severe over time, significantly affecting the quality of life after stroke (House, 1996).

Although less researched, anxiety is almost as prevalent as depression, and it seems to become more evident and persists a few months after the stroke event (Bergersen *et al.*, 2010; Campbell Burton *et al.*, 2013). A systematic review and meta-analysis of observational studies showed anxiety affects about 20% of stroke survivors (Campbell Burton *et al.*, 2013). The comorbidity between anxiety and depression, which is well established in the general population (Kessler *et al.*, 2003), was also shown in stroke; 42 out of 87 of stroke survivors reported experiencing both anxiety and depression 2 to 5 years after discharge from a specialised rehabilitation hospital (Bergersen *et al.*, 2010).

1.3.2.1.2 Impact of post-stroke depression and anxiety

Emotional problems are not only distressing, but are also frequently debilitating, affecting people's cognitive abilities and adjustment (Mukherjee, 2006), being associated with poorer functional and social outcomes (Herrmann *et al.*, 1998; Pohjasvaara *et al.*, 2001) and lower quality of life (Bays, 2001).

Post-stroke depression impacts negatively on rehabilitation, as people with depression show poorer engagement with rehabilitation treatment (Gillen *et al.*, 2001), increased outpatient visits post-discharge (Jia *et al.*, 2006), increased rate of rehospitalisation (Ghose *et al.*, 2005) and greater risk of institutionalisation (Kotila *et al.*, 1999). Additionally, anxiety was found to be associated with reduced social contact, delayed recovery (Astrom, 1996) in activities of daily living and handicap (Sturm *et al.*, 2004).

However, Hadidi *et al.* (2009) criticised many studies for the lack of control for confounding variables. Furthermore, the direction of relationship is unclear. For instance, there is strong evidence that various cognitive difficulties are associated with depression (Mohanty & Heller, 2002) and with anxiety (Barker-Collo, 2007). However, while stroke survivors who are depressed show impaired cognition compared to those who are not depressed (Verdelho *et al.*, 2004), those with cognitive impairment are more likely to develop depression (Nys *et al.*, 2006).

1.3.2.1.3 Etiology of affective disorders after stroke

There is a poor understanding of the factors that trigger and maintain affective disorders after ABI. The etiology is likely to be complex and determined by a combination of factors, including neurologically based changes to cognitive and emotional brain systems, pre-injury factors, psychological adjustment issues and the nature of social and family support (Gracey & Ownsworth, 2012).

Moldover *et al.*'s (2004) ways of conceptualising the etiology of affective disorders, particularly depression, in TBI could also apply to stroke. Thus, depression can be a secondary or neurologically mediated reaction to the brain injury, most common in the first few months and best predicted by the severity of injury and premorbid functioning. Or, a primary affective disorder that typically develops at least six months post-injury, along with the realisation of the limitations resulting from the injury. The latter may be associated with adjustment difficulties, including developing a new identity based on the cognitive, physical and psychosocial changes implicated by the brain injury (Cantor *et al.*, 2005).

1.3.2.1.3.1 Organic etiologies

Neuropathology, for instance damage to areas of the brain that regulate emotions, has been hypothesised as a cause of affective disorders. Post-stroke depression has been typically explained by neurophysiological (e.g. depletion of intra-cerebral neurotransmitters, Gainotti *et al.*, 2001) and anatomical factors (e.g. location of lesion, such as left prefrontal, Lezak *et al.*, 2004; Nitschke & Heller, 2005; Robinson *et al.*, 1983). Further evidence from traumatic brain injury linked depression to neural damage (Jorge *et al.*, 1993; Prigatano & Summers, 1997); especially acute onset depression was linked to left anterior cerebral involvement (Jorge *et al.*, 1993).

However, reviews of studies of post-stroke depression being related to lesion location showed no support for this hypothesis (Carson *et al.*, 2000). Additionally, anxiety does not appear to be consistently related to size or location of lesion either (Bond *et al.*, 1998; Kim *et al.*, 2003).

Furthermore, Fleminger *et al.* (2003) argued that if brain damage were primarily responsible for post-TBI depression then there would be some differences in presentation. Interestingly, the presentation of post-stroke depression was found to

be very similar to that of depression where there was no other physical illness (Cumming *et al.*, 2010) and equally, depression in head-injured and non-head injured individuals (Aloia *et al.*, 1995).

1.3.2.1.3.2 Psychosocial factors

While biological factors, such as discussed above, may contribute to the occurrence of depression after stroke, they are not exclusively responsible.

Premorbid depression or psychiatric illness, dysphasia, functional impairments, living alone, and social isolation have consistently been associated with depression after stroke (Ouimet *et al.*, 2001), as well as divorce, pre-stroke alcohol consumption (Burvill *et al.*, 1997), activities of daily living impairment (Landreville *et al.*, 2009) and locus of control (Thomas & Lincoln, 2006).

Affective distress post-stroke may also be a normal reaction to a major life event and its negative consequences, such as physical and cognitive impairments, reduced or lost ability to work, difficulties with social interactions, discrimination, isolation (Mukherjee *et al.*, 2006). For ABI survivors, life, as previously known to the individual, is lost (Haynes, 1994) and they have to come to terms with tangible losses such as physical health and employment, as well as a perceived loss of control over their life (Tasker, 2003). Therefore, vulnerability to depression in stroke might be related to the recognition of losses (Fleminger *et al.*, 2003).

Other psychological factors have been demonstrated to be involved in adjustment after ABI, and may also be relevant in stroke. Depressed compared with non-depressed TBI survivors reported increased psychological symptoms related more to changes in self-concept (e.g. confidence and self-deprecation) than to somatic markers (Jorge *et al.*, 1993). Also, self-esteem, which is found to be associated with depression, is not only reported as low by TBI survivors, (Anson & Ponsford, 2006), but also appeared as significantly reduced in comparison to retrospectively reported pre-injury levels (Cooper-Evans *et al.*, 2008).

1.3.3 Summary

Stroke is a life changing event, and survivors are left with a range of disabilities, physical and psychological, which impact negatively on the survivors' quality of life.

Anxiety and depression are common emotional consequences after stroke, and can interfere with adjustment and rehabilitation.

However, the etiology of emotional problems post-stroke is unclear. This seems to be complex, partly explained by the neurological changes to emotional brain systems, and also, by issues related to psychological adjustment to a major life event that involves coming to terms with multiple losses, resulting from the cognitive, physical and psychosocial changes implicated by the brain injury.

Amongst other psychological factors, changes in self-concept and self-esteem have also been associated with emotional problems after ABI, generally highlighting a growing area in the literature, which is the concept of identity change or loss following ABI. This is going to be the focus of the next section.

1.4 ABI / STROKE AND IDENTITY

1.4.1 Overview

As pointed out by Ellis-Hill and Horn (2000), although different forms of ABI (e.g. stroke compared to TBI) have slightly different consequences, it can be argued that sense of self is equally likely to be affected due to the sudden changes experienced by survivors in their relationships with their bodies, their family and their community. Indeed, damage to the frontal lobes is common in TBI and is also present following stroke (Mattson & Levin, 1990); this is associated with executive difficulties including self-regulation of emotion and behaviour (Lezak *et al.*, 2004) that can also affect the way survivors think about themselves (Gracey, Brentall *et al.*, 2009, cited in Gracey & Onsworth, 2012). Therefore, the evidence of change in identity following ABI, which comes mostly from TBI, is considered to have relevance for stroke survivors as well, and will be presented alongside evidence from stroke studies.

Life-changing events render people's sense of self fluid (Howard, 2000). Moreover, sudden chronic illness is viewed as disrupting one's predictable life course and so impacting on their identity by producing a biographical disruption (Williams, 2000). Indeed, ABI engenders complex psychological processes with implications for one's

identity and it has been described as a disruption to one's sense of self (Moldover *et al.*, 2004; Muenchberger *et al.*, 2008).

Identity loss following ABI is a growing area in the literature and indeed a commonly reported experience after stroke, due to loss of functional abilities and roles (Ellis-Hill *et al.*, 2000; Salter *et al.*, 2008; Seacrest & Thomas, 1999), manifested as loss of control, uncertainty about the future and social isolation (Haslam *et al.*, 2008; Salter *et al.*, 2008; Teasell *et al.*, 2011).

Loss of identity seems to be a crucial aspect of concern for both ABI survivors (Ben-Yishay, 2008) and their families (Landau & Hissett, 2008). Tyerman and Humphrey (1984) were first to report a significant negative discrepancy between pre and post-injury ratings of self-concept. Now, there is growing evidence that ABI survivors experience a profound change in their current view of themselves compared to pre-injury (Carroll & Coetzer, 2011; Myles, 2004; Nochi, 1997; Wright & Telford, 1996), leading to two images of the self: 'who I am now' and 'who I was before injury' (Cantor *et al.*, 2005).

Similarly, stroke survivors face major psychological and existential challenges to their sense of self (Ellis-Hill, 2000), reporting a 'loss of me', and feeling distanced from their new selves, consequently experiencing their own personhood as strange and unfamiliar (Murray & Harrison, 2004). Moreover, the post-injury views of oneself tend to be more negative; two years on, stroke survivors saw themselves as less active, satisfied, independent or interested, less in control and capable than pre-stroke, and this seems unrelated solely to the severity of the physical symptoms (Ellis-Hill & Horn, 2000). Unsurprisingly, a discrepancy in self-esteem, pre and post-injury, self-esteem being negatively affected after injury, has also been shown in ABI survivors (Cooper-Evans *et al.*, 2008), including stroke survivors (Keppel & Crowe, 2010). Consequently, self-discrepancy leads to discomfort and requires grieving for the lost identity and working towards constructing a new identity (Moldover *et al.*, 2004), which can be a struggle (Morris, 2004).

The aim in this section is to clarify how identity after ABI has been conceptualised, before providing a brief account of the impact of identity change on survivors and those around them. It will then move on to explore the knowledge base pertaining to how brain injury impacts on identity of adult survivors, using a biopsychosocial

framework. Finally, the emerging concept of identity continuity and reconstruction following identity disruption caused by ABI will be discussed.

1.4.2 What is Meant by Identity Change Following ABI

Sense of self or identity has broadly been defined as a construct describing the individuality of a person (Paterson & Stewart, 2002), and plays a central role in how individuals understand themselves and communicate (Muenchberger *et al.*, 2008). It refers to one's internal representation of self, including a representation of self within its social environment (Whitbourne *et al.*, 2002). Identity can usefully be seen as a synthesis between personal identity and social identity, as one's social roles and group memberships contribute to forming and maintaining a sense of self (Gracey & Onsworth, 2012).

Yeates *et al.* (2008) describe "personality" or identity change after ABI as a shift or discontinuity in who the survivor is as a person after the injury compared to who they were before. This is seen as a "subjective discontinuity in their felt, embodied or social experience of who they are" (p.567), and also an observed change by those around, professionals and family alike (e.g. Weddell & Leggett, 2006). As noted by Segal (2010), depending on the theoretical views on the "self", different terms such as "personality", "self-concept", "self-narratives", and "identity" are used in the literature to describe altered personhood following ABI.

As Yeates *et al.* (2008) point out, traditionally, this change has been predominantly explained by the biologically-deterministic account of brain–mind alteration. This is derived from individualist conceptualisations of personality (Eysenck, 1967 cited in Yeates *et al.*, 2008), which assume a direct link between neurological change and changes in personhood. Personality traits are seen as biologically-determined and located in the brain, unique to the individual, and fairly stable in the absence of nonpathological conditions (McCrae & Costa, 1996). Consequently, specific cortical damage is expected to directly alter personality.

However, evidence from social neuroscientists, psychologists and psychosocial theorists challenge this view, arguing for a range of direct and indirect factors, subjective and inter-subjective, that may contribute to the ABI survivors' experience of personality change. Personhood is viewed as heterogeneous and informed by the

wider social context (Antaki & Widdicombe, 1998; Potter & Wetherell, 1987; Tajfel & Turner, 1979 cited in Yeates *et al.*, 2008). Identity thus appears as interactive, developed through social interactions and discourse, and so is fragmented, relative, fluid, and always changing (Benwell & Stokoe, 2006 cited in Wolfenden & Grace, 2012). This leads to new ways of hypothesising personality change after ABI, beyond biological determinism and drawing on psychological and psychosocial explanations, therefore offering a more complex and integrative understanding of this topic.

1.4.3 Impact of Identity Change

Changed conceptions of self (before and after injury) have been shown to be highly distressing, being associated with mental health concerns (e.g. depression, anxiety), which can impact on successful rehabilitation (Cantor *et al.*, 2005), and moreover, can be experienced even despite achievements in significant rehabilitation goals (e.g. work, financial security, mobility) (Cloute *et al.*, 2008). Also, ABI survivors' ability to cope with changes in identity was found to predict anxiety levels (Dewar & Gracey, 2007).

Disruptions to identity have also been shown to be associated with increased difficulties in forming and maintaining social networks (Hoofinen *et al.*, 2003; Engberg & Teasdale, 2004), while maintenance of one's social identity is predictive of well-being following ABI (Haslam *et al.*, 2008). Unsurprisingly, there is an associated lack of positive sense of future and poor quality of life (Cloute *et al.*, 2008); conversely, the development of positive self-identity seems to predict higher levels of quality of life post-injury (Vickery *et al.*, 2005).

1.4.3.1 Impact of perceived change on others

Those around ABI survivors also observe an obvious change in "something" about them (Yeates *et al.*, 2008). Personality change defined by significant others is also related to clinical outcomes. Cross-sectional and longitudinal outcome studies showed relatives' ratings of personality change post ABI to better predict their burden or stress than cognitive or physical changes (Brooks *et al.*, 1987; Oddy *et al.*, 1978; Weddell & Leggett, 2006).

1.4.4 How Brain Injury Impacts on Identity of Adult Survivors

Previously, Yeates *et al.* (2008) used a biopsychosocial framework to investigate identity change following ABI. This was later adopted by Segal (2010) in his review on the same topic, and will also be employed here as it seems a useful way of incorporating the diverse perspectives on the matter, which were highlighted above. This section is based on the work of Yeates *et al.* (2008) and Segal (2010); while the focus will be on stroke, the wider ABI literature will be drawn on to enhance understanding.

1.4.4.1 Biological accounts

Damage to specific prefrontal cortical areas has been associated with lack of social insight, altered emotional processing, disinhibition and euphoria, which are challenging to sustaining social relationships (Mathiesen & Weinryb, 2004; Namiki *et al.*, 2008).

Moreover, particular cortical areas seem linked to socio-affective processes, such as aligning to another's experience and connecting (Segal, 2010). For instance, in a dyadic encounter, inferior parietal and anterior cingulate networks seem to be involved in the complex processes of predicting the other's intentions, aligning to their subjective experience, and influencing their subjectivity and behaviour (Yeates *et al.*, 2008).

Damage to frontal lobes and the limbic system seems to affect one's perceptions of their internal emotional experiences (Blair & Cipolotti, 2000; Park *et al.*, 2001) and their experiencing and expressing empathy (Lezak *et al.*, 2004).

Personality change has also been linked to memory impairment. While in retrograde amnesia, the loss of an autobiographical memory can disrupt the person's narratives about themselves, anterograde amnesia can prevent the construction of new narratives (Yeates *et al.*, 2008). Indeed, ABI survivors who experienced gaps in short or long-term memory found it difficult maintain a coherent and continuous narrative of their experience Nochi (1998).

1.4.4.2 Psychological accounts

Segal (2010) noted that there is a wealth of literature on psychological models of change following ABI, with several terms, such as changes in ego, self-concept, self-schemas, and self-constructs, being used to describe this. However, all acknowledge that a change in the subjective processing of information about oneself directs how the self is experienced (Yeates *et al.*, 2008).

1.4.4.2.1 Cognitive-behavioural approaches

1.4.4.2.1.1 An interacting cognitive subsystems account

As noted by Segal (2010), Ylvisaker and Feeney's (2000) provided one of the first cognitive accounts of self-concept changes after ABI, albeit supported only by anecdotal evidence and case studies. Based on an interacting cognitive subsystems approach, they proposed that people construct schematic mental models of the self through cognitive processes that are based on the association of recurring experiences and their accompanying emotions and behaviours. Changes in self-concept are seen to occur when novel constructions of models of the self are generated automatically by stimuli that are associated with negative emotional states and socially adverse behaviours. Consequently, the biological changes caused by brain injury lead to altered self-coding, which can account for changes in self-conception.

1.4.4.2.1.2 A relational frame theory account

Myles (2004) expanded Ylvisaker and Feeney's (2000) investigation of the "self", by proposing Relational Frame Theory (RFT) (e.g. Hayes, 1994 cited in Myles, 2004), a modern behavioural approach to language and cognition, as a framework for understanding the loss of sense of self after brain injury.

According to RFT, language and cognition facilitate humans to readily derive arbitrary relations between events (e.g. Hayes, 1994 cited in Myles, 2004). From a RFT perspective, there are three distinct senses of self (Myles, 2004):

The *conceptualised self* is seen as the network of relations between one's behaviours and a range of verbal categorical concepts repeatedly applied to these.

This is similar to Ylvisaker and Feeney's (2000) description of the "self-concept", as mental representations of "self" are seen as constructed based on the relationship between one's experiences and their interpretations, resulting in a cohesive self-conception (Segal, 2010).

Self as ongoing process of verbal knowing (self-awareness) refers to one's private subjective experiences comprising of thoughts, emotions, and memories.

Self as the context for verbal knowing develops in early childhood together with an own sense of perspective, distinguished from others'. It refers to the stable viewpoint from which one experiences the world, independent of the nature of the content of their ongoing flow of subjective experience.

The conceptualised self is seen as dominating over the other two selves, as normally, people identify with their psychological content rather than the context from which this is experienced.

Myles (2004) argued that ABI involves a "crisis of the conceptualised self" (p. 494), which leads to "loss of self". This is seen as a verbal and relation process where the survivor is consciously aware of inconsistencies between post-injury functioning and pre-injury conceptualised self, which makes them experience themselves as "not the same". If the pre-injury self-concept is positively evaluated, changes in functioning that are inconsistent with it are likely to lead to negative evaluations, both of those changes and of the resulting new self-concept. This could then lead to emotional distress and denial (Myles, 2004).

Although only anecdotal evidence and case studies from clinical practice were used to support Myles' (2004) claim, he provided a theoretical basis for changes in self-concept following ABI (Segal, 2010).

Myles' (2004) claims are consistent with Cantor *et al.*'s (2005) adaptation of Higgins' (1987) self-discrepancy theory, which proposes that emotional distress following loss of self is due to tensions between pre-injury and post-injury conceptions of self.

1.4.4.2.2 Constructivist approaches

1.4.4.2.2.1 A personal construct psychology account

In a qualitative study with 32 ABI survivors, Gracey *et al.* (2008) employed a personal construct psychology (PCP) approach (Kelly, 1955, cited in Gracey *et al.*, 2008), concerned with meaning making processes as central to experiences of personhood, to understand how survivors make sense of, or construe, themselves post-injury.

According to PCP, through repeated interaction with the world we derive dichotomous constructs (e.g. love - hate) that we then apply to new experiences in order to make sense of them. Similarly to the previous accounts, people make sense of themselves through mental interpretations of their experiences, but with emphasis on contrasts between concepts as crucial in the meaning making process (Segal, 2010).

In their study, Gracey *et al.* (2008) elicited bipolar constructs through systematic comparison of pre-injury, current and ideal selves. Most constructs fell into the theme “experience of self in the world”, followed by “basic skills” (cognitive, sensory, physical, social) and “experience of self in relation to self”. Survivors seemed to make sense of themselves in terms of personal meanings and feelings associated with social and practical activity, such as belonging, capability, the extent to which activities “reinforce who I am”, or how activities make someone “feel part of things”.

1.4.4.2.2.2 A phenomenological account

In a phenomenological qualitative study with TBI survivors, Muenchberger *et al.* (2008) highlighted the profound disruptions to “self” following injury and provided a broader conceptual understanding of the reconstruction of self, seen as a cyclical and ongoing process. Like Gracey *et al.*'s (2008) study this was also about individual meaning and the changes in self-construction over time (Segal, 2010).

According to Muenchberger *et al.* (2008), following injury the self goes through a dynamic process of identity transition, characterised by fluctuations between inter-dependent phases of contraction and expansion of self and tentative equilibrium. These interactions are seen as cyclical and continuous.

Contraction of self seemed the result of the self being under internal and external pressures to conform to a desired state, with limited scope for individualisation, creativity or opportunity for developing self-confidence. Identity contraction involved experiencing a severed sense of personal history, a focus on daily functioning, reliance on others and a sense of being different to before the injury.

Expansion of self was characterised by feelings of being given a second chance at life, thus the focus was on redefining life goals in the pursuit of a different life role. This was accompanied by a greater sense of perspective in coping with the injury, better acceptance of change, interdependence and working towards goals.

A *state of tentative equilibrium* seemed to accompany the oscillation between contraction and expansion of the sense of self. This was explained by the concept of liminality, used previously in cancer and chronic illness research to understand identity reformation (Little *et al.*, 1998; Forss *et al.*, 2004, as cited in Muenchberger *et al.*, 2008), which refers to a state of being in 'limbo' and suspension between former and future states, similar to the void state described by Nochi (1997) below. This was characterised by self-doubt and a sense of fragile progression, an uneasy sense of past, present and future and tensions relating to compliance and need for control.

1.4.4.3 Psychosocial accounts

From a social constructionist perspective, identity is seen as inter-subjective and relational, co-constructed through language, knowledge, processes of interpretation; the self-concept is seen within the realm of social discourse (Gergen, 1985 cited in Segal, 2010). Consequently, all accounts of a self are better understood within the relationships and wider culture in which one is embedded.

Indeed, there is increasing recognition of the multiplicity of factors involved in constituting the self, with a growing literature exploring the role of language, social meanings and discourses in understanding changes to personhood post-injury. In what follows an overview of the relevant work in this area is presented.

1.4.4.3.1 A narrative account

For social scientists, self is defined by the meaning that the individual and others attach to it (Markus & Wurf, 1987; Mead, 1934, cited in Hinojosa *et al.*, 2008), being constructed through the stories that people tell about themselves (Kelly & Dickinson, 1997). This is reflected in Ellis-Hill *et al.*'s (2007) Life Thread Model of acquired disability, based on stroke; identity and sense of self are seen as the combination of the many life threads or stories of oneself, memories and future plans, that constitute one's life-story (McAdams, 1990, cited in Ellis-Hill *et al.*, 2007). These threads or stories establish a sense of coherence and stability, creating continuity between past and future, which is seen as essential for well-being (Ellis-Hill *et al.*, 2007). While self-definitions do change, as new resources for self-construction emerge or as familiar ones are no longer available (Charmaz, 1991, as cited in Hinojosa *et al.*, 2008), this happens slowly, allowing individuals to incorporate the new narratives (McAdams 1993, as cited in Hinojosa *et al.*, 2008). However, in the case of illness or disability, changes may be too rapid to be incorporated efficiently, which can cause a disruption of self (Charmaz, 2002).

Furthermore, Hinojosa *et al.* (2008) argue that in the context of illness, the body, which is an important resource for self-construction (Gubrium & Holstein 2003; Shilling, 2003, as cited in Hinojosa *et al.*, 2008), requires reinterpretation. Thus, stroke can be seen to disrupt one's self-construction by changing one's taken-for-granted experience of the body (Hinojosa *et al.*, 2008). Indeed, the related impairments were shown to affect young stroke survivors perception of their body, forcing them to review their self-concept (Kaplan & Cerullo, 1986, cited in Keppel & Crowe, 2010). Consequently, constructing identities in the same way as pre illness is difficult (Charmaz, 1995) as previous ways of understanding oneself and one's position in the world are challenged, and rendered no longer relevant; thus new explanatory frameworks are needed (Bury, 1982).

Examining the self-narratives of ABI survivors, Nochi (1997, 1998, 2000) revealed their reliance on the broader social contextual dimension. Initially, Nochi (1997) identified a "void" in many survivors' self-narratives as a result of problems recalling their accidents and parts of their recovery, which interferes with self-understanding and leads to "a real crisis of the self" (p. 18). Nochi (1998) later identified three

aspects of “loss of self” following ABI, two of which, loss of self in relation to pre-to-post-injury comparison and discontinuity of identity through lost or disrupted memories, support the work mentioned earlier. The third, loss of self in the eyes of others, emphasises the importance of other people’s views concerning identity change. Indeed, relations were found between perceived personality change and emotional disorder in carers of stroke survivors (Stone *et al.*, 2004). Finally, Nochi (2000) concluded that the reconstruction of coherent self-narratives is facilitated through social interaction, through reorganizing interpersonal relationships and environments to support newly developing and preferred self-narratives.

1.4.4.3.2 A social identity account

Drawing on social identity theory (Tajfel & Turner, 1979), which emphasises the importance of social continuity in maintaining well-being, Haslam *et al.*’s (2008) quantitative study showed that maintaining group membership predicted well-being after a stroke, possibly by increasing the likelihood of coping with and adjusting to change. This highlighted the importance of preserving social identity in neuropsychological rehabilitation, alongside personal identity. Furthermore, qualitative accounts of stroke survivors revealed that family, social and community resources can enhance participation in personally meaningful activities, through social positioning and respectful social relationships (Anderson & Whitfield, 2013). This emphasises the important role social relationships play in helping survivors maintain or regain a position in society and so develop a positive post-stroke identity despite impairments.

1.4.4.3.3 A social discursive account

Using discourse analysis, a social constructionist methodology, Cloute *et al.* (2008) showed how identity following TBI is co-constructed through the language and interactions from dominant medical services. The medical discourse influenced how survivors understood themselves, for instance, as sick, passive and dependent, with little scope for alternative constructions.

In another discourse analytic study, Guise *et al.* (2010) showed that young stroke survivors have to negotiate their identities and attend to related interpersonal issues when accounting for change in self after having acquired a ‘damaged’ identity due to

the stroke. While minimising the negative aspects of stroke and mitigating its implications on their identity, participants were sensitive to how these accounts were perceived by their carers (i.e. not inappropriately positive), who could criticise and challenge them, and offer potentially negative reformulations of these. This suggested some difficulty in maintaining a positive sense of self on the part of the stroke survivors, particularly in the presence of their carers who can play a role in maintaining damaged identities, thus further emphasising how identity-constructions can be influenced in interactions with others.

To summarise, an overview of the diverse epistemological understandings of the impact of ABI on one's sense of self or identity has been provided; this incorporated the biological, psychological and social domains involved in the experience of identity change following ABI. A shift in the way this challenge to identity is conceptualised has been noted, from a psychosocial perspective, which is going to be discussed in the next section.

1.4.5 From Identity Disruption Toward Identity Reconstruction and Continuity

Identity continuity after brain injury (Gracey *et al.*, 2008; Haslam *et al.*, 2008; Hinojosa *et al.*, 2008) is emerging as a key concept, which normalises disruption and emphasises re-construction and desire to achieve continuity, rather than solely focusing on loss and adjustment to loss (Wolfenden & Grace, 2012). Nochi (2000) showed that ABI survivors are not just 'accepting' their injuries with their life implications, rather they revise their self-narratives. Furthermore, in a small qualitative study, Wolfenden & Grace (2012) showed that, while managing biographical disruption, young, higher functioning stroke survivors actively pursued identity re-establishment, for which resumption of life roles and responsibilities were important.

Hinojosa *et al.* (2008) argue that constructing continuity is possible because self is multifaceted (Mead, 1934 cited in Hinojosa *et al.*, 2008) and can be defined in various ways (Markus & Wurf 1987), with many selves being possible, depending on the context and the resources for self-construction used (Giddens, 1991, cited in Hinojosa *et al.*, 2008). Thus, if a favoured identity is threatened by illness one way of constructing continuity would be by focusing on identities that remain unaffected (Hinojosa *et al.*, 2008). This was showed in a study with female stroke survivors

(Kvigne *et al.*, 2004), where although some identities (e.g. being an employee) were compromised, other valued self-constructions (e.g. mother, grandmother, housewife) were preserved, thus facilitating some continuity of the familiar pre-illness self. Later, in a study of narratives of 122 stroke survivors at one month post-stroke, some managed the stroke through their use of discursive resources that remained personally accessible following stroke, such as expectations for aging and religious beliefs, thus enabling them to construct stories of self-continuity (Hinojosa *et al.*, 2008).

Consequently, identity re-construction post-stroke, and indeed any acquired disability involving a sudden and dramatic life change, is seen as a magnification of normal processes rather than an abnormal process (Ellis-Hill *et al.*, 2007). Re-establishing identity presupposes retaining and restoring some life threads while replacing others. However, Ellis-Hill *et al.* (2007) also emphasise the role of others in facilitating this process, in terms of endorsing a positive view of self, and viewing acquired disability as a time of transition rather than simply of loss.

1.4.6 Summary

ABI / stroke can impact on people's sense of who they are, changing how they see themselves, as it seems to cause a discontinuity in who the person is. This can be distressing for both survivors themselves and those around them, and has been explained in various ways.

Traditionally, identity change following stroke would be explained by a biological account, derived from individualist conceptualisations of personality such as Eysenck's (1967), whereby specific cortical damage is expected to directly alter personality. Conversely, psychological and psychosocial accounts argue for a wide range of factors, subjective and inter-subjective, contributing to the stroke survivor's experience of change in personhood, which is seen as heterogeneous and embedded in and informed by the wider social context.

Most accounts of stroke's impact on the survivor's identity imply a biographical disruption, much like in any sudden chronic illness. However, the concept of identity continuity has been emerging recently, to normalise biographical disruption and

emphasise re-construction of identity, which is facilitated by the view of self as multifaceted, allowing for some aspects of the self to be preserved.

If people's view of themselves changes after stroke, especially if the change is negative, it would follow that their self-esteem would be affected. Self-esteem will be considered in the next section.

1.5 SELF-ESTEEM

Self-esteem or a global judgement of self-worth refers to a personal evaluation of the self, positive or negative, representing a reflection of how people experience themselves (Rosenberg, 1965; 1979). As noted by Cooper-Evans *et al.* (2008) self-esteem has been used interchangeably with self-concept (Guindon, 2002; Strein, 1993). While the latter refers to how one views and experiences themselves (Tajfel & Turner, 1979), the former is the emotional valence of this view; self-concept refers to what one thinks about themselves while self-esteem to how one feels about themselves (Brown, 1998). However, as pointed out by Cooper-Evans *et al.* (2008), both have been associated with similar clinical outcomes, and are considered to be strongly related in both general and ABI populations (Kravetz *et al.*, 1995; Man *et al.*, 2003; Vickery *et al.*, 2005).

Self-esteem was shown to be relatively stable during adulthood except at times of acute crisis (Trezesniewski *et al.*, 2003). Indeed, as people's views of themselves change following ABI (Carroll & Coetzer, 2011; Tyerman & Humphrey, 1984; Wright & Telford, 1996), including stroke (Ellis-Hill & Horn, 2000) (see systematic review 1.7), this would be expected to affect their self-esteem. Conversely, a change in self-esteem might be indicative of a change in self-concept.

1.5.1 Self-Esteem and ABI

ABI has been shown to impact negatively on survivors' self-esteem (Curran *et al.*, 2000; Kravetz *et al.*, 1995). As the body is a relevant resource for self-construction (Gubrium & Holstein 2003; Shilling, 2003 cited in Hinojosa *et al.*, 2008) it is unsurprising that body image and self-esteem are at risk following critical neurological events (Keppel & Crowe, 2000). Young adults' self-reported body image

was significantly negatively affected post-stroke compared with retrospective ratings, and this was associated with significantly lowered self-esteem (Keppel & Crowe, 2000). Later, Howes *et al.* (2005) found that both body image and self-esteem were significantly lower among female ABI survivors when compared with a control group.

1.5.2 Self-Esteem and Clinical Outcomes in ABI

Self-esteem is at the centre of psychological theories of depression, the level of self-esteem being related to the development and course of depression (Grubb *et al.*, 1993). Low self-esteem has been consistently shown to correlate significantly with affective disorders in both acutely (Weir *et al.*, 1995) and chronically (Outland & Coonerty, 1995) disabled populations.

A number of studies showed associations between low self-esteem and increased psychological distress following ABI (e.g. Cooper-Evans *et al.*, 2008; Curran *et al.*, 2000; Howes *et al.*, 2005; Keppel & Crowe, 2000; Kravetz *et al.*, 1995; Man *et al.*, 2003). In a series of studies using large samples of stroke survivors, Vickery and colleagues (Vickery, 2006; Vickery, Sepehri, Evans *et al.*, 2008; Vickery *et al.*, 2009) showed both the level and the stability of self-esteem to be associated with post-stroke depression, in acute and rehabilitation settings. Also a negative self-concept has been found to be related to depression and anxiety (Vickery, 2006).

Furthermore, high rates of psychological distress among ABI survivors have been shown to impact seriously upon long-term rehabilitation outcomes (e.g. Hibbard *et al.*, 1998; Morton & Wehman, 1995; Wallace & Bogner, 2000).

In the next section the self-discrepancy theory (Higgins, 1987) will be introduced, which provides a model of how the relative congruence or lack of congruence between aspects of identity might explain affective distress. This might be a useful model in explaining affective distress after brain injury as related to discrepancies between pre-injury and post-injury selves as shown by Cantor *et al.* (2005) in a pilot study with TBI survivors (see section 1.6.1.1 below).

1.6 THE SELF-DISCREPANCY THEORY (SDT)

Higgins (1987) proposed the self-discrepancy theory to describe how certain conflicting beliefs about the self, termed “self-discrepancies”, relate to emotional states such as depression and anxiety.

According to this model there are three basic domains of the self. The *actual self* is a representation of the attributes one believes to actually possess; the *ideal self* is a representation of the attributes one would ideally like to possess; finally, the *ought self* is a representation of the attributes one thinks they ought to or should possess. While the *ideal* domain is a representation of one’s hopes, aspirations and wishes, the *ought* domain is a representation of one’s sense of duty, obligations and responsibilities.

Furthermore, there are two standpoints on the self, one’s own personal standpoint and one’s significant other’s standpoint. Combining one domain of the self (actual; ideal; ought) and one standpoint on the self (own; significant other) there result six basic types of self-state representations: actual/own, actual/other, ideal/own, ideal/other, ought/own and ought/other. These are summarised in Table 1.1 below.

Table 1.1: Self-state representations according to Higgins’ model of self-discrepancy

	Actual	Ideal	Ought
Own	Self-concept	Self-guide	Self-guide
Other	Self-concept	Self-guide	Self-guide

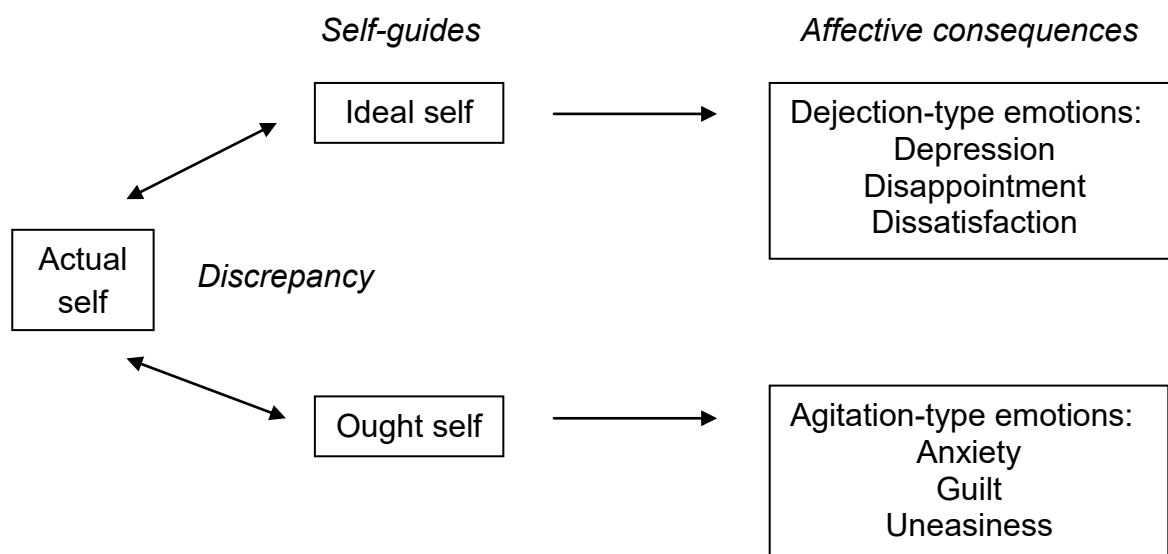
The first two self-state representations, particularly actual/own, represent what is typically referred to by “self-concept” in social psychology, meaning one’s perception of themselves and the attributes they possess. The other self-state representations, involving the domains of ideal and ought selves, are self-directed or acquired, internalised standards for behaviour, termed “self-guides” (Higgins, 1987).

According to this theory, people are especially motivated to meet either one or both of these self-guides. Furthermore, the aim is to reach a condition where the self-concept matches the personally relevant self-guide(s). Therefore, inconsistencies

between one's self-concept (i.e. actual self) and their self-guides (ideal or ought) are thought to lead to emotional discomfort. These incompatible beliefs are cognitive constructs and thus they can vary in both their availability and their accessibility. Construct availability refers to the particular kinds of constructs that are actually present/available in memory to be used to process new information; whereas construct accessibility refers to the readiness with which each stored construct is used in information processing (Higgins & Bargh, 1987; Higgins *et al.*, 1982). Individual differences are thought to arise because people have different constructs available and/or because their relative accessibilities are different.

Furthermore, each type of discrepancy is seen to reflect a particular type of negative psychological situation that is associated with specific emotional problems (see Figure 1.1 below):

Figure 1.1: Higgins's (1987) Self-Discrepancy Theory



The theory postulates that the psychological consequence of discrepancies between perceptions of the actual self and the ideal self is going to be the absence of positive outcomes (actual or expected); this is associated with dejection-type emotions such as disappointment and dissatisfaction, as the person believes their hopes and wishes have not been fulfilled. Thus this leads to depressive states. Consequently, according to this theory, discrepancies between actual and ideal self make one vulnerable to depression (see Figure 1.1 above).

Additionally, the psychological consequence of discrepancies between the actual self and the ought self is going to be the presence of negative outcomes (actual or expected); this is associated with agitation-type emotions such as guilt, self-contempt and uneasiness, as the person believes to have contravened a personal moral standard. Thus this leads to anxious states. Consequently, according to this theory, discrepancies between actual and ideal self make one vulnerable to anxiety (see Figure 1.1 above). From this, it also follows that the greater the extent of a self-discrepancy the more one experiences the emotional distress associated with that particular discrepancy.

In order to measure self-discrepancies, Higgins *et al.* (1985) devised the Selves Questionnaire, which asks participants to list up to 10 traits or attributes for each of a number of different self-states. For example, it asks participants to list the attributes of the type of person they believe they actually are, the qualities of the person they believe they ought to be and the qualities of the person they would ideally like to be. It is administered in two sections, one involving the respondent's own standpoint and the other involving the standpoint of a respondent's significant other (parent, closest friend). The attributes were then compared to see how many matched and a discrepancy score was calculated by subtracting number of matches from number of mismatches. It was considered that spontaneously listing attributes associated to self-states increased the likelihood that the elicited attributes would be important and accessible. Although the Selves Questionnaire has been commonly adopted by researchers (Cornette, 2009; Fairbrother & Moretti, 1998; Scott & O'Hara, 1993), some criticised it (Rodebaugh & Donahue, 2007; Tangney *et al.*, 1998) suggesting that it actually taps into a generalised self-discrepancy that does not demonstrate the relations proposed by Higgins (1987), as they found no support for specific discrepancy-emotion relations. Others also found this, and they subsequently adapted and modified it (e.g. Crane *et al.*, 2008; Strauman *et al.*, 2001).

1.6.1 Empirical Evidence

Several studies provide empirical support for the self-discrepancy theory, attesting that different types of self-discrepancies are linked to depression and anxiety (Higgins, 1987; Higgins *et al.*, 1985; 1986). Furthermore, the extent of the self-

discrepancy has been shown to predict the level of emotional distress (Higgins *et al.*, 1985).

The initial support came from a number of studies on non-clinical populations (e.g. Higgins *et al.*, 1985; 1986). Several studies followed applying this model to affective distress in clinical samples, both psychological and physical health problems. For instance, Fairbrother and Amoretti (1998) and Scott and O'Hara (1993) reported that participants with depression had larger actual/ideal self-discrepancies than controls, and those with anxiety showed larger actual/ought self-discrepancies.

Self-discrepancies and emotional distress were shown to be related in individuals with chronic lower back pain (Kinderman *et al.*, 2011; Waters *et al.*, 2004), cancer (Heidrich, *et al.*, 1994) and brain injury (Cantor *et al.*, 2005). Furthermore, Waters *et al.* (2004) found that the actual/ideal self-discrepancy predicted 14% of the variance in depressive symptoms. Self-discrepancies were also correlated with body dissatisfaction/disordered eating and emotional distress in female and male undergraduates (Strauman *et al.*, 1991).

However, a large study which addressed several limitations of previous supporting research failed to support the distinctiveness of actual/ideal and actual/ought self-discrepancies relating to particular types of emotional distress (Phillips & Silvia, 2010). They showed that discrepancies between ideal and actual self seem to predict depression but discrepancies between ought and actual self predict both anxiety and depression.

1.6.1.1 SDT and affective distress in ABI

While the Self-discrepancy theory is a framework designed to explore inconsistencies within a person's self belief system, it is not a theoretical account of self-concept change after brain injury. However, the 'inconsistency' that occurs following ABI between one's pre-morbid and post-injury sense of self, can be fitted into the SDT model.

Indeed, in a pilot study with community-living individuals with mild to severe TBI, Cantor *et al.* (2005) expanded Higgins' (1987) theory by introducing the pre-injury self and post-injury self, and found that emotional distress following loss of self was significantly related to tensions between pre-injury and post-injury conceptions of

self. Their view (Cantor *et al.*, 2005) was that discrepancies between the pre-injury self (i.e. former actual self) and the post-injury self (i.e. current actual self) would be similar to discrepancies between the actual and the ideal self or the actual and the ought self, proposed by the SDT, in that the pre-injury self becomes idealised and thus leading to discrepancies with the actual self.

Cantor *et al.* (2005) also tested the original SDT model and showed relationships between self-discrepancies and affective distress; however, the distinctiveness of actual/ideal and actual/ought discrepancies relating to depression and anxiety respectively, as would be predicted by the model, was not supported.

1.6.2 Implications for the Treatment of Affective Disorders

Higgins *et al.* (1987) point out that the theory is not proposing that all affective distress is associated with self-discrepancies, instead chronic self-discrepancies between self-concept and self-guides represent one set of predictors of depression and anxiety. This has some implications for clinical treatment, which is seen to involve better alignment of self-guides and self-concept. To achieve this, the authors envisaged cognitive-behavioural therapy, or a behavioural or environmental approach that reduces clients' exposure to situations associated to their problems (Higgins *et al.*, 1987). Later, Strauman (2003) developed self-system therapy, a treatment for affective disorders by reducing one's self-discrepancies, which was shown to be more effective than traditional cognitive-behavioural therapy in individuals with DSM-IV-defined mood disorders, who had actual/ideal discrepancies (Strauman, Vieth, Merrill *et al.*, unpublished observation, 2005 cited in Cantor *et al.*, 2005). Interpersonal Psychotherapy (Strauman *et al.*, 2001) and Mindfulness Based Cognitive Therapy (Crane *et al.*, 2008) were also found to decrease self-discrepancies in people with depression.

1.6.3 Critical appraisal

The SDT is an established model that has been widely tested and supported, and has descriptive, explanatory and predictive power. The theory describes three distinct domains of the self (actual, ideal and ought) and explains psychological distress as resulting from conflicting beliefs about the self, as people compare themselves (i.e. their self-concept) to internalised standards (i.e. their self-guides).

More specifically, the theory predicts which specific negative emotions (anxiety or depression) may be related to certain types of incongruent ideas between representations of the self. Furthermore, this also confers the theory intervention power as it can have direct implications for clinical treatment of affective disorders, since they are seen, at least in part, as the result of discrepancy between self-concept and self-guides; thus the SDT provides a means to systematically reduce negative affect associated with self-discrepancies by reducing the discrepancies, either by adjusting the self-concept or the self-guides.

The SDT has the advantage that its key concepts are operationalisable which has enabled their measurement and so the theory could be tested, which led to a great deal of empirical evidence, as discussed in section 1.6.1 above. However, the theory is only partially supported as some research failed to support the distinctiveness of actual/ideal and actual/ought discrepancies relating to particular types of emotional distress (Phillips & Silvia, 2010; Tangney *et al.*, 1998). Although the SDT has not been applied in stroke populations, it has been tested on a small sample of TBI survivors. However, the distinctiveness of actual/ideal and actual/ought discrepancies relating to depression and anxiety, respectively, was not supported in this case.

It is recognised that the SDT has not been developed as a model of explaining psychological distress in relation to identity change after brain injury, and thus it does not address discrepancies between views of the *current* actual self and *pre-injury* actual self. Although not a theoretical account of self-concept change after brain injury either, the RFT-based conceptualisation of three distinct senses of self (*self as an ongoing verbal process of verbal knowing, self as context and the conceptualised self*; see section 1.4.4.2.1.2) was proposed by Myles (2004) as a framework for understanding and treating loss of sense of self following brain injury. He explained identity change as a crisis of the 'conceptualised self' due to inconsistencies between post-injury functioning and pre-injury conceptualised self. Of the models of identity change after brain injury, Myles' (2004) RFT-based account, is the only one that refers to psychological distress as a result of a change in identity; this is seen as resulting from the relations between changes in functioning and the negative self-evaluations of these, as, according to RFT, humans, through language and

cognition, readily derive arbitrary relations between events (e.g. Hayes, 1994 cited in Myles, 2004).

The other two RFT-based senses of self represent a therapeutically useful idea, as it can help survivors separate their subjective experiences (i.e. 'self as ongoing process of verbal knowing'), which, although painful, are transient, from a more enduring sense of self that is not dependent on the nature of the content that comprises one's ongoing flow of psychological experiences (i.e. the viewpoint from which the world, including painful experiences, is experienced – 'self as context'). However, this is a philosophical proposition; 'self as context' is an abstraction based on the idea of transcending the subjective experience with which one identifies one's self. This is conceptual as one can never be an 'objective' observer of one's own experience; it is not possible to transcend from this because this is the only filter through which one can observe and experience the world. Having said this, the concept of 'self as context' can be helpful in creating a sense of consistency between the pre-injury self and the perceived post-injury self. Thus, it may be pragmatic and therapeutically useful, as indeed it has been shown in therapeutic work with people with TBI. However, unlike the SDT, it is not something that can be measured or tested, and the evidence is coming from case studies from clinical experience.

Clearly, both theories view sense of self as multifaceted and complex, and both the SDT and Myles' account agree that a discrepancy or inconsistency within the sense of self construct can lead to psychological difficulties. However, while Myles only discusses one discrepancy (pre- and post-injury), and that this leads to emotional distress generally, the SDT has the advantage that it also postulates how inconsistencies can lead to distress, and how different types of emotional distress are the product of different discrepancies between the self domains. By extending the SDT to include a pre-injury self, Cantor *et al.* (2005) proposed that it may provide a useful way of explaining affective distress after ABI as partly due to changes in identity. Cantor *et al.* (2005) hypothesised that the discrepancy between pre-injury self and current self would be similar to the discrepancy between actual and ideal, or actual and ought, and thus resulting in depression and anxiety. Thus the pre-injury self could be now seen as representing the new standards of behaviour or self-guides.

This would be plausible, as the functional consequences of ABI may make it difficult for survivors to fulfil their duties and obligations in the same way as before, which would contravene the principles constituting their ought self-guide; this would lead to discrepancies, and so to the presence of negative outcomes (actual or expected), experienced as an impending sense of punishment, and manifested as agitation and anxiety. Equally, the consequences of the injury may prevent people achieving their hopes and aspirations, which would thus lead to discrepancies with their ideal self-guide; this is linked to the absence of positive outcomes (actual or expected) as people may feel they lost or will never obtain a desired goal, and so will experience dejection and disappointment, manifested as depression. Indeed, there is evidence that the pre-injury self might be idealised, as TBI survivors rated their pre-injury self more positively overall than they rated a typical person of same age and sex (Tyerman & Humphrey, 1984); also, a comparison group rated their past self significantly lower than a TBI group, yet the ratings of the two groups were not significantly different for present or future self (Wright & Telford, 1996) (see systematic review), again, suggestive that survivors may idealise their pre-injury self.

To summarise, compared to models of identity change after ABI, the SDT is operationalisable, has explanatory and predictive power, and is supported by empirical evidence; not only does it relate inconsistencies between different types of self to psychological distress, but by adapting it to include the discrepancy between post-injury and pre-injury selves (similar to Myles' conceptualisation of identity change after ABI – the crisis of the conceptualised self), it may also provide a useful way of understanding the psychological mechanisms by which distress after ABI occurs, as described above.

1.6.4 Conclusion

Affective disorders are highly prevalent in stroke, with identity change being a possible etiological factor in affective distress, there being some evidence that changes in self-concept are related to affective distress (Ellis & Horn, 2000), as discussed earlier in this chapter. Consequently, the current study aimed to explore this relationship between changes in self-concept and affective distress after stroke in a systematic way. Given the rationale provided in this section, and building on Cantor *et al.*'s (2005) pilot study, it was considered that the SDT would be an

appropriate model to use and explore further, providing the adaptation proposed by Cantor *et al.* (2005) of including a pre-injury self.

1.7 SYSTEMATIC REVIEW

In this section, a systematic review of the evidence for self-discrepancy following ABI, i.e. of difference between pre-injury and post-injury self, will be presented.

1.7.1 The Aim and Scope of the Current Systematic Review

The studies that investigated the difference in self-concept/identity or self-esteem* following ABI, and met the inclusion and exclusion criteria, were reviewed with respect to their aims, the samples included in the studies, methodology, their findings, and the strengths and limitations of the research.

*Studies looking at a change in self-esteem were included as it was considered that a change in self-esteem after ABI would be indicative of a change in self-concept/identity.

1.7.2 Systematic Review Question

Do survivors perceive/experience a difference in their self-concept/identity after ABI? And if so, is there a relationship between this difference/change and affective distress?

1.7.3 Method

1.7.3.1 Systematic review strategy

To locate relevant studies, the following electronic bibliographic databases were searched Cardiff University Full Text Journals, AMED, Embase, MEDLINE, PsycINFO, PsycArticles, up until 6th May 2014.

1.7.3.2 Search terms

The following search terms were used in each of the above databases.

Search terms for ABI included 'brain injury' and the following specific search terms for stroke: stroke, CVA, cerebral vascular accident, cerebrovascular accident,

cerebral haemorrhage, cerebral infarct, brain haemorrhage, brain ischemia, intracranial haemorrhage, intra-cranial haemorrhage. The search terms for stroke were then combined using Boolean operator 'OR' to give overall topic results for: Stroke (Topic).

Search terms for identity included: identity, self-concept, self concept, sense of self, self-discrepancy, self discrepancy, self-image, self image, self-esteem, self esteem, (personality AND change). These were then combined using Boolean operator 'OR' to give overall topic results for: Identity (Topic).

Identity (Topic) was then combined with Stroke (Topic) and with 'brain injury', respectively, using Boolean operator 'AND'. The results are detailed in Table 1.2 below.

Table 1.2: Systematic literature search results

Search Terms	Articles Retrieved	Articles Reviewed
1) (stroke OR CVA OR "cerebral vascular accident" OR "cerebrovascular accident" OR "cerebral haemorrhage" OR "cerebral infarct" OR "brain haemorrhage" OR "brain ischemia" OR "intracranial haemorrhage" OR "intra-cranial haemorrhage").ti.	170750	
2) brain injury.ti.	52652	
3) (identity OR self-concept OR "self concept" OR "sense of self" OR self-discrepancy OR "self discrepancy" OR self-image OR "self image" OR self-esteem OR self esteem).ti.	75649	
4) (personality AND change*).ti	3176	
5) Combined 3 OR 4	78816	
6) Combined 1 AND 5	96 (39*)	4
7) Combined 2 AND 5	163 (83*)	3

*Number of articles left after removing duplicates

1.7.3.3 Inclusion and exclusion criteria

The following inclusion and exclusion criteria were used to select relevant studies to address the review question.

Inclusion criteria:

1. Must be an empirical study
2. Participants must be adults (age 18 and over)
3. The article must be in English

4. The study must be about survivors' perceived difference in self-concept/identity, or self-esteem, post-stroke / ABI compared to pre-stroke / ABI
6. The study was published in a peer-reviewed journal

Exclusion criteria:

1. Review, opinion article, conference abstract or dissertation
2. The study is not empirical
3. The study is a case study

1.7.4 Selection Process

A total of 259 articles were identified using the search terms and databases outlined above. After removing duplicates, 39 articles remained in relation to stroke and identity change and 83 articles in relation to other ABI and identity change, resulting in a total of 122 articles. These were then reviewed by title and abstract for relevance to the topic of a difference in self-concept/identity after stroke / ABI. Any article that clearly met one of the exclusion criteria was eliminated from the review at this stage, leaving 60 abstracts. These were then examined by the researcher and research supervisor in more detail to ascertain eligibility for inclusion in the study. When there was disagreement regarding the inclusion of a study, this was discussed in a consensus building process until agreement was reached. Of the 60 abstracts 17 full text articles were examined in more detail by the researcher and supervisor and 7 studies were deemed eligible for inclusion. The most frequent reasons to exclude articles were that they were not about the survivors' perceived difference in self-concept or identity or self-esteem, pre compared to post-injury; they were unpublished research such as conference abstracts and dissertations; or they were case studies. A breakdown of this process is detailed in Table 1.3 below.

The bibliographies of all articles that met the inclusion criteria were then examined for relevant studies, as were the reference lists of the review papers and the book chapters identified in the search. Four more studies were identified as a result of this process. Consequently, 11 studies were eligible to be included in the systematic

Table 1.3: Breakdown of selection of studies process

Reason for exclusion	Titles (122)		Abstracts (60)		Full texts (17)	
	Stroke 39	Other 83	Stroke 20	Other 40	Stroke 7	Other 10
review	1	1	0	4	0	0
conference abstract	4	7	0	0	0	0
dissertation	5	10	0	0	0	0
book chapter	1	3	0	0	0	0
erratum	0	2	0	0	0	0
duplicate	2	3	0	0	0	0
not in English	0	2	0	0	0	0
no info / abstract	1	1	0	0	0	0
case study	1	5	0	2	0	0
not with adults	0	5	0	0	0	0
not about survivor's perceived difference	4	4	13	17	3	6
not empirical	0	0	0	7	0	0
unfinished	0	0	0	0	0	1
Total excluded	19	43	13	30	3	7
Total included					4	3

review. However, the literature search was carried out again 14 December 2014 and two more, newly published, relevant studies were identified (Levack *et al.*, 2014; Pallesen, 2014), and were therefore included in the systematic review; however, as these were published after the thesis had been completed, they could not inform the rationale and hypotheses of this study.

1.7.5 Results

1.7.5.1 Overview of the critical review

The studies that met the inclusion and exclusion criteria were critically reviewed to assess their quality. The studies are summarised in Table 1.4 below. As quantitative and qualitative studies were included in the review, two different quality frameworks were required to assess their quality.

The qualitative studies in the review (N = 6) were assessed against Critical Appraisal Skills Programme (CASP) criteria (2013; see Appendix 1 for the criteria), as the checklist has been tested and is recommended for use in the NHS (Campbell *et al.*, 2011). In order to compare and contrast the quality of the studies these were rated with a score between zero and two on each quality indicator. A score of zero reflected no reported adherence, a score of one was awarded if the criterion was

partially fulfilled, and two if the criterion was met. The evaluation of the qualitative studies is presented in Table 1.5 below.

The quantitative studies included in the review (N = 7) were cross-sectional, correlational studies, and therefore their quality was assessed using the quality framework developed by Cardiff University's Support Unit for Research Evidence (SURE) specifically for studies implementing this methodology (SURE, Cardiff University, personal communication, 13 October 2014; see Appendix 2 for the criteria). In order to compare and contrast the quality of the studies, a numerical scoring system was added to the existing scoring guidance; thus, ++ (good) was scored as 2, + (mixed) was scored as 1 and - (poor) or nr (not reported) was scored as 0. The evaluation of the quantitative studies is presented in Table 1.6 below.

As researchers use their judgement when assessing quality (Chenail, 2011), there is still an interpretive element even when applying structured criteria, and there is, for instance, evidence of little inter-rater agreement concerning the quality of studies when applying CASP criteria (Dixon-Woods *et al.*, 2007). However, it could be argued that applying a structured approach would enable the reviewer to be more systematic in their evaluation; therefore, using quality frameworks was considered appropriate in assessing the quality of the studies included in the review. In order to enhance reliability of scores, studies were rated following discussion with the researcher's research supervisor. Also, a narrative description of the review, regarding aims, samples included in the studies, methodology, findings, and the strengths and limitations of the research is presented below.

Table 1.4: Summary of studies included in the systematic review

Reference	Aim	Sample characteristics	Method	Findings	Conclusions
Cantor <i>et al.</i> (2005), USA	Examine the utility of Higgins' (1987) self-discrepancy theory in explaining post-TBI anxiety and depression.	<p><u>ABI (type, severity, time)</u> TBI (N = 21) mild (N=11) moderate (N=4) severe (N=6) 2 - 33 years since injury (M = 9)</p> <p><u>Gender</u> 11 Male 10 Female</p> <p><u>Age</u> 22 - 77 years (M = 55)</p>	<p><u>Design</u> Cross-sectional, within subjects, correlational</p> <p><u>Recruitment</u> Community living TBI survivors, involved in other research studies.</p> <p><u>Measures</u> Selves Interview (SI) and Selves Adjective Checklist (SAC) to measure current actual, ideal, ought, and pre-injury actual self. BDI-II BAI</p> <p><u>Analysis</u> Spearman's correlations between self-discrepancy and affective distress</p>	<p>Post-injury self rated more negatively than pre-injury self, on both SI and SAC. Only discrepancy M (SD) reported: SI: -17 (13) & SAC: 0.8 (2.1) Unclear if there is a significant difference between the pre and post-injury self states.</p> <p>Significant correlations between BDI-II and BAI, respectively, and self-discrepancy for all the selves comparisons using SAC:</p> <p>Discrepancies between post-injury and pre-injury selves associated with depression (.82, $p < .001$) and anxiety (.54, $p = .012$); discrepancies between post-injury self and ideal self associated with depression (.83, $p < .001$) and also with anxiety (.54, $p = .011$); discrepancies between post-injury self and ought self associated with anxiety (.60, $p = .004$), and also with depression (.82, $p < .001$).</p> <p>No significant correlations on self-discrepancy scores on the SI and BDI-II and BAI; nor between SAC and SI.</p> <p>Majority of participants did not have clinically significant scores on either BDI-II or BAI.</p>	<p>Significant relationships between self-discrepancies and affective distress.</p> <p>The discrepancies between pre-injury self and post-injury self, which are seen as negative, seem related to emotional distress.</p>
Carroll & Coetzer (2011),	Investigate perceived identity	<p><u>ABI (type, severity, time)</u> TBI (N = 29) severe (N=18)</p>	<p><u>Design</u> Cross-sectional, within subjects, correlational</p>	<p>Present-self seen significantly more negatively than pre-injury self ($t(28) = 4.61, p < .001$).</p>	<p>Individuals experience change in self-concept after TBI and the new self is</p>

UK	change and explore association between identity change, grief, depression, self-esteem and self-awareness.	<p>moderate (N=2) mild (N=9) (based on GCS and LOC (N=26), self-report (N=3)) 2.25 - 40 years since injury (M = 11.17)</p> <p><u>Gender</u> 21 Male 8 Female</p> <p><u>Age</u> 22 - 64 years (M = 46.3)</p> <p><u>Other</u> No additional neurological problems, concurrent difficulties with substance misuse or severe psychiatric disorder.</p> <p>Sufficient language and communication skills for reliable completion of questionnaires.</p>	<p><u>Recruitment</u> Community brain injury rehabilitation service.</p> <p><u>Measures</u> HISDS-III (measure past and present self) RSES HADS Brain Injury Grief Inventory Awareness Questionnaire</p> <p><u>Analysis</u> T-test to measure difference between pre and post-injury selves. Pearson's correlations between self-discrepancy and depression, grief, self-esteem, awareness; and between awareness and self-esteem, depression.</p>	<p>Positive associations between change in identity and depression ($r = .58, p < .01$), and grief ($r = .53, p < .01$); and between depression and grief ($r = .753, p < .01$).</p> <p>Negative associations between identity change and self-esteem ($r = -.365, p < .05$), adjustment ($r = -.354, p < .05$).</p> <p>Awareness (indicated by discrepancy scores) negatively associated with self-esteem ($r = .35, p < .05$) and positively associated with depression ($r = -.38, p < .05$). No significant associations between awareness and perceived identity change.</p>	<p>rated negatively compared to pre-injury self.</p> <p>The perceived change in identity negatively associated with self-esteem and positively associated with depression and grief.</p>
Cooper-Evans <i>et al.</i> (2008), UK	Explore effects of severe ABI on self-esteem.	<p><u>ABI (type, severity, time)</u> TBI (N = 19) Stroke (N = 1) Viral infection (N = 2) Severe ABI (based on GCS or PTA). 16 - 348 months since injury (M = 122.05)</p> <p><u>Gender</u> 17 Male 5 Female</p> <p><u>Age</u> 20 - 61 years (M = 43)</p>	<p><u>Design</u> Cross-sectional, within subjects, correlational</p> <p><u>Recruitment</u> Neurobehavioural services</p> <p><u>Measures</u> RSES (to measure pre and post-injury self, and at 2 weeks follow-up). HADS Behavioural Assessment of Dysexecutive Syndrome Wechsler Test of Adult Reading Wechsler Adult Intelligence Scale –</p>	<p>Significant lower ratings for post-injury compared to pre-injury self-esteem ($t(21) = -3.43, p < .01$).</p> <p>Level of self-esteem consistent over time ($r = .86, p < .01$).</p> <p>Post-injury self-esteem significantly correlated with depression ($r = .65, p < .01$) and anxiety ($r = .71, p < .01$).</p> <p>Level of current self-esteem not associated with magnitude of acquired cognitive impairment.</p>	<p>Self-esteem is negatively affected after ABI.</p> <p>Lower self-esteem tends to be associated with higher degree of awareness of impairment, more intact cognitive and / or executive functioning as well as with higher rates of psychological distress.</p>

		<p><u>Other</u> Data available on cognitive functioning.</p>	<p>III (from casenotes)</p> <p><u>Analysis</u> T-test to measure changes in self-esteem. Pearson's correlations between post-injury self-esteem and affective distress, level of cognitive impairment, awareness.</p>	<p>Those with higher self-esteem had less awareness of executive difficulties, and greater impairment in executive function associated with higher self-esteem.</p>	
Ellis-Hill <i>et al.</i> (2000), UK	Explore perceived life and identity changes following a single stroke	<p><u>ABI (type, severity, time)</u> First-time stroke survivors (N = 8) Survivors interviewed in hospital (mean 20 weeks), at 6 months, and 1 year</p> <p><u>Gender</u> 5 Male 3 Female</p> <p><u>Age</u> 56 – 82 years (M = 67)</p> <p><u>Other</u> No cognitive or communication difficulties, no previous physical disability.</p>	<p><u>Design</u> Qualitative, life narrative interviews with survivors and their spouse.</p> <p><u>Recruitment</u> Identified and first interviewed in hospital.</p> <p><u>Procedure</u> Interviewed participants while in hospital, then at 6 months, and a year after stroke, resulting in 24 interviews.</p> <p><u>Analysis</u> Themes were identified.</p>	<p>A prominent theme was a changed relationship between stroke survivors and their body, which was experienced as separate and out of control, unreliable and perplexing; and even rebellious.</p> <p>The self-body relationship was also a dynamic relationship that becomes more apparent in social situations where the survivors are faced with the challenge of having to explain to others the change, and feeling “like a freak” because of not being like before.</p>	Stroke seemed to challenge the individual's whole being; particularly, participants experienced a self-body split, which was the focus even a year after the stroke.
Ellis-Hill & Horn, (2000), UK	Determine whether stroke survivors report a change in identity following stroke.	<p><u>ABI (type, severity, time)</u> First-time stroke survivors (N = 26) 4 – 26 months since injury (M = 13.58)</p> <p><u>Gender</u> 17 Male 10 Female</p> <p><u>Age</u> 50 - 83 years (M = 71.4)</p>	<p><u>Design</u> Cross-sectional, within subjects. Also used comparison group – hospital volunteers matched for age, gender, time from which past self-concept was considered.</p> <p><u>Recruitment</u> Stroke survivors discharged directly home from the acute hospital.</p> <p><u>Measures</u> HISD II (pre-stroke and present self)</p>	<p>Stroke respondents rated present self-concept as similar or more negative than past self-concept, many of these being significant changes, as was the overall change ($p = .0003$). However, there was wide variation in change.</p> <p>No significant changes in self-concept in the control group.</p> <p>Increased anxiety and depression and reduced level of activity in the stroke group compared to the control group.</p>	<p>Individuals experience a negative change in their sense of self after stroke.</p> <p>Sense of self is stable in a nonclinical group.</p>

		<p><u>Other</u> At the most able end of the physical recovery spectrum (large proportion could walk independently without aids when indoors).</p> <p>Equal proportion of left and right weakness.</p> <p>No history of, or present cognitive, or severe communication difficulties, no previous physical disability.</p>	<p>HADS Frenchay Activity Index</p> <p><u>Analysis</u> Wilcoxon signed ranks test to measure changes in self-concept. Mann-Whitney test to measure differences between stroke group and comparison group regarding affective distress and activity level.</p>		
Gracey <i>et al.</i> (2008)	How people make sense of themselves after brain injury.	<p><u>ABI (type, severity, time)</u> TBI (N = 22) Haemorrhage (N = 5) Encephalitis (N = 2) Other (N = 3) Severe (N = 16) Less than severe (N = 5) Not recorded (N = 1) Not applicable (N = 10) (from casenotes) 1–10 years post-injury (M = 3)</p> <p><u>Gender</u> 23 Male 9 Female</p> <p><u>Age</u> 21 – 59 years (M = 38)</p> <p><u>Other</u> In the average range of pre-injury intellectual functioning on the Speed and Capacity of Language Processing “Spot the Word” subtest (SCOLP). No significant severe mental health issues, substance misuse.</p>	<p><u>Design</u> Qualitative, Kelly’s personal construct psychology.</p> <p><u>Recruitment</u> Neurorehabilitation services.</p> <p><u>Procedure</u> Personal constructs relating to pre-injury, current (post-injury) and ideal (post-injury) selves were elicited in structured group discussions with 2-5 participants.</p> <p><u>Analysis</u> Themes were identified using the inductive phenomenological thematic analysis procedure of Boyatzis (1998).</p>	<p>25% of constructs were part of the “experience of self in the world” theme with the subcategories: belonging, independence, activity and assertiveness.</p> <p>18% of constructs were categorised as “basic skills” (cognitive, physical, sensory and social ability).</p> <p>15% of constructs were related to the “experience of self in relation to self” theme, referring to self-reflections.</p> <p>Other constructs were related to emotions, social relating, motivation and uncertainty.</p>	<p>The differences in self-construing post-injury referred particularly to the personal meanings and feelings associated with practical and social activity, and also with the experienced changes in cognitive, physical, sensory and social ability, as well as, with existential concerns.</p>

<p>Guise <i>et al.</i> (2010), UK</p>	<p>Examine construction of identity and change in identity.</p>	<p><u>ABI (type, severity, time)</u> Young stroke survivors (suffered stroke under age of 55 years, unclear if only one stroke) (N = 12)</p> <p><u>Gender</u> Not reported</p> <p><u>Age</u> Under age of 55 years (range and mean not reported)</p>	<p><u>Design</u> Qualitative, discourse analytic methodology.</p> <p><u>Recruitment</u> Community support groups.</p> <p><u>Procedure</u> Focus group interaction between 12 stroke survivors and five carers.</p> <p><u>Analysis</u> Discourse was analysed and patterns were identified in the data.</p>	<p>While minimising the negative aspects of stroke and mitigating its implications on their identity, participants were sensitive to how these accounts were perceived by their carers (i.e. not inappropriately positive), who could criticise and challenge them, and offer potentially negative reformulations of these.</p>	<p>Stroke survivors seemed to have acquired a 'damaged' identity, and it may be difficult to maintaining a positive sense of self, particularly in the presence of their others who can play a role in maintaining damaged identities.</p>
<p>Keppel & Crowe (2010), Australia</p>	<p>Examine the perceived effect of stroke on body image and self-esteem in young adults.</p>	<p><u>ABI (type, severity, time)</u> First-time stroke survivors (N = 33) Mean time since injury = 7 months (no range available)</p> <p><u>Gender</u> 13 Male 20 Female</p> <p><u>Age</u> < 60 years (no range reported)</p> <p><u>Other</u> Those with previous history of neuropathology, learning impairment, psychiatric disorder, or global or receptive aphasia excluded.</p> <p>First stroke based on medical opinion (supported or confirmed by CT and MRI).</p>	<p><u>Design</u> Cross-sectional, within subjects, correlational</p> <p><u>Recruitment</u> Rehabilitation programmes.</p> <p><u>Measures</u> RSES Tennessee Self-concept Scale 2 - only the physical self-concept scale (PHY), personal self-concept (PER) and total self-concept (TOT). Body-Cathexis/Self-Cathexis Scale All measures administered pre stroke, i.e. two weeks before the stroke, and post-stroke, i.e. over the last two weeks.</p> <p><u>Analysis</u> T-test to measure differences in self-esteem/self-concept. Pearson's correlations between self-esteem and body image.</p>	<p>All measures of self-esteem and self-concept negatively affected after stroke, and no significant gender differences (PHY: $t = -3.59, p = .001$; PER: $t = -3.03, p = .005$; TOT: $t = -2.60, p = .014$; RSES: $t = -3.24, p = .003$).</p> <p>No significant relationship between measures of body image, self-esteem, and time since stroke.</p> <p>Prior to stroke only physical self-esteem and body image were strongly correlated. All post-stroke ratings of self-esteem correlated positively with post-stroke ratings of body image (RSES $r = .53, p = .001$; PHY $r = .62, p = .000$; PER $r = .45, p = .004$; TOT $r = .54, p = .001$).</p>	<p>Self-esteem changed negatively after stroke. These changes were correlated with negative changes in body image.</p>
<p>Levack <i>et al.</i> (2014), New</p>	<p>Develop a client-derived framework to</p>	<p><u>ABI (type, severity, time)</u> TBI (N = 49) Mild to severe (based on self-</p>	<p><u>Design</u> Qualitative, grounded theory.</p>	<p>Themes: Central concept of desiring to be or having lost a sense of being an</p>	<p>Reinforces the notion that change in self-identity is an important aspect of life</p>

Zealand	underpin development of a measure reflecting the impact of TBI on self-identity.	<p>reported length of unconsciousness). 6 months - 36 years post injury (M = 12.7)</p> <p><u>Gender</u> 34 Male 15 Female</p> <p><u>Age</u> 21 – 79 years (M = 52.7)</p> <p><u>Other</u> Ethnically diverse (Maori).</p>	<p><u>Recruitment</u> Local organisations from 8 urban and rural communities in New Zealand that supported people with TBI and their families in the community.</p> <p><u>Procedure</u> 8 focus groups (one in each region; two Maori only)</p> <p><u>Analysis</u> Constant comparative methods.</p>	<p>integrated and valued person</p> <ol style="list-style-type: none"> 1. having a coherent, satisfying and complete sense of oneself 2. respect, validation and acceptance by others 3. having a valued place in the world. 	after TBI, and provides information on what this concept means to people with TBI.
Nochi (1998), Japan	Explore how TBI survivors experience themselves.	<p><u>ABI (type, severity, time)</u> TBI (N = 10) Severity not reported. 2 -12 years post injury</p> <p><u>Gender</u> 6 Male 4 Female</p> <p><u>Age</u> 24 – 49 years</p>	<p><u>Design</u> Qualitative, interviews.</p> <p><u>Recruitment</u> Community support groups.</p> <p><u>Procedure</u> Face-to-face semi-structured interviews, using open-ended questions.</p> <p><u>Analysis</u> Grounded theory.</p>	<p>Themes:</p> <ol style="list-style-type: none"> 1. Loss of clear self-knowledge due to memory loss. 2. Loss of self by comparison of pre with post-injury self-images 3. Loss of self in the eyes of others due to labels imposed on them by others. 	Types of loss of self that TBI survivors might experience were identified, a common theme being a comparison between current with pre-injury state.
Pallesen (2014), Denmark	Identify, from a long-term perspective, stroke survivors' self-identity, their views of any associated disabilities and how they manage their lives after stroke.	<p><u>ABI (type, severity, time)</u> First-time stroke survivors (N = 15) Severity not reported. 5 years post injury</p> <p><u>Gender</u> 10 Male 5 Female</p> <p><u>Age</u> 42 – 88 years (mean not reported)</p>	<p><u>Design</u> Qualitative, interviews.</p> <p><u>Recruitment</u> Based on respondents to a previous questionnaire study in a geographical area in Denmark.</p> <p><u>Procedure</u> Face-to-face semi-structured interviews, using open-ended questions. Supplemented with phone, email conversations.</p>	<p>Themes:</p> <ol style="list-style-type: none"> 1. Body experiences (unreliable and 'forcibly present body', new bodily discomfort, emotional reactions) 2. Coping (resigning, struggling) 3. Altered life 4. Self-identity (view of self in relation to stroke, relation to others, view of others) 	Stroke survivors suffered considerable ongoing and changing difficulties in relation to disability, self-perception and to coping with a new life.

		<p><u>Other</u> Reasonable variation re functional ability, education, occupation and marital status. Some with a degree of aphasia (N=3; assisted).</p>	<p><u>Analysis</u> Phenomenological analysis. Interviews encoded using NVivo 8.</p>		
Tyerman & Humphrey (1984), UK	Explore changes in self-concept arising from severe head injury.	<p><u>ABI (type, severity, time)</u> TBI (N = 25) Severe TBI (based on LOC and PTA). 2 - 15 months since injury (M = 7)</p> <p><u>Gender</u> 23 Male 2 Female</p> <p><u>Age</u> 17 to 32 years (M = 22)</p> <p><u>Other</u> Neuropsychological assessment: current intellectual level compared with estimated pre-morbid level. N=18 suffered some generalised intellectual impairment (N = 5 severe), N=21 exhibited memory/learning impairment (N = 5 severe), and N=2 showed marked difficulty in visuo-spatial processing. Those with severe communication disorders excluded.</p>	<p><u>Design</u> Cross-sectional, within subjects.</p> <p><u>Recruitment</u> Neurorehabilitation centres.</p> <p><u>Measures</u> 20 item Semantic Differential Scale (to measure past, present and future self (1 year on) (N=25), and ratings for typical head injured person and typical person of own age and sex (N=14). Leeds Scales of Anxiety and Depression (LSAD) Litman Physical Disability Self-Conception Scale</p> <p><u>Analysis</u> Wilcoxon matched pairs, signed ranks test to measure difference between different types of self.</p>	<p>Significant differences between present self and past self on all but 3 of the 20 items.</p> <p>Significant positive change anticipated, with no difference between past and future self.</p> <p>Present self perceived more positively than a typically head injured person, past self rated more positively overall than a typical person of same age and sex, and a typical head injured person was rated more negatively than a typical person.</p> <p>Significant psychological disturbance (64%); 60% clinically depressed; 44% clinically anxious.</p>	<p>Profound changes in self-concept following severe head injury, but anticipated return to pre-morbid self within a year.</p> <p>Psychological distress (anxiety and depression) was common).</p> <p>Reduced sense of personal worth and self-conscious about their disabilities.</p>

<p>Wright & Telford (1996), UK</p>	<p>Examine extent of psychological distress six months (time1) and three years (time2) after a predominantly minor head injury.</p> <p>Describe the relationship of these symptoms to the process of revision and rebuilding of self-perceptions post-injury.</p>	<p><u>ABI (type, severity, time)</u> TBI (N = 50 at time1 and N = 21 at time2), but only 36 completed HISD at time1 and 15 at time2. Predominantly minor injuries; GCS for N = 30: mild (N = 27) moderate (N = 2) severe (N = 1). 6 months post injury (time1) and 3 years post injury (time2)</p> <p><u>Gender</u> 32 Male 18 Female</p> <p><u>Age</u> 17 - 86 years (M = 46)</p> <p><u>Other</u> Participants not excluded due to alcohol consumption before accident (26%), previous head injury (34%) or history of mental health problems (12%).</p> <p>For some English not first language (N = unknown).</p>	<p><u>Design</u> Cross-sectional, within and between subjects, longitudinal. Control group matched for age, sex, socio-economic and marital status, and history of mental health problems.</p> <p><u>Recruitment</u> Admitted to one of two district general hospitals with a head injury over a three-month period.</p> <p><u>Measures</u> HISD (N=36 at time1; N=15 at time2) to measure past, present and future selves. Interview – Questions regarding psychological changes (N=24 at time1) GHQ-12 (N=42 at time1; N=18 at time2) Impact of Events Scale (IES; N=39 at time1; N = 16 at time2)</p> <p><u>Analysis</u> T-test to measure difference in types of self. Correlations (correlation test used not reported) between emotional distress and differences with past-self ratings and IES.</p>	<p>Significant difference in the construct ratings of past/present self ($t(35) = 4.21, p < .0001$) and present/future ($t(35) = -4.33, p < .0001$), but not between past/future self. No significant differences from time1 to time2.</p> <p>Negative changes described at time1; 3 reported a positive change post injury.</p> <p>Control group rated past self significantly lower than injured group, but was not significantly different for present or future self. Significantly greater symptoms than control group ($t = 5.4, p < .01$). Significant decrease from time1 to time2.</p> <p>Significant correlations between emotional distress, GHQ ($-0.57, p < .001$) and IES, and differences with past-self ratings, but not for the control group.</p>	<p>Discontinuity in the sense of self following mild brain injury.</p> <p>Significant relationship between changes in sense of self and psychological symptoms.</p>
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Table 1.5: Quality review of qualitative studies

Study	Aims Was there a clear statement of the aims of the research?	Methodology Is a qualitative methodology appropriate?	Design Was the research design appropriate to address the aims of the research?	Recruitment Was the recruitment strategy appropriate for aims of the research?	Data collection Were data collected in a way that addressed the research issue?	Reflexivity Has the relationship between researcher and participants been adequately considered?	Ethics Have ethical issues been taken into consideration?	Data Analysis Was the data analysis sufficiently rigorous?	Findings Is there a clear statement of findings?	Value of research How valuable is the research?	Total score (0-20)
Ellis-Hill <i>et al.</i> (2000), UK	Clear aim and why relevant/important. =2	Qualitative methodology appropriate. =2	Research design appropriate and justified (narrative approach). =2	Explained how and why participants were recruited. =2	Explained how data were collected and analysed. =2	Role/influence of researcher alluded to but no critical consideration. =1	No reference to ethical issues. =0	Detailed description of analysis process and how themes were derived; sufficient data provided to represent themes. =2	Findings are explicit and discussed in relation to research question; credibility discussed. =2	Implications discussed and further areas of research identified. =2	17/20
Gracey <i>et al.</i> (2008)	Clear aim and why relevant/important. =2	Qualitative methodology appropriate. =2	Research design appropriate and justified (personal construct approach). =2	Explained how and why participants were recruited. =2	Detailed procedure of how data were collected and analysed. =2	Role/influence of researcher not considered. =0	No reference to ethical issues. =0	Detailed description of analysis process and how themes were derived; sufficient data provided to represent themes. =2	Findings are explicit and discussed in relation to research question; credibility discussed. =2	Findings discussed in relation to existing knowledge; some implications discussed. =2	16/20

Study	Aims Was there a clear statement of the aims of the research?	Methodology Is a qualitative methodology appropriate?	Design Was the research design appropriate to address the aims of the research?	Recruitment Was the recruitment strategy appropriate for aims of the research?	Data collection Were data collected in a way that addressed the research issue?	Reflexivity Has the relationship between researcher and participants been adequately considered?	Ethics Have ethical issues been taken into consideration?	Data Analysis Was the data analysis sufficiently rigorous?	Findings Is there a clear statement of findings?	Value of research How valuable is the research?	Total score (0-20)
Guise <i>et al.</i> (2010), UK	Clear aim and why relevant/important. =2	Qualitative methodology appropriate. =2	Research design appropriate and justified (discursive analysis). =2	Only stated participants were recruited via support groups, but no detail of recruitment procedure. =1	Explained how data were collected and analysed. =2	Role/influence of researcher not considered. =0	Ethical considerations (approval, consent, confidentiality) discussed. =2	Adequate description of analysis process; sufficient data provided to represent themes. =2	Findings are explicit and discussed in relation to research question; no reference to credibility. =1	Findings discussed in relation to existing knowledge; some implications discussed. =2	16/20
Levack <i>et al.</i> (2014), New Zealand	Clear aim and why relevant/important. =2	Qualitative methodology appropriate. =2	Research design appropriate and justified (grounded theory). =2	Explained how and why participants were recruited. =2	Explained how data were collected and analysed. =2	Some consideration of role/influence of researcher. =1	Some ethical references (consent). =1	Adequate description of analysis process; sufficient data provided to represent themes. =2	Findings are explicit and discussed in relation to research question; credibility discussed. =2	Findings discussed in relation to existing knowledge; implications discussed. =2	18/20

Study	Aims Was there a clear statement of the aims of the research?	Methodology Is a qualitative methodology appropriate?	Design Was the research design appropriate to address the aims of the research?	Recruitment Was the recruitment strategy appropriate for aims of the research?	Data collection Were data collected in a way that addressed the research issue?	Reflexivity Has the relationship between researcher and participants been adequately considered?	Ethics Have ethical issues been taken into consideration?	Data Analysis Was the data analysis sufficiently rigorous?	Findings Is there a clear statement of findings?	Value of research How valuable is the research?	Total score (0-20)
Nochi (1998), Japan	Clear aim and why relevant/ important. =2	Qualitative methodology appropriate =2	Research design appropriate but not justified (grounded theory). =1	Explained how and why participants were recruited. =2	Explained how data were collected and analysed. =2	Role/influence of researcher not considered. =0	Some ethical references (consent). =1	Detailed description of analysis process and how themes were derived; sufficient data provided to represent themes. =2	Findings are explicit and discussed in relation to research question; credibility discussed. =2	Findings discussed in relation to existing knowledge; implications discussed and further areas of research identified. =2	16/20
Pallesen (2014), Denmark	Clear aim and why relevant / important. =2	Qualitative methodology appropriate =2	Research design appropriate and justified (phenomenological analysis). =2	Explained how and why participants were recruited. =2	Explained how data were collected and analysed. =2	Role/influence of researcher not considered. =0	Ethical issues have been taken into consideration. =2	Detailed description of analysis process and how themes were derived; sufficient data provided to represent themes. =2	Findings are explicit and discussed in relation to research question; credibility discussed. =2	Findings discussed in relation to existing knowledge; some implications discussed. =2	18/20

Table 1.6: Quality review of quantitative studies

Criteria		Cantor <i>et al.</i> (2005), USA	Carroll & Coetzer (2011), UK	Cooper-Evans <i>et al.</i> (2008), UK	Ellis-Hill & Horn, (2000), UK	Keppel & Crowe (2010), Australia	Tyerman & Humphrey (1984), UK	Wright & Telford (1996), UK
Population	Is the source population or source area well described?	TBI survivors currently or previously involved in studies on community integration of TBI survivors. = 2	TBI survivors from a community brain injury rehabilitation service. = 2	People with non-progressive neurological damage from a neurobehavioural service (mostly very severe injuries). = 2	Stroke survivors in receipt of occupational therapy in a county hospital. = 2	Stroke survivors from rehabilitation programmes at two teaching hospitals. = 2	Adults with head injury attending one of two medical rehabilitation centres specialising in treatment of neurological disorders. = 2	All adults (N=82) admitted to one of two district general hospitals with a head injury over 3 months. = 2
	Is the eligible population or area representative of the source population or area?	Small sample, only TBI. = 1	Small sample, only TBI. = 1	Small sample, mostly TBI. = 1	Small sample, first-time stroke survivors. = 1	Small sample, first-time stroke survivors, aged under 60 years. = 1	Small sample of adults with severe head injury. = 1	50 consented and did not differ significantly on severity, gender, age, employment status or social class to the others = 2
	Do the selected participants or areas represent the eligible population or area?	Mix of severity, wide age range. = 1	Moderate to severe TBI. Those with additional neurological problems, current substance misuse or severe psychiatric disorder excluded. = 1	Those with gross language impairments excluded. = 1	Those who moved out of area, had previous physical disability, were discharged to rest/nursing home, transferred to long-term elderly care excluded. = 1	Those with previous history of neuropathology, learning impairment, psychiatric disorder, global or receptive aphasia excluded. = 1	Those with severe communication disorders excluded. = 1	Small sample, predominantly minor injuries; no exclusion due to alcohol use before accident (26%), previous head injury (34%) or history of mental health problems (12%). =1

Criteria		Cantor <i>et al.</i> (2005), USA	Carroll & Coetzer (2011), UK	Cooper-Evans <i>et al.</i> (2008), UK	Ellis-Hill & Horn, (2000), UK	Keppel & Crowe (2010), Australia	Tyerman & Humphrey (1984), UK	Wright & Telford (1996), UK
Method of selection of exposure (or comparison) group	Selection of exposure (and comparison) group. How was selection bias minimised?	Selected from pool of TBI survivors involved in other research studies. = 0	Selected from residents of community brain injury rehabilitation service. Clinicians introduced research to those on caseload they considered met criteria. = 1	Selected from neurobehavioural service for people with non-progressive neurological damage. = 1	Selected on consecutive basis from those discharged from hospital OT service over the 2 previous years. Comparison group selected from hospital volunteers matched for age, gender, time from which past self-concept was considered. = 1	Selected from rehabilitation wards or still involved in outpatient rehabilitation support services. = 1	Selected from rehabilitation centres for treatment of neurological disorders. = 1	All adults (N=82) admitted to hospital with head injury over 3 months were asked to participate but only 50 consented. None excluded. Control group from authors' formal and informal network, matched for age, sex, socioeconomic and marital status, and history of mental health problems. = 1
	Was the selection of explanatory variables based on sound theoretical basis?	Yes, variables based on theoretical background / previous research. = 2	Yes, variables based on theoretical background / previous research. = 2	Yes, variables based on theoretical background / previous research. = 2	Yes, variables based on theoretical background / previous research. = 2	Yes, variables based on theoretical background / previous research. = 2	Yes, variables based on theoretical background / previous research. = 2	Yes, variables based on theoretical background / previous research. = 2
	Was contamination acceptably low?	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Criteria	Cantor <i>et al.</i> (2005), USA	Carroll & Coetzer (2011), UK	Cooper-Evans <i>et al.</i> (2008), UK	Ellis-Hill & Horn, (2000), UK	Keppel & Crowe (2010), Australia	Tyerman & Humphrey (1984), UK	Wright & Telford (1996), UK
How well were likely confounding factors identified and controlled? *most scored poorly but in community studies it is recognised that extraneous variables inevitably exist and it is normal to assume that they are not systematically related to the study variables.	Reference to demographic variables, injury severity, psychiatric disorder, employment, social support, coping but not investigated. = 0	Impact of demographic and injury related variables tested and controlled for = 2	Potential confounds related to self-esteem identified (physical impairments, functional ability, age, time in rehab) but not investigated. = 0	No reference to possible confounding factors. =0	Considered gender, lesion location and body image, but not other demographic variables. = 1	No reference to possible confounding factors. =0	Age, IQ, occupational and social functioning, social support identified but not investigated. = 0
Were rigorous processes used to develop the questions (e.g. were questions piloted/validated?) (N.B. Here, "questions" refers to measures of self-concept)	Selves Interview (version of Selves Questionnaire) and Selves Adjective Checklist (developed by authors), not validated. = 0	HISD-III to measure selves. = 2	RSES to measure self-esteem. = 2	HISD-II to measure selves. = 2	RSES, Tennessee Self-concept Scale 2 (only the physical self-concept scale PHY, personal self-concept PER and total self-concept TOT) to measure self-esteem / self concept. = 2	HISD (psychometric properties not reported) = 0	HISD to measure selves, questions regarding psychological changes. = 2
Is the setting applicable to the UK?	Yes =2	Yes =2	Yes =2	Yes =2	Yes =2	Yes =2	Yes =2

Criteria		Cantor <i>et al.</i> (2005), USA	Carroll & Coetzer (2011), UK	Cooper-Evans <i>et al.</i> (2008), UK	Ellis-Hill & Horn, (2000), UK	Keppel & Crowe (2010), Australia	Tyerman & Humphrey (1984), UK	Wright & Telford (1996), UK
Outcomes	Were the outcome measures and procedures reliable? (Here, this refers to dependent variables)	BAI & BDI = 2	HADS, RSES, Brain Injury Grief Inventory and Awareness Questionnaire = 2	DEX-S and DEX-O (awareness) part of BADS = 2	HADS & Frenchay Activity Index = 2	Body -Cathexis / Self-Cathexis Scale = 2	Psychometric properties of used measures not reported. = 0	GHQ-12 Impact of Events Scale (IES) = 2
	Were the outcome measurements complete?	Not reported = 0	All measures completed. = 2	Not reported = 0	All measures completed. = 2	Not reported = 0	All (N=25) completed present, past and future self; N=14 completed typical person and typical head injured person; unclear re other measures. = 1	N=42 completed GHQ-12 at time 1 and N=18 at time 2. N=39 completed IES at time 1 and N=16 at time 2. N=36 completed HISD at time 1 and N=15 at time 2. = 1
	Were all important outcomes assessed?	Psychological distress assessed. = 1	Psychological distress, self-esteem and grief assessed. = 1	Psychological distress assessed. = 1	Psychological distress and activity level assessed. = 1	Only body image and self-esteem assessed. = 0	Psychological distress assessed. = 1	Psychological distress and traumatic symptoms assessed. = 1

Criteria		Cantor <i>et al.</i> (2005), USA	Carroll & Coetzer (2011), UK	Cooper-Evans <i>et al.</i> (2008), UK	Ellis-Hill & Horn, (2000), UK	Keppel & Crowe (2010), Australia	Tyerman & Humphrey (1984), UK	Wright & Telford (1996), UK
	Was there a similar follow-up time in exposure & comparison groups?	No follow-up = 0	No follow-up = 0	Follow up of self-esteem measure (but not the others). No control group. = 1	No follow-up = 0	No follow-up = 0	No follow-up = 0	Follow-up but numbers reduced, sample considered representative. Control group not followed up. = 1
	Was follow-up time meaningful?	No follow-up = 0	No follow-up = 0	2 weeks later. = 1	No follow-up = 0	No follow-up = 0	No follow-up = 0	3 years after. = 2
Analyses	Was the study sufficiently powered to detect an effect if one exists?	Small sample (N=21), no reference to power analysis, however effects found. = 1	Small sample (N=29), no reference to power analysis, however effects found. = 1	Small sample (N=22), no reference to power analysis, however effects found. = 1	Small sample (N=26), no reference to power analysis, however effects found. = 1	Small sample (N=33), no reference to power analysis, however effects found. = 1	Small sample (N=24, N=14 for some measures), no reference to power analysis, however effects found. = 1	Small sample (N=36 at time 1 and 15 at time 2), no reference to power analysis, however effects found. = 1
	Were multiple explanatory variables considered in the analyses?	No = 0	Those identified (e.g. employment status) controlled for. = 2	No = 0	No = 0	Gender, lesion location and body image considered, but other demographic variables not investigated. = 1	No = 0	No = 0

Criteria	Cantor <i>et al.</i> (2005), USA	Carroll & Coetzer (2011), UK	Cooper-Evans <i>et al.</i> (2008), UK	Ellis-Hill & Horn, (2000), UK	Keppel & Crowe (2010), Australia	Tyerman & Humphrey (1984), UK	Wright & Telford (1996), UK
Were the analytical methods appropriate?	Descriptive data for discrepancy scores but not demographics. Non-parametric correlations (Spearman's) as variables non-normal. = 1	Descriptive data. Parametric statistics used (as data normally distributed) – paired sample t-test and Pearson's correlations. = 2	Descriptive data and parametric statistics used (paired sample t-test and Pearson's correlations) but unclear if justified. = 1	Descriptive data and non-parametric statistics used (Wilcoxon signed ranks test and Mann-Whitney). = 2	Descriptive data and parametric statistics used (paired sample t-test, Pearson's correlations and hierarchical regression) but unclear if justified. = 1	Descriptive data only for intellectual level. Non-parametric statistics used (Wilcoxon signed ranks test). = 1	Descriptive data and parametric statistics used (paired sample and independent t-test) but unclear if justified. Unclear what correlation coefficient used. = 1
Was the precision of association given or calculable? Is association meaningful?	Some statistical values reported (correlation coefficients and significance level) and implications discussed. No measure of difference. =1	Statistical values reported (t-test values, correlation coefficients and significance level) and implications discussed. =2	Statistical values reported (t-test values, correlation coefficients and significance level) and implications discussed. =2	Statistical values reported (median, range and significance level) and implications discussed. =2	Statistical values reported (t-test values, correlation coefficients and significance level) and implications discussed. =2	Only significance level reported for self-differences; implications discussed. = 1	Statistical values reported (t-test values, correlation coefficients and significance level) and implications discussed. =2

Criteria		Cantor <i>et al.</i> (2005), USA	Carroll & Coetzer (2011), UK	Cooper-Evans <i>et al.</i> (2008), UK	Ellis-Hill & Horn, (2000), UK	Keppel & Crowe (2010), Australia	Tyerman & Humphrey (1984), UK	Wright & Telford (1996), UK
Summary	Are the study results internally valid (i.e. unbiased)?	Retrospective rating of pre-injury self, recall bias, possible awareness bias. = 1	Retrospective rating of pre-injury self, recall bias, possible awareness bias. = 1	Retrospective rating of pre-injury self-esteem, recall bias, possible awareness bias. = 1	Retrospective rating of pre-injury self, recall bias, possible awareness bias. Control group recruited from hospital volunteers so possibly more active/positive people. = 1	Retrospective rating of pre-injury self-esteem, recall bias, possible awareness bias. = 1	Retrospective rating of pre-injury self, recall bias, possible awareness bias. = 1	Retrospective rating of pre-injury self, recall bias, possible awareness bias. = 1
	Are the results generalizable to the source population (i.e. externally valid)?	Relatively “well” participants; women over-represented. Some generalisability to community-living TBI survivors. = 1	Relatively “well” participants, limiting generalisation of findings to TBI and wider ABI population. = 1	Relatively “well” participants, limiting generalisation of findings to wider ABI population. = 1	Participants at the most able end of stroke recovery, limiting generalisation to stroke or wider ABI population. = 1	Those with less severe stroke not included, limiting generalisation to stroke or wider ABI population. = 1	Severe TBI; limited generalisability to TBI and wider ABI population. = 1	Mild TBI; limited generalisability to TBI and wider ABI population. = 1
Total		16/38	27/38	22/38	23/38	21/38	16/38	25/38

1.7.5.2 Aims of the studies reviewed

Five of the studies in this review involved stroke survivors. Ellis-Hill & Horn (2000), Ellis-Hill *et al.* (2000) and Guise *et al.* (2010) set out to investigate identity changes following stroke, while Pallesen (2014) aimed to identify, from a long-term perspective, stroke survivors' self-identity, as well as their views of any associated disabilities and how they manage their lives after stroke. Keppel & Crowe (2010) aimed to examine the perceived effect of stroke on body image and self-esteem in young adults; however, they also used a measure of self-concept as an indication of self-esteem (see section 1.7.5.5.1 below).

The remaining eight studies in the review involved mostly TBI survivors. Nochi (1998), Gracey *et al.* (2008) and Levack *et al.* (2014) explored how survivors experience and make sense of themselves after brain injury, and investigated their experience of change and reconstruction of self-identity. Cooper-Evans *et al.* (2008) explored the effects of severe ABI on self-esteem; Carroll and Coetzer (2011), and Tyerman and Humphrey (1984) investigated perceived identity or self-concept change after head injury; Cantor *et al.*, (2005), Wright and Telford (1996), and also Carroll and Coetzer (2011) explored the relationship between perceived identity change and emotional distress.

1.7.5.3 Samples included in the studies

This section will review the target population employed in the studies in terms of characteristics of the brain injury (e.g. type of injury, severity and time since injury), current level of functioning, number of participants, gender and age; also, the matching variables will be reviewed when a control group is used.

1.7.5.3.1 Characteristics of the brain injury (type, time since injury and severity)

Four of the seven studies were with first-time stroke survivors (Ellis-Hill *et al.*, 2000; Ellis-Hill & Horn, 2000; Keppel & Crowe, 2010; Pallesen, 2014). The time since injury in Ellis-Hill and Horn's (2000) study was 4-26 months with a mean of 14, which is a strength of this study as it considers a relatively small range of time after the injury. The mean time post-stroke in Keppel and Crowe's (2010) study was 7 months, although the range of times is not reported. Ellis-Hill *et al.* (2000) interviewed stroke survivors while in hospital, where they had been from between three weeks to four

months (mean 20 weeks), then again at six months, and a year. As Pallesen (2014) investigated a long-term perspective, the participants were five years post-stroke. Finally, the participants in Guise *et al.*'s (2010) study suffered stroke at a young age but it was not reported if they suffered a single stroke. There was no reported level of severity for either of the stroke studies. Ellis-Hill and Horn (2000) reported their sample had an equal proportion of left and right weaknesses.

The remaining eight studies were mostly with TBI survivors (Cantor *et al.*, 2005; Carroll & Coetzer, 2011; Cooper-Evans *et al.*, 2008; Gracey *et al.* (2008); Levack *et al.* 2014; Nochi, 1998; Tyerman & Humphrey, 1984; Write & Telford, 1996). Although Cooper-Evans *et al.* (2008) and Gracey *et al.* (2008) employed a mixed ABI sample, 19 out of the 22 participants were TBI survivors in the former, and 22 out of 32 in the latter. It is of note that in the latter study, five participants were classified as "haemorrhage". The mean time since injury varied from 6 months (Wright & Telford, 1996) to 11 years (Carroll & Coetzer, 2011). However, the range of time post injury varied widely in three of the studies, from 2 to 33 years, mean = 9 (Cantor *et al.*, 2005), 6 months to 26 years, mean 12.7 (Levack *et al.*, 2014) and 2 to 40 years, mean = 11 (Carroll & Coetzer, 2011), which could be considered a limitation of these studies as there may be other confounding variables at play at different stages post injury.

Most TBI studies reported the severity of the injury, based on either the Glasgow Coma Score (GCS), loss of consciousness (LOC) or post-traumatic amnesia period (PTA), or a combination of these. Severe injuries were predominant in three of the studies, 62% (Carroll & Coetzer, 2011), 86% (Cooper-Evans *et al.*, 2008) and 100% (Tyerman & Humphrey, 1984). In the other two, mild injuries were predominant, 52% (Cantor *et al.*, 2005) and 90% in Wright and Telford's study (1996). However, for the latter study, the percentage was calculated based on the total number of participants for whom the GCS was available, i.e. only 30 participants out of 50; furthermore, only 36 out of the 50 participants completed the self-concept measure and it is unclear for how many of these 36 there was data available regarding their GSC, and consequently the percentage cited may not be an accurate representation of the level of injury severity in the participants who did complete the self-concept measure. Gracey *et al.* (2008) reported half of the participants having a severe injury, based on the medical records, but without reporting how this had been established; whereas

Levack *et al.* (2014) reported participants having mild, moderate and severe TBI based on self-reported length of unconsciousness. Nochi (1998) did not report severity of injury.

The vast majority of participants across all the reviewed studies were TBI survivors, mostly with severe injuries; the mild injuries were fairly represented, whereas injuries of moderate severity were poorly represented. This raises the question of how generalisable the findings are across levels of severity, and indeed to the wider ABI population considering that the majority of cases are mild ABIs, with moderate cases accounting for 8-10% and severe cases for less than 10% (Lezak *et al.*, 2004).

1.7.5.3.2 Current level of functioning

Most participants were recruited from people living in the community, from support groups and organisations (Guise *et al.*, 2010; Levack *et al.*, 2014; Nochi, 1998), or who were attending neurorehabilitation services (Carroll & Coetzer, 2011; Cooper-Evans *et al.*, 2008; Gracey *et al.*, 2008; Keppel & Crowe, 2010; Tyerman & Humphrey, 1984), or who were known from participating in previous research studies (Cantor *et al.*, 2005), or who had been discharged directly home from the acute hospital (Ellis-Hill & Horn, 2000). The participants in Wright and Telford's (1996) study had been identified while in a general hospital at the time of the injury, and followed up six months and three years after the injury, being unclear at what stage in their recovery they were at those times; whereas the participants in Ellis-Hill *et al.*'s (2000) study were first interviewed while in hospital, then again at six months and a year. However, the stage of recovery may not be as relevant as Wright and Telford (1996) found no significant differences between ratings of self-states over time, at six months compared to three years after the injury.

All participants had to have sufficient language and communication abilities to enable them to complete questionnaires or take part in interviews or study related activities/discussions, those with severe communication difficulties being excluded. Also, most studies seemed to employ participants who were generally at the more able end of the spectrum, limiting the generalisability of findings. However, Pallesen (2014) ensured there was reasonable variation regarding functional ability, and also included three individuals with a degree of aphasia.

The premorbid level of functioning, and indeed the degree of decline may be important factors in terms of impact on someone's sense of self post injury. Only two studies, both of which were with severe TBI, considered the pre-morbid level of cognitive functioning and the degree of decline. In the Tyerman and Humphrey's (1984) study, 72% suffered generalised intellectual impairment following injury and 84% exhibited memory/learning impairment (as measured by a battery of cognitive tests including WAIS, NART), with a mean of 95.1 for current level of intellectual functioning (WAIS). Cooper-Evans *et al.* (2008) also showed a decline in the participants' level of cognitive functioning, mean WTAR FSIQ was 103.11 and mean WAIS-III-R FSIQ was 89.45; however, no significant relationship was found between the degree of cognitive decline and level of self-esteem. Gracey *et al.* (2008) reported participants were in the average range of pre-injury intellectual functioning on the Speed and Capacity of Language Processing "Spot the Word" subtest (SCOLP; Baddeley *et al.*, 1992) but did not report current intellectual level.

1.7.5.3.3 Sample size

The total sample sizes in the quantitative studies ranged from 19 (Cooper-Evans *et al.*, 2008) to 36 (Write & Telford, 1996). Although the total sample size employed by Wright and Telford (1996) was 50, only 36 completed the self-change measure, and since this is the focus of this review it was this sample size that was considered instead. The mean sample size was 27. Only two studies used a 'non-injured' control group, with a sample size of 26 (Ellis-Hill & Horn, 2000) and 36, respectively (Wright & Telford, 1996), with a mean sample size of 31. The former control group was only matched for age and gender, whereas the latter was also matched for other variables such as socio-economic and marital status, and history of mental health problems, which could be considered a strength of the latter study.

All studies thus had relatively small sample sizes. This raises the question of whether there was sufficient statistical power, which might weaken the conclusions that can be made from the findings.

In the qualitative studies, there were ten TBI survivors in Nochi's (1998) study, 49 TBI survivors in Levack *et al.*'s (2014) and 32 ABI survivors in Gracey *et al.*'s (2008); Ellis-Hill *et al.* (2000) interviewed 8 stroke survivors together with their spouse; Guise *et al.*'s (2010) study employed 12 stroke survivors and five people who were carers

for some of the survivors; whereas Pallesen (2014) interviewed 15 stroke survivors, with a family member taking part in a section of the interview in six of the interviews.

1.7.5.3.4 Gender

All studies employed a mixed-gender sample, apart from Guise *et al* (2010) who did not specify the gender of the stroke survivors.

In five of the eight studies with TBI survivors (Carroll & Coetzer, 2011; Cooper-Evans *et al.*, 2008; Gracey *et al.*, 2008; Levack *et al.*, 2014; Write & Telford, 1996), there were more males than females, consistent with the male-female ratio in the TBI surviving population where the incidence of TBI is significantly higher in men compared to women. Cantor *et al.*, (2005) and Nochi (1998) had an almost equal ratio of males and females (11:10 and 6:4 respectively), thus females being overrepresented, and another study (Tyerman & Humphrey, 1984) had mostly males (23:2), with males being possibly overrepresented.

In the other studies with stroke survivors, there were more females than males (20:13) in Keppel and Crowe's (2010) and more males than females (16:10) in Ellis-Hill and Horn's (2000) and Pallesen (2014; 10:5); in Ellis-Hill *et al.*'s (2000) qualitative study there were 5 male and 3 female. Stroke incidence is approximately 25% higher in men than in women, but as women generally live longer than men, there are more strokes in women (Townsend *et al.*, 2012). It is unclear to what degree the samples used in these studies are representative of the general stroke population in terms of gender.

1.7.5.3.5 Age

The age ranges of participants varied amongst the studies. The studies with TBI survivors used a wider age range, from 17 (Tyerman & Humphrey, 1984) to 86 (Wright & Telford, 1996), with the mean age ranging from 22 (Tyerman & Humphrey, 1984) to 55 (Cantor *et al.*, 2005). In the studies with stroke survivors, participants ranged in age from 42 to 84 (mean not reported; Pallesen, 2014); 50 to 83 (mean age of 71; Ellis-Hill & Horn, 2000) or from 56 to 82 (mean age of 67; Ellis-Hill *et al.*, 2000). Keppel and Crowe (2010) recruited stroke survivors who were under 60 years of age but did not state the mean age, whereas Guise *et al.* (2010) recruited

participants who suffered a stroke before the age of 55 but did not report the age of the participants at the time of the study.

It could be argued that age could have an impact on someone's sense of self in terms of the extent of roles and activities one is engaged in at different stages in their life, but also in terms the strength of their sense of identity at various ages. The age ranges used in the studies seem representative of the populations investigated, with a younger population in the TBI samples, and an older population in some stroke samples. Additionally, the younger stroke survivors were the focus of Keppel and Crowe's (2010) and Guise *et al.*'s (2010) studies, suggesting that the results may be generalisable to the wider stroke population.

1.7.5.3.6 Other sample characteristics

Some studies reported additional information regarding the sample they employed. There were no additional neurological problems, concurrent difficulties with substance misuse or severe psychiatric disorder (Carroll & Coetzer, 2011; Gracey *et al.*, 2008), no previous physical disability (Ellis-Hill *et al.*, 2000; Ellis-Hill & Horn, 2000), no history of psychiatric disorder (Keppel & Crowe, 2010), no gross language impairments (Cooper-Evans *et al.*, 2008) and no history of neuropathology, cognitive difficulties (Ellis-Hill *et al.*, 2000; Ellis-Hill & Horn, 2000; Keppel & Crowe, 2010).

However, Wright and Telford (1996) did include participants with history of mental health problems (12%), and participants with a previous head injury (34%), although it is unclear what the percentage was amongst those who completed the self-concept measure. Also, Pallesen (2014) included seven participants with cognitive problems in varying degrees such as difficulties with speech processing, overview, planning, concentration and memory, and three had moderate aphasia. It could be argued that the samples employed in the latter studies were more representative of an ordinary community sample.

On the other hand, having a previous head injury could be a confounding variable as could previous physical disability or chronic illness, including mental health, as it would be difficult to ascertain the level of distress associated with the brain injury itself, as opposed to other factors. On the other hand, the exclusion criteria employed by the studies discussed also means that samples are of relatively well

participants, which has implications for generalising the results to the wider ABI population.

1.7.5.4 Study design and methodology

1.7.5.4.1 Quantitative methodology

The quantitative studies included in this review were cross-sectional; two of the studies were also longitudinal as they assessed post-injury self-concept (Wight & Telford, 1996) and self-esteem (Cooper-Evans *et al.*, 2008) respectively, at two different points in time. All studies employed a within-participants design, comparing measures of self-concept or self-esteem (Cooper-Evans *et al.*, 2008; Keppel & Crowe, 2010) pre-injury (assessed retrospectively) and post-injury. Ellis-Hill and Horn's (2000) study also included a comparison group to investigate self-concept in a non-injured group, and compared the stroke and the non-injured group, but only on measures of psychosocial functioning. Also, the comparison group was formed by hospital volunteers who were likely to be particularly active or more positive people, thus increasing the risk of selection bias. Wright and Telford (1996) also employed a control group, and compared the two groups on measures of self-concept, as well as on emotional distress.

Some studies (Cantor *et al.*, 2005; Carroll & Coetzer, 2011; Wright & Telford, 1996) also carried out correlational analyses between emotional distress and self-discrepancies. Wright and Telford (1996) also did this for the non-injured group. Although Cooper-Evans *et al.* (2008) did investigate the association between self-esteem and mood, it was the current level of self-esteem, rather than the discrepancy between pre and post injury ratings, that was considered.

Cross-sectional studies collect data at one point in time, therefore it could be argued that the participants' view of themselves may vary at different points in time. One of the studies (Cooper-Evans *et al.*, 2008) measured self-esteem at two weeks follow-up as well, which was a strength of this study, showing that self-esteem was stable over time. However, it could be argued that the interval between the two measures was too short. Another study (Wright & Telford, 1996) assessed self-concept and emotional distress at two points in time, six months (time 1) and three years post injury (time 2), respectively, and showed no significant differences over time in terms

of self-concept ratings. However, the number of participants at time 2 had been dramatically reduced compared to time 1; only 41% completed the self-concept measure and 43% completed the mood measure at time 2, respectively, meaning that this analysis was carried out with only 15 participants.

Additionally, showing a change in identity does not necessarily mean that this change is caused by the brain injury. Therefore, using comparison groups (Ellis-Hill & Horn, 2000; Wright & Telford, 1996) constitutes a methodological strength in that it clarifies this relationship. Furthermore, using a correlational design, like in the case of the studies that investigated the relationship between identity change and psychological distress, would not imply a causal relationship between the two variables.

1.7.5.4.2 Qualitative methodology

Different methodologies were used by the six qualitative studies included in the systematic review. One of the earlier studies used the grounded theory method (Glaser & Strauss, 1967; Corbin & Strauss, 1990) to discover main themes and categories in the experiences of loss of self of TBI survivors (Nochi, 1998). Face-to-face semi-structured interviews were conducted using open-ended questions about life before the injury, rehabilitation experience, present concerns, and future expectations. Additional information was also collected through participant observations by the researcher while joining in the activities in which the respondents frequently took part; from the postings of three participants from a TBI support list over a period of a year, referring to their thoughts, feelings and experiences regarding themselves and their brain injuries; and through personal correspondence. This yielded about 50 hours of interviews and observations; concepts relating to self-image were identified and organised in categories. The findings were confirmed by a senior researcher who read researcher's analytic memos, and by eight TBI survivors, including some of the participants, who read a manuscript about the findings.

Grounded theory was also the methodology used by Levack *et al.* (2014) as their study aimed to develop a framework for the operationalisation of impact of TBI on self-identity, being intended as the first step in developing a psychometric measure. Data was collected via eight focus groups meetings with four to nine TBI survivors in each, which were attended by two researchers. Participants were invited to talk

about how TBI and its consequences had influenced their sense of who they were as people, and factors that they thought helped them or others regain a positive sense of self-identity after TBI. The discussions were digitally recorded and transcribed verbatim. Data analysis was carried out using NVivo software (QSR International), and occurred concurrently with ongoing data collection, thus data from each focus group influenced the refinement of questions in subsequent meetings. Initial coding was undertaken independently by two researchers who then compared and debated their findings, along with personal reflection, before sharing the initial analysis for discussion with the research team. Instances incongruent with the emerging model were used to further test and explore the emerging theory, and data collection continued until theoretical saturation was reached.

On the other hand, Ellis-Hill *et al.* (2000) carried out life narrative interviews with eight stroke survivors (and their spouse) while in hospital, and six months and one year post-discharge, yielding 24 interviews. Participants were told that the researcher was interested in how they felt the stroke related to their overall lives. The topics covered in the first interview were life from childhood onwards, the stroke event, hospital experiences, and views of the future; second interview covered hospital experiences and views of the present and future; last interview explored participants' experience from first having the stroke, including first being at home, and their views of the present and future. The texts were analysed by one researcher to explore themes relating to the stroke; interviews were compared within participants to see if/how the themes changed over one year; and similarities/differences between the themes were compared for all the participants. A sample of the transcripts was read by two independent assessors and the themes identified were compared, discussed and agreement reached.

In order to aid understanding of self and identity changes post-brain injury, Gracey *et al.* (2008) adopted a constructivist epistemology (Neimeyer & Neimeyer, 1993). Representations making up the self-concept were operationalised as dichotomous personal constructs, as defined in Kelly's personal construct psychology, and themes were identified using the inductive phenomenological thematic analysis procedure of Boyatzis (1998). A personal construct elicitation method (Fransella *et al.*, 2004) was used to identify constructs relating to pre-injury, current (post-injury) and ideal (post-injury) selves in structured group discussions with 2-5 participants. The data

collected from a the first sub-sample of 18 participants were analysed first, then the data from a second sub-sample, comprising of 14 participants, were used for development of initial themes derived from the first sub-sample, and for verification and reliability of coding.

In their study with stroke survivors, Guise *et al.* (2010) examined the ways in which survivors talk about early stroke and its effects on identity, by adopting a social constructionist perspective. The data were collected via focus group interaction and analysed using a discourse analytic methodology, which focuses on the use of language; discourse is seen as a phenomenon in its own right with specific properties that impact on people and social interactions, rather than merely a medium that facilitates access to people's inner worlds. Thus the focus was on issues of identity as they arose in the talk of stroke 12 survivors and five carers. Participants were invited to discuss the question 'in what ways has your illness affected you as a person?', and recurrent patterns were identified in the data.

More recently, Pallesen (2014) interviewed participants from a previous questionnaire study which had been aimed at isolating characteristics of a stroke population 5 years after first stroke, and focusing on functioning and health. Semi-structured interviews were conducted from a social-phenomenological theoretical perspective to explore survivors' perceptions and interpretations of their own experiences; they addressed how the participants experienced their body and their self-identity, how their disability influenced daily living and how this had changed since the stroke. The interviews were conducted in the stroke survivors' homes, and were sometimes supplemented with telephone conversations and e-mail correspondence. In a few cases, a family member also took part in a section of the interview, mainly to help with supplementing the stroke survivor's memories, and only if requested by the interviewee; the data from the stroke survivors and family members were analysed separately. The analysis and interpretation was inspired by Giorgi (1975) and Kvale and Brinkmann (2008), and supported by NVivo 8 computer programme. The analytical process involved provisional thematisation of each individual interview, then an analytical generalisation of the material was carried out; this also involves condensing the expressed views and experiences and thereby deriving still more essential meanings (Kvale & Brinkmann, 2008). A reflective log book was also kept.

1.7.5.5 The measurement of self-discrepancies and psychological distress

The tools used in the quantitative studies to measure self-discrepancies and psychological distress will be outlined below.

1.7.5.5.1 Self-discrepancy measures

In order to measure changes in self-concept in their study, Tyerman and Humphrey (1984) devised a 20 item Semantic Differential Scale, which was adapted from Osgood *et al.* (1957, as cited in Tyerman & Humphrey, 1984). This was a self-report measure comprising of adjective pairs seen as pertinent to severe head injury (e.g. bored-interested, helpless-in control, aggressive-unaggressive), rated on a seven-point scale. This became known as the Head Injury Semantic Differential (HISD) and was later modified following clinical practice, by adding or replacing items. Different versions of this, with reported good psychometric properties, were used by other three studies in this review, which makes them more comparable. All these studies retrospectively measured the past (pre-injured) self, 6 months before injury (Ellis-Hill & Horn, 2000; Tyerman & Humphrey, 1984; Wright & Telford, 1996) and the present (post injured) self. Tyerman and Humphrey (1984) and Wright and Telford (1996) also measured future self. In addition, Tyerman and Humphrey (1984) asked participants to rate how they perceived a typical head injured person and a typical person of their own age and sex.

On the other hand, Cantor *et al.* (2005) used the Selves Interview (SI) and the Selves Adjective Checklist (SAC) to measure pre and post injured selves, together with ideal and ought selves. The SI was a modified version of Higgins' (1987) Selves Questionnaire (SQ) and involved asking the participant to describe different self-states by providing at least six brief descriptors for each state, and then rate each descriptor on a scale of 1 (slightly true of me) to 5 (extremely true of me). The SAC was specifically developed for their study; instead of generating descriptors, participants selected from a given list of descriptors, comprising of 38 paired antithetical adjectives (e.g. calm-anxious), by choosing the adjective in the pair that was most descriptive of the self-state being evaluated. However, the correlations between SAC and SI were not statistically significant, raising the question of whether they both measure self-discrepancy. Furthermore, the SQ was criticised in the past as not distinguishing between the self-discrepancies. Also, it could be argued that

generating descriptors may be more difficult for people with ABI due to retrieval or executive function difficulties.

In addition to using psychometric tools, Wright and Telford (1996) also interviewed participants in terms of psychological changes since the injury. Unlike the SI where participants are asked to provide descriptors, this interview involved inquiries relating to motivation, aggression, difficulties with family and social relationships, feeling change in self, restriction in social activities and details of return to work. This may have helped the participants to describe themselves by providing a framework, and without imposing specific descriptors.

Both studies that investigated a discrepancy between pre and post-injury self-esteem (Keppel & Crowe, 2010; Cooper-Evans *et al.*, 2008) used the Rosenberg Self Esteem Scale (RSES) (Rosenberg, 1965), which makes it easier to compare these studies. RSES represents a global sense of self-worth and consists of 10 items rated on a 4-point scale, from strongly agree to strongly disagree. The items reflect feelings about self and are either positive, “on the whole, I am satisfied with myself” or negative, “I certainly feel useless at times”. The measure is widely used, including with brain injury populations (Vickery, Sepehri & Evans, 2008), and has high reliability and construct validity (Crandall, 1973; Rosenberg, 1965; Wylie, 1974). Carroll and Coetzer (2011) also used this measure, however only for rating current self-esteem.

In addition to RSES, Keppel and Crowe (2010) also used the Tennessee Self-Concept Scale – second edition (TSCS: 2), shown to have high reliability and internal consistency (Fitts & Warren, 1996). The scale consists of 82 self-descriptive statements, rated on a 5-point scale from ‘always false’ to ‘always true’, that assess self-concept on several dimensions: Physical, Moral, Personal, Family, Social and Academic/Work. Scores are provided on each dimension, along with a total self-concept score as a measure of global self-concept. Keppel and Crowe (2010) used only three dimensions in the analysis in their study: the physical self-concept scale (PHY), the personal self-concept (PER) and the total self-concept (TOT). PHY reflects the person’s view of their body, state of health, physical appearance, skills and sexuality. This is highly associated with global self-esteem across the lifespan, and is pertinent to the physically disabled. PER is a personality factor independent of

general self-esteem, seen as a good indication of overall personality integration, reflecting the person's self-worth, feeling of adequacy as a person (Fitts & Warren, 1996). TOT reflects the person's overall self-concept and associated levels of self-esteem, and was found to correlate highly with the HISD Scale (Vickery *et al.*, 2005). However, Keppel and Crowe (2010) referred to PHY, PER and TOT as measures of self-esteem.

Finally, probably the greatest limitation of all studies reviewed is that they used retrospective appraisals of self-concept or self-esteem, which can be an important source of bias; thus, reports may not be reliable, due to memory problems or a possible tendency to idealise pre-injury self (Wright & Telford, 1996).

1.7.5.5.2 Measures of psychological distress

All but one of the seven quantitative studies included in the review also measured psychological distress. As the current study focuses on the relationship between self-discrepancy and affective distress (namely anxiety and depression), this review will consider only the psychometric tools for anxiety and depression that these studies employed.

Three studies (Carrol & Coetzer, 2011; Cooper-Evans *et al.*, 2008; Ellis-Hill & Horn, 2000) used the Hospital Anxiety and Depression Scale (HADS), which has sound psychometric properties (Zigmond & Snaith, 1993). This is a brief, 14-item self-report questionnaire that provides a measure of overall psychological distress as well as separate scores for anxiety and depression, respectively, which can be compared to cut-off scores. It is useful in measuring distress in people with brain injury because of emphasis on affective and behavioural aspects while excluding items related to physical difficulties. The HADS has also been validated in the brain injury population, including stroke (Aben *et al.*, 2002; Johnston *et al.*, 2000). However, it can be argued that some items can be the direct result of the brain injury rather than a reflection of mood. For instance, the item 'I can enjoy a good book or radio or TV programme' can be related to language or cognitive impairment and the item 'I feel as if I am slowed down' can be related to motor or language or cognitive impairment.

Tyerman and Humphrey (1984) used the Leeds Scales of Anxiety and Depression (LSAD) (Snaith *et al.*, 1976), comprising of 15 items describing common symptoms

and anxiety and depression. However, no psychometric properties were reported for this measure.

On the other hand, Cantor *et al.* (2005) used two separate measures for assessing depression and anxiety, the Beck Depression Inventory second edition (BDI-II) (Beck *et al.*, 1996) and the Beck Anxiety Inventory (BAI) (Beck, 1993). They are both 21-item self-report measures, and widely used with people with TBI (Fleming *et al.*, 1998; Trahan *et al.*, 2001; Wallace & Bogner, 2000). BDI-II addresses somatic, affective and cognitive aspects of depression, used to quantify the level of depression. The BAI addresses subjective, somatic and panic-related symptoms associated with anxiety. While previous research showed that these measures of affective symptoms are consistently correlated with self-discrepancies (Strauman, 1992), both the BAI and the BDI-II contain somatic items which in the case of people with a brain injury may be more related to the injury itself rather than emotional distress.

Although not a measure of anxiety or depression per se, the General Health Questionnaire was employed by Wright and Telford (1996) to assess psychological distress. This is a self-report measure of current mental health that focuses on two major areas – the inability to carry out normal functions and the appearance of new and distressing experiences. The 12 item version was used (GHQ12), each item being rated on a four-point scale. The GHQ12 has satisfactory reliability and validity (Banks, 1983; Goldberg & Williams, 1988). Furthermore, like in the case of the BAI and BDI-II, somatic symptoms following brain injury may confound the results, resulting in false positives. To adjust this, the researchers raised the cut-off by one point.

1.7.5.6 Key findings

The studies included in the review examined a change in either self-concept or self-esteem following ABI, either stroke or TBI. Although other aspects were sometimes investigated, this section focuses on the findings related to a perceived difference in identity/self-esteem, affective distress (anxiety and depression), and associations between self-discrepancies and distress.

While the qualitative studies provided rich evidence of the experienced change in self-concept following injury, both as subjective and social experience, it can be argued that their generalisability is limited. However, their findings were supported by quantitative studies, which are sensitive to assessing and measuring identity change, but lack the specificity of the qualitative approaches. It is important, when considering the findings described below, to bear in mind the methodological limitations of the studies reviewed (see Tables 1.5 and 1.6).

1.7.5.6.1 Change in self-concept and self-esteem

All studies showed that individuals experienced a change in self-concept after the injury. In his qualitative study with TBI survivors, Nochi (1998) found a common theme in their narratives whereby survivors compared a new self-image, developed after the trauma, with another self-image maintained from before the injury, a common story in their narratives being that whatever they were like before the injury, they were not like that after the injury; and the difference between these two self-images can lead to the experience of loss of self. This was illustrated with a couple of examples of a survivor who was suffering from fatigue, stating that since the injury they stopped working on “automatic” and everything is done “manually”; and another survivor who experienced a difference in the quality of his feelings about his young son. Thus the difference resulting from such comparisons can be related to social interactions as well as functional status. Two participants in Nochi’s (1998) seemed to cope by focusing on negative aspects of their lives before the accidents to emphasise positive aspects of their present lives.

The concept of loss or change in self-identity following TBI was one that clearly resonated with the participants in Levack *et al.*’s (2014) large qualitative study, which is a particularly strong study in that provides a sound foundation for the development of a measure of self-identity after TBI. Although the extent of the change differed from individual to individual, many continued to struggle with this years after physical recovery from the initial injury had plateaued. The overarching theme was that of desiring to be or having lost a sense of being an integrated, valued person. Many participants experienced a profound disruption to their sense of wholeness as a person as the abilities and roles based on which personal attributes were previously derived were no longer available, a common experience being of feeling as if one’s

self-identity had become fragmented, whereas some referred to their 'self' prior to TBI and their 'self' after TBI as two separate identities (e.g. "I'm probably like Dr Jekyll and Mr Hyde. There's two of us."; "it was literally like I'd stepped into someone else's shoes."). However, some participants described positive experiences such as 'growing' as an individual after TBI, or feeling like a stronger or better person (i.e. being more giving, empathic, friendlier).

Being somehow fundamentally changed following injury was a recurring theme in Ellis-Hill *et al.*'s (2000) study of the life narratives of stroke survivors up to a year following their stroke, with the stroke challenging the individual's whole being; one survivor described being shattered by the stroke and being "only half a person". On the other hand, five years after their stroke, survivors in Pallesen's (2014) study saw themselves as fundamentally the same people as before the stroke, suggesting some identity reconciliation further down in the recovery journey; however several considered that "they were struck by a bolt out of the blue, whose consequences they will always have to live with" (p237).

Taking a personal construct approach to understanding how ABI survivors make sense of themselves, Gracey *et al.* (2008) identified salient patterns of self-construing by eliciting bipolar constructs through systematic comparison of pre-injury, current and ideal selves. Most self-constructs (25%) were categorised into a theme relating to the "experience of self in the world", defined in terms of activity or social participation and the perception of self in this context. More specifically, the constructs in this theme referred to belonging (e.g. not fitting in - feeling part of things), independence (e.g. being able - feeling like a waste of space), activity (e.g. engaged – loss of key activities), and assertiveness and confidence (e.g. believing in oneself – lacking confidence). The second most frequent self-constructs were categorised as "basic skills", referring to cognitive, physical, sensory and social ability (e.g. energetic – tired, rude – polite). This was followed by the "experience of self in relation to self" theme, referring to self-reflections (e.g. self-acceptance). Finally, survivors also construed themselves in terms of emotional experiences (e.g. happy – depressed, stressed – relaxed), lifestyle and motivation. These findings suggest that the differences in self-construing post-injury refer particularly to the personal meanings and feelings associated with practical and social activity, as indicated by the most frequent constructs; and also with the experienced changes in

cognitive, physical, sensory and social ability, as well as, with existential concerns. The constructs elicited in this study are the product of the interaction between a specific group of individuals in a specific context, and possibly narrower than an individual's self-construing due to limitations imposed by using only three elements (pre-injury, post-injury and ideal selves), and therefore they are not exhaustive. However, Gracey *et al.*'s (2008) study could be considered a particularly strong study as the personal construct approach confers it both sensitivity to the subjectivity of the individual, and rigour.

A change in survivor's sense of self is also supported by quantitative evidence. All studies found an effect despite using relatively small samples, however, apart from Carrol and Coetzer's (2011) study, it is unclear whether using parametric analyses was justified (Cantor *et al.* (2005) and Ellis-Hill and Horn (2000) rightly used non-parametric statistics).

Furthermore, the post-injury self was perceived as significantly more negatively than the pre-injury self, both in the case of stroke and TBI survivors: Carroll and Coetzer (2011) reported $t(28) = 4.61, p < .001$; Wright and Telford (1996) reported $t(35) = 4.21, p < .0001$; Keppel and Crowe (2010) showed significant negative changes on all three self-concept measures (PHY: $t = -3.59, p = .001$; PER: $t = -3.03, p = .005$; TOT: $t = -2.60, p = .014$). Ellis-Hill and Horn (2000) reported a significant difference in the summed pre and post-injury self-concept scores ($p = .0003$); and Tyerman & Humphrey (1984) reported only the changes on individual self-concepts, and showed significant differences on all apart from three (unfeeling-caring, withdrawn-talkative and unfriendly-friendly). Although a relatively weaker study (smallest sample, unvalidated measures of self-concept; see Table 1.6), Cantor *et al.* (2005) also found a negative change post-injury; however, it is unclear whether this was statistically significant as they reported only the means and standard deviations of the pre-post comparisons. Self-esteem ratings were also significantly lower for post-injury compared to pre-injury: Cooper-Evans *et al.* (2008) reported $t(21) = -3.43, p < .01$, and Keppel and Crowe (2010) reported $t = -3.24, p = .003$. Additionally, Carroll & Coetzer (2011) also found negative associations between identity change and self-esteem ($r = -.365, p < .05$).

Only a couple of studies assessed self-concept / self-esteem at a later point in time, which is a relative strength of these studies; post-injury levels of self-esteem and self-concept were shown to be consistent over time, after two weeks (Cooper-Evans *et al.*, 2008) and three years (Wright & Telford, 1996). However the number of participants in the latter study dropped at follow-up by more than 50%, which might have influenced the findings. Nonetheless, this suggests that survivors' experience of change in their sense of self is enduring and thus time since injury may not have relevant influence on self-concept.

A prominent theme in Ellis-Hill *et al.*'s (2000) study with stroke survivors was a changed relationship with their body, experienced as a split between the self and the body which are normally seen to be inseparable, a sense of self emerging through the relationship of the body with the external world (Leder, 1990; Merleau-Ponty, 1963 both cited in Ellis-Hill *et al.*, 2000). Formerly taken for granted, after the injury the body is experienced as separate and out of control, and becomes very much part of conscious awareness as it is seen as unreliable and perplexing; furthermore, the body is experienced as rebellious - being uncooperative, only allowing the person to do what they wanted to do slowly or with great effort, or preventing them from doing it altogether. This is echoed in Pallesen's (2014) study which showed that the body was experienced as an inconvenience, at times also as unreliable and forcible presence, which then led to an altered life (e.g. more inactive), survivors recounting how ordinary, everyday tasks required extra attention and concentration. Thus the survivor's body seems to lie at the centre of their awareness and dependence, with the identity of body and self becoming strengthened, since their physical condition takes up so much of their concentration and focus.

Ellis-Hill *et al.* (2000) found that the self-body relationship was still the focus a year after stroke. Furthermore, Pallesen (2014) found that situations that either split the identity of the body and the self or demanded a revision of self-perceptions were still common, even five years on, however, the self-body relationship was experienced in a less distinct way. This has also been shown to be a dynamic relationship that becomes more apparent in social situations as bodily experiences take place in interaction with their surroundings and in the company of other people. Consequently, the survivors are faced with the challenge of having to explain to others the change that they do not really understand themselves, and feeling "like a

freak” because of not being like before (Ellis-Hill *et al.*, 2000). This is congruent with another theme identified by Nochi (1998) which is the loss of self in the eyes of others whereby the discrepancy between self-images seems more evident when being around other people; TBI survivors felt that the message received from others was that they were not the person whom they believed to be, and imposing a negative label upon them, such as being defined as “crazy”. Pallesen (2014) also showed that in addition to loss of continuity in relation to the person they were formerly, stroke survivors also described a loss of the image others had of them. And for the participants in Levack *et al.*'s (2014) study, others (partners, family, friends, co-workers, health professionals) could strengthen or undermine an individual's sense of self and their perceived status as a 'person' in society by how they treated the survivors in terms of respect, validation and acceptance.

Furthermore, analysing the discourse between stroke survivors and carers, Guise *et al.* (2010) found that survivors not only seemed to have acquired a 'damaged' identity following their stroke, but they displayed sensitivity to the way this was expressed in the interaction with their carers; for instance, by describing their experiences in a way that minimized the potentially negative inferences that others might make about them. For example, a change in self which was related to achieving something that the survivor would have done before the stroke, was constructed as one of motivation rather than (in)ability in order to maintain a positive identity. Also, while minimising the negative aspects of stroke and mitigating its implications on their identity, participants were sensitive to how these accounts were perceived by their carers (i.e. not inappropriately positive), who could criticise and challenge them, and offer potentially negative reformulations of these. This suggested some difficulty in maintaining a positive sense of self on the part of the stroke survivors, particularly in the presence of their carers who can play a role in maintaining damaged identities. These findings further emphasise how identity-constructions are context-dependent and can be influenced in interactions with others. It could be argued that this study used a more appropriate method of analysis, given the inter-subjective, relational nature of identity, which is co-constructed through language, and thus embedded in the realm of social discourse.

Finally, only a couple of the quantitative studies used a comparison group, which is a relative strength of these; Ellis-Hill and Horn (2000) found no significant change in

self-concept in the non-injured group, suggesting that the change in self-concept is related to the injury, in this case, stroke. Additionally, Wright and Telford (1996) found that the comparison group rated past self significantly lower than the injured group, but not significantly different for present self, or future self. This suggests that survivors may idealise their pre-injury self, which supports Tyerman and Humphrey's (1984) findings of survivors rating past self more positively overall than a typical person of same age and sex, which may then increase the self-discrepancy.

1.7.5.6.2 Psychological distress

There was a mixed picture in terms of level of psychological distress reported by participants in the quantitative studies.

In the Cantor *et al.*'s (2005) study, the majority of participants did not have clinically significant scores on either the depression (BDI-II) or anxiety (BAI) measure. Similarly, in Wright and Telford's study (1996), less than half (48%) of the participants in the injured group reported significant distress (as measured by GHQ), when the higher cut-off score was used; however, this went up to 60%, when the conventional cut-off score was used. Both these studies were with mild TBI. However, the majority of the respondents (64%) in the Tyerman and Humphrey's (1984) study, who had severe TBI, showed significant psychological disturbance, with 60% scoring as clinically depressed and 44% as clinically anxious (as measured by LSAD).

In the comparison studies, the injured group reported significantly greater symptoms than the control group, $t = 5.4$, $p < .01$ (Wright & Telford, 1996), and specifically increased anxiety ($p = .009$) and depression ($p = .0004$) (Ellis-Hill & Horn, 2000).

1.7.5.6.3 Identity change and affective distress

As discussed earlier in this chapter, both organic and psychosocial factors have been associated with depression post brain injury. One psychological factor that is emerging from this review, which may be contributing to survivors' distress post injury, is a change in their identity. Carroll and Coetzer (2011), which is also possibly the strongest of the quantitative studies in terms analysis (see Table 1.6), found that survivors' perceived change in identity was positively associated with depression (measured by the HADS depression scale), using Pearson's correlation ($r = .58$, $p <$

.01). Furthermore, significant correlations were reported by Wright & Telford (1996) between emotional distress (measured by GHQ) and differences between present and past-self ratings (-.57, $p < .001$), however, not for the control group. However, the correlation analysis used in this study was not reported.

Although a weaker study in terms of analysis (see Table 1.6), Cantor *et al.* (2005) investigated the relationship between self-discrepancies and distress in more detail, using separate measures of anxiety (BAI) and depression (BDI-II). They found significant correlations (Spearman's rho), between measures of anxiety and depression, respectively, and self-discrepancy for all the selves comparisons, but only using the SAC. Discrepancies between current actual and pre-injury actual selves were associated with depression (.82, $p < .001$) and anxiety (.54, $p = .012$). Additionally, discrepancies between the current actual and current ideal selves were significantly associated with depression (.83, $p < .001$), and also with anxiety (.54, $p = .011$). At the same time, the discrepancies between current actual and current ought selves were significantly associated with anxiety (.60, $p = .004$) and also with depression (.82, $p < .001$).

Notwithstanding being based on only three studies the evidence supports the hypothesis that post-injury distress might be explained, in part, by a perceived change in identity. This relationship merits further investigation.

1.7.6 Summary

The systematic review process identified thirteen suitable articles that investigated changes in self-concept/identity or self-esteem following ABI. The studies were reviewed with respect to their aims, samples used, methodology and findings, and their quality was assessed using formal quality frameworks.

Stroke survivors in the five studies reviewed saw themselves as different, i.e. in a negative way, somehow 'damaged', following their stroke; the remaining eight studies, involving mostly people with TBI, of either severe or mild severity, brain injuries of moderate severity being underrepresented, also showed a negative change in the sense of self of survivors, following their injury. Notwithstanding the various limitations highlighted throughout (particularly, small sample sizes, large variability in the samples, the bias of retrospective reporting, limited generalisability

of findings) the studies showed a negative change in survivors' sense of self following brain injury, regardless of the injury type. Furthermore, three of the studies reviewed, all with TBI survivors, also showed that the change in identity was positively associated with affective distress.

1.8 RATIONALE, AIMS AND HYPOTHESES OF THE CURRENT STUDY

1.8.1 Rationale

Stroke can be a debilitating event, impacting negatively on the survivors' quality of life due to its physical and psychological consequences. It is well evidenced that mood disturbance such as depression and anxiety are common following stroke, and can interfere with adjustment and rehabilitation.

Furthermore, there is a growing body of literature, provided mostly by qualitative studies, and supported by wider evidence from ABI, that following stroke, survivors experience a challenge to their identity. This was also supported by further evidence from quantitative studies, with stroke and TBI, which found significant changes in survivors' sense of self by viewing themselves in more negative terms following, compared to prior to the brain injury, regardless of the injury type. These changes have been shown to be associated with emotional problems after ABI, which has been explained using Higgins' (1987) self-discrepancy model.

This study will extend Cantor *et al.*'s (2005) pilot study with TBI survivors, aiming to examine whether there is a discrepancy between the post-stroke self and the pre-stroke self, and to explore the relationship between this discrepancy and a person's adjustment and mood.

1.8.2 Aims

In summary, this study aims to:

A1: Explore self-discrepancies in a large sample of stroke survivors:

i) the discrepancy between the post-stroke self (actual current self or self-concept) and the pre-stroke self (actual pre-morbid self).

ii) the discrepancy between the post-stroke self (actual current self or self-concept) and the ideal self.

iii) the discrepancy between the post-stroke self (actual current self or self-concept) and the ought self.

A2: Employ a correlational approach to investigate the association between self-discrepancies and anxiety, depression, self-esteem and quality of life.

A3: Employ mediation analysis to explore the mediation of the relationship between pre-post stroke self-discrepancy and affective distress through self-esteem.

1.8.3 Hypotheses

Based on the aims of the study and the literature to date, the following hypotheses will be tested:

H1: There will be a significant discrepancy in stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their pre-stroke self (actual pre-morbid self), with the post-stroke self being rated more negatively.

H2: Discrepancies between stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their pre-stroke self (actual pre-morbid self) will be positively associated with affective distress (anxiety and depression).

H3: Discrepancies between stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their ideal self will be positively associated with depression, as predicted by the self-discrepancy theory (Higgins, 1987).

H4: Discrepancies between stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their ought self will be positively associated with anxiety, as predicted by the self-discrepancy theory (Higgins, 1987).

H5: Discrepancies between stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their pre-stroke self (actual pre-morbid self) will be negatively associated with their perceived self-esteem.

H6: Discrepancies between stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their pre-stroke self (actual pre-morbid self) will be negatively associated with their perceived quality of life.

H7: Stroke survivors' perceived self-esteem will be negatively associated with affective distress (anxiety and depression).

H8: Stroke survivors' perceived quality of life will be negatively associated with affective distress (anxiety and depression).

H9: Stroke survivors' perceived self-esteem acts as a mediator in the relationship between the discrepancy in stroke survivors' ratings of their post-stroke self and their pre-stroke self, and affective distress (anxiety and depression).

CHAPTER 2

METHOD

2.1 CHAPTER OUTLINE

This chapter will describe the method used in this research study, considering the design, sample, the procedure for gathering the data, the measures, ethical considerations, and methods of analysis.

2.2 DESIGN

This was a retrospective cross-sectional study that employed a within subjects design to compare perceived changes in the self-concept of stroke respondents. Correlation analyses were used to determine relationships between self-discrepancies and psychological distress, quality of life and self-esteem, respectively; and the relationship between psychological distress and quality of life and self-esteem, respectively. Also mediation analysis, using bootstrapping, was employed to determine whether self-esteem is a mediator the relationship between self-discrepancies (pre and post-stroke) and psychological distress.

2.3 SAMPLE

A power analysis was carried out using G Power (Faul *et al.*, 2007). To detect a small correlation of .3 with $\alpha = .05$ and power = 0.8, a total sample size of 67 would be required. Therefore, the initial sample comprised of 67 first-time adult stroke survivors (over 18 years of age).

2.3.1 Recruitment

Stroke survivors were recruited from the following sources (see Table 2.1 below for a breakdown of participants recruited from each source):

1. Voluntary stroke clubs in South Wales
2. Headway groups in the South-West of England

3. Stroke Association groups in Wales (South and West) and the South-West of England
4. Internet adverts placed on the web pages of two nationwide stroke charities, Different Strokes and the Stroke Association, and the nationwide brain injury charity, Headway.

Table 2.1: Breakdown of participants recruited from each source and data collection means

	Phone	Face-to-face	Total
Voluntary groups	0	3	3
Stroke Association	9	47	56
Headway	0	3	3
Internet advert	4	1	5
Total	13	54	67

There were a further 29 potential participants who, for reasons detailed below, did not complete stage 5 (see Procedure section 2.4).

There were four potential participants who changed their mind about taking part, at stage 5 (see Procedure section 2.4). In the case of two other participants, who also were at stage 5 (see Procedure section 2.4), data collection was aborted as one of them became distressed during the administration of questionnaires, and with regards to the other, it became apparent that they lacked understanding of the instructions, which questioned their capacity for taking part.

Eighteen potential participants who completed stage 4 (see Procedure section 2.4) did not progress to stage 5 as 12 of them were not at the stroke group when the researcher attended and 6 of them were attending a group whose coordinator could not be reached to organize a visit, despite several attempts. For 5 out of these 18 potential participants, further information was required to determine eligibility.

All these 24 potential participants were recruited via the Stroke Association.

As a result of the internet adverts, five extra potential participants expressed an interest in talking part; one was deemed not eligible as they were less than six months post-stroke (see Inclusion/Exclusion Criteria section 2.3.2) and were not

living in the UK at the time, three did not reply after they made the initial contact, and one made contact after data collection and analysis process had been completed.

2.3.2 Inclusion/Exclusion Criteria

Inclusion criteria

1. Experienced stroke after the age of 18 years.
2. Experienced one stroke; if two or more strokes were experienced, these occurred within one month of each other.
3. At least six months post stroke, but no more than 15 years post stroke (post last stroke if more than one experienced).
4. No severe communication, cognitive or perceptual difficulties to prevent the completion of questionnaires.
5. Be able to communicate well in English.
6. Have sufficient mental capacity to determine consent to participate in this study.

Exclusion criteria

1. Experienced stroke before the age of 18 years.
2. Less than 6 months post stroke, or more than 15 years post stroke.
3. More than one stroke, experienced within longer than a month between them.
4. Cognitive and/or communication difficulties of such magnitude that would make it difficult to ensure understanding or the individual's informed consent for participation.
5. Previous severe serious physical disability, learning disability, diagnosis of dementia, or Parkinson's disease.

This study was carried out in the community and inclusion/exclusion was determined by self-report and the knowledge of the stroke club facilitators about individual participants. When there was uncertainty about the eligibility of a potential participant, the researcher consulted with the stroke group coordinator and the individual's carer (if they were present at the group).

The time post injury in the samples employed by the quantitative studies that investigated discrepancy in the sense of self post ABI varied widely, from four months to a maximum of 40 years post injury (see Systematic Review section 1.7). Following consultation with the research supervisor, it was decided that at least six

months should have passed since the stroke so that participants were past the acute phase and had some time to adjust to life after stroke, and a maximum of 15 years post stroke.

It was important to ascertain whether there were cognitive and/or communication difficulties of such magnitude that would make it difficult to ensure participants' understanding when completing the questionnaires, and indeed their ability to provide informed consent for participation. Although the cognitive functioning of the participants was not assessed formally, eligibility was based on consultation with the stroke club facilitators, who knew the stroke survivors well, and the researcher's clinical judgement upon meeting and conversing with potential participants.

Previous severe physical disability was in the exclusion criteria because the emphasis of the study was on the transition from no disability to living with disability.

The participants' demographic information is outlined in Table 3.2 in Chapter 3, section 3.3.

2.4 PROCEDURE

The stages of the study are described below:

Stage 1: The study was approved by the Psychology Research Ethics Committee, Cardiff University (see Appendix 3). Approval was also obtained from the regional directors of the stroke association, all group facilitators and from the web administrators (at Stroke Association, Different Strokes and Headway). Further details about ethical considerations are given in section 2.6.

Stage 2: Potential participants were alerted to the study via the on-line advert (see Appendix 4) or via paper-flyers (see Appendix 4) distributed by their group facilitator.

Stage 3: Potential participants who indicated interest in taking part in the study, by contacting the researcher directly by email, or via their group facilitator, were given a questionnaire pack. This was distributed via their group facilitator, email or post, and included:

1. A Participant Information Sheet (see Appendix 5). This was to provide more information about the study to help potential participants to make an informed decision as to whether to take part.
2. A Reply Slip (see Appendix 6). This was to enable contact with potential participants and give them the opportunity to indicate if they wished to ask more questions about the study before deciding. They could also indicate whether they would like a summary of the research findings.
3. A Demographic Questionnaire (see Appendix 7). This is described in more detail in section 2.5.
4. A Consent Form (see Appendix 8).
5. A pre-paid envelope for those who wanted to return the Reply Slip, Demographic Questionnaire and Consent Form by post.

The Demographic Questionnaire was sent at this stage as it provided useful information for alerting the researcher whether there were questions regarding some aspects of eligibility (e.g. time since stroke, number of strokes).

Stage 4: Participants returned their Reply Slip, Demographic Questionnaire and Consent Form, whilst at the group, by email or by post. In the one case where the participant chose to email the consent form, they were asked to email confirmation that they read the information and that they agreed to sign the consent form, prior to completing the questionnaires. In a small number of cases, consent was obtained over the telephone, by providing confirmation that they read the information and expressed their agreement to sign the consent form, and a note dated and timed of this was made separately.

Stage 5: A battery of questionnaires was administered to the participants who met inclusion criteria, and were still interested to take part. The administration was carried out in one of the following ways: face-to-face, individually or in a small group of participants (maximum 5) at the stroke club, or individually via the telephone. The administration was carried out in a one-off session which lasted 45-60 minutes, including a 10-15 minute break.

The measures (see section 2.5) were administered in the following order:

- The Head Injury Semantic Differential III to assess pre-stroke self
- The Barthel Index
- The Stroke Specific Quality of Life Scale
- The Rosenberg Self-Esteem Scale
- The Hospital Anxiety and Depression Scale

Break

- The Head Injury Semantic Differential III to assess post-stroke self
- The Head Injury Semantic Differential III to assess ideal self
- The Head Injury Semantic Differential III to assess ought self
- Open question

Stage 6: Participants were given or sent a thank you and debriefing letter (see Appendix 9).

Stage 7: Participants who indicated that they wished to receive a summary of the results of the study were sent this by October 2014.

2.5 MEASURES

The questionnaire consisted of a demographic questionnaire and a battery of validated questionnaires:

2.5.1 Demographic Questionnaire (see Appendix 7)

Participants were asked to complete a demographic survey. The purpose was to provide an overview of the sample and an indication of issues of interest. Items were identified via the literature search and through consultation with research supervisor, who has expertise in stroke. Items included information about age, gender, education, marital status, occupational status, length of time since stroke, number of strokes, side of stroke, level of communication, history of previous physical disability, serious illness, or cognitive difficulties. Participants were also asked if they suffered with anxiety or depression before and after the stroke.

2.5.2 Self-Concept

The Head Injury Semantic Differential Scale – III (HISD-III; Tyerman & Humphrey, 1984) (see Appendix 10) is an updated version of the original HISD, based on the semantic differential paradigm that was piloted by Tyerman and Humphrey in 1984. For many years semantic differential methodology has been used to measure subjective constructs and is thus considered useful in studying self-concept (Ellis-Hill & Horn, 2000). The technique was originally developed by Osgood *et al.* (1957) (for a description see Snider & Osgood, 1969 and Warr & Knapper, 1968), and adapted by Tyerman and Humphrey (1984). The original HISD comprised 20 adjective pairs addressing aspects of personality considered to be pertinent to head injury (e.g. bored–interested). The pairs are rated on a 7-point scale (1 = negative pole, 7 = positive pole), giving a total possible score of 20–140, with higher scores indicating a more positive view of self. The first item is used as an example.

The scale was later revised following use in clinical practice. In 1991, two skills-related items (e.g., clever–stupid) were replaced by items with greater relevance to personality (e.g., aggressive–unaggressive) and the wording of three additional items was changed. In 1997, two items (caring–unfeeling and cooperative–uncooperative) were removed, being considered inappropriate for self-rating, and the presentation of another item (impatient–patient) was reversed to balance the positive–negative ordering of items. The items were thus reduced from 20 to 18 on the HISD III, with total score scale ranging from 20-126. A separate relatives' version (HISD-R) was also introduced (Tyerman, personal communication, 19 December 2012).

The original scale was shown to have internal reliability (Cronbach's alpha 0.88, split half Guttman's 0.87), based on the ratings of Present Self by 60 persons with very severe head injury on admission to rehabilitation. The present-self ratings of the updated version HISD II have been reported to have internal reliability (Cronbach alpha 0.93, split half Guttman's 0.93) in a sample of 42 adults with severe head injury (Tyerman, personal communication, 19 December 2012).

This scale has also been used with stroke survivors (Ellis-Hill & Horn, 2000) and was thus considered a valid instrument for the current study. Although three scales are

available (past, present and future self), ratings were obtained only for pre-stroke self (six months before the stroke) and post-stroke self (over the two weeks prior to interview). These forms were kept separate within the questionnaire to discourage participants from comparing the ratings.

According to the HISD-III instructions, as outlined by Tyerman the first item was used as an example and the participants were asked to place a mark (X) on the respective line to indicate whether they saw themselves in the past (i.e. 6 months prior to injury) as being 'greatly bored, fairly bored, slightly bored, half/half, slightly interested, fairly interested, greatly interested'. In order to facilitate rating a small change was made in that 'greatly, fairly, slightly' were added at the top of the scale (see Appendix 10).

Ratings were also obtained for actual ideal self and actual ought self. For the former, participants were asked to indicate how they would ideally like to be, in terms of their hopes, wishes, aspirations. For the latter, participants were asked to indicate how they think they ought to be or should be, in relation to their duties, responsibilities, obligations.

2.5.3 Level of Functioning

The Barthel Index (Mahoney & Barthel, 1965) (see Appendix 11) consists of 10 items that measure a person's functioning on a range of different day-to-day activities or 'activities of daily living' (Collin *et al.*, 1988), centred around personal care and mobility. It is a tool that is commonly used to assess the level of independence of stroke survivors (Kwakkel *et al.*, 2011) as it is scored on the basis of whether the person can do the task independently or with help from others. The items are scored using a scale: 0, 5, 10, 15 giving a total score of 0-100 (Mahoney & Barthel, 1965) with higher scores indicating increased independence (Kwakkel *et al.*, 2011).

The measure has been shown to be reliable and valid (see Kwakkel *et al.*, 2011 for a review). Although the measure is traditionally administered by a health professional who observes the patient, it is also possible to interview the patient or a relative to obtain scores (Kwakkel *et al.*, 2011). Self-report, as well as self-report by telephone, have also been shown to be reliable (Collin *et al.*, 1988). In this study, the original version was used and was scored based on self-report.

2.5.4 Quality of Life

The Stroke Specific Quality Of Life scale (SS-QOL; Williams, Weinberger, Harris, Clark *et al.*, 1999) (see Appendix 12) is an outcome measure intended to provide an assessment of health-related quality of life specific to individuals with stroke. It is a self-report scale, individuals having to respond to each question of the SS-QOL with reference to the past week. Scale domains and items were derived from a series of interviews with post-stroke patients (Williams, Weinberger, Harris, Clark *et al.*, 1999). There are 49 items in 12 domains: mobility, energy, upper extremity function, work/productivity, mood, self-care, social roles, family roles, vision, language, thinking, and personality.

Items are rated on a 5-point Likert scale and there are three different response sets: 'total help' (1) to 'no help needed' (5); 'couldn't do it at all' (1) to 'no trouble at all' (5); 'strongly agree' (1) to 'strongly disagree' (5). Respondents must rate each item using the corresponding response set as indicated on the scale (Williams, Weinberger, Harris, Clark *et al.*, 1999). For example, the item 'did you have any trouble doing daily work around the house?' requires the second response set, which ranges from 'couldn't do it at all' to 'no trouble at all'. Higher scores indicate better functioning. The SS-QOL yields both domain scores and an overall SS-QOL summary score. The domain scores are unweighted averages of the associated items while the summary score is an unweighted average of all twelve domain scores (Williams, Weinberger, Harris & Biller 1999).

Williams, Weinberger, Harris, Clark *et al.* (1999) examined the internal consistency of the SS-QOL in 34 individuals with stroke and found that Cronbach's alpha ranged from adequate (alpha = 0.75 for work/productivity subscale) to excellent (alpha = 0.89 for self-care), suggesting that the SS-QOL has a strong internal consistency. Excellent test-retest reliability ($r = 0.92$) was also shown (Williams *et al.*, 2000). Most domains of the SS-QOL correlate with the Barthel Index. The self-care domain was adequately correlated with the Barthel Index ($r = 0.45$); upper extremity function showed a positive but poor relationship with the Barthel Index ($r = 0.18$) (Williams, Weinberger, Harris, Clark *et al.*, 1999). The scale can also be administered to individuals with stroke reliably over the telephone (Williams *et al.*, 2000).

For the purpose of this study, the scale has been modified by removing the following domains: mobility, upper extremity function, self-care, vision and language. This was in order to retain those domains that complemented the Barthel Index by providing information on more psychological and social aspects of functioning, and to keep the overall administration time of the battery as brief as possible.

2.5.5 Self-Esteem

The Rosenberg Self Esteem Scale (RSES; Rosenberg, 1965) (see Appendix 13) is a measure of global sense of self-worth comprising of 10 items requiring respondents to rate feelings about the self on positive (“on the whole, I am satisfied with myself”) and negative (“I certainly feel useless at times”) items. The items are scored using a 4-point Likert-type scale ranging from strongly agree (4) to strongly disagree (1), with negative items being reverse scored. Scores below 25 are considered to be indicative of clinically significant low self-esteem (Anson & Ponsford, 2006),

The RSES is a widely used measure with high reliability and construct validity (Keppel & Crowe, 2000), high test–retest correlation having been shown at one and two week intervals in the general population (Fleming & Courtney, 1984). It has a strong research base and has been used with ABI populations, including stroke (Cooper-Evans *et al.*, 2008; Keppel & Crowe, 2000; Vickery *et al.*, 2005) and was therefore deemed a valid measure to use.

2.5.6 Level of Distress

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) (see Appendix 14) is a brief, 14 item, self-report questionnaire used to measure psychological distress, that yields an overall score as well as separate scores for anxiety (HADS-A) and depression (HADS-D) that can be compared to cut-off scores.

Zigmond and Smith (1983) developed this tool to detect anxiety and depression in people with physical health problems, to be used in general medical outpatient clinics, and it is now widely used in clinical practice and research (Hermann, 1997). It is a useful tool for measuring psychological distress in people with ABI, including stroke, because it emphasises affective and behavioural symptoms while excluding items related to physical difficulties. The HADS has also been validated on stroke

population (Aben *et al.*, 2002). However, it can be argued that some items can be the direct result of the stroke rather than a reflection of mood. For instance, the item 'I can enjoy a good book or radio or TV programme' can be related to language or cognitive impairment and the item 'I feel as if I am slowed down' can be related to motor or language or cognitive impairment.

The questionnaire consists of seven items related to anxiety and seven items related to depression. Five of the items assessing depression are markers for anhedonia (an inability to experience pleasure), and two concern appearance and feelings of slowing down. Two of the anxiety items assess autonomic anxiety (panic and butterflies in the stomach) and the remaining five assess tension and restlessness (Dunbar *et al.*, 2000).

Each item is scored on a 0-3 (not at all, from time to time, occasionally, a lot of the time and most of the time) scale, giving a total score of 0 - 21 for either anxiety or depression, with higher scores indicating higher levels of distress. In stroke, the recommended cut-off points range from 4/5 (Sagen *et al.*, 2009) to 7/8 (Aben *et al.*, 2002) for depression, and from 4/5 (Sagen *et al.*, 2009) to 5/6 (Johnson *et al.*, 1995) for anxiety. The HADS total score has been used as a measure of psychological distress (Aben *et al.*, 2002; Johnston *et al.*, 2000; Sagen *et al.*, 2009) for detecting both anxiety and depression.

The HADS has been found to be reliable and valid as a screening tool, sensitive to change and predictive of psychosocial outcome (Herrmann, 1997). Its construct validity and utility with stroke survivors has been shown by demonstrating its capacity to differentiate anxiety and depression and its ease of use in populations with serious physical illness (Johnston *et al.*, 2000).

Two studies have examined internal consistency of the HADS in a stroke population. Aben *et al.* (2002) reported excellent internal consistency (Cronbach's alpha = 0.85) in a study with 200 first-time stroke survivors. In a study with 68 individuals with acute stroke Johnston *et al.* (2000) found adequate internal consistency at one month post-stroke (Cronbach's alpha for the HADS-A = 0.76; HADS-D alpha = 0.79, and overall HADS alpha = 0.79); and at six months post-stroke, excellent internal consistency for the HADS-A and overall HADS (alpha = 0.87; 0.89, respectively), and adequate for the HADS-D (alpha = 0.76). Aben *et al.* (2002) also found the

mean correlation between the depression and anxiety subscales of the HADS to be excellent ($r = 0.67$).

The HADS has also been compared to other scales. A review of 747 identified papers that examined the concurrent validity of the HADS in non-stroke populations report excellent correlations between the HADS and other commonly used questionnaires, ranging between 0.49 to 0.83 (Bjelland *et al.*, 2002).

The HADS specificity and sensitivity values were found to be satisfactory (Lincoln, 2012). Three studies with stroke survivors showed that its sensitivity ranged from 0.8 to 0.92 and its specificity ranged from 0.46 to 0.79 (Aben *et al.*, 2002; Johnson *et al.*, 1995; O'Rourke *et al.*, 1998).

The HADS can also be interviewer administered in person or over the telephone for clients who may have difficulty with self-administration (Snaith, 2003). However, there are no studies that examined the validity of this form of administration in clients with stroke.

2.5.7 Open Question

At the end, participants were presented with an open question: 'In a few words, please describe yourself as you are today compared to what you were like before the stroke.' This was in order to give participants the opportunity to provide any additional information on how they perceived the changes, if any, in themselves post stroke. Responses were written down either by participants themselves or researcher, depending on participants' individual motor ability or wish.

2.6 ETHICAL CONSIDERATIONS

2.6.1 Capacity for Informed Consent

It was considered that it was unlikely for potential participants without capacity for consent to be nominated by charity workers or family, or for the potential participants to refer themselves following the adverts. Furthermore, the researcher applied their clinical judgment (based on their clinical experience of working with people with severe and enduring mental health problems, people with learning disabilities and

people with cognitive impairments) to decide if the potential participant had the capacity to give informed consent. This judgement was made during the initial conversation the researcher had with the potential participant, and involved an evaluation of their understanding and communication using simple questions.

Only once consent was given, the researcher proceeded with the administration of the questionnaire battery. The consent form (see Appendix 7) summarised the main points about participating in the study. Before completing the questionnaires with the participants, these points were reiterated, as a reminder, and to ascertain whether there was any doubt regarding the participants' capacity to provide consent and ensure that participants had made an informed decision.

If, at any stage, there were concerns that the participant may lack capacity to consent, the process came to a halt immediately and they were excluded from the study. The reason was explained and the data gathered by that point was destroyed.

2.6.2 Inducement

Potential participants were alerted to the study through the on-line advert or their group facilitator and only participants who had expressed an interest in the study were then contacted by the researcher. It was also emphasised that their participation was entirely voluntary and that they could withdraw from the study at any time and without providing an explanation, both in writing (see Participant Information Sheet and Consent Form, Appendices 4 and 7) and orally, before and during the battery administration. It was hoped that these measures reduced the likelihood of people to feel undue pressure to participate.

2.6.3. Anonymity and Confidentiality

Questionnaires were coded and participants were asked not to write their names or any personal identifiable information on them. Once the questionnaires were coded and completed, they were attached to the demographic questionnaire after removing the name of the participant from it. Reply slips were kept only when participants had indicated they wanted a summary of the results of the study, otherwise they were returned to the participants after the completion of the questionnaires. Reply slips and consent forms were kept separately from questionnaires in a locked case.

Participants were informed of the confidentiality arrangements on their participant information sheet (see Appendix 4), consent form (see Appendix 7) and debriefing letter (see Appendix 8), and reminded before completing the questionnaires.

2.6.4 Demands on Participants

In order to reduce any potential burden on participants, measures were selected that had suitable psychometric properties (see measures section, 2.5), while also being relatively quick and straight-forward for participants to complete. Due to time constraints and concerns of not being able to recruit the needed number of participants, and as the measures had already been used in previous research studies with people with brain injuries, it was decided against piloting the questionnaires with stroke survivors. However, they were trialled by the researcher on herself, allowing for extra time as might be needed when completed by stroke survivors, and they were deemed to be comprehensible and sufficiently brief.

There was some potential for distress to be caused by some questionnaire items as it required participants to reflect on the experience of themselves before and after the stroke, and on their life post-stroke. Procedures planned to minimise or respond to this distress included stopping the administration of the questionnaires immediately once a participant became distressed and offering the participants debriefing or to have a conversation with the research supervisor who is a Consultant Clinical Psychologist in Stroke Care, and whose contact details were on the correspondence given to the participants. Participants were also reminded that their participation was entirely voluntary and that they had no obligation to continue if they changed their mind for any reason. Their wellbeing was monitored throughout the administration of the questionnaires. Participants were also advised to contact their stroke club facilitator if they found any of the material upsetting.

2.6.5. Attending a Stroke Group

By entering a group setting there was the potential for disrupting routine activities and dynamics. In order to reduce this, the researcher arranged the visit in advance, in collaboration with the group facilitator, at a time that was suitable for the group, and to alert both participants and non-participants that the researcher would be attending the club. Also, the researcher introduced themselves, and briefly the study,

to the whole group. In order to minimise the disruption to the rest of the group, and to minimise distraction and ensure confidentiality, the administration of questionnaires was carried out in a separate room.

2.7 DATA ANALYSIS METHODS

The methods of analysis were as follows:

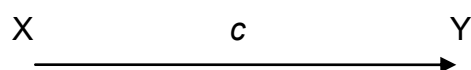
Paired-samples t-test to examine the difference between the means of stroke survivors' ratings of their pre-stroke self and of their post-stroke self.

Pearson's Product-moment correlation to determine the relationship between self-discrepancies and affective distress, quality of life, self-esteem; also the relationship between psychological distress and quality of life and self-esteem, respectively.

Mediation analysis using bootstrapping to examine the impact of self-esteem (as a mediating variable) on the relationship between pre-post stroke self-discrepancy (independent variable) and affective distress (dependent variable).

If a variable X (self-discrepancy) is assumed to have an effect on an outcome variable Y (affective distress), as modelled in Figure 2:1 below, path *c* is called the *total effect*. This total effect, interpreted as the amount by which Y changes if X changes by one unit, may be the result of both direct and indirect forces. Thus, the effect of X on Y may be mediated by a process or intervening variable, called mediator (M), and the variable X may still affect Y.

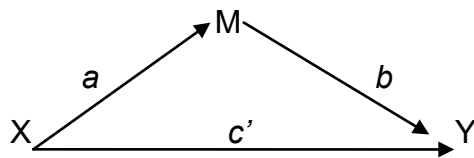
Figure 2.1: Unmediated model



A simple mediation model (see Figure 2:2 below) would postulate that variable X (self-discrepancy) exerts an effect on M (e.g. self-esteem) (path *a*), which in turn affects the outcome variable Y (affective distress) while controlling for self-discrepancy (path *b*). The mediation is the product of these two relationships (*ab*), called the *indirect effect* (Baron & Kenny, 1986; Preacher & Hayes, 2008). This is

interpreted as the amount by which Y changes if X is held constant and M changes by the amount it would have changed if X increased by one unit. Path c' is called the *direct effect*, which is interpreted as the part of the effect of X on Y that is independent of the pathway through M (Hayes, 2009).

Figure 2.2: Mediated model



If variable X no longer affects Y once M has been controlled, and thus path c' is zero, that would mean that the mediation is complete. If the path from X to Y is reduced in absolute size but is still different from zero when the mediator is introduced, then the mediation would be partial (Kenny, 2014). However, the tests of c and c' have relatively low power, especially in comparison to the indirect effect (ab); thus, caution is required about claims of complete mediation based on the non-significance of c' (e.g. Kenny & Judd, 2014). Others (e.g. Hayes, 2013) even argue that one should never make any claim of complete or partial mediation, being more appropriate to talk about the indirect effect of X on Y through M (Mathieu & Taylor, 2006).

There are several methods of testing mediation hypotheses, the causal steps approach by Baron and Kenny (1986) being the most commonly used; this focuses on the individual paths described above, assessing whether certain statistical criteria are met. However this has been criticised for being the lowest in power (Fritz & MacKinnon, 2007; MacKinnon *et al.*, 2002); the existence of an indirect effect is not tested directly, instead it is inferred logically by the outcome of a set of hypothesis tests (Hayes, 2009); and the method is prone to violations of the parametric assumption of normality (MacKinnon *et al.*, 2002; Preacher & Hayes, 2004).

Alternative methods of analyses, such as the Sobel test (Sobel, 1982; 1986), focus on the indirect effects (the product term ab). This uses a standard normal distribution for deriving a p value for the indirect effect, thus requiring the assumption that the sampling distribution of the indirect effect is normal; however, the sampling distribution of ab tends to be highly skewed (Bollen & Stine, 1990; Stone & Sobel,

1990), being normal only in large samples. Thus the test falsely presumes symmetry as it uses a normal approximation which presumes a symmetric distribution. Consequently this test has very low power.

Bootstrapping, which is a non-parametric resampling procedure (Preacher & Hayes, 2004; 2008) addresses the weakness of the Sobel test and is considered one of the more valid and powerful methods for testing intervening variable effects (MacKinnon *et al.*, 2004; Williams & MacKinnon, 2008). It directly assesses the significance of the indirect effect, and does not impose the assumption of normality of the sampling distribution; thus it is particularly suitable when data sets are small (Preacher & Hayes, 2004). Bootstrapping involves k samples of the original size being taken from the obtained data (with replacement after each specific selected number) and mediation effects are then calculated in each sample (Preacher & Hayes, 2004). In this study, parameter estimates will be based on 10,000 bootstrap samples and a bias-corrected confidence interval will be provided for the tested mediator; if lower and upper bounds do not pass through zero, the indirect effect is significant at the $p < .05$ level.

The mediation analysis is thus more than a correlational analysis as it explores the underlying mechanism of a known relationship (between self-discrepancy and affective distress), and the mediator (e.g. self-esteem) would serve to clarify the nature of this relationship.

CHAPTER 3

RESULTS

3.1. CHAPTER OUTLINE

In this chapter the results of the current study will be presented. The chapter covers preliminary data analysis carried out to ensure that the quality of the data was sufficient for the statistical tests used; the descriptive statistics for the sample and measures used; and the statistical analysis, where the results will be reported in relation to the stated hypotheses. These operations were carried out using Statistical Package for the Social Sciences (SPSS, Version 20) with additional Custom Dialogues for PROCESS to run mediation analyses (Hayes, 2013). The chapter will end with a presentation of the themes elicited through inductive thematic analysis (Patton, 1990) of the qualitative data that was generated by the open question.

3.2. PRELIMINARY DATA ANALYSIS

3.2.1. Error Analysis

Minimum and maximum values for each variable were screened in order to test whether data fell within the possible range on an item. Three data points were identified as input errors using this method and subsequently corrected after referring back to the raw data¹.

3.2.2 Missing Data

Missing data for continuous variables were relatively low (13 item scores) and randomly distributed. The maximum of data missing from any one data set was of four scores. The missing data were replaced using the scale mean for that participant.

¹ One item on the Barthel Index was incorrectly entered as '55' instead of '5'; one item on the HISD Pre-stroke and one on the HISD Ought were incorrectly entered as '77' instead of '7'.

3.2.3 Assumptions

3.2.3.1 Normality

A paired-samples *t*-test was used to test whether survivors' ratings of themselves before and after the stroke differed. As a *t*-test assumes data is normal, the distribution of HISD scores, pre and post-stroke respectively, was tested for normality using the Kolmogorov-Smirnov test. The test was non-significant for the post-stroke scores ($D(65) = 0.094$, $p = .20$) thus this assumption was met in this case. On the other hand, the pre-stroke scores were found to deviate from the normal distribution (skewness of -0.68 (SE = 0.30) and kurtosis of -0.39 (SE = 0.59)). However, the *t*-test is robust against non-normality, unless there are serious outliers (see section 3.2.3.4 below), or when sample sizes are small and distributions are far from normal (Snijders, 2011). Consequently, it was decided that using a *t*-test was appropriate; as a precaution, a non-parametric analysis, the Wilcoxon signed rank test, was also carried out.

Correlational analyses were also conducted to examine associations between self discrepancies and emotional distress, self-esteem and quality of life respectively; and between emotional distress and self-esteem and quality of life respectively. Parametric correlations also require normally distributed scores on variables (Field, 2009). This was assessed with the Kolmogorov-Smirnov test for each variable.

The discrepancy scores between pre and post-stroke selves ratings and the discrepancy scores between post-stroke self and ideal self ratings were found to be non-significant and therefore normally distributed ($D(65) = 0.079$, $p = .20$; $D(65) = 0.10$, $p = .082$, respectively). The scores for self-esteem, quality of life, depression (HAD-D) and overall emotional distress (HADS) were also non-significant and therefore normally distributed ($D(65) = 0.080$, $p = .20$; $D(65) = 0.078$, $p = .20$; $D(65) = 0.099$, $p = .19$; $D(65) = 0.072$, $p = .20$, respectively). The discrepancy scores between post-stroke self and ought self were found to deviate from the normal distribution (skewness of 0.78 (SE = 0.30) and kurtosis of -0.002 (SE = 0.59)); as were the anxiety scores (HAD-A) (skewness of 0.44 (SE = 0.30) and kurtosis of -0.64 (SE = 0.59)).

The scores for both ideal and ought selves deviated from the normal distribution (skewness of $-.99$ (SE = 0.30) and kurtosis of $.23$ (SE = 0.59); skewness of $-.49$ (SE = 0.30) and kurtosis of $-.73$ (SE = 0.59), respectively), as did the functioning scores (skewness of -1.001 (SE = 0.30) and kurtosis of $.76$ (SE = 0.59)).

As Havlicek and Peterson (1977) have found that Pearson's correlation coefficient (r) is a robust measure and that probability statements for r are accurate even when there is extreme deviation from normality, it was decided to report on correlations in terms of this measure.

3.2.3.2 Linearity

Parametric correlations require a linear relationship between variables (Field, 2009).

Scatter plots of pre-post discrepancy scores against anxiety (HAD-A), depression (HAD-D), overall emotional distress (HADS), self-esteem and quality of life respectively, were visually inspected to check for linearity. Scatter plots of post-stroke and ideal selves discrepancy scores, and of post-stroke and ought selves discrepancy scores, against depression, anxiety and overall emotional distress, respectively, were also inspected. Finally, scatter plots of self-esteem and quality of life scores against anxiety, depression and overall emotional distress respectively, were investigated. All scatter plots showed a linear distribution.

3.2.3.3 Homoscedasticity

The assumption of homoscedasticity (or equal scatter) requires similar variance at each level of the predictor variable (Field, 2009). Scatter plots as described above were visually inspected and appeared homoscedastic.

3.2.3.4 Outliers

Parametric tests assume that there are no extreme scores or outliers. Boxplots of each variable were inspected and a number of outliers were identified: there were two outliers on the pre-stroke self variable, one on the post-stroke self variable, three on the self-esteem variable and one on the level of functioning variable. These were adjusted to be one unit above/below the next highest/lowest score in the sample which was not an extreme score, as recommended by Dancey and Reidy (2004).

3.3. DESCRIPTIVES

Two datasets were excluded. In one case the stroke survivor had suffered the stroke over 15 years ago (see exclusion criteria, section 2.3.2). In the other case, the stroke survivor had a severe physical disability (see exclusion criteria, section 2.3.2), and the way they completed the ideal and ought measures raised questions about their understanding of instructions overall, which questioned the validity of that data set. The final sample therefore consisted of 65 stroke survivors.

3.3.1 Demographics of Stroke Survivor

The age of survivors ranged from 37 to 82, with a mean of 61.6, and standard deviation (*SD*) of 11.4 (see Table 3.1 below). This suggests that at least one survivor was as young as 37 years of age and that the majority of survivors were between 50 and 72 years of age. The mean time since experiencing a stroke was of 5.6 years (*SD* 4.25), range from 6 months to 15 years; six participants were under a year post stroke, ranging between 6 – 11 months, and were coded as 1 year since stroke.

Table 3.1: Stroke survivor age and years since stroke

	(<i>N</i>)	Mean	<i>SD</i>	Range
Age	65	61.6	11.4	37 - 82
Years since stroke	65	5.57	4.25	1 - 15

^a *N* = number of stroke survivors

There was a proportionate number of male (44.6%) and female (55.4%) participants; most were white British (60%), a quarter identified themselves as being Welsh (24.6%), one African-Caribbean, while nine survivors did not report on their ethnicity. The majority of the participants were married (60%) and retired (75.4%) or not working (12.3%) (see Table 3.2 below).

Only half of the participants reported on the type of stroke they experienced; haemorrhagic (21.5%) or ischemic (27.7%). Half of the participants (49.2%) reported the left side of the body was affected following the stroke, and most of the others (36.9%) reported the right side being affected, while 3 participants did not report on this. Over a quarter of participants (27.7%) reported they suffered with anxiety/depression before the stroke, which more than doubled (64.6%) after stroke. This, however, was based on their yes/no answer to the question “*Did you suffer with*

anxiety/depression before/after your stroke?” in the Demographic Questionnaire. Although the Demographic Questionnaire also contained a question regarding the level of education, the data obtained were not codable, and therefore not reported.

Table 3.2: Stroke survivor demographics ^a

		N	%
Gender	Male	29	44.6
	Female	36	55.4
Ethnicity	White British	39	60
	Welsh	16	24.6
	Other	1	1.5
	Missing	9	13.8
Type of stroke	Haemorrhage	14	21.5
	Ischemic	18	27.7
	Missing/Don't know	33	50.8
Side of body affected	Right	24	36.9
	Left	32	49.2
	Both	1	1.5
	Neither	5	7.7
	Missing	3	4.6
Pre-stroke anxiety/depression	Yes	18	27.7
	No	47	72.3
Post-stroke anxiety/depression	Yes	42	64.6
	No	23	35.4
Marital status	Married	39	60
	Separated/divorced	10	15.4
	Single/never	9	13.8
	Widowed	7	10.8
Occupational status	Retired	49	75.4
	Unemployed	8	12.3
	In employment	7	10.8
	Missing	1	1.5

^a N = number of stroke survivors; %=percentage of total sample.

3.3.2 Descriptive Statistics (see Table 3.3 below)

The participants were at a high level of functioning, as shown by the mean level of functioning score of 77.3 for the sample. Mean scores on measures of self-esteem and quality of life were $M = 25.3$, $SD = 5.55$ and $M = 67.8$, $SD = 20.7$ respectively.

In terms of emotional distress, the mean scores suggested that survivors reported similar levels of anxiety and depression ($M = 8.31$, $SD = 4.85$; $M = 7.27$, $SD = 3.74$ respectively). Most of survivors met cut-off point for post-stroke anxiety, whether 4/5 (Sagen *et al.*, 2009) or 5/6 (Johnson *et al.*, 1995); and for post-stroke depression, if

cut-off considered at 4/5 (Sagen *et al.*, 2009), whereas the 7/8 cut-off (Aben *et al.*, 2002) was met by more than half of survivors. The mean for overall emotional distress was 15.6 ($SD = 7.61$).

Table 3.3: Descriptive statistics ^a

	<i>N</i>	Mean	Max. Range Possible	Actual Range	Standard Deviation
Level of functioning	65	77.3	0 - 100	20 - 100	20.3
Self-esteem	65	25.3	10 - 40	13 - 37	5.55
Quality of Life	65	67.8	25 - 125	35 - 121	20.7
Anxiety	65	8.31	0 - 21	0 - 20	4.85
Depression	65	7.27	0 - 21	0 - 14	3.74
Overall Mood	65	15.6	0 - 42	1 - 29	7.61
Pre-Stroke Self	65	106	18 - 126	72 - 126	15.1
Post-Stroke Self	65	86	18 - 126	35 - 126	23.5
Ideal Self	65	119	18 - 126	98 - 126	7.46
Ought Self	65	115	18 - 126	95 - 126	8.93

^a *N* = number of survivors

The means on the pre-stroke and post-stroke self measures, respectively, suggested that survivors rated themselves highly, and more positively before the stroke compared to after the stroke ($M = 106$, $SD = 13$; $M = 86$, $SD = 23.5$ respectively). Survivors' ratings for the ideal and ought selves were higher than for pre-stroke self, and there seemed to be less difference between participants in terms of both how they would like to be and how they think they should be ($M = 119$, $SD = 7.46$; $M = 115$, $SD = 8.93$, respectively). Although the scores for both ideal and ought selves deviated from the normal distribution (as discussed earlier, see section 3.2.3.1), this is not surprising given that participants were asked to rate how they would ideally like to be as a person, and how they think they ought to be.

3.4 STATISTICAL ANALYSIS

3.4.1 Comparison of Means

A paired-samples *t*-test was used to test hypothesis H1: There will be a significant discrepancy in stroke survivors' ratings of their post-stroke self and their pre-stroke self, with the post-stroke self being rated more negatively.

A paired-samples *t*-test found that HISD scores for post-stroke self were significantly lower than HISD scores for pre-stroke self (mean for difference = 19.7, *SD* = 24.6; $t(64) = 6.464, p = .000$). As the pre-stroke scores were not normally distributed, a related samples Wilcoxon signed rank test was also carried out and showed a significant difference between pre and post-stroke selves ratings ($p = .000$).

Table 3.4: Changes in the self-concept scores, pre and post-stroke

HISD item	Median	Median	Sig. (2-tailed)
	(interquartile range) Pre-stroke	(interquartile range) Post- stroke	
Interested	7 (1)	6 (4)	.000
Happy	7 (1)	6 (3)	.000
In Control	7 (1)	5 (4)	.000
Relaxed	6 (4)	5 (4)	.043
Satisfied	6 (2)	5 (3)	.004
Hopeful	6 (1)	6 (4)	.001
Self Confident	7 (1)	5 (3)	.000
Stable (emotionally)	7 (1)	6 (3)	.001
Attractive (as a person)	6 (2)	5 (3)	.000
Of Value	6 (1)	6 (1)	.000
Unaggressive	6 (4)	6 (4)	.994*
Calm	6 (2.5)	6 (4)	.053*
Capable	7 (1)	5 (3)	.000
Independent	7 (1)	5 (4)	.000
Active	7 (1)	5 (4)	.000
Talkative	7 (2)	6 (3)	.002
Friendly	7 (1)	6 (1)	.000
Patient	6 (3)	6 (4)	.069*

* $p = N.S.$

Wilcoxon related samples signed rank tests were carried out for each individual HISD item and showed that survivors saw themselves as significantly less positively post stroke on most dimensions ($p < .05$). For instance, they saw themselves as less interested, happy, in control, self confident, attractive, capable, independent, active and of less value ($p = .000$). However, survivors saw themselves as similarly calm, patient, and in terms of level of aggressiveness (see Table 3.4 above).

This confirms the first hypothesis and it can therefore be concluded that stroke survivors in this sample saw themselves significantly in more negative terms than before the stroke.

3.4.2 Correlational Analyses

Correlational analyses using Pearson's Product-moment correlation were conducted to test hypothesised associations between self-discrepancies and affective distress, self-esteem and quality of life respectively, as well as associations between emotional distress and self-esteem and quality of life respectively (see H2 to H8, section 1.8.3). The results of the correlational analyses are shown in Tables 3.7 and 3.8 below. All these correlations are given in terms of Pearson's correlation coefficient (r), for which significance was tested at the one-tailed level.

A Pearson correlation matrix between continuous variables, tested at the two-tailed significance level, is also presented in Table 3.5 below. It is acknowledged that multiple comparisons increase the chance of Type 1 error across the whole series of comparisons (i.e. rejecting the null hypothesis when this is true). This can be addressed using a Bonferroni correction which involves adjusting the significance level by dividing it by the number of analyses performed on the dependent variable (Dancey & Reidy, 2004). However, in this case, the purpose of the matrix was not multiple hypotheses testing but rather to provide a context for the results and to identify other, non-predicted, potential explanatory variables for affective distress. The use of Bonferroni is not conventional when using correlation in this way (i.e. when not testing multiple hypotheses, but rather using correlations in an exploratory manner). Moreover, it is known to be conservative and could obscure potentially interesting or confounding relationships when used in an exploratory manner (Perneger, 1998; Rothman, 1990).

Table 3.5: Pearson correlation matrix of continuous variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age	-														
2. Years since Stroke	.271* .029	-													
3. Level of Functioning	-.261* .036	-.099 .431	-												
4. Self-Esteem	.182 .147	.173 .168	.195 .119	-											
5. Quality of Life	.154 .219	.033 .795	.454** .000	.638** .000	-										
6. Pre-Stroke	.242 .052	.250* .044	-.163 .194	.310* .012	.180 .151	-									
7. Post-Stroke	.229 .066	.211 .091	.439** .000	.700** .000	.676** .000	.245* .049	-								
8. Ideal	-.091 .471	-.186 .138	.223 .074	.266* .032	.337** .006	.114 .364	.372** .002	-							
9. Ought	-.038 .763	-.056 .660	.095 .452	.145 .249	.230 .066	.186 .137	.157 .211	.602** .000	-						
10. Anxiety	-.145 .248	-.084 .508	-.176 .162	-.663** .000	-.635** .000	-.313* .011	-.598** .000	-.223 .075	-.075 .551	-					
11. Depression	-.365** .003	-.112 .373	-.335** .006	-.649** .000	-.678** .000	-.187 .135	-.742** .000	-.270* .030	-.079 .551	.565** .000					
12. Overall Mood	-.272* .028	-.108 .390	-.276* .026	-.741** .000	-.738** .000	-.292* .018	-.745** .000	-.274* .027	-.087 .492	.914** .000	.851** .000				
13. Pre-Post Discrepancy	-.071 .576	-.049 .700	-.519** .000	-.479** .000	-.536** .000	.378** .002	-.805** .000	-.285* .021	-.036 .775	.379** .002	.594** .000	.533** .000	-		
14. Post-Ideal Discrepancy	-.278* .025	-.291* .019	-.396** .001	-.662** .000	-.612** .000	-.225 .072	-.948** .000	-.058 .646	.036 .774	.567** .000	.705** .000	.707** .000	.768** .000	-	
15. Post-Ought Discrepancy	-.241 .053	-.230 .066	-.398** .001	-.637** .000	-.582 .000	-.172 .170	-.929** .000	-.141 .262	.220 .078	.562** .000	.703** .000	.703** .000	.782** .000	.951** .000	-

*p<0.05; **p<0.01 (two-tailed)

H2: Discrepancies between stroke survivors' ratings of their post-stroke self and their pre-stroke self will be positively associated with affective distress (anxiety and depression).

The discrepancy scores between stroke survivors' ratings of their post-stroke self and their pre-stroke self were found to be positively correlated with anxiety ($r = .38, p < 0.01$), depression ($r = .59, p = .000$) and overall mood ($r = .53, p = .000$; see Table 3.7).

The correlation matrix between variables (see Table 3.5 above) was investigated for significant associations with demographic variables that could have an impact upon the relationship between discrepancy and psychological adjustment, by causing covariation and therefore producing a correlation between them. The matrix showed no significant correlations between time since stroke and affective distress. However, there were significant correlations between age and depression and overall mood, respectively. Although not a demographic variable per se, it was considered that level of functioning, which was an indication of survivors level of physical independence, could also potentially interfere with adjustment; the matrix showed significant relationships between level of functioning and depression and overall mood, respectively. Crucially, both age and level of functioning also correlated with aspects of pre-post discrepancy.

Table 3.6: Measures of association between affective distress and gender and premorbid anxiety/depression

Association	Eta	Standard error	z
Anxiety * Gender	.174	.125	1.39
Depression * Gender	.100	.125	0.80
Overall mood * Gender	.160	.125	1.28
Anxiety * Premorbid anx/dep	.103	.125	0.82
Depression * Premorbid anx/dep	.130	.125	1.04
Overall mood * Premorbid anx/dep	.130	.125	1.04

Furthermore, the associations between current affective distress and gender and premorbid anxiety/depression respectively, were investigated by inspecting Eta values; this showed no significant associations between either gender or premorbid anxiety/depression and affective distress scores (see Table 3.6 above).

Therefore, additional correlational analyses were carried out, namely partial correlations, between self-discrepancy and affective distress whilst controlling for age and level of functioning. This still showed significant relationships between pre-post discrepancy and anxiety ($r_p = .31, p = .014$), depression ($r_p = .47, p = .000$) and overall mood ($r_p = .42, p = .001$).

Although self-esteem and quality of life were also significantly associated with affective distress and discrepancy, this was not investigated through partial correlation. These variables were not pre-existing and relatively stable characteristics that could have exerted an historical influence on outcomes. On the contrary, they were outcome variables in their own right that could just as plausibly be the result of affective distress and self-discrepancy as their cause, and as such partialling them out could have obscured an otherwise important functional relationship.

Consequently, these results confirm our hypothesis. They also support the findings of Cantor *et al.* (2005), Wright and Telford (1996), and Carroll and Coetzer (2011).

H3: Discrepancies between stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their ideal self will be positively associated with depression.

The discrepancy scores between stroke survivors' ratings of their post-stroke self and their ideal self were found to be positively correlated with depression ($r = .71, p = .000$), which confirms our hypothesis and supports Higgins (1987) self-discrepancy theory. Positive correlations were also found between the post-stroke and ideal selves discrepancy and anxiety ($r = .57, p = .000$), and mood overall ($r = .71, p = .000$; see Table 3.7 below). Higgins (1987) theory does predict that discrepancies will be related to both depression and anxiety, but that these relationships are strongest between actual/ideal discrepancies and depression and between actual/ought discrepancies and anxiety (Higgins *et al.*, 1985). Indeed, the correlation

between the post-stroke self / ideal self discrepancy and depression was stronger than the correlation between the same self-discrepancy and anxiety ($z = 1.66, p = .049$).

H4: Discrepancies between stroke survivors' ratings of their post-stroke self (actual current self or self-concept) and their ought self will be positively associated with anxiety.

The discrepancy scores between stroke survivors' ratings of their post-stroke self and their ought self were found to be positively correlated with anxiety ($r = .56, p = 0.000$), which confirms our hypothesis and supports Higgins (1987) self-discrepancy theory. Positive correlations were also found between the post-stroke and ought selves discrepancy scores and depression ($r = .70, p = .000$), and mood overall ($r = .70, p = .000$; see Table 3.7 below). However, the correlation between the post-stroke self / ought self discrepancy and anxiety was weaker than the correlation between the same self-discrepancy and depression ($z = -1.68, p = .046$), which would be inconsistent with the theory.

H5: Discrepancies between stroke survivors' ratings of their post-stroke self and their pre-stroke self will be negatively associated with their perceived self-esteem.

H6: Discrepancies between stroke survivors' ratings of their post-stroke self and their pre-stroke self will be negatively associated with their perceived quality of life.

Negative correlations were found between the discrepancy scores of pre-post stroke selves and survivors' self-esteem scores ($r = -.48, p = .000$), as well as their quality of life ($r = -.54, p = .000$; see Table 3.7 below). These findings therefore confirm hypotheses H5 and H6.

H7: Stroke survivors' perceived self-esteem will be negatively associated with their ratings of depression and anxiety.

Self-esteem scores were found to be negatively correlated with anxiety ($r = -.66, p = 0.000$), depression ($r = -.65, p = .000$) and overall mood ($r = -.74, p = .000$; see Table 3.8 below). This confirms our hypothesis.

Table 3.7 Correlations between self-discrepancies and affective distress,

self-esteem and quality of life

		Anxiety	Depression	Overall Mood	Self-Esteem	Quality of Life
Pre - Post Discrepancy	<i>r</i>	.38*	.59**	.53**	-.48**	-.54**
	Sig (1 tailed)	.001	.000	.000	.000	.000
	<i>N</i>	65	65	65	65	65
Post – Ideal Discrepancy	<i>r</i>	.57**	.71**	.71**		
	Sig (1 tailed)	.000	.000	.000		
	<i>N</i>	65	65	65		
Post – Ought Discrepancy	<i>r</i>	.56**	.70**	.70**		
	Sig (1 tailed)	.000	.000	.000		
	<i>N</i>	65	65	65		

* $p < 0.01$; ** $p < 0.001$

Table 3.8 Correlations between self-esteem and quality of life respectively, and affective distress

		Anxiety	Depression	Overall Mood
Self-Esteem	<i>r</i>	-.66*	-.65*	-.74*
	Sig (1 tailed)	.000	.000	.000
	<i>N</i>	65	65	65
Quality of Life	<i>r</i>	-.64*	-.68*	-.74*
	Sig (1 tailed)	.000	.000	.000
	<i>N</i>	65	65	65

* $p < 0.001$

H8: Stroke survivors' perceived quality of life will be negatively associated with their ratings of depression and anxiety.

Quality of life scores were also found to be negatively correlated with anxiety ($r = -.64, p = .000$), depression ($r = -.68, p = .000$) and overall mood ($r = -.74, p = .000$; see Table 3.8 above). This confirms our hypothesis.

3.4.3 Mediation Analyses

Mediation analysis (Hayes, 2013) was used to investigate if the effect of pre-post stroke self-discrepancy on affective distress was mediated by self-esteem. Self-esteem was chosen as a possible mediator based on previous research findings of stroke being associated with emotional distress and a decrease in self-esteem, and self-esteem being associated with low mood after stroke; furthermore, findings from TBI showing positive associations between changes in self-concept and distress and negative associations between changes in self-concept and self-esteem (see chapter 1).

Three mediation analyses were carried out. The non-parametric bootstrapping approach (Preacher & Hayes, 2004; 2008) was used, which assesses the significance of the indirect (mediating) effect, and is recognised as the best available test of mediation. Bootstrapping involves k samples of the original size being taken from the obtained data (with replacement after each specific selected number) and mediation effects are then calculated in each sample (Preacher & Hayes, 2004). In the present analyses, parameter estimates are based on 10,000 bootstrap samples and a bias-corrected confidence interval is provided for the tested mediators; if lower and upper bounds do not pass through zero, the indirect effect is significant at the $p < .05$ level. This approach is preferred to the Sobel test of mediation (Hayes, 2013).

H9: Stroke survivors' perceived self-esteem acts as a mediator in the relationship between the discrepancy in stroke survivors' ratings of their post-stroke self and their pre-stroke self and affective distress (anxiety and depression).

3.4.3.1 Self-esteem as a mediator (M) between the pre-post self-discrepancy (IV) and overall mood (DV)

The mediation analysis produced a significant model, adjusted $R^2 = .59$; $F(2,62) = 44.6$; $p = .000$. The total effect of self-discrepancy gave $B = 0.17$; $SE(B) = 0.033$; $p = .000$, and the direct effect, i.e. when controlling for self-esteem, $B = 0.072$; $SE(B) =$

0.029; $p = .015$. The indirect effect of self-discrepancy on overall mood through self-esteem (10,000 bootstrap samples) was 0.094; Boot SE = 0.025; 95% confidence interval 0.051 – 0.150. This shows that in this sample of stroke survivors, self-esteem was a mediator in the relationship between pre-post self-discrepancy and overall mood (as measured by the HADS).

3.4.3.2 Self-esteem as a mediator (M) between the pre-post self-discrepancy (IV) and depression (DV)

The mediation analysis produced a significant model, adjusted $R^2 = .52$; $F(2,62) = 34.2$; $p = .0000$. The total effect of self-discrepancy gave $B = 0.090$; $SE(B) = 0.015$; $p = .000$, and the direct effect, i.e. when controlling for self-esteem, $B = 0.056$; $SE(B) = 0.015$; $p = .0005$. The indirect effect of self-discrepancy on depression through self-esteem (10,000 bootstrap samples) was 0.035; Boot SE = 0.012; 95% confidence interval 0.015 – 0.064. This shows that in this sample of stroke survivors, self-esteem was a mediator in the relationship between pre-post self-discrepancy and depression (as measured by HADS-D).

3.4.3.3 Self-esteem as a mediator (M) between the pre-post self-discrepancy (IV) and anxiety (DV)

The mediation analysis produced a significant model, adjusted $R^2 = .44$; $F(2,62) = 24.8$; $p = .0000$. The total effect of self-discrepancy gave $B = 0.075$; $SE(B) = 0.023$; $p = .0018$, and the direct effect, i.e. when controlling for self-esteem, $B = 0.016$; $SE(B) = 0.021$; $p = 0.4615$. The indirect effect of self-discrepancy on anxiety through self-esteem (10,000 bootstrap samples) was 0.059; Boot SE = 0.015; 95% confidence interval 0.033 – 0.093. This shows that in this sample of stroke survivors, self-esteem was a mediator in the relationship between pre-post self-discrepancy and anxiety (as measured by HADS-A). As discussed in Chapter Two (see pages 92-94), it is not advisable to make claims of full mediation based on the non-significance of the direct effect (Hayes, 2013; Kenny & Judd, 2014), as was the case of the direct effect of self-discrepancy on anxiety.

Therefore, it can be concluded that, in this sample of stroke survivors, there was an observed indirect effect of pre-post stroke self-discrepancy on affective distress through their perceived self-esteem, confirming our last hypothesis.

3.5 QUALITATIVE ANALYSIS

62 stroke survivors (95.38%) answered the open question which required them to describe in a few words how they saw themselves after the stroke compared to before the stroke. The qualitative information generated by the open question was analysed using inductive thematic analysis (Patton, 1990). Key themes were identified by the researcher, which were then reviewed by the researcher's. The key themes of how stroke survivors saw themselves before and following the stroke are presented below.

3.5.1 Before Stroke

One theme was identified for how survivors described themselves before the stroke:

Engaged in life

Stroke survivors described themselves before the stroke as being active, working, and being social ("very active and energetic", "always on the move, cycling, walking, swimming", "I had two jobs, very independent, kept a house", "enjoyed socialising", "out every night").

3.5.2 After Stroke

Three meta-themes were identified for how survivors described themselves following the stroke: psychosocial impact (with three subthemes), efficacy (with two subthemes) and positive changes and benefits.

3.5.2.1 Psychosocial Impact – subthemes:

Identity disruption and reconstruction

Survivors described the impact that the stroke had on themselves as a person ("Big knock to sense of identity, no longer the fixing person, from physically capable...", "Not the person I was, not as physically fit", "I do what I can do, not what I want to do", "Before the stroke I felt as if I belonged now I don't") and their attempt to make sense of and adjust to the stroke ("big blow, I spend fair amount of time putting bits of life back together, adapting to it", "big step, grief and anger to work through, I

needed to accept big changes”, “My role in life has changed dramatically, for better, for worse? Perhaps just different”).

Relationships

Survivors described themselves in terms of how their relationships with friends have been affected (“not as talkative because speech is affected which affects relationships”, “unable to do certain things with friends”, “unable or no energy / enthusiasm to get out and meet others”, “because you are not active your circle of friends lose interest and contact with you and you become withdrawn”); as well as their relationships with their family (“I rely on my daughter whereas before she relied on me”, “I can’t pick up my children, this really hurts me”, “unable to communicate with my young grand and great grandchildren”, “I don’t play with grandchildren as much as before”).

Self-esteem

Survivors described themselves as “greatly aware of my limitations”, “a lot less confident”, “incapable of taking on tasks or challenges therefore little self-esteem / satisfaction”, “feel absolutely worthless”, “contributing little to others, particularly my family”, “sometimes I wonder what use I can be to society”, “helpless, powerless, robbed of all the things that made me, not able to work full time, not able to provide for my son / family”, “lost my dignity”.

3.5.2.2 Efficacy - subthemes:

Loss of physical abilities, independence and meaningful activity

Stroke survivors described themselves in terms of loss of physical abilities, which affects daily life (“physically less capable”, “can’t cook”, “having to plan so not a lot of walking”, “can’t go shopping”); loss of independence (“more dependent on others, I’m lost”, “initially extremely dependent which I disliked immensely”, “I was good with money and bills, now my friend sorts out the bills”); and loss of work or meaningful activity (“retired now”, “main concern I have not gone back to work”, “one of the worst things for me is the singing, used to be in a choir, but stroke has affected my voice, all my life I’ve been in a choir since 14 years old”, “I’d like to return to oil painting and sewing”, “I was writing a book which I have no interest in at the moment”).

Cognitive and mood changes

Survivors also described themselves in terms of their cognitive difficulties (“A lot slower”, “forgetful”, “I can’t concentrate”, “I need to plan... list to remember”), as well as being emotionally different (“frustrated a lot, shorter fuse, agitated more”, “Irritable, bad mood, dissatisfied, argumentative”, “I worry about every little thing, frightened of things, depression got worse”, “More emotional”, “I don’t get excited, not relaxing”).

3.5.2.3 Positive changes and benefits (this theme permeates across the other themes)

Survivors also described how the stroke changed them for the better, both in themselves (“not as shy, and more talkative”, “More confident, I speak my mind”, “Laugh more”, “Looking forward to things more, no expectations, relieved”, “Happier now”, “Became fairly relaxed, I used to worry about things but now I don’t let things bother me”, as well as in relationship with others (“not as selfish”, “Nicer person now than before”, “appreciating people more whereas before I took them for granted”, “relationship with my wife is closer, before I was not as emotionally honest”).

3.5.3 Summary of Qualitative Analysis

The stroke seemed to have been experienced as a major life event that impacted on survivors’ sense of who they are as a person, both negatively and positively. The stroke survivors in this sample generally described themselves in more negative terms following the stroke, in terms of a number of losses (loss of physical ability, independence, work), negative mood and cognitive difficulties, a decrease in self-esteem, as well as a negative shift in their social relationships. It is of note that survivors had much more to say about their post-stroke selves than the pre-stroke selves. At the same time, some positive outcomes were also identified, where the experience of surviving a stroke seemed to have contributed to becoming a better person, with a positive effect on survivors’ relationships.

3.6 RESULTS SUMMARY

Stroke survivors in the sample used in this study saw themselves in significantly more negative terms than before the stroke on most aspects examined, but as

similarly calm, patient, and in terms of their level of aggressiveness. For instance, they saw themselves as more dependent, less capable, self-confident and in control, and less attractive as a person. The qualitative analysis supported the findings of the statistical analysis; additionally, it identified some positive descriptions as well. Overall, it can be concluded that self-concept was affected negatively after stroke, despite some benefits.

The discrepancy between how survivors saw themselves before and after the stroke was positively correlated with affective distress, and negatively correlated with their perceived self-esteem and quality of life, respectively. The discrepancies between survivors' perceived post-stroke self (their current actual self) and how they would like to be (their ideal self) on one hand, and how they think they should be (their ought self), on the other hand, were also positively correlated with affective distress. However, the relationships between different discrepancies and affective distress were undifferentiated. Discrepancies between post-stroke (current actual) self and ideal self were not only related to depression but also to anxiety, with the latter association being weaker; and discrepancies between post-stroke (current actual) self and ought self were not only related to anxiety but also to depression, with the latter association being stronger.

Survivors' perceived self-esteem was a mediator in the relationship between the discrepancy in how survivors saw themselves before compared to after the stroke and their affective distress.

Therefore, it can be concluded that all stated hypotheses were confirmed.

CHAPTER 4

DISCUSSION

4.1 CHAPTER OUTLINE

In this chapter, after situating the current study in the context of existing literature, the main findings will be summarised and then each of the hypotheses will be considered in light of the findings; the strengths and weaknesses of the study will then be described, followed by a reflection on the theoretical and clinical implications of the results; finally, areas of future research will be outlined.

4.2 OVERVIEW

Stroke is a life changing event, involving a sudden transition from being able-bodied to disabled, leaving survivors with a range of physical, psychological and social impairments, which impact negatively on the survivors' quality of life (e.g. Carlsson *et al.*, 2003; Edwards *et al.*, 2006).

Anxiety and depression are common emotional consequences after stroke (e.g. Ayerbe *et al.*, 2013; Cambell-Burton *et al.*, 2013; Hackett *et al.*, 2005) and can interfere with adjustment and rehabilitation (e.g. Mukherjee *et al.*, 2006; Pohjasvaara *et al.*, 2001). The etiology of emotional problems post-stroke appears to be complex, partly explained by the neurological changes (e.g. Gainotti *et al.*, 2001; Lezak *et al.*, 2004; Robinson *et al.*, 1983), and also, by issues related to psychological adjustment to a major life event that involves coming to terms with multiple losses (e.g. Mukherjee *et al.*, 2006).

The concept of identity change or loss following brain injury is a growing area in the ABI literature, and a commonly reported experience after stroke. The evidence that brain injury poses a challenge to survivors' identity is provided both by qualitative and quantitative studies, demonstrating significant changes in survivors' sense of self by viewing themselves in more negative terms following, compared to before the injury (Carrol & Coetzer, 2011; Cantor *et al.*, 2005; Gracey *et al.*, 2008; Tyerman &

Humphrey, 1984; Wright & Telford, 1996). However, only few studies have shown this in a population of stroke survivors (e.g. Ellis-Hill & Horn, 2000; Keppel & Crowe, 2010).

Furthermore, changes in self-concept have been shown to be associated with emotional problems by studies with TBI survivors (Carrol & Coetzer, 2011; Cantor *et al.*, 2005; Wright & Telford, 1996). This association has been explained by Cantor *et al.* (2005) using Higgins' (1987) self-discrepancy theory.

The current study extended Cantor *et al.*'s (2005) study, by examining the discrepancy between the post-injury self and the pre-injury self in a large sample of stroke survivors, and exploring the relationship between this discrepancy and a person's adjustment and mood.

4.3 SUMMARY OF MAIN FINDINGS

The main findings of this study suggested that there was a significant discrepancy between the post-injury self and the pre-injury self of stroke survivors, by seeing themselves in more negative terms following the stroke than before the stroke.

The discrepancy between how the stroke survivors saw themselves before and after the stroke was positively associated with affective distress, and negatively associated with their perceived self-esteem and quality of life, respectively. The discrepancies between survivors' perceived post-stroke self and their ideal self and ought self, respectively, were also positively correlated with affective distress.

Survivors' perceived self-esteem was a mediator in the relationship between the discrepancy in how survivors saw themselves before compared to after the stroke and their affective distress.

4.4 DISCUSSION OF HYPOTHESES

4.4.1 Hypothesis 1: Pre-Post Stroke Self-Discrepancy

Survivors' perception of their post-stroke self was significantly different, and more negative, than their perceived pre-stroke self. Furthermore, it was found that survivors saw themselves as significantly less positively post-stroke on all dimensions of the HISD apart from aggressiveness, calmness and patience (see Table 3.4 in Chapter 3). However, these results were generated by exploratory multiple Wilcoxon signed rank tests.

These results confirmed hypothesis one showing that self-concept underwent profound changes following stroke, which is indicative of perceived alterations in identity; survivors viewed themselves as substantially different on a wide range of constructs, which provides support for ideas of biographical disruption as a result of chronic illness (Bury, 1982; Williams, 2000).

The qualitative data generated by the open question largely supported this, showing that the stroke impacted on survivors' sense of who they are as a person, with survivors generally describing themselves in more negative terms following the stroke, in terms of a number of losses. However, some positive outcomes were also identified, where the experience of surviving a stroke seemed to have contributed to becoming a better person, with a positive effect on relationships. This is consistent with research on post-traumatic growth, showing that following a traumatic event, including stroke (Collicutt McGrath & Linley, 2006), people may also report positive psychological changes, some of which are related to the perception of self and improved relationships (Linley & Joseph, 2006). Finally, interestingly survivors had much more to say about their post-stroke selves rather than the pre-stroke selves, which might suggest that survivors were more reflective following the stroke, or it may be due to difficulties with memory.

The current study supports previous work on identity in brain injury (Carroll & Coetzer, 2011; Tyerman & Humphrey, 1984; Wright & Telford, 1996), including the findings of Ellis-Hill and Horn (2000) in a sample of stroke survivors; in the latter study, stroke survivors saw themselves as more aggressive after the stroke, but more caring and just as calm, friendly and hopeful. However, the sample employed

in their study was smaller and the low power may have resulted in some changes being undetected. At the same time, in Wright and Telford's (1996) study it was shown that the control group rated past self significantly lower than TBI survivors, with no significant differences between the two groups in terms of ratings of their present self. This might suggest that survivors of brain injury tend to idealise their pre-injury selves, thus increasing discrepancies between pre and post-injury selves.

Nevertheless, the results of the current study add to the body of evidence of changes in self-concept after stroke, and also add to the wider evidence of such changes after ABI, showing that people view themselves more negatively after brain injury. This evidence is ever growing, with two more studies published after this thesis had been completed (see systematic review, section 1.7); a large qualitative study showed that the central concept derived from the experience of TBI survivors was that of desiring to be or having lost a sense of being an integrated and valued person (Levack *et al.*, 2014), and another qualitative study showed that even five years on, stroke survivors continued to deal with changes to their self-identity (Pallesen, 2014). Therefore, it can be argued that the wider evidence supports the view that individuals experience change or loss of identity after ABI regardless of the type of injury, time since injury or severity.

4.4.2 Hypothesis 2: Pre-Post Stroke Self-Discrepancy and Affective Distress

The discrepancies between stroke survivors' perceived post-stroke and pre-stroke selves were significantly positively associated with affective distress (anxiety, depression and overall mood).

The results confirmed hypothesis two, and they also provide support for the findings from studies with TBI survivors. Previously, Cantor *et al.* (2005), Wright and Telford (1996) and Carroll and Coetzer (2011) showed that changes in identity following brain injury were related to psychological adjustment. However, these studies employed small samples; the former study used two measures for assessing self-concept, different from the one used in the current study, only one of which showed a significant relationship between self-discrepancy and emotional distress; the second study used a global measure for psychological distress; and the latter study only reported a relationship between self-discrepancy and depression.

Although Ellis-Hill and Horn (2000) found increased anxiety and depression in their sample of stroke survivors compared to the control group, no relationship was reported between the experienced emotional distress and self-discrepancies.

In terms of the level of distress reported, most of the stroke survivors in this study met cut-off point for anxiety, whether 4/5 (Sagen *et al.*, 2009) or 5/6 (Johnson *et al.*, 1995); and for depression, if cut-off considered at 4/5 (Sagen *et al.*, 2009), whereas the 7/8 cut-off (Aben *et al.*, 2002) was met by more than half of survivors.

Ellis-Hill and Horn (2000) expressed the reported level of distress in their clinical sample based on medians, which were 5.5 for anxiety and 5 for depression, whereas in the current study the medians were 7 for both anxiety and depression. However, the current study employed a larger sample and the mean time since the stroke was 5.57 years, whereas the participants in Ellis-Hill and Horn's (2000) study were much sooner after their stroke (mean 13.6 months), and thus they may be in different stages of adjustment (Kerr, 1977). The level of depression within the present sample was similar to that reported by Carroll and Coetzer (2011) among individuals with mostly severe TBI ($t(45) = 0.75, p = .77$) and by Cooper-Evans *et al.* (2008) among individuals with severe ABI ($t(30) = 0.034, p = .51$); the level of anxiety was similar to that reported by Cooper-Evans *et al.* (2008) ($t(35) = 0.367, p = .64$).

It can be concluded that this is the first study to show a relationship between pre-post-injury self-discrepancy and affective distress in stroke survivors. However, the direction or causality of this relationship cannot be inferred from this methodology; the discrepancy in how survivors view themselves now compared to before the stroke may lead to increased symptoms of anxiety and depression; or it may be that the participants who were more depressed or anxious rated their current self in more negative terms, hence inflating discrepancy scores. However, depression would also affect their recall of self-referent information, meaning they would also rate their pre-stroke self more negatively (Clark & Beck, 1999). The findings of Tyerman and Humphrey (1984) of no difference between TBI survivors' ratings of past and future selves would also contradict the hypothesis that the ratings were influenced by depression, as significant positive change was anticipated by survivors, suggesting that they possibly expected to return to their pre-morbid self sometime in the future.

It is also possible that survivors idealised their pre-morbid self, which would also inflate discrepancy scores; Tyerman and Humphrey (1984) showed that TBI survivors rated their pre-injury self more positively overall than a typical person of same age and sex, which was later supported by Wright and Telford (1996) who showed that the comparison group rated past self significantly lower than the TBI group, yet the ratings of the two groups were not significantly different for present or future self.

At the same time, it is more likely that self-discrepancy and affective distress are bound in a reciprocal and cyclical relationship. Nonetheless, this finding contributes to our understanding of the psychological factors underpinning the emotional difficulties commonly reported after ABI, including stroke.

4.4.3 Hypotheses 3 and 4: Post-Stroke Self / Ideal Self and Post-Stroke Self / Ought Self Discrepancies and Affective Distress

As predicted, the discrepancy between survivors' post-stroke self (current actual self) and their ideal self was positively associated with depression, yet also with anxiety and mood overall. Similarly, the discrepancy between survivors' post-stroke self and their ought self was positively associated with anxiety as predicted, yet also with depression and mood overall.

These findings still confirm both hypotheses, and they are similar to Cantor *et al.*'s (2005) who also found discrepancies between post-TBI and ideal and ought self, respectively, to be related to both depression and anxiety. This adds to previous research that also failed to support the distinctiveness of actual/ideal and actual/ought self-discrepancies relating to particular types of emotional distress (e.g. Phillips & Silvia, 2010; Tangney *et al.*, 1998).

Higgins (1987) self-discrepancy theory does predict that discrepancies will be related to both depression and anxiety, but that these relationships are strongest between actual/ideal discrepancies and depression and between actual/ought discrepancies and anxiety (Higgins *et al.*, 1985). Indeed, the correlation between the post-stroke self (actual self) / ideal self discrepancy and depression was stronger than the correlation between the same self-discrepancy and anxiety (see section 3.4.2). However, the correlation between the post-stroke self (actual self) / ought self

discrepancy and anxiety was weaker than the correlation between the same self-discrepancy and depression (see section 3.4.2). The lack of differentiation between types of discrepancy and types of distress may also be due to the significant relationship between the depression and anxiety scores ($r = .57, p = .000$).

In conclusion, the findings of the current study are not inconsistent with Higgins' (1987) self-discrepancy theory, and thus they add to the limited evidence for the theory in clinical populations, showing a relationship between self-discrepancies and emotional distress in a stroke population.

4.4.4 Hypothesis 5: Pre-Post Stroke Self-Discrepancies and Self-Esteem

The discrepancies between survivors' perceptions of their post-stroke self and their pre-stroke self were negatively associated with their perceived self-esteem. The finding confirmed the hypothesis and supports the results of Carroll and Coetzer (2011) who also found negative associations between changes in self-concept and self-esteem, but in a sample of TBI survivors.

While self-concept refers to how one views and experiences themselves (Tajfel & Turner, 1979) and self-esteem is the emotional valence resulting from the evaluation of the self (Rosenberg, 1965), these concepts are considered to be closely related in both general and ABI populations (Kravetz *et al.*, 1995; Man *et al.*, 2003; Vickery *et al.*, 2005). Furthermore, self-esteem was shown to be relatively stable during adulthood except at times of acute crisis (Trezesniewski *et al.*, 2003).

Survivors' more negative view of their post-stroke self, e.g. in terms of being more helpless and dependent and less happy and satisfied, is not surprising given the multiple challenges they are faced with and the uncertain future, and thus may be seen as presenting a threat to self and self-esteem. Reduced self-esteem following ABI was proposed by Ford (1976) as part of the secondary personality changes, which also included loss of self-assurance and confusion, thought to result from repeated failure and frustration, and eventually leading to the disintegration of personality.

If scores below 25 are considered to be indicative of clinically significant low self-esteem, as proposed by Anson and Ponsford (2006) then 27 (42%) participants in the present study reported levels of self-esteem that would be classed as clinically

significant low self-esteem. This could also be consequential to the psychosocial consequences of disability, including the social stigma and inequality associated with physical disability (Earle, 2003), as well as possible financial struggle, limiting access to self-esteem enhancing opportunities. A comparison of means showed that the reported level of self-esteem in the current sample was lower ($t(56) = 3.44, p = .001$) than that reported by the sample of stroke survivors in Keppel and Crowe's (2010) study; and higher, yet not significantly, ($t(27) = 1.84, p = .096$) than that reported by a sample of ABI survivors, only one of which was a stroke survivor, most of them being TBI survivors (Cooper-Evans *et al.*, 2008).

However, it is possible that survivors may retain some degree of self-esteem, as Tyerman and Humphrey (1984) showed that people with severe brain injuries viewed themselves somewhat more positively than a Typical Head Injured Person and not dissimilar from a Typical Person.

4.4.5 Hypothesis 6: Pre-Post Stroke Self Discrepancies and Quality of Life

The discrepancies between survivors' perceptions of their post-stroke self and their pre-stroke self were negatively associated with their perceived quality of life, confirming the hypothesis.

Ratings of self-concept have been previously found to be correlated with perceived quality of life in a small sample of ABI survivors, showing that poorer view of self was associated with lower subjective quality of life (Vickery *et al.*, 2005). However, the current study is the first to show an association between the discrepancy in how survivors viewed themselves post compared to pre-injury and their perceived quality of life, in a large sample of stroke survivors.

The experience of difficulties and failures in everyday situations, which did not previously pose any problems, may highlight for survivors the differences between the person they used to be, i.e. able to cope, and the person they are now, i.e. unable to cope. Consequently, social and task orientated situations are perceived as a threat to self and thus they give rise to anxiety, making brain injury survivors likely to withdraw or avoid the situation to reduce the anxiety and return to a less threatened self (Riley *et al.*, 2004). This may lead to giving up on previously valued and meaningful activities, which would then impact on their quality of life. Stroke

survivors who reported a high quality of life, despite functional disabilities, were shown to focus on activities most salient their identity, even if in a modified form, thus maintaining a sense of continuity in their life (Clarke & Black, 2005). At the same time, if their quality of life is restricted due to physical impairments, being unable to engage with life as they did pre-morbidly, this might make them more reflective on the differences in their abilities, and thus perceive higher discrepancies between their current and pre-morbid selves.

4.4.6 Hypothesis 7: Self-Esteem and Affective Distress

Stroke survivors' perceived self-esteem was negatively associated with their reported affective distress, confirming the hypothesis. It is likely that as survivors' self-esteem suffers due to seeing themselves in more negative terms, such as being less capable, less in control, more dependent on others, and less attractive as a person, they are then less inclined to attempt to engage with the world around them, which is perceived as threatening, giving rise to anxiety. Individuals with brain injury were shown to make subjective threat appraisals in social situations such as being seen as stupid, not fitting in or when doing things (e.g. "when things go wrong it reminds me of my injury") (Riley *et al.*, 2004). Consequently, they may try avoiding such situations to avoid failure, criticism or judgement. However, this then offers less opportunity for gaining a sense of achievement or pleasure, which might contribute to depressive feelings, and maintain anxiety through avoidance; and therefore further affecting how they see and feel about themselves.

This study contributes to the body of evidence of associations between low self-esteem and increased psychological distress following stroke. This comes mostly from a series of American studies with large samples of stroke survivors in acute and rehabilitation settings, by Vickery and colleagues (e.g. Vickery, 2006; Vickery, Sepehri, Evans *et al.*, 2008; Vickery *et al.*, 2009) who showed that both the level and the stability of self-esteem were associated with post-stroke depression. Thus the results of the current study extend this evidence by showing an association of lower self-esteem ratings with higher levels of general emotional distress in a stroke population in the community, in the UK. They also add to the wider evidence of such associations following ABI (e.g. Curran *et al.*, 2000; Howes *et al.*, 2005).

4.4.7 Hypothesis 8: Quality of Life and Affective Distress

Stroke survivors' perceived quality of life was negatively associated with their reported affective distress, confirming the hypothesis and suggesting that emotional problems following stroke are associated with lower quality of life. The results are consistent with previous research, e.g. Bays' (2001b) findings of depression after stroke being associated with lower quality of life ratings, and similar findings in a mixed ABI sample (Vickery *et al.*, 2005).

Emotional problems and low perceived quality of life after stroke are well researched. A review of 39 studies of life after stroke (Bays, 2001a) concluded that quality of life after stroke declined markedly, and that it was consistently lower than that experienced by healthy adults. Although associations between subjective quality of life and emotional problems have been established, the direction of effect is not straightforward.

Equally, all the associations established by the current study do not imply causal relationships between the variables involved.

4.4.8 Hypothesis 9: Self-Esteem As A Mediator Between Self-Discrepancy and Affective Distress

Self-esteem was found to be a mediator in the relationship between the discrepancies in how survivors perceived themselves pre and post-stroke and affective distress. The results, thus, confirmed the last hypothesis, adding to the evidence of self-esteem as a mediator of better psychosocial functioning.

Self-esteem has been seen as acting as a buffer against negative effects when confronted with a stressful life situation, such as illness (Gammon & Mulholland, 1996; Hobfall & Walfisch, 1984; Schroevers *et al.*, 2003). It has been suggested that higher self-esteem can increase active coping by employing more adaptive coping strategies and enhancing health-promoting behaviours and beliefs, thus enabling adjustment to illness, and consequently improving psychosocial functioning and quality of life (Anson & Ponsford, 2006; Essex & Klein, 1989; Li & Moore, 1998; Conn *et al.*, 1992). Indeed, self-esteem has been previously shown to have a mediating role in the relationship between emotional functioning and functional status in inpatient stroke survivors (Vickery, Sherer *et al.*, 2008).

However, although mediation is more than a correlational relationship, it still does not show causation. In the case of the current study, mediation suggests that the discrepancy between pre and post-stroke selves influences self-esteem, and in turn, self-esteem has an effect on emotional distress, the mediation being the combination of these two relationships. Feeling less than the person that used to be before the stroke, not being able to engage with the world in quite the same way as prior to illness, would pose a threat to self-esteem. This may trigger behaviours aimed to protect or enhance self-esteem, which may then interfere with the process of self-regulation (Baumeister & Vohs, 2003), that is, changing goal selection and affecting engagement in goal-relevant behaviours and the monitoring of progress towards those goals (Brown, 1998). Furthermore, low self-esteem makes it likely for individuals to generalise discrete failures to being representative of overall level of competence, which can then diminish motivation to attempt or engage with other tasks (Brown & Dutton, 1995). Also, task perseverance may be compromised, especially when they are perceived as challenging, and thus individuals may quit the task early (McFarlin *et al.*, 1984; Sandelands *et al.*, 1988), or avoid challenges altogether (Waschull & Kernis, 1996). Consequently, this would maintain or even increase the level of anxiety experienced by stroke survivors; it would also mean that there are limited opportunities for individuals to derive a sense of achievement or pleasure, which can then lead to developing depressive symptoms.

Thus it can be argued that the results of the current study provide a possible explanation regarding the underlying mechanism of the relationship between the discrepancy in the stroke survivors' sense of self, pre and post-stroke, and the experienced affective distress.

4.5 STRENGTHS AND LIMITATIONS OF THE RESEARCH

This study presents with a number of theoretical and methodological strengths and limitations which will be the focus of this section.

4.5.1 Strengths

The current study represents one of the very few quantitative studies investigating changes in identity following ABI, benefiting from a systematic review of these

studies; and it is only the second study to examine a change in the sense of self in a sample of stroke survivors, which follows the study carried out by Ellis-Hill and Horn (2000). However, a much larger sample (N = 65) was employed in the current study than in the previous study, and indeed larger than the samples of all the other studies with ABI survivors in the review. Even though the sample size was just under what was indicated in the power analysis, it still conferred this study more statistical power than that of previous research. It was thus confirmed in this study that following stroke, survivors experience profound alterations in their sense of self, viewing themselves as having changed considerably, and for the worse, on a wide range of constructs.

Drawing on Cantor *et al.*'s (2005) pilot study, the current study extended Higgins' (1987) self-discrepancy theory to include pre-stroke and post-stroke selves, being the first to show that discrepancies between these two selves are related to emotional distress in a large sample of stroke survivors. At the same time, it is the first time that discrepancies between actual self and ideal and ought self respectively have been investigated in relation to people who suffered stroke. Thus, the study also contributes to the evidence base by providing empirical support for Higgins' (1987) self-discrepancy theory in a different clinical population.

In addition, this study goes further by providing a possible explanation regarding the underlying mechanism of the relationship between the perceived discrepancy in the stroke survivors' sense of self, pre and post-stroke, and their experienced affective distress, by identifying self-esteem as a mediator of this relationship.

Furthermore, self-concept was assessed using a well-established measure (HISD); Ellis-Hill and Horn (2000), who employed an earlier version of this measure (HISD II) in their study of identity change in stroke survivors, and also used a comparison group, showed that the ratings for past and present self-concepts did not differ in the non-clinical group, thus suggesting that the scale is sensitive to identity changes perceived by stroke survivors. Additionally, the quantitative data resulting from the use of the self-concept measure was complemented by also eliciting some qualitative information from stroke survivors by asking them to describe themselves in terms of how they perceive themselves as a person after compared to before the stroke, thus enriching the data generated by this study.

4.5.2 Limitations

4.5.2.1 Design

Retrospective correlational design was employed in this study. A retrospective design was essential due to the unpredictable nature of stroke, however, retrospective appraisals of pre-injury self can be subject to recall bias. Furthermore, the time since stroke varied within the sample of this study between one year post-stroke and up to 15 years post-stroke. This questions the reliability of evaluating the pre-stroke self, due to memory problems, as the longer the post-stroke period, the more difficult it may be to think back at the pre-stroke self. However, in their study with mild TBI survivors, Wright and Telford (1996) found no significant differences in how survivors retrospectively rated their pre-injury self-concept three years after their injury, compared to how they rated it only six months after the injury. On the other hand, the longer the post-injury period, the further someone may be in their adjustment process, which could then distort retrospective appraisals of their pre-injury self.

Being a correlational study, the direction of the relationships established cannot be clarified and thus there are limitations in drawing conclusions of causality. For instance, self-discrepancy was found to be related to affective distress; this could mean that the perceived discrepancy between the pre-stroke and post-stroke selves may lead to increased symptoms of anxiety and depression; and it could also mean that experiencing emotional distress makes stroke survivors more prone to seeing themselves in more negative terms than before the stroke, thus enhancing self-discrepancies. A mediation analysis was also carried out, which is more than a correlational relationship as it refers to the processes through which changes are hypothesised to occur (Preacher & Hayes, 2008); although the mediation analysis provided an explanation for the mechanism underlying the relationship between self-discrepancies and affective distress, it still does not show causation.

Additionally, only self-esteem was investigated as a potential mediator in this study. The decision of testing self-esteem as a mediator was based on previous research findings of stroke being associated with emotional distress and a decrease in self-esteem, and self-esteem being associated with low mood after stroke; furthermore, findings from TBI showing positive associations between changes in self-concept

and distress and negative associations between changes in self-concept and self-esteem (see Chapter 1).

A longitudinal design would help monitor if and how individual stroke survivors' perceptions of themselves change over time following stroke. Wright and Telford (1996) found no significant differences in the self-concept ratings between time 1 (six months after the injury) and time 2 (three years after the injury) in their sample of mild TBI survivors; this was later supported by Cooper-Evans *et al.*'s (2008) study which found that self-esteem ratings were consistent over time following injury. However, the number of participants in the Wright and Telford's (1996) study had been dramatically reduced from time 1 to time 2, and Cooper-Evans *et al.* (2008) reassessed self-esteem only after a two-week period. Wright and Telford (1996) also showed that psychological distress was significantly decreased three years after the injury, although there was no change in symptomatology based on the concept of caseness. Consequently, following a sample of first-time stroke survivors over a period of time, by conducting a series of assessments at different points in time after the injury would enhance our understanding of the impact of stroke on self-concept and its relationship with affective distress.

Finally, there was no comparison group in this study; by using a control group from the general population, matched in terms of demographic variables, including functioning level and quality of life, would show whether and to what extent self-concept also changes in the nonclinical population. Ellis-Hill and Horn (2000) showed the stability of self-concept in a non-clinical sample, but their sample was small and possibly biased. However, there is evidence that self-image is generally stable in the absence of severe illness. In a longitudinal study, Mortimer *et al.* (1982, as cited in Demo, 1992) found that self-attitudes were stable from late adolescence into early adulthood despite several major life changes that occurred during this period. Also, self-esteem was shown to be relatively stable during adulthood, except at times of acute crisis (Trezesniewski *et al.*, 2003). In view of this evidence of stability it seems highly likely that the discrepancies found in this study were attributable to the stroke.

4.5.2.2 Sample

This study was with first-time stroke survivors. However, as the participants were recruited in the community, through charities, rather than from stroke services, so without access to medical records, this was established based on self-report and with the aid of group coordinators and carers. Although eligibility was deemed appropriate in the case of more than one stroke as long as subsequent strokes occurred within a month of each other, it is possible that some participants may have suffered more than one stroke with greater time lapse between them. This would make it difficult to ascertain the extent of the impact of each stroke on identity; those who experienced a previous stroke several months or years ago may report fewer changes in self-concept after a subsequent stroke.

Similarly, while comorbidity was not assessed formally a few participants reported comorbid illnesses such as cardiac problems, cancer, diabetes, which are not surprising considering this population. However, the findings could have also been related to other comorbid disorders or those participants may have reported fewer changes in their sense of self following the stroke. Also over a quarter of the participants (27%) reported experiencing anxiety and depression before the stroke, thus premorbid mental health problems may also have influenced the findings.

The age range in the sample was fairly wide, which might have different implications for self-concept (Erikson, 1959), as was the time since experiencing the stroke, which may mean that the participants were at various stages in their adjustment to disability, e.g. expectancy of recovery or mourning, or indeed adjustment (Kerr, 1977); it may be that if individuals are better adjusted they may have integrated the changes and thus report less distress. The extended period of time since the stroke, in some case, may also mean that other life events may have contributed to changes in self-concept. However, there is evidence, as cited above, of stability of self-concept despite major life changes (Mortimer *et al.*, 1982 cited in Demo, 1992).

Although the cognitive functioning of the participants was not formally assessed, it was apparent that they did not present with severe cognitive or communication difficulties and it may be argued that they were a more able group of stroke survivors, as shown also by their current level of functioning. This has implications for the extent to which the findings can be generalised to the wider stroke population.

However, if even those who have made a better recovery report such profound changes in identity following stroke, it could be argued that those with severe sequelae following stroke may experience even greater changes (Ellis-Hill & Horn, 2000). For instance, Shadden and Agan (2004) and Shadden (2005) highlighted the importance of identity to stroke survivors with aphasia as identity can be influenced in interactions with others, which may be affected by aphasia, and thus resulting in a need to re-negotiate their identity. On the other hand, as lower self-esteem seems to be associated with higher level of awareness of impairment and more intact cognitive functioning (Cooper-Evans *et al.*, 2008), it may be that those with severe cognitive impairments are less aware of their deficits, and thus may actually report fewer changes.

Finally, this was a convenience sample of stroke survivors who attended stroke groups or who responded to the online advert, therefore these may be individuals who chose to take part because the research topic was relevant to them, in terms of experiencing themselves as somewhat different following the stroke; whereas those who did not perceive themselves as different after the stroke may have chosen not to respond. Most of the respondents attended stroke groups, which in itself might have affected their sense of self, either positively by conferring membership to a group (Haslam *et al.*, 2008), with an equally positive effect on their mood as well, or negatively, by conferring membership to a group that may be perceived as socially disadvantaged.

In conclusion, although the sample used in this study presents with a number of limitations that impact on its representativeness of stroke survivors in general, it could be argued that the variation in the sample may render it fairly representative of stroke survivors living in the community. On the other hand, considering this very variation, and the premorbid medical or psychological problems of some participants, some of the findings may not be due solely to stroke.

4.5.2.3 Measures

4.5.2.3.1 Self-reporting and brain injury

Using self-report measures has added challenges with individuals with an acquired brain injury. On one hand, this is due to the presence of cognitive deficits, particularly

memory, as self-report could vary significantly on different administrations (Man *et al.*, 2003). On the other, due to impaired self-awareness or “insight”, that is the ability to consciously process information about oneself while maintaining a relatively objective view as well as one’s own unique phenomenological experience (Prigatano, 1997), which is also commonly affected following ABI (Sherer *et al.*, 1998). This could then compromise the participants’ ability to provide data on changes in their sense of self, as well as reporting on their emotional adjustment, and thus resulting in unrealistic self-appraisals.

For instance, lower levels of awareness were found to be associated with a more positive sense of self in a sample of adults with dementia (Naylor & Clare, 2008), while higher levels of awareness were found to be associated with poorer self-esteem following ABI (Cooper-Evans *et al.*, 2008). In terms of self-awareness and reported emotional distress, the findings are equivocal. Increased distress has been associated with higher levels of awareness (Cooper-Evans *et al.*, 2008; McBrinn *et al.*, 2008), and was also identified among individuals with poorer self-awareness (Hoofien *et al.*, 2004); at the same time, improvements in awareness did not lead to increased emotional distress (Roberts *et al.*, 2006). Moreover, shifts in mood could also lead to changes in levels of awareness (Fleminger *et al.*, 2003).

As a result, the reliability of using self-report measures among individuals with ABI has been questionable. On the other hand though, there is also supporting evidence that despite severe ABI, people are able to effectively use self-report measures in order to identify a wide range of problems (e.g. Giacino & Cicerone, 1998; Gordon *et al.*, 2000; Green *et al.*, 2001).

From the studies investigating change in “self” following ABI included in the systematic review, only a couple took into consideration the potential role of self-awareness underlying such ratings, by including awareness measures. Firstly, Cooper-Evans *et al.* (2008) used the Dysexecutive Questionnaire (DEX), included in the BADS battery (Wilson *et al.*, 1996) to determine awareness of executive difficulties and found that those with higher levels of self-esteem had less awareness of executive difficulties, consistent with previous research. Later, Carroll and Coetzer (2011) used the Awareness Questionnaire (Sherer *et al.*, 1998) and also showed that lower levels of self-awareness were associated with higher levels of self-esteem,

while correlations between self-awareness and depression were weak, and those between awareness and perceived change in identity were non-significant.

Alternatively, in order to ascertain the validity of self-reported self-esteem in their study with severe ABI survivors, Cooper-Evans *et al.* (2008) repeated the measure after two weeks and demonstrated the stability of subjective self-esteem despite variable levels of cognitive impairment, thus indicating that participants' view of themselves was stable. Indeed, Tyerman & Humphrey (1984) argued that even though the accuracy of self-appraisals may be limited by cognitive impairment and poor self-awareness, it is the subjective experience that is distressing for people with brain injury, and it also influences their psychological adjustment as it provides an indication of what is required to help them understand better their reaction to their illness (Prigatano, 1997). Consequently, as pointed out by Cooper-Evans *et al.* (2008), the emphasis ought to be on the personal perspective and meaning of survivors of brain injury, rather than the reliability of self-report, in order to support their adjustment and rehabilitation.

4.5.2.3.2 Measures of self-concept and affective distress

Self-concept is considered to be generally stable in the absence of severe illness (Mortimer *et al.*, 1982, as cited in Demo, 1992), which is also supported by evidence that self-esteem is relatively stable during adulthood, except at times of acute crisis (Trezesniewski *et al.*, 2003). In this study, self-concept was measured using the Head Injury Semantic Differential Scale – III (HISD-III; Tyerman & Humphrey, 1984), which was designed to measure changes in self-concept in people with TBI, and was also employed by previous studies (see Systematic Review). Furthermore, as in previous studies, pre-injury self has been measured retrospectively. Thus, when considering the results, it is important to consider the test-retest reliability of the HISD.

However, the current study found significant correlations between pre-stroke and post-stroke HISD scores (see correlation matrix, Table 3.5) as well as significant mean differences between these; furthermore there were significant correlations between the pre-stroke and the post-stroke variables, respectively, and other variables. This would not occur if the test were highly unreliable. Scores for an unreliable test would be affected by random error and would not correlate before and

after stroke, and would not be consistently higher or lower before and after stroke; consequently, there would be no pre-post difference or correlation. This is because an unreliable test has random error in the scores by definition and thus would generate large random errors in estimating true scores (Rust & Golombok, 2009). The fact that there was a significant correlation between pre-stroke and post-stroke HISD ratings also supports using the HISD to assess pre-injury self retrospectively.

Although in their study with mild TBI survivors, Wright and Telford (1996) found that three years after their injury survivors rated their pre-injury self very similarly to how they rated it six months after the injury, does not necessarily provide further support for the reliability of the HISD, as it was established as a non-significant mean difference (which could have resulted from undependable scores due to low test reliability) rather than a correlation between ratings. Similarly, in their study with stroke survivors and using a control group, Ellis-Hill and Horn (2000) showed the stability of self-concept, as measured by the HISD, in the non-clinical sample who also rated past self (retrospectively) and present self; but again, this was based on a non-significant mean difference rather than a correlation. Conversely, the data from the current study supports adequate HISD reliability, as explained above.

Furthermore, Vickery *et al.* (2005) used the HISD to evaluate a self-concept group intervention for people with brain injury and showed significant overall improvement in self-concept, suggesting that HISD scores are reliable and can be used to detect systematic change in the context of rehabilitation. However, further psychometric analysis is needed regarding both temporal stability and sensitivity to change in the context of intervention (Ownsworth, 2014).

Considering that the current study investigated self-discrepancy and affective distress following stroke, it could be argued that the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI) may have been more appropriate tools for assessing affective distress, as previous research (e.g. Strauman, 1992) showed that these measures of affective symptoms are consistently correlated with self-discrepancies. Indeed, these were the measures employed by Cantor *et al.* (2005) in their study of self-discrepancy and affective distress in TBI survivors. However, the BDI and the BAI contain somatic items that may be more attributable to the brain injury itself rather than reflect affective symptoms, and they also take longer to

complete. The HADS, on the other hand, while being a reliable and valid measure of anxiety and depression in the stroke population, also has the advantage of being brief and therefore quicker to complete. The HADS was thus deemed a more suitable measure to use, especially as it was important to maintain the overall administration time as brief as possible in order to reduce the demand on participants. Also, this was the measure of choice for affective distress in other studies in the systematic review, including Ellis-Hill and Horn's (2000) study of identity change in stroke survivors.

There were significant negative correlations between pre-stroke self ratings and anxiety ($r = -.313, p < 0.05$) and overall mood ($r = -.292, p < 0.05$), but not with depression; there were also significant negative correlations between post-stroke self ratings and anxiety ($r = -.598, p < 0.01$), depression ($r = -.742, p < 0.01$) and overall mood ($r = -.745, p < 0.01$). This could be a consequence of a functional relationship, or of an overlap between items within the self-concept measure (HISD) and the distress measure (HADS). Many constructs, by their very nature, require measurement by items that are superficially similar, but nevertheless tap distinct psychological processes. In the current study this question could be addressed using Campbell and Fiske's (1959) multitrait-multimethod (MTMM) approach, which compares how different measures of separate constructs perform in elucidating and differentiating the constructs. The procedure requires investigation of the convergent and discriminant validity evidence. However, a full implementation of this approach is beyond the scope of this study.

Nevertheless, a supplementary analysis was carried out. Three items on the HISD were considered by researcher and the researcher's supervisor as potentially overlapping with some HADS items (unhappy - happy with HADS item 6, worried-relaxed with HADS items 5 and 7, and calm - irritable with HADS item 11). An analysis of the correlations with the three identified HISD items removed demonstrated that the correlations remained large and highly significant², suggesting that item overlap is not the principal reason for the observed association. Additionally, the HISD and the HADS were considered appropriate measures to use

² Self-discrepancy and anxiety ($r = .33, p < 0.01$), self-discrepancy and depression ($r = .58, p < 0.01$), self-discrepancy and overall mood ($r = .50, p < 0.01$).

by Carroll and Coetzer (2011) for investigating the relationship between self-discrepancy and depression in TBI survivors.

Finally, it could also be argued that given the administration order of the measures, the pre-stroke self ratings might have primed the ratings of psychological distress, which then might have primed the post-stroke self ratings. This could have been addressed by random administration of measures, although this would not be necessary when measures are carefully designed to tap into experientially distinct and accessible states that have particular phenomenological salience and identity for individuals.

4.5.2.3.3 Other considerations

Due to practical considerations, there was variation in the administration of the measures i.e. face-to-face, individually or part of a small group, and over the telephone, and participants might have responded differently in different circumstances; for instance, completing the measures over the telephone may confer more of a sense of anonymity. This may have introduced various data collection biases. Ideally, there should be consistency in administration across all participants.

It could be argued that the administration of the HISD three times consecutively to assess different aspects of self, i.e. post-stroke, ideal and ought selves, may have led to interactions between these ratings due to confusion about what was being rated, fatigue or boredom. Furthermore, it is possible that the psychometric scales may have cued the answers to the open question about differences between pre and post-stroke, which was asked at the end of the data collection. Therefore, randomising the administration order of the scales might have helped with counterbalancing the order effects.

Indeed, the ratings for ideal and ought selves were highly correlated ($r = .60$, $p = 0.01$); although this might be to be expected, it is questionable to what extent participants were able to distinguish between the two concepts. To assess for this, there could have been an additional question to ascertain participants' understanding of the concepts of ideal and ought self respectively and the differences between them. Cantor *et al.* (2005) argued that the TBI survivors in their study were able to

discern between the different selves; however, this appeared to be based on the fact that they were able to provide descriptors for each of the selves in the Selves Interview. Even though the differences were explained individually at the point of the administration of the HISD, and participants were prompted during the rating as to which type of self they were rating, it is still possible that the concepts may have got mixed up. For instance, this may have been more likely when the participants would complete the measures as part of a group.

Finally, participants rated their pre-stroke self retrospectively, as was the case with all the studies in the systematic review, which is a major source of bias and therefore might compromise the accuracy of the data. However, as discussed earlier, survivors' subjective experience would be more relevant in terms of understanding their distress.

4.5.2.4 Generalisability of findings

As discussed in the introduction, brain injury, regardless of the cause, can have consequences for physical, cognitive, emotional and behavioural domains. This can then have implications for the survivor's occupational performance, their sense of self-efficacy, and their relationships, and can result in role changes. While these may be common occurrences for brain injury survivors, with implications for their self-concept and mood, the psychosocial context of people with different types of brain injury also needs consideration.

For instance, stroke survivors tend to be older than TBI survivors, and stroke is associated with medical conditions such as hypertension (Lawes *et al.*, 2001) and diabetes (The Emerging Risk factors Collaboration, 2010). This means that the likelihood of comorbidity with other physical disorders and chronic illnesses is increased in the stroke population, and so they may have had previous challenges to their self-concept (Charmaz, 2002). Also, the health of stroke survivors could have been deteriorating for some time before the occurrence of the stroke and although the stroke event itself, like TBI, is sudden, there may be some awareness or expectation of deterioration in functioning; this may allow for new narratives about the self to be slowly incorporated, which may not lead to a disruption of self (Charmaz, 2002).

Furthermore, expectations of aging may influence how stroke survivors interpret and cope with the deterioration, as they may see it as part of normal aging; thus, there may be less of an impact on their self-concept. Additionally, after a stroke, the risk of a further one is significant (Mohan *et al.*, 2011), thus, the expectations of recovery after stroke versus TBI may be different, which may impact more negatively on the mood of stroke survivors.

The likelihood of depression increases with age, partly due to increased likelihood of physical illness, which is associated with increased risk of depression; also, social isolation and loneliness, and persistent sleep problems were identified as risk factors for depression in older people (Graham *et al.*, 2011). Furthermore, pre-existing depression may be amplified following stroke, and inadequate coping skills and diminished emotional reserve may further impact on adjustment.

On the other hand, as TBI survivors tend to be younger men, the injury is likely to interfere with their education and career, and also with forming or maintaining long-term relationships; therefore, it could be argued that the injury may interfere with the performance of important social roles and thus may have greater impact on their identity. In this sense, it could also be argued that younger stroke survivors may be more similar with TBI survivors in terms of psychosocial circumstances.

Unlike in the case of stroke, where there may be unaddressed health risk factors, TBI may be an event over which the person had no control, with implications for their perceived locus of control. People with a more internal locus of control may adapt better to illness (Partridge & Johnston, 1989); indeed, the externality of locus of control predicted distress in non-aphasic stroke survivors (Thomas & Lincoln, 2006), and lower externality of locus of control was associated with significantly lower mood disturbance in TBI survivors (Moore & Stambrook, 1992). Furthermore, TBI survivors may also be involved in stressful insurance, medical and legal processes, with likely implications for their mood.

In conclusion, all factors discussed above may have different implications for a survivor's self-concept and mood. Consequently, generalising results from one population of brain injury survivors to another may require caution.

4.6 THEORETICAL AND CLINICAL IMPLICATIONS

4.6.1 Theoretical Implications

Consistent with Higgins' (1987) self-discrepancy theory, this study showed that in a sample of stroke survivors discrepancies between the actual self (i.e. post-stroke self) and their ideal self were significantly associated with depression, and discrepancies between their actual self and their ought self were significantly associated with anxiety. However, discrepancies between actual self (i.e. post-stroke self) and ideal self were also significantly associated with anxiety, and discrepancies between actual self and ought self were also significantly associated with depression.

Although the theory predicts that both types of discrepancies can individually be related to both depression and anxiety, as it was found by the current study, the relationships between actual - ideal self- discrepancy and depression, and between actual - ought self-discrepancy and anxiety, respectively, should be strongest (Higgins *et al.*, 1985). However, in the current study, this was the case for the correlation between the post-stroke - ideal self-discrepancy and depression, but not for the correlation between post-stroke - ought self-discrepancy and anxiety, thus providing only limited support for Higgins' theory.

While there may have been sufficient power, due to the size of the sample, to allow for differentiation of these relationships, it may be that the HADS, being a screening tool, was not an appropriate measure of distress for differentiating between anxiety and depression, which would then make it difficult to differentiate between the different discrepancy-distress relationships.

The findings of the current study are consistent with other studies that failed to support the distinctiveness of actual - ideal and actual - ought self-discrepancies relating to particular types of emotional distress (e.g. Cantor *et al.*'s, 2005; Phillips & Silvia, 2010; Tangney *et al.*, 1998). However, the findings are not inconsistent with Higgins' (1987) self-discrepancy theory; they provide some support for the theory, albeit not unequivocal. Nonetheless, the study adds to the limited evidence for the theory in clinical populations, showing a relationship between self-discrepancies and emotional distress in a stroke population.

Furthermore, by adapting the SDT to include pre-stroke versus post-stroke self discrepancies, the theory may provide a useful model for understanding affective distress following stroke that could then inform rehabilitation. This was based on Cantor *et al.*'s (2005) view that the pre-injury self may become idealised, which would lead to discrepancies with the present self, and thus to affective distress. However, Higgins' theory explores discrepancies between self-states as they are perceived currently, and not retrospectively. Consequently, the theory may not hold for discrepancies involving retrospective self-state appraisals.

Additionally, the post-injury self would also reflect the social construction of self in a new context that may be disability-averse, fostering negative attitudes toward people with disability; these may become internalised and survivors may identify with the disabled self, which could also explain the associated affective distress. Survivors reported having lost a sense of being an integrated and valued person (Levack *et al.*, 2014), which is relational, and it is in these social interactions that the post-injury changes become more evident (Ellis-Hill *et al.*, 2000). As discussed in the introduction, others' (e.g. family, professionals) views and interactions with survivors also play an important role in how identity change after ABI is experienced and negotiated. For instance, medical discourse can influence how survivors understand themselves (Cloute *et al.*, 2008), and carers can play a role in maintaining damaged identities (Guisse *et al.*, 2010).

Furthermore, the idea of the pre-injury self becoming idealised may not always be applicable, or indeed helpful, as it also means that it does not accommodate for the possibility of survivors experiencing post-traumatic growth. It has been shown that people may also report positive psychological changes after a traumatic event, including stroke (Collicutt McGrath & Linley, 2006), and some of these changes refer to the perception of self and improved relationships (Linley & Joseph, 2006). Indeed, some survivors in this study also identified some positive outcomes in terms of having become a better person, which had a positive effect on their relationships. This means that in some cases the post-injury self may actually be seen as more positive, and so possibly closer to an ideal self, than the pre-injury self. Indeed, clinically it would be useful to facilitate the experience of post-traumatic growth.

4.6.2 Clinical Implications

Stroke rehabilitation still seems to centre heavily around restoring physical functioning (Guise *et al.*, 2010; Keppel & Crowe, 2010), at the detriment of survivors' interests and experiences, who may be more concerned about their changed roles and relationships than recovery of physical function (Kirkevold, 2002). Indeed, identity issues may come in the way of physical rehabilitation (Parry, 2004).

Thus, while regaining physical function is important in order to increase independence and thus enable survivors to re-engage with their life and increase participation, restoring some quality of life, it is equally important to attend to the cognitive and emotional responses to the stroke (Bornstein & Brown, 1991). Williams and Evans (2003) also highlighted psychological adjustment to brain injury as central to the rehabilitative journey. Indeed, modern neuropsychological rehabilitation emphasises a biopsychosocial approach, thus aiming at improving the cognitive, emotional, psychosocial and behavioural sequelae of brain injury (Wilson, 2008), and has been conceptualised in different ways.

Prigatano (2008) views neuropsychological rehabilitation as involving three levels, with the first two referring to recovery of function and reduction of disability by developing compensatory strategies to improve functional outcome. The findings of this study have implications at the third level of neuropsychological rehabilitation as conceptualised by Prigatano (2008) that is the survivors' subjective experience of their brain damage, which is seen as central to effective rehabilitation.

These results show the value of self-reported change in self-concept in understanding the experience of stroke survivors, and emphasise once again the importance of re-establishing a coherent identity. Consequently, a crucial part of the rehabilitation process involves supporting stroke survivors to create a continuous and positive sense of self.

Perceived identity change can be taken into account throughout the clinical cycle, from the initial assessment, to inform clinical formulation and rehabilitative journey, and the provision of therapy. Thus, along with screening for anxiety and depression, clinicians can enquire whether survivors experience themselves as somewhat different to the person they were before the stroke; clinicians can also formally

assess changes in self-concept using the HISD measure, which was used in the current study. The identified discrepancies between pre-stroke and post-stroke self can form the basis of further conversation with the stroke survivor and their family to contextualise the changes, and enhance clinician's understanding of their client's subjective experience and of the meaning these changes hold for them; increased attention could be given to the traits that are most salient to the individual with the aim to reduce those particular discrepancies. All this information can then be integrated in the individual's formulation and considered as a possible contributing factor to the aetiology of their psychological distress. Yeates *et al.*'s (2008) biopsychosocial framework for considering the neurobiological, psychological and psychosocial influences on perceived personality change following brain injury can be useful in helping clinicians understand these changes, and then facilitate the understanding of survivors and their families.

Psychotherapy with brain injury survivors focuses on adjusting to changes in functioning, to which acceptance is seen as a critical psychological factor, and on developing a new self-concept (e.g. Bennett, 1989; Harrell & O'Hara, 1991; Kinney, 2001; Fraas & Calvert, 2009). Reconciling identity loss and creating a sense of coherence and continuity may involve reconciling the pre-stroke with the post-stroke self; emphasising the similarities between the two (Stern, 1985) and focusing on preserved opportunities and abilities (Wright & Telford, 1996), thus bridging the gap between them, integrating aspects of their former identity within a new identity; or developing a new identity.

Interventions that proved useful in reducing self-discrepancies between self-domains (e.g. actual self – ideal self), such as Strauman's (2003) Self-System Therapy, Interpersonal Psychotherapy (Strauman *et al.*, 2001) and Mindfulness Based Cognitive Therapy (Crane *et al.*, 2008) may also help with reducing discrepancies between pre-injury and post-injury selves, if appropriately adapted to be used with this clinical population. Other possible interventions that could contribute to re-constituting identity may include the following:

Acceptance and Commitment Therapy

Myles (2004) proposed Acceptance and Commitment Therapy (ACT), which is the clinical application of RFT, as a useful approach to re-establish a sense of self after

a brain injury. ACT involves working with clients to accept painful private experiences that interfere with following their key life values (Hayes *et al.*, 1999). Metaphors and experiential exercises (Hayes & Wilson, 1994; Hayes *et al.*, 1999), adapted to suit the cognitive needs of the client (Myles, 2004), can be used to facilitate knowing that there exists a sense of self that is stable over time, independent from the survivor's ongoing flow of private experiences, however painful (i.e. *the self as context*). Myles (2004) argues that contact with *self as context* may facilitate acceptance by creating a safe place from which the survivor can know and accept the changes in functioning and self-concept.

Narrative approaches

Clinicians could work with survivors to normalise their experience, allowing time to grieve (Fraas & Calvert, 2009) and help them make sense of their new world and who they are, by helping them revise their self-narratives. This would involve identifying the different strands to their identity, and strengthening those valued constructions of self that are preserved (Hinojosa *et al.*, 2008) in order to facilitate some continuity of the familiar pre-stroke self. It would also involve developing a positive current and future sense of self (Ellis-Hill *et al.*, 2008) by constructing new, preferred self-narratives; at the same time, the survivor can be helped to develop a "grown self" (Nochi, 2000) narrative by identifying ways in which the injury contributed positively to who they are as a person. Developing self-narratives of coping would also help with improving their self-image (Nochi, 2000). Rebuilding a sense of identity based on new possibilities and capacities, rather than solely attempting to restore the pre-injury self (Hill, 1999) may further serve to enhance their self-esteem. This may enable survivors to move forward and accept new identities.

However, the reconstruction of coherent self-narratives is facilitated through social interaction, through reorganising interpersonal relationships and environments to support the newly developing self-narratives (Nochi, 2000). As managing relationships with others can be challenging for people with ABI (Gracey & Onsworth, 2012) interventions may firstly involve helping them to rebuild their social relationships. Additionally, clinicians could work with the survivors' families and carers to enable them to support survivors' developing positive sense of self rather

than inadvertently maintain their 'damaged' identities by criticising and challenging their accounts (Guise *et al.*, 2010). Furthermore, work would involve tackling the medical discourse, both within services and at a wider societal level, that can make brain injuries survivors see themselves as sick, passive and dependent (Cloute *et al.*, 2008), to make room for alternative constructions.

Increasing participation in meaningful occupations

Meaningful engagement in relevant social and life activities seems to play a role in the construction of self after injury (e.g. Gracey *et al.*, 2008; Gracey & Onsworth, 2012; Haslam *et al.*, 2008; Ylvisaker & Feeney, 2000; Ylvisaker *et al.*, 2007). Therefore, in the safe therapeutic space, the survivor can be helped to develop an understanding of their strengths and difficulties, and then focus on meaningful occupations and develop the skills that facilitate goal achievement (Wilson *et al.*, 2009). Increasing their skills and developing compensatory strategies would help with reengagement in valued, goal-directed and identity congruent activities. This would facilitate reconstructing a more positive post-stroke identity that is closer to the pre-stroke self (Broomfield *et al.*, 2010), but in a new context. Furthermore, those people who engaged in activities that were particularly salient to their identity also reported higher quality of life post-stroke (Clarke and Black, 2005). These ideas consistent with Gracey, Evans *et al.*'s (2009) Y-shaped model of rehabilitation, which is based on the approach advocated by Wilson *et al.* (2009).

4.7 FUTURE RESEARCH

The current study provided evidence that following stroke there is a dramatic negative change in the sense of self of survivors, and that the perceived discrepancy between pre and post selves is strongly related to reported psychological distress, with self-esteem as the mediator of this relationship. In light of the above discussion, there are several ideas regarding future research.

Firstly, comorbidity with other physical illnesses, common in the stroke population, would need to be considered due to potential implications for both mood and self-concept, as well as survivors' premorbid anxiety and depression. Replicating this study with a larger sample would allow multivariate modelling in order to investigate

the relevance of different variables in understanding perceived identity change after stroke by grouping participants according to variables and comparing different groups. For instance, a lower sense of loss of self was experienced by TBI survivors who were in employment (Carroll & Coetzer, 2011). Also, lesion location was not included in the analysis in this study; stroke survivors with anterior lesions seemed to report a more positive view of self (Keppel & Crowe, 2010). Thus, the extent of the role that variables such as engagement in meaningful activities, relationship status, age, level of functioning, time since injury, location and size of lesion might play in pre-post stroke self-discrepancy would be worth investigating to help identify those who are at increased risk of experiencing self-discrepancies. These variables might be moderators of the relationship between self-discrepancies and affective distress.

Only self-esteem was tested as a mediator of the relationship between self-discrepancies and affective distress in this study. It would be interesting to explore which of the self-descriptor discrepancies correlated the strongest with self-esteem. Other possible mediating factors of this relationship could also be investigated, such as premorbid personality traits, different coping styles with the perceived change, and perceived locus of control. Those with a more internal locus of control may adapt better to illness having a better overall health outcome (Partridge & Johnston, 1989). Lower externality of locus of control and using coping strategies such as self-controlling and positive reappraisal were associated with significantly lower mood disturbance in TBI survivors (Moore & Stambrook, 1992). The externality of locus of control was also found to be predictive of distress in non-aphasic stroke survivors, and locus of control was found to mediate the relationship between coping style and distress (Thomas & Lincoln, 2006).

In their study investigating identity change in stroke survivors, Ellis-Hill and Horn (2000) also used a matched comparison group and found no significant changes in self-concept in the control group. However, this was a small sample. Another relevant area for further research would be to carry out a study with a large comparable group of people without stroke to assess the stability of perceived self-concept in a non-clinical population.

According to Higgins' (1987) self-discrepancy theory, there are two standpoints on the self, one's own personal standpoint, considered in this study, and one's

significant other's standpoint. It would be interesting to investigate discrepancies between the post-stroke self, that is how survivors perceive themselves, and their ideal and ought selves from the standpoint of a significant other; that is survivors' beliefs about a significant other's hopes, wishes, or aspirations on one hand (ideal self) and duties and responsibilities, on the other (ought self). And also investigate how these discrepancies might relate to experienced distress. This might help identify unhelpful expectations that survivors perceive others to have for them, as being unable to live up to perceived expectations may also contribute to their distress. Indeed, comparing stroke survivors' perceptions with their significant other's or carer's perceptions of their post-stroke self might also be helpful.

Other further studies might investigate changes in self-concept in stroke survivors with more severe cognitive impairments and awareness; or, compare relationships between self-discrepancies and affective distress in both stroke survivors with and without clinically significant anxiety and depression. Furthermore, a longitudinal study to monitor changes in self-concept over a period of time, during different stages of recovery would help identify crucial points of intervention.

4.8 SUMMARY AND CONCLUSION

The concept of identity loss or change following brain injury, including stroke, has been supported mostly by qualitative studies, and there is also emerging quantitative evidence demonstrating significant negative changes in survivors' sense of self following injury (Carrol & Coetzer, 2011; Cantor *et al.*, 2005; Tyerman & Humphrey, 1984; Wright & Telford, 1996). However, only two studies have shown this in a population of stroke survivors (Ellis-Hill & Horn, 2000; Keppel & Crowe, 2010).

Furthermore, studies with TBI survivors showed that changes in self-concept were associated with emotional distress (Carrol & Coetzer, 2011; Cantor *et al.*, 2005; Wright & Telford, 1996), which was explained using Higgins' (1987) self-discrepancy theory by expanding it to include pre-injury self (Cantor *et al.*, 2005).

The current study is the first to investigate changes in self-concept in a large sample of stroke survivors, and to employ Higgins' (1987) self-discrepancy theory in order to

explore the relationship between perceived changes and a person's psychological adjustment.

This study has shown a significant discrepancy between the post-stroke self and the pre-stroke self, with survivors viewing themselves in more negative terms following the stroke, which is supporting previous research. Furthermore, these changes in self-concept were positively associated with affective distress, and negatively associated with perceived self-esteem and quality of life, respectively. Discrepancies between survivors' perceived post-stroke self and their ideal self and ought self, respectively, were also positively correlated with affective distress; this provides only partial support for the self-discrepancy theory, as the respective relationships were not differentiated. Additionally, survivors' perceived self-esteem was a mediator in the relationship between the discrepancy in how survivors saw themselves before compared to after the stroke and their affective distress.

Notwithstanding the limitations discussed earlier in this chapter, the findings of this study provide an understanding of the psychological factors underlying the common difficulties concerning emotional adjustment to stroke, and indeed individuals with acquired brain injury; this has significant implications in terms of rehabilitation, restating the importance of creating a continuous and positive sense of self after brain injury at the centre of the rehabilitative process, which highlighted the need for developing interventions to help with the re-establishing of a coherent identity. Additional research would need to clarify further the relationship between self-discrepancies and affective distress and investigate changes in self-concept in survivors with different degrees of severity of impairments.

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Appendix 1 CASP Qualitative Research Checklist



10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

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Screening Questions

1. Was there a clear statement of the aims of the research? Yes Can't tell No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate? Yes Can't tell No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

- Is qualitative research the right methodology for addressing the research goal?

Detailed questions

3. Was the research design appropriate to address the aims of the research?

Yes Can't tell No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

Yes Can't tell No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?

Yes Can't tell No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and been adequately considered?

Yes Can't tell No participants

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
 - (a) Formulation of the research questions
 - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? Yes Can't tell No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? Yes Can't tell No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? Yes Can't tell No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix 2 Quality Appraisal of Correlation Studies or Cross-sectional Surveys

++ = good, + = mixed, - = poor, nr = not reported, na = not applicable

Cells are colour-coded to demonstrate the relationship with the summary questions below.

Study identification (include full citation details)			
Study design:		Other	
Evaluation criteria		Quality ++ + - nr na	Guidance topic:
		Assessed by:	
P Population	Section 1: Population		
	1.1 Is the source population or source area well described?		
	1.2 Is the eligible population or area representative of the source population or area?		
	1.3 Do the selected participants or areas represent the eligible population or area?		
E Exposure (& Comparison)	Section 2: Method of selection of exposure (or comparison) group		
	2.1 CS : Selection of exposure (and comparison) group. How was selection bias minimised?		
	2.2 CS : Was the selection of explanatory variables based on sound theoretical basis?		
	2.3 CS : Was the contamination acceptably low?		
	2.4 How well were likely confounding factors identified and controlled?		
	2.5 XSS : Were rigorous processes used to develop the questions (e.g. were the questions piloted / validated?)		
	2.6 Is the setting applicable to the UK?		
O Outcomes	Section 3: Outcomes		
	3.1 Were the outcome measures and procedures reliable?		
	3.2 Were the outcome measurement complete?		
	3.3 Were all important outcomes assessed?		
T Time	3.4 CS : Was there a similar follow-up time in exposure & comparison groups?		
	3.5 CS : Was follow-up time meaningful?		
R Results	Section 4: Analyses		
	4.1 CS : Was the study sufficiently powered to detect an effect if one exists?		
	4.2 CS : Were multiple explanatory variables considered in the analyses?		

	4.3 Were the analytical methods appropriate?		
	4.4 Was the precision of association given or calculable? Is association meaningful?		

Summary	Section 5: Summary		
	5.1 Are the study results internally valid (i.e unbiased)?		
	5.2 Are the results generalisable to the source population (i.e externally valid)?		



Appendix 3 Ethics Approval (received via email)

Ethics Feedback - EC.13.02.06.3404R

On Monday, 4 March 2013, 9:10, psychethics <psychethics@Cardiff.ac.uk> wrote:

Dear Irina,

The Ethics Committee has considered your revised postgraduate project proposal:
Self-discrepancy
and affective distress after stroke (EC.13.02.06.3404R).

The project has now been approved.

Please note that if any further changes are made to the above project then you must notify the
Ethics Committee.

Best wishes,

Natalie Moran

School of Psychology Research Ethics Committee
Tower Building
Park Place
CARDIFF
CF10 3AT

Ffôn /Telephone: +44 (0) 29 2087 0360

Ffacs/Fax: +44 (0) 29 2087 4858

<http://psych.cf.ac.uk/aboutus/ethics.html>



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Appendix 4 Electronic/Flyer Recruitment Advert

Self-discrepancy and affective distress after stroke

Volunteer stroke survivors needed for research exploring the relationship between change in the sense of self before and after stroke (who I was before and who I am now) and the way that this affects adjustment and mood

Who can take part?

To take part you must have had a stroke (or a series of strokes), which must have occurred after the age of 18 years. Also, at least 6 months must have passed since the last stroke, but no more than 15 years.

What is the purpose of the study?

Research suggests that acquired brain injury, such as stroke, can impact on one's sense of self, which can lead to significant discomfort and can interfere with successful rehabilitation. It has also been shown that anxiety and depression are commonly experienced after stroke.

This study looks at whether there is a difference in the stroke survivors' sense of who they are now compared to who they were before the stroke. It also explores whether there is a relationship between the experienced difference in the stroke survivors' sense of self and how they feel emotionally, and what might affect this relationship. This will help to inform and improve psychosocial rehabilitation following stroke.

What does it involve?

Stroke survivors will be asked to complete some questionnaires that last approximately 45-60 minutes, including a 10 minute break. The questionnaires can be completed face-to-face, while attending the stroke club, or over the telephone. In certain circumstances, the researcher may be able to come to the participant's home to complete the questionnaires. The answers to the questionnaires will be anonymised and kept confidentially.

How can you take part?

If interested or for further information about the study, please contact Irina Lapadatu (Trainee Clinical Psychologist) on 029 208 70582 or at lapadatuil@cardiff.ac.uk, or by post at the address above.

Tel/Ffon: 029 208 70582 Email/Ebost: CAV_Psychology.Training@wales.nhs.uk



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Appendix 5 Participant Information Sheet

Self-discrepancy and affective distress after stroke

Dear Stroke Survivor,

You are invited to take part in a research study which is being carried out by Irina Lapadatu, Trainee Clinical Psychologist, under the supervision of Professor Reg Morris, Consultant Clinical Psychologist, South Wales Doctoral Programme in Clinical Psychology. The results of the research will be written up as a dissertation and submitted as part of the researcher's examinations towards a Doctorate in Clinical Psychology. It may also be published as a journal article, but no participants will be identified in either published work. Before you decide whether you would like to take part, please read this information sheet which explains the purpose of the research and how you can help with it. Please feel free to discuss this with others or contact the researcher (details below) to ask any questions if there is anything you are not sure about, or if you would like more information.

What is the purpose of the study?

Research suggests that acquired brain injury, such as stroke, can impact on one's sense of self, which can lead to significant discomfort and can interfere with successful rehabilitation. It has also been shown that anxiety and depression are commonly experienced after stroke.

This study looks at whether there is a difference in the stroke survivors' sense of who they are now compared to who they were before the stroke. It also explores whether there is a relationship between the experienced difference in the stroke survivors' sense of self and how they feel emotionally, and what might facilitate this relationship. This will help to inform and improve psychosocial rehabilitation following stroke.

Tel/Ffon: 029 208 70582 Email/Ebost: CAV_Psychology.Training@wales.nhs.uk

Do I have to take part?

You are free to decide whether or not you would like to take part, as participation in this research study is entirely voluntary.

If you decide to take part, please return the completed reply slip, demographic questionnaire and the signed consent form in the way that you have already agreed with the researcher, Irina Lapadatu.

If you decide to take part you are free to withdraw at any time without giving a reason.

What is involved if I do agree to take part?

If you decide to partake in the research and you are eligible for participating in the study we will ask you to fill in a set of questionnaires. These should take no longer than 60 minutes to complete, including a break.

If you agree to partake in the study the researcher, Irina Lapadatu, will contact you to arrange to meet you at the stroke club to complete the questionnaires. This may happen on an individual basis or in a small group of participants. Alternatively, you will be asked to complete the questionnaires over the telephone at a time that is convenient for you. In certain circumstances, the researcher may be able to visit you at home to complete the questionnaires.

What are the possible advantages of taking part?

Your participation will contribute to increasing understanding of the impact of stroke upon one's sense of self and mood. Addressing the loss and reconstruction of identity of stroke survivors may prove a crucial component for successful rehabilitation.

What are the possible disadvantages of taking part?

This study is a psychological study and there are no known risks involved in taking part. However, if at any point during the interview you feel that you would like to withdraw from the study you will be free to do so.

If you feel concerned by any issues that arise as part of completing the questionnaires you would be able to contact Professor Reg Morris on 029 208 70582 or by email at reg.morris@wales.nhs.uk to discuss this with him.

Will my participation in this study be confidential?

Your participation in the research and your answers to the questionnaires will be made anonymous by removing your name once they are received and collated for analysis by the researcher. Once this is done you will not be able to be identified by anyone. The questionnaires that you complete will be seen only by the researcher (Irina Lapadatu) and Research Supervisor (Reg Morris) and will be kept in a locked filing cabinet.

What will happen to the results of the study?

The results of the research will be written up as a dissertation and submitted as part of the researcher's Doctorate in Clinical Psychology and may be published in a research article. All data will be anonymised and so will any information that could allow the participants to be identified. You may ask to see all the anonymous data at any time. You also have the right to withdraw your data without explanation up to the point that it is made anonymous, after which, it will not be traceable back to you individually.

If you would like a summary of the findings (available Oct 2014) please tick the appropriate box on the reply slip.

What if I have a problem with the study or want to make a complaint?

If you have questions and/or concerns about any aspect of this study, please contact the researcher (contact details below) who will do her best to answer your questions. If you remain unhappy and wish to complain formally you will be given contact details of the Cardiff University School of Psychology Research Ethics Committee who may be able to respond to your concerns.

Who has reviewed the study?

All research is looked at by a Research Ethics Committee in order to protect your safety, rights, wellbeing and dignity. This study has been reviewed and approved by the Cardiff University School of Psychology Research Ethics Committee.

Further information

If you have any further questions about taking part in the study or **need** any more information please do not hesitate to contact the researcher (Irina Lapadatu) at the South Wales Doctoral Programme in Clinical Psychology on 029 208 70582, email

(lapadatuil@cardiff.ac.uk) or return the contact slip to the address below, and you will be contacted as soon as possible.

If you do not wish to take part, you do not have to do anything more and you will not be contacted again.

Thank you very much for taking the time to read this information sheet, your help is greatly appreciated.

Irina Lapadatu

Trainee Clinical Psychologist

Professor Reg Morris

Consultant Clinical Psychologist

Programme

Director



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Park Place
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Appendix 6 Reply Slip Self-discrepancy and affective distress after stroke

Please tick all that apply:

- I am interested in taking part in the research.
- I would like more information before I decide whether or not to take part.
- I would be comfortable completing the questionnaires as part of a group of people.
- I would like a summary of the findings and my email or postal address is:
.....
.....
.....
.....

The following information is to enable contact; it will not be used in the study.

Name: _____

Email Address (if available): _____

Telephone number: _____

Can a message be left at this telephone number (please tick)?

- Yes
- No

If you would like to take part in the research, please return this reply slip together with the completed demographic questionnaire and consent form to Irina Lapadatu, Trainee Clinical Psychologist, in the way that you have already agreed.

Thank you.

Tel/Ffon: 029 208 70582 Email/Ebost: CAV_Psychology.Training@wales.nhs.uk



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Appendix 7 Demographic Questionnaire

ID number (to be completed by the researcher): _____

Self-discrepancy and affective distress after stroke

This information will be used anonymously in the study. Please answer as many questions as possible. However, you DO NOT have to answer anything you do not want to. Thank you for your time.

Sex (tick one): Male Female

Year of Birth: _____

Marital Status (tick one) Married Single – never married
 Separated/divorced Widowed

Ethnic origin: _____

Highest level of education obtained: _____

Retired (please tick): Yes No If no: _____

Current occupation: _____

Occupation prior to retirement or stroke (if different): _____

Date of stroke: ____/____/____ Type of stroke, if known (e.g. haemorrhagic, infarct): _____

Have you suffered more than one stroke (please tick) Yes No

Side(s) of body affected (please tick) Right Both Left Neither

Is your speech affected following the stroke? (please tick) Yes No

If yes, please briefly describe how your speech is affected:

Is your comprehension affected following the stroke? (please tick) Yes No

If yes, please briefly describe how your comprehension is affected:

Other effects of stroke (e.g. loss of balance or vision): _____

Is there previous history of (please tick):

Serious illness Learning disability Physical disability

Serious head injury Diagnostic of dementia or Parkinson's

Did you suffer with anxiety/depression before your stroke? (please tick) Yes No

Have you suffered with anxiety/depression since your stroke? (please tick) Yes No

Name (block capitals):Date:.....

Tel/Ffon: 029 208 70582 Email/Ebost: CAV_Psychology.Training@wales.nhs.uk



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Appendix 8 Participant Consent Form

Self-discrepancy and affective distress after stroke-

- I understand that my participation in this study will involve completing a set of questionnaires, face-to-face (individually or as part of a small group) while at the stroke club, or over the phone. This will require approximately 45-60 minutes of my time, including a break.
- I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time, without giving a reason.
- I understand that I am free to ask any questions at any time. I am free to discuss any concerns with Professor Reg Morris, Consultant Clinical Psychologist and Programme Director on the South Wales Doctoral Programme in Clinical Psychology.
- I understand that the information provided by me will be held confidentially. All my answers to the questionnaires will be made anonymous when the data are collated. After this point data cannot be withdrawn from the study because it will not be traceable back to me individually anymore. All information will be retained for up to 5 years when it will be destroyed.
- I understand that at the end of the study I can be provided with additional information and feedback about the purpose and results of the study.

I, _____(NAME) consent to participate in the study conducted by Irina Lapadatu, South Wales Doctoral Programme in Clinical Psychology, Cardiff University with the supervision of Professor Reg Morris

Signed (participant):

Date:

Tel/Ffon: 029 208 70582 Email/Ebost: CAV_Psychology.Training@wales.nhs.uk



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Appendix 9 Participant Debrief Sheet

Self-discrepancy and affective distress after stroke

Dear Stroke Survivor,

Thank you for taking part in the research, your time and input is very much appreciated.

The aim of the research is to explore whether there is a difference in the stroke survivors' sense of who they are after the stroke compared to who they were before the stroke. It also explores whether there is a relationship between the experienced difference in the stroke survivors' sense of self and how they feel emotionally, and what might affect this relationship.

You have completed some questionnaires that explored one's sense of self, self-esteem, mood and adjustment after stroke.

This information you provided will be put together with the information from all the other participants in this research project and analysed statistically. The results will help to increase understanding of the impact of stroke upon one's sense of self and mood. This will then be helpful in informing psychosocial rehabilitation.

The information you have provided is being held anonymously. Your answers to all the questionnaires were made anonymous when your data were collated. All information will be retained for up to 5 years when it will be destroyed. You may ask to see all the anonymous data at any time. You also have the right to withdraw your data without explanation up to the point it is made anonymous, after which it will not be traceable back to you individually anymore.

If you would like to make any comments and/or complaints, please contact Professor Reg Morris.

Many thanks,

Irina Lapadatu
Trainee Clinical Psychologist

Professor Reg Morris
Consultant Clinical Psychologist
Programme Director

The following appendices have been removed for copyright reasons:

Appendix 10 Head Injury Semantic Differential III

Appendix 11 The Barthel Index

Appendix 12 Stroke Specific Quality of Life Scale (SS-QOL)

Appendix 13 The Rosenberg Self-Esteem Scale

Appendix 14 Hospital Anxiety and Depression Scale