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The social construction of identity: Integrating theoretical and therapeutic approaches

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**CITY UNIVERSITY
LONDON**

**Portfolio submitted in fulfilment of the Professional Doctorate
in Counselling Psychology, DPsych**

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p. 246-273, Section C: Client Case Study

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Declaration

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Preface to the Portfolio

This doctoral portfolio is about combining methods, analyses and interpretations to seek multiple perspectives on human nature and experience. It comprises three sections; the first section is an empirical research project that investigated how eight individuals with traumatic brain injury (TBI) (re)constructed identity. The second section consists of part of this work formatted as an article for submission to a journal. The third section is a clinical case study describing my work with a client with substance addiction. Each piece of work has been completed during my training in counselling psychology at City University, London. The sections aim to demonstrate my competence and development in counselling psychology, providing evidence of my knowledge and skills in theory, research and practice. Each of the three pieces examines the role of bringing together different theories, research and clinical work that create a multidimensional relational framework. Combining theoretical methods and psychological approaches will be described below, followed by introduction of the three pieces of work that comprise this portfolio.

Combining approaches

All three pieces of work examine the role of combining approaches to theory, research and practice. The aim for combining approaches is derived from my empirical view that exploring a subject or a problem from different interpretative 'lenses' will provide richer knowledge and understanding.

Multiple qualitative methods research is defined as the application of more than one qualitative method when analysing data (Chamberlain, Cain, Sheridan & Dupuis, 2011). The rationale for combining different theories and methodologies is that this offers a more holistic view of other people's experience and provides insights that cannot be gained by using one method alone (Chamberlain et al., 2011; Frost, 2011). One consideration when using multiple qualitative methods is how to do justice to the depth and breadth of the data without making the analysis fragmented. However, multiple qualitative methods will generate many different findings, which will be of interest and provide paths for further research (Frost, 2009).

In the case study, I used an integrative therapeutic approach. Integration can be referred to as combining two or more diverse theoretical concepts into a coherent and (hopefully) more effective theory (Gilbert & Orlans, 2011). The aim is to develop a therapeutic framework that is flexible enough to fit the needs of different clients and contexts (Palmer & Woolfe, 2000). Integrating different therapeutic models can also complement the limitations of each (approach) (Gilbert & Orlans, 2011). I believe that combining different theoretical approaches allows a therapist to understand a client's experience from different perspectives (Hollanders, 1999). This may assist tailoring the therapeutic work to the unique needs of each client (Cooper & McLeod, 2011).

I am also interested in the common factor hypothesis (Hubble, Duncan & Miller, 1999) of psychological therapies, which suggests that multiple factors facilitate each other to affect psychological change, and that there are no differential outcomes between different approaches. The common factor hypothesis emphasises the focus of a client-therapist relationship as a fundamental process of therapy and understanding of humanity.

One criticism of an integrated theoretical approach is that it may be difficult to combine diverse and potentially opposing philosophies, then apply this coherently to psychological practice (Gilbert & Orlans, 2011). However, integration can be understood as a continuing process of engagement rather than a settled position and is thus constructed as an open, rather than closed, system (Hollanders, 1999). Another criticism for an integrative framework is that bringing several theories together is ineffective as it results in a lack of conceptual depth, diagnosis and treatment. Therefore, it is important for my development that I acquire a profound knowledge and understanding of the psychological theories and therapies that I may consider applying in my clinical work. I also need to be reflective and aware of the limits of my competence at each development stage. This may be accomplished through further clinical experience, critical evaluation of research findings and supervision.

Doctoral thesis

The first piece of work presented in this portfolio is a doctoral thesis titled: '(Re)Constructions of identity following traumatic brain injury: A discourse analysis'. My interest in this area stems from conversations with my partner who works in

Emergency Medicine and cares for people who have had traumatic injuries. We discussed how individuals with traumatic brain injury (TBI) frequently expressed concerns of feeling like a 'different person' post-injury and how these changes had an adverse impact on their lives. I am very interested in identity and performed a literature search, which identified several studies that explored the experiences of individuals with TBI concerning (their) loss of identity and loss of sense-of-self. Those affected were often young and reported a high rate of post-injury psychological morbidity, which required multidisciplinary support to help integrate them back into society and regain a good quality of life. Many studies concluded that there was a need for more qualitative research in this field to better understand the client needs and develop the therapeutic approaches offered. I formulated my study proposal and approached a head injury charity. I met with the staff and volunteers who emphasised the lack of understanding and awareness about TBI in our society, including health care professionals. They showed a great interest in and enthusiasm for the proposal, and offered their support.

My initial reading about identity made me question different theories and concepts about the topic. I am interested in how our culture, society and language influence our construction of identity. Therefore, I decided to take a social constructionist (Burr, 2003) perspective of identity, which claims that identity is constructed through the discourses culturally available to us, and through our communication with other people.

I wanted to approach the participants' narratives from different interpretative perspectives in order to acquire a holistic understanding. Foucauldian discourse analysis, FDA (Willig, 2013) was used to explore the understanding of the use of discourses when (re)constructing identity following TBI. Positioning theory (Davies & Harré, 1990) was used to explore how available discourses create different subject positions. Frank's (1995) illness narratives were used to further explore the observations of the discourses and positionings. I was interested in how discourses may constrain, enable, limit or facilitate individuals' psychological flexibility and how this may affect rehabilitation. I was also interested in re-positioning and the process of shifting from positions, for example, from positions of dependence and disempowerment to positions of independence and empowerment.

I think it is important that theory and research integrate with clinical practice in order to instigate debate, potentially leading to the subsequent developments in patient care. In

the discussion of this thesis I suggest clinical psychological approaches that could be considered part of a holistic community-based neurorehabilitation. These clinical suggestions derive from the findings of the current study, published TBI research and research into other chronic illnesses. The approaches that I outline and discuss include the process of empowerment, (Burr, 1995; Fenton & Hughes, 1989; O'Hara & Harrell, 1991), and acceptance and commitment therapy, ACT (Hayes, 2004, 1995).

Article for Submission

The second piece of work of the portfolio is a paper formatted as an article for submission to a journal. It shares the same name as the thesis, '(Re)Constructions of identity following traumatic brain injury: A discourse analysis'. The article derives its data, analysis and findings from part of the thesis. I have chosen to present some aspects of the research project. The aim of the article is to highlight discourses and subject positions that were particularly prevalent to the population.

For potential submission I have chosen the journal, 'Neuropsychological Rehabilitation' as it publishes clinical research related to neuropsychological assessment, neuropsychological therapies, recovery and rehabilitation. It is aimed at clinicians who wish to inform their practice of the latest scientific approaches in this field. My literature search identified several papers published in this journal involving individuals with TBI, exploring psychological difficulties including disruption in normal cognitive, behavioural, emotional, physical functioning, and identity construction. The article was written in accordance with Neuropsychological Rehabilitation's guidelines for authors.

Case study

The third piece of work of the portfolio is a clinical case study, 'Working with an integrative approach: Cognitive behavioural therapy and person centred therapy' which was undertaken in the final year of my doctoral training. It presents a piece of therapeutic work that I undertook during my placement at an NHS drugs advisory service. The client was a woman in her late 40s, who I saw for the duration of 20 sessions of psychological therapy. During the initial assessment she presented with symptoms of depression, anxiety, low self-esteem and substance addiction.

The case study presents an integrated approach, applying both cognitive behavioural therapy (CBT) (Beck, 1995; Beck, 1976) and person centred therapy (PCT) (Mearns & Thorne, 2007; Rogers, 1957). The aim of using PCT was to facilitate the client's self-actualisation, self-responsibility and process of empowerment. CBT interventions were incorporated within the PCT framework. I found it helpful to consider the client's presenting problems from both a CBT formulation and a PCT interpretation. A CBT formulation explores problems as interactions between thoughts, emotions, behaviour, physical symptoms and the environment in which the person operates (Beck, 1995). PCT considers conditions of worth laid down in childhood, core beliefs, denial and distortion of experience, state of incongruence, and psychological difficulties (Simms, 2011). I found PCT vital in order to create a non-judgmental and safe therapeutic alliance.

My intention to complete this case study was to deepen my knowledge and understanding of integrative theory and practice. I also wanted to present an integrative piece of clinical work as part of the portfolio to demonstrate my learning and development within this approach.

In summary, these three pieces of work describe different ways of applying multiple approaches within multiple theoretical frameworks and integrated psychological therapies. The process of working with this portfolio has been an enriching journey. I hope this portfolio demonstrates my ongoing development in counselling psychology: to become a reflective practitioner who is able to assess, formulate and deliver therapy; to demonstrate the ability to engage critically with the psychological literature of different theoretical orientations, and to continue to conduct research with an empirical, curious and flexible conviction.

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SECTION A – DOCTORAL RESEARCH

(Re)Constructions of Identity Following Traumatic Brain Injury: A Discourse Analysis

Cecilia Wolfenstein

Supervised by Dr Julianna Challenor

Abstract

Traumatic brain injury (TBI) can cause a wide range of challenging and persistent difficulties, including disruption of normal cognitive, behavioural, emotional and physical functioning. TBI can also increase the risk of psychological and social problems. Personality disturbance, loss of sense-of-self and change in identity are key issues following brain injury and will constitute the main focus in this study. Eight individuals who acquired TBI between eight and 37 years prior to the study were interviewed. The text was analysed using two different theoretical approaches. Foucauldian discourse analysis (FDA) was used to explore how people with TBI (re)construct identity within their society and culture. The aim of using this perspective was to focus deeply on the social constructions of health, disability and illness, which have particular relevance for rehabilitation. The study also focused on the role of subjective experience of the individual and subject positionings within discourses. The analysis distinguished 33 discourses, which were conceptualised and integrated under five discourse themes: 'identity in relation to disability and invisibility', 'identity as rebirth and ongoing development', 'identity as awareness and uncertainty', 'identity in relation to perceived normality and social belonging' and 'identity in relation to independence, acceptance and recovery'. A second reading applied Frank's illness narratives (restitution, chaos and quest) to the text, in order to take the analysis and interpretive work in a different direction by placing the participants' accounts of identity within a broader meaning-making process. The findings support the social constructionist view of identity as a fluid and multidimensional construct. The analysis suggests that while subject positionings of disempowerment and helplessness were common, the subject positioning of dependence has a shifting nature. The findings of this study may inform how clients with TBI adjust and accept 'new' identities following their brain injury. Clinical implications are discussed in terms of how psychologists could use psychological approaches to provide opportunities for clients to access alternative, more empowering discourses and subject positionings.

CHAPTER 1 - INTRODUCTION

Traumatic brain injury (TBI) defines injuries with a wide range of severity, from concussion to severe brain injury or death (Hyder, Wunderlich, Puvanachandra & Kobusinguye, 2007). Individuals who suffered TBI have reported experiences of disturbance, loss of sense-of-self and change in identity (Nochi, 1997; Prigatano, 1992). Several studies (e.g., Freeman, Adams & Ashworth, 2015; Levack, Kayes & Fadyl, 2010) suggest that more qualitative research is needed to understand the diversity of psychological difficulties and individual needs for this client group. The aim of this study is to gain an understanding of the (re)construction of identity for individuals with TBI. It is intended that this study will contribute to the awareness of TBI for health care professionals and the public, and facilitate improvement in psychological approaches and rehabilitation.

In this chapter I will present data on the prevalence and classification of TBI, then describe the resulting somatic, cognitive and affective symptoms, including personality disturbance. I will then review prevalent disability models, approaches to neurological rehabilitation, and theories of identity. I will discuss major qualitative studies exploring TBI and identity. Finally, I will present the aims of this thesis.

1.1 Search methods

A comprehensive literature search was conducted of articles for the qualitative review using PsycARTICLES, PsycINFO, SCOPUS, Science Direct, Web of Science, E-Journals, Academic Search Complete, MEDLINE (accessed via EBSCO host and City University Library), EMBASE, Cochrane Database of Systemic Reviews (accessed via OVID) and the 'grey' literature (research produced by organisations outside the traditional publishing channels) using Google internet search and Google Scholar. To maximise the sensitivity of the search, each database was searched in its entirety: no date limits were applied. Only English language papers were included as no translation services were available. Book chapters were also identified using the above search strategy and a hand search was made of relevant textbooks available through City University Library. Multiple searches were performed between April 2013 and May

2016. Additional references were identified from the material obtained in the literature search.

The search terms were tailored to identify papers that referred to four key components of the review topic:

1. Traumatic brain injury (e.g. search terms such as 'traumatic brain injury', 'acquired brain injury', 'classification', 'symptoms').
2. Rehabilitation (e.g. search terms such as 'neurological rehabilitation', 'disability', 'psychological therapy', 'disability models, 'illness models').
3. Identity models (e.g. search terms such as 'identity', 'identity models', 'identity theories', 'social constructionism'); and
4. The types of research of interest (e.g. search terms such as 'quantitative research', 'qualitative research', 'discourse analysis', 'Foucauldian discourse analysis', 'social constructionism', 'discursive psychology', 'narrative analysis', 'pluralistic approach', 'multiple research methods', 'identity', 'personality change', 'sense-of-self', 'loss', 'personality disturbance', 'awareness').

A wide range of papers were read to develop a broad understanding of the topic and research published to date, from which the epistemological stance of the study was defined. I chose to take a social constructionist stance (Burr, 2003) that is critical of assumptions around knowledge, worldview and the idea of a stable reality. It suggests that all ways of understanding are historically, socially and culturally relative (Burr, 2003). The research also applies Foucault's Genealogical investigate method (Foucault, 1977), which provides an intrinsic critique of the present context, and a historical account of the discursive construct under investigation.

1.2 Traumatic brain injury

1.2.1 Prevalence

TBI is the result of an external source in forceful contact with, or rapid acceleration/deceleration movements of, the head (Kushner, 1998). The acquired injury results in variable alteration of cognitive and behavioural functioning. These effects may be transient, long-lasting or permanent, depending on injury specifics and severity (Roebuck-Spencer & Cernich, 2014). Common causes include assault, falling

from height and motor vehicle accidents (Barrow, Ndilkum & Harris, 2012). The risk groups are children under four years old, adolescents between the ages of 15 and 24 years old, males, and adults over 75 years old. Males are twice as likely as females to sustain TBI (Roebuck-Spencer & Cernich, 2014). Additional risk factors are a history of substance or alcohol abuse (Smith & Kraus, 1988), military and combat environment (French, 2009) and participation in sport (Cantu, 1998). TBI can result in significant socioeconomic problems for the individual, and can have long-lasting and devastating effects on an individual's ability to return to family and work (Roebuck-Spencer & Cernich, 2014).

In the UK, around 700,000 people attend emergency departments with TBI each year, which has increased by about one-third during the last decade (Barrow et al., 2012). A review of the global world impact of TBI concluded that approximately 10 million people experience TBI leading to either death or hospitalisation every year (Hyder et al., 2007). However, the proportion of people living with TBI is not known and is likely under-recorded as many countries lack robust reporting systems (Stoler & Hill, 1998). The vast majority of brain injuries are categorised as minor, which are difficult to assess (Barrow et al., 2012). Initial scan results are frequently normal and patients may initially be free of symptoms, but then seek medical attention some days or weeks post-injury (Stoler & Hill, 1998). TBI may not be reliably described when caused by war and civil unrest, as it is often associated with multiple traumatic injuries and consequently not recognised as contributing to death and disability. Although, The World Health Organisation (WHO) has defined parameters for adult central nervous system disorders in 1993, there is no internationally accepted method of defining severity or longevity of childhood disability from TBI (Hyder et al., 2007).

1.2.2 Classification

The effects of brain injury are wide ranging and result from multiple factors, including the type, location and severity of injury (Barrow et al., 2012). There are several formal definitions of TBI. For example, Centers for Disease Control and Prevention (CDC, Marr & Coronado, 2004) define TBI as:

An occurrence of injury to the head that is documented in the medical record with one of the following conditions attributed to head injury: (1) observed or

self-reported decreased level of consciousness, (2) amnesia, (3) skull fracture, or (4) objective neurological or neuropsychological abnormality or diagnosed intracranial lesion. (p. 6)

The severity of TBI is typically classified as mild, moderate or severe based on the person's level of consciousness at initial presentation using the Glasgow Coma Scale (GCS), which scores verbal, motor and eye-opening reactions to stimuli on a scale of 3 to 15 (Levin & Eisenberg, 1991). Mild TBI is classified as a GCS 13-15, moderate as 9-12 and severe as 3-8 (Levin & Eisenberg, 1991). GCS is a good predictor of initial mortality and morbidity (Roebuck-Spencer & Cernich, 2014). Another method of classifying the severity of TBI is duration of post-traumatic amnesia (PTA). The Russell PTA classification scheme (Russell & Smith, 1961) classifies TBI as mild (less than 24 hours in coma), moderate (1-14 hours in coma), severe (1-7 days in coma) and very severe (more than 7 days in coma). Classification may also be based on anatomical changes identified by neuroimaging (Daisley, Tams & Kischka, 2009). While all of these injury indicators are good predictors of outcomes, each has strengths and weaknesses. Classifications of *initial* injury severity should not be confused with *long-term* behavioural and functional outcomes, which can be dramatically different between individuals initially classified with the same severity (Roebuck-Spencer & Cernich, 2014). The classification of TBI has recently been reviewed by the National Institute of Disorders and Stroke of America (Saatman et al., 2008) and a new multidimensional classification was proposed for use in clinical trials, but this has not been widely accepted by researchers.

1.3 Traumatic brain injury: Symptoms

Many individuals report experiencing symptoms post TBI that can be grouped into three clusters: somatic, cognitive and affective (Sheerer & Sander, 2014).

1.3.1 Somatic symptoms

Individuals with TBI frequently experience physical symptoms, including headaches, dizziness, fatigue, muscle rigidity, paralysis, seizures, speech impairment, sensory problems, loss of sight, loss of smell or taste, loss of co-ordination and sexual problems (Sheerer & Sander, 2014). Physical disability often leads to serious social

problems (Wood, 2013). Many individuals never recover full social independence and remain largely dependent on family and health care support (Wood, 2013).

1.3.2 Cognitive symptoms

Cognitive symptoms of TBI include memory impairment, slow processing speed, poor attention and concentration, problems with planning and organisation, and loss of insight, awareness and initiative (Sheerer & Sander, 2014). This complex pattern of neurobehavioral disability is the product of the interaction between damaged neural systems, neurocognitive impairment, pre-morbid personality traits, social environment and post-injury learning (Worthington & Wood, 2008).

Different parts of the brain may have different functions, so injuries to specific areas are commonly associated with particular outcomes (Sherry, 2006). People with TBI tend to have less damage to the temporal lobe structures, but frequently have marked damage to frontal lobe structures, which may impact on memory performance (Burgess & Alderman, 2014). Cognitive symptoms and neuro-behavioural disability are associated with injury to the prefrontal cortex (Wood, 2013). Injury to the dorsolateral (i.e. back and side) frontal lobe is associated with loss of executive function (inability to plan, poor initiative and complex reasoning) and working memory (Wood, 2013), altered regulation of emotions (Uotomo, 2000), increased impulsivity, irritability, aggression (Chow, 2000) and loss of theory of mind (Alexender, 2002). Damage to the temporal lobe may result in loss of speech production and understanding (Higgenbottom, 1998).

Individuals with TBI may have impaired retrieval of working (short-term) memory and long-term memory, which interferes with autobiographical memories and self-narratives (Nochi, 1998). Deficits in working memory affect the process of storing new memories, so individuals forget recently acquired information, have difficulties learning new skills, repeat the same information and forget changes in routine or where objects have been placed (Evans, 2014). Long-term memory is the permanent repository of knowledge of events that has been acquired from minutes to decades previously. Tulving (1972) divided long-term memory into semantic and episodic memory systems. Semantic memory is a store of factual knowledge of the world and includes knowledge of word meanings, objects and people. Haslam, Jetten, Haslam, Pugliese and Tonks (2011) emphasised that semantic memory and episodic memory influence what a person

understands about themselves. They proposed that the strength of one's sense of identity is associated with enhanced understanding of 'the self' and thereby shapes memory retrieval.

1.3.3 Affective symptoms

Individuals with TBI are at high risk of developing psychological and mental health difficulties, including depression, anxiety, post-traumatic stress disorder (PTSD), loss of motivation and difficulty controlling anger (Brown, 2014). The most commonly diagnosed mood disorders are depression and anxiety (Hibbard, Uysal, Kepler, Bogdany & Silver, 1998). Jorge, Robinson, Starkenstein and Arndt (1993) found major depression in 26% of participants one month following TBI and in 42% during the following year. A long-term study by Varney, Martzke and Roberts (1987) identified major depression in 77% of participants three years post-injury, while Hibbard et al. (1998) found 61% of participants suffered from depression eight years following brain injury. Hibbard et al.'s study also showed a high rate of comorbidity, with 44% of participants presenting with two or more Axis I diagnoses (e.g. major depression and general anxiety disorder). Individuals diagnosed with depression post-injury were also likely to develop substance abuse disorders. A neuroimaging study by Yurgelun-Todd et al. (2011) revealed that frontal contusion (bruises) increases suicide risk. TBI may result in physical scarring, however, many individuals with TBI have no or few visible sequelae and the consequences are often 'invisible' (Sinnakaruppan & Williams, 2001). Steadman-Pare, Colantonio, Ratcliff, Chase and Vernich (2001) found that the lack of recognition of the participants' invisible injuries was a major factor influencing their life satisfaction.

1.3.4 Personality disturbance

Personality disturbance is common following brain injury (Prigatano, 1992). Following TBI, changes in the biological state of the brain can result in temporary or permanent changes in emotional and motivational responses (Prigatano, 1992). When these changes are more permanent, they can manifest as personality changes. For example, injuries to the limbic system and associated neocortical structures can directly affect personality (Macchi, 1989). The disturbance of neural tissue can lead to changes of control or expression of emotions and behaviour (Macchi, 1989). There are many indirect effects on personality following TBI. For example, individuals who repeatedly

fail on cognitive tasks may develop anxiety or depression. Psychosocial changes related to brain injury may cause increased irritability, agitation, anger or apathy (Prigatano, Pepping & Klonoff, 1986). Because of the complexity and multiple causes, it is very difficult to conceptualise or measure changes of personality (Prigatano, 1992). Morris et al. (2005) conducted a study involving individuals with moderate to severe disability who had sustained TBI one to 10 years previously and from which they had residual difficulties. Most of the participants reported social, cognitive, physical, behavioural and emotional difficulties. Participants also reported concerns about loss of sense-of-self and sense of identity. They reported that they felt they had lost the person they were prior to the trauma, as well as reporting other types of loss: of work, friends and partners. Participants raised the issue of not being understood by others; for example, friends and relatives appeared not to understand why the participants were depressed or exhausted in the absence of external signs of injury (Morris et al., 2005).

1.4 Neurological Rehabilitation

The Royal College of Physicians and British Society of Rehabilitation Medicine (RCP/BSRM, 2003) defines rehabilitation as:

Conceptual definition: A process of active change by which a person who has become disabled acquires knowledge and skills needed for optimal physical, psychological and social function.

Service definition: The use of all means to minimise the impact of disabling conditions to assist disabled people to achieve their desired level of autonomy and participation in society. (p. 7)

The National Institute of Clinical Excellence (NICE, 2003) published national guidelines for rehabilitation following acquired brain injury (ABI, which includes brain injuries such as TBI, strokes and tumours) focusing on the 48 hours following acute injury. Post-acute rehabilitation and long-term care are covered by RCP/BSRM (2003) guidelines, which aim to reduce morbidity, restore function and improve participation. These guidelines state that every patient with ABI should have access to specialist neurological rehabilitation services and that these need to be matched to the needs,

strengths and capacities of each person. They also state that patients with mood disorders should be offered individual or group psychological interventions. However, they do not specify which psychological approaches should be available nor how to access them. Banja and Johnston's (1994) evaluation of outcomes within TBI rehabilitation found that professionals focused on narrowly defined functional outcomes, which often disenfranchised persons with TBI. The authors had little confidence that outcome measures chosen by experts within rehabilitation will necessarily reflect the personal and social values of individuals with TBI.

Neurological rehabilitation can be considered as a complex health care intervention that involves the negotiation of suitable goals with multidisciplinary health care professions. Several theories and models of neurological rehabilitation exist (Coetzer, 2008). Broadly, these models include behavioural (often applied to motor problems, memory impairments, language disorders), cognitive (influential in language and reading disorders) and compensatory (enabling people with brain injury to deal with everyday life) interventions (Gracey & Wilson, 2014).

1.4.1 Community-based rehabilitation and empowerment

There is evidence that intensive, community-based outpatient holistic rehabilitation results in favourable outcomes (Cicerone, Mott, Azulay & Friel, 2004). Goldstein (1959) proposed 'the organismic theory' in developing 'holistic' neurological rehabilitation. The organismic theory proposes that the fundamental motivation of an individual is to realise their identity. The holistic model of rehabilitation emphasises a need for developing self-awareness and therefore identifies psychotherapy as part of the treatment package (Coetzer, 2008). Ben-Yishay and Prigatano (1990) developed a contemporary approach to holistic neurological rehabilitation from Goldstein's use of the 'therapeutic milieu', and describe a number of ordered stages that the patient must work through, including engagement, awareness, mastery, control, acceptance and identity.

Yates (2003) reviewed the literature on psychological adjustment to acquired disability and chronic health conditions subsequent to ABI. Yates argues that community-based rehabilitation programmes based around a biopsychosocial model may improve psychosocial functioning and social role outcomes for survivors of TBI. Yates

emphasises that both psychological (cognitive, behavioural, and emotional) and social (environmental, cultural and political) concerns need to be accounted for when considering the process of adjustment to disability. Yates (2003, p. 298) demonstrated, through a case study, 'the challenges of community integration and the need to work with both individuals and families simultaneously to maximise outcomes and ensure sustained consistent intervention and support'. A second case study emphasises 'the frequency, intensity and structured nature of input required in the community setting for individuals whose neuropsychological status has widespread social consequences' (Yates, 2003, p. 300). Both case studies present the challenges of achieving occupational dependence. Yates's literature review of vocational rehabilitation involves enabling individuals with severe TBI to develop work roles. This also includes enabling the environment by changing other people's attitudes towards people with disabilities and working towards social inclusion (Campbell & Oliver, 1996). Yates (2003) emphasises the importance of integrating the concept of 'empowerment' as a part of intervention and rehabilitation programmes, particularly the elements of 'personal power' (the power of the individual to influence their environment) and 'power with' (social power where people come together as equals), as formulated by Neath and Shiner (1998). Attending to these forms of power could facilitate the shaping of flexible and community-enabling interventions as part of long-term rehabilitation. Yates's (2003) review provides an extensive overview of research including disability, adjustment and the importance of developing community-based rehabilitation. The review could have been strengthened by including more than two case studies.

Another holistic/integrated approach is the empowerment rehabilitation model, developed by O'Hara and Harrell (1991) to assist patients with TBI, their families and treatment providers in addressing unmet needs and to enhance enablement and empowerment. They argued that rehabilitation often causes patients to adopt a helpless victim role, which hinders them in achieving treatment goals. The empowerment rehabilitation model comprises several components including enhancing motivation, enabling patients with information and skill, and empowering them with self-awareness, acceptance and self-respect.

1.5 Models of illness and disability

Several models have been developed to conceptualise illness and disability. The way in which disability is defined is important because the language people use to describe disabilities influences the identities, interactions, expectations and positionings of those with disability within society (Barton, 2009). Over the past 50 years, in Western society, the two prominent models of disability discourses have been the medical and social model (LoBianco & Sheppard Jones, 2008).

In this section I define the medical model (Brittain, 2004), the social model (Oliver, 1990) and the social constructionist approach to illness and disability (Foucault, 1977), which is the epistemological stance of this study. I also discuss The World Health Organisation's International Classification of Functioning, Disability and Health (WHO ICF, 2001) as it provides a coherent view of different perspectives on health: biological, individual and social. The rationale for including these models in this section is to offer a broad and critical overview of the theoretical framework that has been applied to the psychological treatments used to help individuals with disability and TBI.

Brittain (2004) suggested that, in modern Western society, the power of the medical profession was gained through its ability to define, diagnose and cure illnesses. This 'cognitive authority' has put the medical profession in a strong position to create and perpetuate discourses in relation to many aspects of life, including disability. Sherry (2006) outlines major themes from the medical model of illness and disability including:

The assumption that it is possible to accurately diagnose an impairment; the assumption that it is possible to accurately diagnose an impairment; the perceived need for a team of health professionals to control the process of recovery; the promotion of rehabilitation as a way of teaching disabled people how to 'compensate' for their 'deficits'; and the assumption that social disadvantage stems from an underlying pathology. (p. 41)

From a medical model perspective, disability is understood as a physical phenomenon resulting in limited functioning and that is seen as deficient (Fitzgerald, 2006; Mitra, 2006; Palmer & Harly, 2012). The model assumes that illnesses and disabilities are universal and invariant to the social context (Conrad & Baker, 2010). Under the

medical model, treatments for individuals with disabilities are focused on 'fixing' the impairment so that they can 'function' in society (Bingham, Clarke, Michielsens & Van De Meer, 2013). This can perpetuate dependency and be disempowering for disabled people (Sherry, 2006). The medical model can make an important contribution to the understanding of TBI by describing which cognitive, perceptual, behavioural and affective symptoms may be expected from a pattern of anatomical TBI (Sherry, 2006). However, an issue with this model is that it fails to consider the subjective experience of individuals with long-term medical conditions and the wider social context (Conrad & Baker, 2010). Another critique of the medical model is the persistence of negative perceptions that are embedded in the model (Brittain, 2004). The discourse of pathologising individuals with disabilities has been internalised and accepted by society, and is used by institutions and organisations to inform policy (Humpage, 2007). It is therefore difficult to develop alternative discourses within this societal context (Brittain, 2004).

In the 1970s and 1980s the social model of disability was developed as a reaction to the medical model (Oliver, 1986). The social model sees disability as a societal problem and not as an attribute of the individual (Oliver, 1990). The social model argues that society imposes disability on individuals with impairments (Bingham, 2013; Mitra, 2006; Oliver, 1990). In the context of the social model, there is a sharp distinction between impairment and disability (Oliver, 1990). Impairment is seen as an abnormality of the body, such as a restriction or functional limitation caused by physical, mental or sensory symptoms (Goodley, 2001). Disability is the disadvantage or restriction of opportunities caused by a society that does not take into account individuals with impairments and excludes them from participating in community life. This suggests that it is not a person's bodily function per se that limits their abilities but society's lack of inclusion and adaptation to it (Goodley, 2001). Oliver (1990) describes disability as a form of 'social oppression' by public attitudes and environments. The social model is important as it highlights the discrimination, negative positioning, stigmatisation and lack of opportunities that disabled people experience as a consequence of the medical model (Sherry, 2006).

The social constructionist approach to disability and illness is a version of the social model of disability. This emphasises the meanings and experiences of illness, how impairment is shaped by the cultural and social context (Barnes, Mercer &

Shakespeare, 1999; Conrad & Baker, 2010), the distinction between disease (the biological condition) and disability (the social meaning of the condition) (Eisenberg, 1977). The social constructionist approach does not deny biophysiological conditions or naturally occurring events. However, Barnes et al. (1999) state that the attributes of impairment and the meaning of being disabled vary across time and culture, and disability cannot be reduced to a mere problem in an individual's body. Oliver and Barnes (1998) proposed that individuals with impairments are not always disabled in every context, which suggests that being 'disabled' or 'non-disabled' is not a static state, but that such categories are constantly refined, progressed and transformed in different socio-political environments.

The social models (including the social constructionist approach) have been criticised for not taking into account issues of embodiment (Corker & French, 1999; Sherry, 2006). Embodiment of disability can be briefly defined as how disabled people experience and interpret their body's identities in a social context (Frank, 1990). By separating disability and impairment, the social model does not fully account for the lived experiences of individuals with disabilities (Palmer & Harley, 2012). Another critique of the social model is that it does not account for differences between individuals with disabilities. This critique suggests that the social model cannot understand an individual's experiences of disability independent of other attributes such as race, gender and sexual orientation (Fitzgerald, 2006).

Taken individually, neither the medical model nor the social model of disability fully encompasses the experiences of the individual. The models are not adequate as disability is a complex phenomenon that involves both a level of impairment of a person's body and a social problem. The WHO's ICF (WHO, 2001) is based on the biopsychosocial model of disability, which views disability as an interaction between biological, psychological, social and contextual factors. Contextual factors include personal factors (such as age and coping styles) and environmental factors (including both individual and societal). While the individual level refers to a person's immediate environment (home, workplace, school) the societal level refers to overarching systems, such as health services. The ICF is the international and conceptual basis for the definition, measurement, and formulation of policy for health and disability. The model has become an important conceptual framework in rehabilitation services, and has provided a global and collective language for health and disability. In ICF, the term 'functioning' refers to all body functions, activity and participation, while the term

'disability' refers to impairments, activity limitations and participation restrictions. Wade and Halligan's (2003) review concludes that the ICF model has many strong features but fails to describe the experience of an individual with long-term illnesses in several ways. First, the authors point out that the ICF does not include diagnosis and classification of disease, which is currently covered by the World Health Organisation's International Classification of Diseases (WHO ICD-10, 1992). They suggest that integrating the ICF and ICD-10 would give more attention to the social consequences of the disease and provide critical thinking in several areas of health care. Secondly, the authors argue that the terminology of ICF uses negative terms, including the word 'disability'. They instead propose four words that denote the underlying healthy or normal structures and functioning that are disrupted in illness. For the body, the authors suggest the word 'anatomy' and, for the associated structure, 'capacity'; for the organ, they suggest the word 'histology', and the associated functioning 'physiology'. Thirdly, the authors note that the current ICF classification is based only on the time period 'here and now', and suggest a revised classification that would include past experiences and future expectations, which are of great importance to the individual's rehabilitation. Finally, they concluded that the ICF requires revision from to become a more patient-centred model, emphasising the multifactorial nature of illness. During the last couple of decades there has been a profound change in the epistemological basis of the discourse of disability. One reason for this is that disabled people have increasingly been involved in studies of disability, which helped to develop the available discourse and shift positioning (Sullivan, 1991).

1.6 Concepts of identity

1.6.1 Brief historical overview of identity approaches

Varied and occasionally contradictory approaches exist to define the concepts of self and identity. In this section I describe some of the major theories used to define and construct identity, self and ego. A brief historical description of concepts of identity provides a theoretical background, and the rationale for providing this is to highlight how concepts of identity differ, that identity is a construction of the culture and historic episode we live in, and how this has changed and continues to change with time. I

have chosen to describe the social constructionist view of identity in more detail, as this is the epistemological stance of the current study.

The concept of 'identity' was unthinkable in the pre-modern and feudal era (Taylor, 1989). However, during the age of Enlightenment and the secularisation of the 1600s, identity became a topic of philosophers such as Descartes (1596-1650) and Locke (1632-1704) (Benwell & Stokoe, 2014). Descartes proposed that the self (or soul) was created by a person's 'mental states' and was distinct from the body. Both Descartes and Locke viewed identity and self as entities that pre-exists all social experiences. Later, in the Romantic era (1800-1850), the 'subject' is theorised as something innate, but predicated on sensibility and feeling rather than cognition. In the 1900s, Mead (1934) asserted that society played a part in the development of a person's identity and made a distinction between two types of labelling, namely 'I' and 'me'.

Freud's (1923) structural model of the mind conceptualises the human psyche as an interaction of three parts: the id, ego and superego. The id is entirely unconscious. It is present from birth and is the location of drives including sexuality and aggression. The ego has both conscious and unconscious aspects. The conscious ego is what is referred to as 'self' (Freud, 1923), and the terms 'ego' and 'self' are often used interchangeably (Lemma, 2003). The superego incorporates the values and morals of society and is learnt from parents and others. The superego is divided into two parts: the ego ideal (ideal self), what the ego aspires to be; and the conscience, what punishes and directs the ego when it fails. Intra-psychic difficulties are said to arise because of conflicts between the id, ego and superego (Freud, 1923). Erikson's (1980) theory of psychosocial development suggests that identity develops in a series of stages and is affected by social experiences throughout life. One of the main aspects of this theory is the development of the 'ego-identity'. According to Erikson (1980), ego-identity is the conscious sense-of-self that individuals develop through social interaction. Our ego-identity is constantly changing due to new experiences in our daily interactions with others.

Tajfel (1982; Tajfel & Turner, 1986) developed social identity theory (SIT) originally to understand the psychological basis for discrimination. They suggested that identity is conceptualised into different levels: personal and social. They propose that, rather than one self, an individual has several selves that correspond to different categories or

group memberships. Social identity is an individual's knowledge of belonging to a social category (Turner, Hogg, Oakes, Reicher & Wetherell, 1987). A social group is a set of individuals who hold common social identifications or view themselves as members of the same social category. Much of SIT seeks to explain intergroup relations: how people come to see themselves as a member of one category rather than another (Turner et al. 1987).

1.6.2 Social constructionist view of identity

Some theorists claim that identity cannot exist without language. Lacan (1953) states that sense of identity is an illusion and that we are constructed solely in and through (and subjected by) language. Social constructionists suggest that human experience including knowledge is understood in a social, historical, cultural, environmental and linguistic context (e.g. Burr, 2003; Foucault, 1982). Our identity is therefore constructed, combining the different levels of discourses that are culturally available to us, for example, discourses of age, class, sexuality, illness and many more (Burr, 2003). According to social constructionism, all accounts of human experience are constructed through language. Thus, identity is constructed in daily life by drawing on available discourses and in communication with others; language is part of identity construction (Burr, 2003). Identity is constructed continuously, and this implies that identity is an unstable and fluid state (Burr, 2003). All social and psychological phenomena, such as identity, memory and subjectivity, are constructed through language. Therefore, identity is not perceived as an 'inner reality' (as in the phenomenological approach) but as socially constructed psychological phenomena (Potter & Wetherell, 1987) that exist as discursive actions rather than as cognitive processes (Burr, 2003). Bamberg, De Fina and Schiffrin (2011, p.178) argued that the process of constructing an identity involves positioning oneself in relation to three 'identity dilemmas' over time: between agency and non-agency, difference and belonging, and sameness and change.

Foucault (1977, 1982) was critical of the traditional concept of 'subject', which suggests that an individual has an autonomous and stable 'core of self'. For Foucault, a subject and self-knowledge are produced through discourses in two different senses or places. Firstly, the discourse itself produces 'subjects'. The subjects have attributes that are defined by the discourse: a 'madman' and a 'hysterical woman', for example. These

subjects are formed within the knowledge of a particular historical period. Secondly, the discourse also produces subject positionings, from which particular knowledge becomes meaningful. For example, individuals may differ in their social class, gender or ethnicity, but they will not be able to make meaning until they have identified with the positions that the discourse constructs. By positioning themselves in relation to the discourse's 'rules', they become subject to its power/knowledge relationship (Hall, 1997).

Harré (Harré & van Langhove, 1999; Davies & Harré, 1990) developed the positioning theory, which considers power dynamics that shape interaction and the positioning processes. The main underlying premise is that people negotiate meaning about self and other by strategically positioning themselves throughout a dialogue. Our identities as manifestations of our selves require the dynamic co-operation of other people; this allows individuals to create multiple identities in different situations, and implies a multidimensional construct of identity that undergoes constant change throughout a lifetime.

The current study is informed by social constructionism (Burr, 2003) and follows a positioning theory (Davies & Harré, 1990; Harré & van Langhove, 1999) view of identity. It also draws on Foucault's (1977) concept of discourse and identity as it seeks to explore how discourses produce particular and different versions of identity, as constructed by people with TBI. It will take into account Foucault's (1982) concept of power/knowledge relationship and examine how people with TBI position themselves within the current discourses available in the current historical period (London, UK, 2014-2016).

1.7 Literature review of previous qualitative studies of individuals with TBI and identity

In this section I review existing qualitative research conducted with individuals with TBI. To be included in this review, studies were required to meet the following criteria: be published in a peer-reviewed journal, be published in English, use qualitative methodology, and use data that reported experience and narrative of individuals with acquired TBI. I focus on studies exploring identity and TBI. I discuss studies of self-

awareness, subjective experience and changes in identity following TBI. I then discuss studies related to loss of identity, invisibility and disempowerment in this area.

1.7.1 Discourses of self-awareness following TBI

Qualitative research on the subjective experience of people with TBI of personality disturbance and altered identity has increased since the 1990s. Before then, individuals with TBI were considered to lack self-awareness about their enduring neuropsychological impairments and the emotional and social consequences (Chrisp, 1994). Tyerman and Humphrey (1984) proposed that individuals with TBI might have more awareness than appreciated. More recently, Prigatano (2000) suggested that by assuming that individuals with TBI have subjective experiences, including the capacity to comment on their sense-of-self (even if lost or altered), it is possible to develop a deeper understanding of the phenomenological experience of people with TBI.

Yeates, Henwood, Gracey and Evans (2007) used discourse analysis to explore awareness of disability following ABI within a family context, and interviewed individuals with ABI and their relatives. The authors suggested that individuals with brain injury who were identified as having poor awareness were able to reflect on their experiences of themselves in relation to others and their past-self. The authors found that both individuals with ABI and their relatives struggled to make sense of the changes in identity. The study also identified how, at times, the person with the injury drew on discourses of themselves pre-injury to make sense of change post-injury. In response, relatives presented alternative accounts of the changes in identity of the person with ABI, sometimes describing the injured person as 'brain damaged' or 'childlike, growing up again', which may suggest a disempowering discourse. Yeates et al. suggested that such 'contesting accounts' may play out in interactions where the individual with the brain injury feels the need to defend their identity, yet the relatives perceive lack of awareness. However, due to the small sample (three individuals with ABI and three relatives), generalisability is limited. Another limitation of this study's method was that clinicians identified and recruited participants who were perceived to have a significant lack of awareness of their executive and social disability. This might have created a selection bias when recruiting participants, which could have influenced the findings.

1.7.2 Subjective experience and changes in identity following TBI

Levack, Kayes and Fadyl (2010) conducted a meta-synthesis of 23 qualitative studies, published between 1965 and 2009, investigating the lived experience of recovery from TBI acquired in adulthood. The aim was to inform debate on the selection of outcome measurement tools to evaluate disability and rehabilitation services for people with TBI. The review highlights some important issues, including mind and body disconnection, disconnection with pre-injury identity, social disconnection, emotional sequelae, internal and external resources, reconstruction of identity, and reconstruction of a place in the world. The authors concluded that there are outcome measures for some but not all of the issues identified in qualitative research. Levack et al. suggested that further research and in-depth analysis of identity was needed to develop outcome measures to evaluate experiences of loss of identity, satisfaction with reconstruction of identity, and sense of connection with one's body and one's life following TBI. Overall, the qualitative meta-synthesis made an important contribution to TBI research by investigating outcome evaluation. However, one critique is that outcome measurements might not always be an appropriate, reliable or valid method to understand complex discourses around identity change. Another critique is the lack of suggestions for alternative methods of evaluating rehabilitation needs of individuals with TBI, such as engaging the service users in developing their own methods of assessment and evaluation. A limitation of all qualitative meta-syntheses is that the interpretations are at least three times removed from the participants' lived experience, as they involve the interpretation of studies, which are themselves interpretations of multiple researchers' interpretations of the participants' experiences. Therefore, one might question how a meta-synthesis can serve as a credible basis to direct effective and safe practice (Sandelowski & Barroso, 2007).

Nochi (2000) used grounded theory to explore coping strategies and adjustment to disability and living with TBI. He focused on the self-narratives of individuals who felt 'at ease' with their current situation, perhaps implying positive or neutral views of the current situation. Five common narratives were identified: 'the self better than others', 'the grown self', 'the recovering self', 'the self-living here and now', and 'the protesting self'. Nochi suggested that 'the grown self' enabled the person to acquire positive values of themselves, which could provide an opportunity to create goals for their future lives. Moreover, Nochi concluded that successful developments of self-

narratives needed to occur in interaction with other people, society and culture, as opposed to isolated rehabilitation. This may involve reorganising interpersonal relationships and environments so that they support newly developing and alternative self-narratives. A limitation with this study was that Nochi only focused on the positive views of the participants' situation. However, by also investigating the participants' negative views, the study might have generated further information for clinical application.

Gracey et al. (2008) conducted a thematic analysis of identity in relation to pre-injury, current (post-injury) and ideal (post-injury) selves. The authors conclude that following ABI, people make sense of themselves in terms of the meanings and felt experiences of social and practical activities. Definitions of self and identity were taken from SIT (Tajfel & Turner, 1986), which describes identities negotiated in social contexts. Nine themes were derived from participant group discussions. The majority of material fell into the themes 'experience of self in the world', 'basic skills' (cognitive, sensory, physical and social) and 'experience to self in relation to self'. The researchers endorsed the need for rehabilitation to focus on skills in the domains of cognitive, physical, sensory and social functioning. However, they recognised that, from the client's perspective, the need to focus on 'meaning' and activity together might be more important. For example, in functional goal setting for independent living, one might ask the individual questions about the meaning of the goal. The study elicited important findings for developing future rehabilitation models. However, a critique with this study was that the participants all attended a holistic rehabilitation programme, which limits the generalisability of the findings. Also, the themes were elicited through participant group discussions and were a specific product of the interaction between these individuals in one context. It is possible that alternative themes would have derived from a different individual or group context.

A recent study by Freeman, Adams and Ashworth (2015) used thematic analysis to explore the experience of perceived changes in sense-of-self related to the social identity of men with TBI. Semi-structured interviews were conducted with five men, who all attended a holistic neuropsychological rehabilitation centre. Some major themes identified were 'perceived stigmatisation', 'a sense of abnormality', 'TBI being an invisible injury', 'being treated differently', 'loss of social status' and 'shame'. The authors also found themes of 'positive personal growth' in relation to individuals'

understanding and acceptance of their identity. However, these positive themes were not representative of all men in this study. The authors attribute this to loss of independence and loss of ability to make decisions about themselves. However, the participants might have perceived themselves as belonging to different levels of pre-injury social categories (depending on level of education or professional job roles). This might have influenced how the participants experienced feelings of e.g. loss of independence and loss of status. Another limitation of this study was that the sample might not have been a 'typical' population of men following TBI: these men had undergone holistic rehabilitation and received psychological therapy. This might have helped them to develop a psychological and emotional awareness, which could have influenced their responses.

1.7.3 Discourses of loss of identity following TBI

Nochi (1997) found that the participants carried a 'void' in their understanding of their past and current selves, and suggested that the 'void' manifests in different ways. Firstly, a 'void' that is associated with participants' sense of loss resulting from the changes in physical and cognitive functioning after sustaining TBI; secondly, a 'void' of memories that makes it difficult to build a consistent narrative of the past; and thirdly, a 'void' within the present self. Nochi highlighted the importance of rehabilitation professionals considering how their clients interpret their TBI and self in everyday life. However, a limitation of this study was that the qualitative research methods were not well described; themes and narratives were described but the method section lacks detail about how the analysis was performed. In addition, data collection was obtained by interviews and observations, but it was not clear how participants' subjective experience was inferred from, or distinct from, observation.

Nochi (1998) used grounded theory to explore how interactions with society affect the sense-of-self of individuals with TBI. He identified three concepts of 'loss of self' following TBI: 'loss of self in relation to pre- and post-injury comparison', 'loss of self in the eyes of others', and 'discontinuity of identity through lost disrupted memories'. Nochi suggested that the diverse nature of loss of self reflects the complexity of self and that the self is constantly generated and modified by the person's interaction with the world. A main theme expressed by participants was that society attached both negative and positive images to TBI that often contradicted their own self-perception.

Participants also felt that negative diagnostic labels such as TBI were associated with an image of abnormality, craziness or stupidity. Nochi recommended that health professionals should assist individuals with TBI in constructing alternative self-narratives as strategies to avoid or minimise loss of self. Importantly, he also discusses the importance of the health professional in addressing societal factors that might influence the experience of loss of self. A limitation of this study was that the results are heavily focused around 'loss of self' and lack any discussion of alternative narratives. Grounded theory is designed to study a social process 'from the bottom up', and encourages the researcher to approach the data without preconceptions (Willig, 2013). However, the article lacks a detailed description of the methodology and might be biased towards a hypothesis of 'loss of self', ('from the top down') generated from previous research.

Landua and Hissett's (2008) study explored the combined impact of TBI on loss of self, ambiguous identity and relational breakdown. The authors interviewed individuals suffering from mild TBI and their families, and demonstrated that the symptoms experienced by the patients changed how they related to themselves and the people closest to them. Many of the participants expressed a sense of loss of self, which was conceptualised as 'ambiguous loss' and 'boundary ambiguity'. Ambiguous loss is described as 'the most stressful loss' in that it defies closure. Boundary ambiguity can be defined as a family member being physically present but psychologically absent. This is different from experiencing the death of a family member, which is a stressful event but is validated through sociocultural processes and allows others to move on. Landua and Hissett identified relationship conflicts such as alienation, guilt, blame and rejection as common themes, and suggest that early recognition of these issues and early therapeutic intervention may prevent relationship breakdown. One consideration with this study was that the authors stated a hypothesis, which predicted a positive correlation between 'boundary ambiguity' and rate of relationship breakdown. In qualitative studies, researchers tend not to attempt to prove or disprove hypotheses, and doing so might limit the exploration of the complex phenomena in a study (Creswell, 2012). Moreover, the method used to analyse the data was not described, which does not allow for the rigour or the transferability of the study to be determined.

1.7.4 Discourses of invisibility and disempowerment following TBI

A narrative study by Chamberlain (2006) found that one year post-injury individuals experienced complex grief and emotional difficulties related to the 'invisible' nature of TBI disability. The participants' narratives emphasised the relations between invisibility, disappearing as a person and withdrawing from society. The participants also reported that they felt distressed by the lack of empathy from health professionals concerning their 'invisible' symptoms. Chamberlain suggested that a psychological intervention could be to replace negative self-narratives with positive ones. One limitation with this study was that all the narrative interviews were conducted one year post-injury. This is a relative short time period following the participants' injuries, which could have limited their adjustment to TBI and influenced their narratives.

Cloute, Mitchell and Yates (2008) used discourse analysis to explore the co-construction of identity with family members. They interviewed six adults with TBI together with one or two significant others. The analysis identified 29 interpretative repertoires (IRs), which were categorised under four overarching IRs including: 'medical model of referencing', 'dependence as intrinsic to TBI', 'TBI as deficit and progression' and 'productivity as key life-defining features'. The authors also located the IRs under the relevant timeframe: pre-injury; post-acute injury; intermediate; current; and future. Their analysis showed a common pattern of passive positioning in relation to a 'medical model of referencing'. Cloute et al. found that the experience of memory impairment was used as a key factor in the discursive negotiations around passive positioning. The authors proposed that understanding identity as occurring in conversational discourse might be clinically useful in helping individuals co-constructing a more empowered self-narrative. However, the methodology used in this study might have posed specific challenges in exploring identity construction. Participants with TBI might have presented more passively during an interview in the presence of their significant other. Hence, the interpersonal dynamic could have been co-constructed through specific time periods, particularly post-acute injury when the person with TBI might have been highly dependent on their partner. It would have been interesting to also interview participants separately to perhaps elicit alternative constructions and positionings.

1.8 Combined research methodologies in relation to chronic illness

In recent years, psychological researchers have begun to use a combination of qualitative research methodologies. Frost (2009) argued that multiple methodologies used within a single study allows for a multi-layered understanding of the data. Studies using multiple methods have been shown to offer a more holistic view and provide insight that cannot be gained by one method alone (Chamberlain, Cain, Sheridan & Dupuis, 2011; Frost, 2011). In brief, this might include combining different interpretations of the data; comparing different researchers' interpretations of the same data; or using different methods to gather data (Frost, 2011). The literature search identified a small number of studies using multiple qualitative methodologies to investigate chronic illness.

Todres and Galvin (2005) and Galvin, Todres & Richardson (2006) completed a qualitative study, combining narrative and descriptive phenomenological analyses to explore the experience of caring for a significant other with Alzheimer's disease. The narrative analysis focused on sense-making and the carer's changing identity and role, while the phenomenological analysis focused on the experience of living as carer. The authors conclude that the two methodological approaches complemented each other in terms of gaining knowledge of 'breadth' (narrative identity) and 'depth' (lived experiences), giving some support for a philosophical position that shows a person as both active and passive agent, constructively making sense of narrative identity as well as being constructed by their lived experiences. One critique of this study was that it was limited to one carer's experiences. It might be important to include the person with Alzheimer's disease and explore their feelings and experience, should they have sufficient cognition to participate. Khunti (1999) used multiple research methods to elicit factors affecting quality of care for patients with diabetes. The different qualitative methods included brainstorming, a focus group and interviews with health professionals and patients. A systemic literature review was also carried out. The study identified practice-related factors, patient-related factors and organization-related factors. The authors concluded that each evaluation method provided unique data that could not have been obtained using a single method. The methods were used to identify themes related to good quality diabetes care. However, the themes themselves were not presented in great depth, and obtaining additional interview data might have enriched the results further.

A study by Godwin, Chappell and Kreutzer (2014) used multiple research methodology to explore how couples adjusted following one of the partners sustaining TBI. Firstly, grounded theory was used to explore lived experiences and analyse narratives written by individuals with TBI and their partners. A second analysis was conducted of clinician-authored literature. Triangulation and constant comparative analysis of the data was then performed through substantive and theoretical coding. Two grounded theories were developed: relational coring and relational recycling. Relational coring included themes that impacted the couples, such as ambiguous losses. Relational recycling refers to the process of emotional healing and an evolving couple identity. The authors found that healing strategies for couples could involve developing a new connection with each other and renewing shared purposes. Godwin et al. (2014) suggested that rehabilitation professionals need to construct treatment plans that include patients coupled relationships. One limitation of this study was the exclusive use of written experiences and clinician-authored literature, which could have been edited during the writing and the publication process.

1.9 Aims of the research

I will now summarise the main findings from the literature review and explain how these informed the aims of this study. There is a growing body of literature exploring subjective experiences following brain injury (Gracey et al., 2008; Nochi, 2000). However, some authors concluded that a need remains for more in-depth qualitative analyses that focus on TBI in relation to identity, psychological therapies and experience (Levack et al. 2010; Nochi, 2000). Cloute et al. (2008) noted that social constructionist approaches are rare within the brain injury literature and recommended that further research was required, particularly discursive analyses of TBI and identity. Cloute et al. also suggested that further research should involve the empowerment of service users, and proposed that by being aware (as mental health professionals) of the impact of our own discourse, we can engage in conversation that promotes empowering identities for others.

The aim of this study was to add to the discursive research of Cloute et al. (2008) and to facilitate further understanding of how discourse is used to (re)construct identity following TBI. The current study explored the data using different qualitative methods,

and it was hoped that using a multiple qualitative approach would allow for a multi-dimensional picture of living with TBI and the (re)construction of identity post-TBI. To facilitate this, an analysis combining different interpretations was applied:

1. Foucauldian discourse analysis (Willig, 2013) was used to explore what kind of discourses individuals with TBI used to (re)construct their identity. This part of the analysis was interested in how people with TBI (re)construct identity in their society and culture.
2. Positioning theory (Davies & Harré, 1990) was used to explore how available discourses create different subject positions. It was concerned with the relationship between discourse and subjectivity, with the aim of considering how individuals are positioned within their context. The intention was to gain further understanding about the dynamic processes of identity (re)construction by individuals with TBI.
3. Frank's (1995) illness narratives (restitution, chaos and quest) were used to explore identity in TBI and their role in helping to (re)construct identity. Frank's illness narratives were applied to take the analysis and interpretive work in a different direction, by placing participants' account of identity following brain injury within a broader meaning-making process.

The main research questions are:

1. What discourses do individuals with TBI use to (re)construct aspects of identity?
2. What subject positionings are made available by these discourses?
3. What narratives are used within the identified discourses and positionings?

CHAPTER 2

METHODOLOGY PART ONE

Epistemological stance and theoretical framework

In this section, I discuss the epistemological stance and theoretical framework applied in this study. I will define social constructionism (Burr, 2003), discourse approach (Wiggins & Potter, 2013), Foucauldian discourse analysis (FDA, Willig, 2013), positioning theory (Davies & Harré, 1990) and narrative approach (Frank, 1995). I will explain my rationale for applying a multiple qualitative approach in this study. I will also discuss the limitations of each approach, and multiple qualitative approaches. Finally, I will reflect on the development of my research question and the subsequent methodology.

2.1 Social constructionism

The present study uses a social constructionist framework, which explores how reality is constructed in society, and the consequences these particular constructions have for groups of people (Potter & Wetherell, 1987). Social constructionism takes a critical stance concerning assumptions around knowledge, worldview, and the idea of a stable reality (Burr, 2003). The term 'worldview' is used here to describe a basic set of beliefs that make up an individual's entire social, historical and cultural environment (Guba, 1990). Social constructionists claim that knowledge and reality are the currently accepted ways of understanding the worldview, but that this varies both historically and cross-culturally (Burr, 2003). According to a social constructionist view, our identity is constructed through the discourses culturally available to us, and through our communication with other people. Language provides a framework for how a person thinks, and is a pre-condition for thoughts (Potter & Wetherell, 1987). Consequently, the role of language is fundamental to social constructionism. Social constructionists claim that language can be viewed as a form of social action, as our reality is constructed through conversations between people (Potter & Wetherell, 1987). This implies that all objects of our consciousness (everything we think and talk about), including our identities, are constructed through language (discourses). What is outside of language cannot be known; a discourse provides a frame of reference, a way of

interpreting the world and giving it meaning (Burr, 1995). Social constructionists believe that 'essential' psychological properties, such as attitudes, opinions, personalities and motivations, can only be understood in the terms of discourse, and are an effect of language (Crossley, 2000). Thus psychological characteristics do not originate from the person's private experience, but from the discursive culture they inhabit (Burr, 2003).

Social constructionists have not achieved a consensus as to how a worldview is formed. There is an ongoing discussion that can be referred to as the realism-relativism debate (Andrews, 2012). Realism proposes that an external world exists independently of our representations of it (Searle, 1995). In contrast, a relativist position claims that there is no absolute truth, and therefore that all perspectives on the world are equally valid (Gergen, 2001).

Cromby and Nightingale (1999) are critical of the relativist position and argue that if individuals do not have any innate or essential psychological characteristics, they are 'empty'. Parker (1992) takes a critical realist view, suggesting that people do have personality traits, attitudes, emotions and motivation, and that is not possible to reduce all human experience to discourse and language. Critical realists argue that events such as natural disasters, physical suffering, illness and death are real, and not only social constructions (Burr, 2003). The counter argument in support of relativism is that individuals' subjective experiences are provided by the discourses in which they are embedded (e.g., Gergen, 2001). Andrews (2012) argues that there is an objective reality, but that social constructionism is concerned with how knowledge is constructed and understood; social constructionism therefore takes an epistemological not an ontological perspective.

The current study draws on the insights offered by the realist side of the debate within social constructionism. It takes the view that there is a reality outside discourse, and that this reality provides the raw material from which we construct our knowledge (Parker, 1992). It aims to address the criticisms aimed at social constructionism by exploring the role of subject positionings within discourses (Davies & Harré, 1990). It will apply Frank's (1995) illness narrative approach to explore the meaning of participants' discourses and positionings.

2.2 Discourse approach

The theoretical framework for this study draws on FDA (Willig, 2013) and positioning theory (Davies & Harré, 1990). Discourse approaches are concerned with language and how identity is constructed by the use of language within a specific culture (Willig, 2008). A 'discourse' refers to a coherent set of meanings, metaphors, representations, images, stories and statements that together construct a particular version of events (Wiggins & Potter, 2013). One event may be subject to a variety of discourses produced by multiple alternative versions and meanings (Wiggins & Potter, 2003). This suggests that there may be a variety of different discourses surrounding any individual, each with a different narrative and representation of the world (Burr, 1995). Different discourses bring different aspects into focus and raise different issues for consideration. Discourse also refers to the spoken interchanges between people. The meaning of what is said depends upon the discursive context in which the words are embedded (Burr, 2003).

2.2.1 Turn to language

In the 1970s and 1980s, social psychologists challenged cognitive psychology with the concept of a 'turn to language' (Potter & Wetherell, 1987). Their critique of cognitivism was based on its assumption that psychological processes such as thoughts, emotions and perceptions were expressed in individual and interpersonal behaviour (Burr, 2003). Language was seen to provide an external reality to individuals' internal cognition (Willig, 2013). Instead, from a discourse analytical point of view, language was seen to construct versions of social realities and to achieve social objectives (Willig, 2008). Discursive psychologists argue that taking part in a conversation has a social purpose in which all participants have a stake. In order to make sense of what people say one has to understand the context in which the conversation takes place (Willig, 2013). This implies that all knowledge of the world is socially constructed, and that the world can be understood in multiple ways (Burr, 2003).

2.2.2 Action orientation

Discursive psychologists are interested in how different psychological phenomena are constructed through discourse (Potter, 2012). They study how people use language in

their everyday interactions (their discourse) with each other. They are also interested in the consequences and the effects of participants' 'talk' (Willig, 2012). The focus of the analysis in discursive psychology is on 'how' participants use discursive resources, and the effects of those resources. This can be defined as the 'action orientation' of talk (Willig, 2013). Discursive psychologists are interested in how participants manage, negotiate and stake their interpersonal interests, and how discursive strategies, such as justification, rationalisation or disclaiming, function in a particular discursive context (Willig, 2013). Moreover, discourse is constructed from a range of resources including grammatical structures, metaphors, analogies, graphic description and figures of speech. Part of the analytic work is to explore the underlying meanings and action orientations of these resources (Potter, 2012).

2.3 Foucauldian discourse analysis (FDA)

All discourse analyses focus upon language as a subject of investigation rather than viewing it as a neutral communicative resource (Wetherell, Taylor & Yates, 2001a). FDA also investigates language, but in a broader context than other forms of discourse analysis: it looks at the relationship between discourse, knowledge and power (Wetherell, Taylor & Yates, 2001b). It is concerned with language, interpersonal communication and its role in the construction of social and psychological life (Willig, 2013). This form of analysis has often been used in studies focusing on issues of identity, subjectivity, personal and social change, and power relations (Willig, 1999).

FDA was developed by social psychologists in the 1970s. The original authors were influenced by the texts and ideas of post-structuralism, including the work of Michel Foucault (1971, 1980, 1982), Jacques Derrida (1976), and Roland Barthes (1973). Foucault was concerned with three major themes: (1) the concept of discourse; (2) knowledge and power; and (3) the question of the subject (Wetherell et al., 2001b).

2.3.1 The concept of discourse

Foucault's definition of 'discourse' is a set of statements that provide a language for talking about a particular topic at a particular moment in time (Wetherell et al., 2001a). Foucault (1971) emphasised alternative ways of thinking and differing practices during

particular periods in history. He explored discourses relating to diverse social groups, for example, prisoners, prostitutes and 'the insane', linking these discourses to the specific locations within which they were practiced. Foucault theorised that something was the 'truth' only in a particular context of history. For example, he suggested that mental illness was not an objective fact, but differed in different historical and cultural contexts. It was only within a particular discursive formation or culture that 'madness' could have a meaning (Hall, 1997). FDA therefore focuses upon the availability of discursive resources within a culture, and the implications of this for those who live within it. It also takes a historical perspective and explores how discourses may have changed with time (Willig, 2013). FDA shows that the cultural and historical context in which people live both facilitates and enables, and limits and constrains what they can say or do (Willig, 2013). It is concerned with the distinction between what is said (language) and what is done (practice) (Hall, 1997). The current study examines how people with TBI (re)construct their identity, and how the culture in which they live has implications for how they construct this.

2.3.2 Power and knowledge

Foucault (1977) was concerned with how knowledge was used in particular institutional settings to regulate the conduct of others. He studied the relationships between power and knowledge, how power operated 'within an institutional apparatus' compromised particular discursive formations (Hall, 1997). Foucault (1980) did not see power as something people possess, but as an effect of discourse. For example, the construction that some people are 'mad' and some are 'sane' produces one particular knowledge that brings with it a power inequality between these groups (Burr, 2003). Power is not always negative and repressive, it also produces knowledge and other constructions. For example, the discourse of punishment produces laws, regulations, resistance, debates, and books (Burr, 2003). FDA is therefore concerned with the role of discourse and individuals in wider social processes and contexts (Willig, 2013). FDA explores the relationship between institutions and individuals' discourses. It examines how discourses reinforce and legitimate social and institutional structures (Hall, 1997). According to Foucault (1977), different institutions can construct multiple discourses. The knowledge represented by these discourses is then categorised into power relations in institutional settings such as medicine, law and psychology. For example, a medical discourse is related to a patient's pathology, and structures the model of the patient, who then becomes an object to a health profession (Hall, 1997).

2.3.3 The question of the subject

The traditional concept of the 'subject' is of an individual who possesses consciousness, an autonomous entity and a 'core of self' (Benwell & Stokoe, 2014). This concept privileges the individual as a source of identity, meaning and knowledge (Hall, 1997). However, for Foucault (1982), it is not the subject but the discourse that produces knowledge. Subjects might produce texts but these are regulated by the 'truth' of the current discursive context (culture or historical period) in which they operate. According to Foucault (1980), the subject is produced within a discourse and cannot exist outside a discourse. The subject submits to a discourse's rules and characteristics surrounding power and knowledge. The subject can be the holder of the kind of knowledge that a discourse produces, and can become the object through which power is communicated (Hall, 1997).

2.4 Positioning theory

This study also engages with the positioning theory (Davies & Harré, 1990; Harré & van Langhove, 1999), and its perspective concerning the way in which people form identity. Positioning theory proposes that people's identities are formed through their positioning within a discourse (Burr, 2003). Davies and Harré (1990) suggest that positioning is mainly a conversational phenomenon, but also includes non-verbal contributions to the conversations. The concept of positioning can be related to the notion that a person has multiple 'selves' or 'identities' that are actively constructed through conversations with others. Davies and Harré (1990) define positioning as:

...the discursive process whereby selves are located in conversations as observable and subjectively coherent participants in jointly produced story lines. There can be interactive positioning in which what one person says positions another. And there can be reflexive positioning in which one positions oneself.
(p. 48)

Harré and Davies (1990) argued that there are four central processes that underpin the acquisition and development of our identity, and that provide the framework through which the world is interpreted from our own perspective:

1. Learning categories that include and exclude, including such linguistic divisions as male/female, father/daughter, and patient/health professional. It is important to remember that people may understand these cultural categories and discourses differently.
2. Participating in various discursive practices that construct meaning within those categories.
3. Having an identity (self) that is positioned as 'belonging' in some of these categories and not others, for example, as a woman and not as a man, or as a person with TBI and not as a person without TBI.
4. Recognising the self as having characteristics that locate it in various categories and not in others. This develops a sense of 'belonging' in the world in certain ways, and thus seeing the world from this perspective. A psychological and emotional allegiance to the categorical system develops, which underpins the sense of belonging.

All four processes are integrated through language and the pronoun, 'I', by which a person understands themselves as historically unitary.

Davies and Harré (1990) define 'subject positioning' in the following way:

A subject position incorporates both a conceptual repertoire and a location for persons within the structure of rights for those who use that repertoire. Once having taken up a particular position as one's own, a person inevitably sees the world from the vantage point of that position and in terms of the particular images, metaphors, storylines and concepts, which are relevant within the particular discursive practice in which they are positioned. At least a possibility of notional choice is inevitably involved because there are many and contradictory discursive practices that each person could engage in. (p. 46)

Davies and Harré argued that the contradictions a person experiences between the disparate elements of their multiple identities provides the dynamic for their understanding of personhood, themselves and others. In other words, a person's experience of gender, race, class or social identity can only be understood through the categories available to them within the discourse in which they practice (Frazer, 1990).

A person can alter the way they think about themselves over the course of their lives, due to changes in their own circumstances and wider changes in the social and historical epoch in which they are embedded (Davies & Harré, 1990). In the current study, the narrative aspects of the interviews were explored in order to determine the identifying positions through which participants interpreted their world and identity post-brain injury.

2.5 The limitations of a discourse approach

One criticism of discourse approaches is that people are seen as 'empty' and without internal experiences such as identity, subjectivity and memory (Langdridge, 2004). However, discourse analysis is still interested in psychological concepts and processes, but it is concerned with the discursive construction of these, rather than with cognitive experience (Willig, 2013). Furthermore, discourse analysis does not address questions about subjectivity, including sense of self, self-awareness and autobiographical memories (Willig, 2013). However, in this study the question of subjectivity is addressed by exploring subject positionings within the discourses available to participants.

Discourse approaches have also been criticised for being totally dependent on texts such as interviews and conversations to underpin their analysis (Willig, 2008). This dependence is problematic in the light of Foucault's (1980) assertion that the meaning of a conversation cannot be fully understood if it is not looked at in a wider historical and cultural context. Therefore, it is important that the researcher considers and reflects on the historical and cultural context in which data collection takes place.

A further problem with a discourse approach arises from the possibility of ascribing theorised labels (e.g., a medical discourse of identity) to participants' narratives (Benwell & Stokoe, 2014). The criticism is that social interaction (including talk in interviews) is too complex to reduce to discourses (Benwell & Stokoe, 2014). Wooffitt (2005) has argued that this approach offers an impoverished view of human conduct, and that social interaction and human behaviour are too multifaceted to consider language only. Wooffitt has also noted that many studies of interview data identify only a small number of discourses. For example, Murray's (2003) work with cancer patients

identified only three broad narratives. Such a small number of discourses in a study might not represent the variety within and differences between participants' narratives.

2.6 Narrative approach and Frank's illness narratives

The current study was also informed by Frank's (1995) illness narrative approach. Hiles and Čermák (2008) have suggested that narratives dominate human discourse, and are foundational to the cultural processes that structure human action and experience. Through constructing narratives about their lives, people make connections between and interpret events (Silver, 2013). Narrative psychology is interested in the ways in which people organise and thus bring order to their experience. Narrative approaches have been used in health psychology research to explore meaning-making around identity among people living with illness. Emerson and Frosh (2004) have argued that narrative approaches are well suited to the exploration of identity, because they are particularly sensitive ways to interpret subjective meaning-making and social processes. People use stories to make sense of their experience and to define their identity (Murray, 2003). Narratives also contribute to the maintenance and construction of identities, and establish individuals' positionings (Silver, 2013). Studying narratives thus provides a researcher with a means to understand how individuals make sense of their identities and their world.

Narrative researchers explore the content and the structure of participants' narratives. They also consider how participants' narratives are constructed by wider social and cultural narratives (Murray, 1999). People use narratives that are entrenched within their culture, and thus the researcher needs to consider the form and dynamics of the interview, as its narratives are not constructed in isolation but as a result of the communication of interviewer and participant (Murray, 1999). There are a range of narrative approaches, each with different conceptions of identity, epistemologies and emphases (Hiles & Čermák, 2008). For example, researchers may use an approach that identifies linguistic features such as Labov's structural model (Labov, 1972), or focus on the interpersonal context of the narration using critical narrative analysis (Emerson & Frosh, 2004). Some narrative approaches focus on 'what' is told, others on 'how' it is told (Smith & Sparkes, 2006).

Frank, (1995) in his book *The Wounded Story Teller* describes illness as loss of the 'destination and map' that previously guided a person's life. Frank identified three types of narratives told by people who have experienced illness: restitution narrative, chaos narrative, and quest narrative. Frank (1995, p. 76) described these types of narrative as devices that 'aid listening to the ill' by helping the listener to untangle different, sometimes contradictory 'narrative threads'. Each type of narrative reflects cultural, social and personal preferences. Thus, this narrative approach allows the researcher to examine individual, social, and cultural influences on personal narratives.

Illness can be considered as a disruption to the continuity of one's life (Becker, 1994). Frank (1995) suggests illness narratives function as a means of reconstructing identity and re-establishing a sense of continuity. Frank (1995, p. 53) also sees stories as 'the self's medium of being': stories also 'repair the damage that illness has done to the ill person's sense of where she is in life and where she might be going'. Frank argues that the three main illness narrative types (restitution, chaos, quest) are engaged in such repair work. Illness narratives are considered fluid and continually developing, and tend to combine all three types, with each interrupting the other two.

2.6.1 Restitution narrative

Frank saw the restitution narrative as the 'culturally preferred' narrative, related to the technology of a medical cure and a restorable body-self. The restitution narrative has the basic story line: 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again'. In this sense, 'wellness' is being defined in contrast to 'illness'. The narrator of the restitution story wants the body's former predictability back again. The temporarily broken-down body splits from self, and becomes 'it' to be 'cured'. One part of the ill person's own desire for restitution is socially constructed through an expectation that other people want to hear restitution stories (Frank, 1995). This can be associated with the idea that contemporary Western culture treats 'health' as the normal condition that people ought to have restored (Sherry, 2006). Metaphoric phrases like 'as good as new' are at the core of the restitution narrative. These kinds of phrases are reflexive reminders that the story is not about illness but rather about health and recovery (Frank, 1995).

2.6.2 Chaos narrative

Chaos stories are the opposite of restitution, and can be as anxiety-provoking as they reveal vulnerability, futility and powerlessness (Frank, 1995). Hearing these stories can be difficult as listeners find it hard to face what is being described as a possibility for their own lives. In the chaos narrative, the plot is that life will never improve and no one is in control. Stories are chaotic in their absence of narrative order. Chaos narrative is an 'anti-narrative' as a narrative implies a sequence of events connected to each other through time. However, chaos is told without sequence or mediation, and speaking about oneself without being fully able to reflect on oneself (Frank, 1995). These stories cannot literally be told but can only be lived, as the person living the chaos story has no distance from her life, and no reflective grasp on it. The body is imprisoned in the frustration of needs of the moment. Individuals living in the chaos narrative describe experiencing an 'emotional battering' stemming from a rejection of their suffering by clinicians and by others (Frank, 1995).

2.6.3 Quest narrative

In the quest narrative, individuals are more accepting of their illness (Frank, 1995). Quest stories are defined by the ill person's belief that something is gained through the experience. The illness becomes a journey with new meaning as its destination. Quest stories tell of searching for alternative ways of being ill, and of the ill person gradually realising a sense of purpose (Frank, 1995). The ill storytellers are not passive, helpless victims of their fate, but are presented as 'wounded story tellers', drawing narrative power from their sick body. The quest narrative differs from the restitution narrative where individuals are not solely seeking recovery from illness. Quest narratives can function as counter-narratives, which can provide alternative maps and different meaning-making regarding disability and impairment (Smith & Sparkes, 2005). For example, Swain and French (2000) describe the affirmative model of disability, which was developed from the social model of disability (Oliver, 1996). The affirmative model of disability is defined as a non-tragic narrative of disability and impairment, which encompasses positive individual and social identities for disabled people based on the benefits and experiences of being impaired and disabled (Swain & French, 2000). By deviating from socially constructed assumptions about being disabled, for example, that disability is a tragedy that ruins a life, this model challenges the mainstream

stories that disabled people have had to adapt to. Therefore, as a counter-narrative, the affirmative model has therapeutic and transformative possibilities for the individual and for the community, by making alternative ways of living as a disabled person available (Smith & Sparkes, 2005). In the current study the focus was on the content of the narratives and their central themes. This process was to explore meaning-making and identify relationships among these themes.

2.7 The limitations of a narrative approach

Frank (1995) suggested that the narrator always tells their story to a person or an audience and inevitably this will affect the content of the data. It is therefore important to think about how the researcher may impact both what is said and how it is said. It is necessary to consider and reflect on how the participant's narrative is influenced by the interviewer's presence, questions, initiation of topics, listening, encouragements, interruptions and termination of responses (Mishler, 1986). Moreover, in narrative analysis, the researcher brings in her or his own assumptions and beliefs. Therefore, it is important for the researcher to reflect on her or his interpretations of how the narratives are constructed (Silver, 2013).

Moreover, the narrative interview involves joint construction of the narrative, that is, the interviewer and the participant create a joint narrative (Silver, 2013). Therefore, there may be concerns with validity and authenticity presented in the narrative. The same issue arises within interpretations of data, which involves a joint construction of the participant's narrative and the researcher's analysis (Silver, 2013). Therefore, it is vital that the researcher adopts a highly reflective mindset and a rigorous commitment to staying close to the data.

2.8 Rationale for a multiple qualitative approach

The analysis adopted a multiple qualitative approach. This approach combines methods, analysis or interpretations to seek multiple perspectives on human experience (Frost, 2011). The assumption behind a multiple qualitative research is that people's experiences are multi-dimensional. Consequently, the rationale for combining different theories and methodologies is that this offers a more holistic view of other

people's experience and provides insights that cannot be gained by using one method alone (Chamberlain, Cain, Sheridan, & Dupuis, 2011; Frost, 2011).

Another advantage of combining approaches is that this allows for flexibility by building up multi-perspective layers of insight. Each layer can be relevant to understanding someone else's reality and experience (Frost, 2011). Combining multiple qualitative methods can also achieve greater methodological rigour via triangulation (validating the data through interpreting from different positions) (Chamberlain et al., 2011). For example, Frost (2009) combined several different models of narrative analysis to explore a woman's expectations of second-time motherhood, achieving a multi-dimensional interpretation and building layers of understanding. The interpretations showed that initial understandings of the narratives were gradually enriched through each successive theoretical lens.

The rationale for using multi-perspective layers in qualitative research is further emphasised by Willig (2012):

The rationale behind advocating a pluralistic approach to qualitative research is that, given that human experience is complex, multi-layered, and multi-faceted, a methodology that aims to amplify meaning, rather than seeking to pin down meanings, may be more appropriate. (p. 160)

My rationale for using multiple qualitative methods was also informed by Wetherell (1998). In Wetherell's (1998) study of the construction of middle class masculine identities, she applied and criticised conversational analysis (Schegloff, 1991) and a post-structuralist account of subject positions (Mouffe, 1992) in evaluating her interviews. Wetherell argued that using a 'synthetic mesh' (an eclectic combination) of two approaches aimed to identify normative practices, values and sense making, through both historical and synchronic (linguistic) textual analysis. Wetherell argued that only a synthesis of discourse approaches allowed the discursive researcher to produce a reading that paid attention both to the situated and shifting nature of discursive construction, and to the wider social and cultural frameworks in which these were constructed.

In the current study, the same interview was viewed through two different qualitative interpretative 'lenses' - FDA (Willig, 2013) and Frank's (1995) illness narrative approach. FDA asked questions about what identities, actions and practices were possible within discourses, while the narrative approach asked questions about meaning-making and experiences of identity within discourses (Silver, 2013). The narrative reading also tried to view the narrative as a whole and not broken down into themes (Willig, 2013). FDA explored what discourses were used to (re)construct identity within participants' available contexts. It looked at relationships between discourses, action orientation, positions and power relationships. However, one of the limitations with FDA is the main focus of language and that it does not consider interpretation of meaning-making and experience (Willig, 2013). Therefore, the narrative part of the analysis was used to develop a better understanding of participants' discourses, positions and stories.

2.9 The limitations of a multiple qualitative approach

One consideration in using multiple qualitative methods is how to do justice to the depth and breadth of the data without making the analysis fragmented. The method draws on several approaches, analyses, and techniques and combined the findings. This might suggest that no one method is necessarily followed through to its saturation point (Chamberlain et al., 2011). However, multiple qualitative methods will generate many different findings, which will be of interest and provide paths for further research (Frost, 2009).

Another critique of multiple qualitative methods is the potential for contradictions and inherent subjectivity, which might arise when revisiting a text (Frost, 2009). Using several different researchers in the interpretation process could provide a further layer of accountability and highlight subjective interpretations (Yin, 1989). In the current study, I adopted a reflexive position to acknowledge potential contradictions and subjective interpretations. Further consideration is that a pluralistic approach is a lengthy process. It involves re-visiting the data multiple times with a different focus, which is time-consuming (Chamberlain et al., 2011). In the current study, taking time produced a range of benefits. For example, it allowed time for reflection and for interpretations to deepen.

One important aspect of using multiple qualitative methods is that they should not give rise to ontological or epistemology clashes. These should be aligned with the research objects (Chamberlain et al., 2011). Furthermore, being aware of the assumptions behind the research, and their relation to the research practices utilised, is essential for high quality research, regardless of how many methods are employed (Crotty, 1998). In the current study, the epistemological stance was social constructionism, which is in line with the epistemological assumptions for both methods used – the discourse approach and the narrative approach.

2.10 Reflections on the development of the methodology

Epistemological reflexivity is concerned with the assumptions the researcher makes during the process of conducting the research (Willig, 2008). Research from a social constructionist perspective is concerned with identifying various ways of constructing social reality. Therefore, as the researcher, I needed to be aware of the current historical and social environment in which I live and practice, as well as the participants' environment. For example, I draw on 'non-disabled' discourses to define part of my identity, and some participants drew on a 'disability' discourse to (re)construct aspects of their identity. Thus, I needed to adopt a reflexive position to acknowledge my own interests in relation to the topic, and how this could lead to potentially biased interpretations.

Both discourse analysis and the narrative approach require a high level of reflexivity on the part of the researcher (Willig, 2013). I needed to reflect on my own knowledge and on the discourses I used to construct it. I was concerned about the discourses and subject positions that were constructed between participants and myself during the interviews. Frosch and Baraitser (2008) suggested that in a research situation, the participant constructs discourses (unconsciously and consciously) specially for the research. This meant that I needed to bring myself into the analytic process, and I needed to reflect on the ways in which 'I' (as a researcher) was implicated in the participants' construction of their subjectivity. A recommendation found in the literature for conducting ethically sound discursive analyses was to interpret the interviews with cautious interpretations and possibilities rather than as certain knowledge (Potter & Wetherell, 1987).

There has been a prevailing tendency to interview caregivers rather than individuals with TBI about post-TBI experiences. Thus, there has been an underlying assumption that people with moderate to severe TBI do not have the ability to contribute their subjective experiences (Paterson & Scott-Findlay, 2002). However, some authors argue that populations with disabilities represent a unique culture in which memory and recall are cultural representations. Therefore, it is important that these people are included in research that investigates living with their disabilities (Crowe, 1998; Paterson & Scott-Findlay, 2002). In the current study, several of the participants suffered from impaired short-term and/or long-term memory. Some of the participants experienced attention deficits and became fatigued during the interview. I needed to pay attention to how this could affect participants' answers, and how their cognitive difficulties interfered with their ability to recall and relate to autobiographical situations. I used some strategies from the literature to mitigate and attend to these challenges. For example, Paterson and Bramadat (1992) recommended having a preliminary meeting before the interview, to provide an opportunity for interviewers to become acquainted with participants. I met with all the participants prior to the interview to introduce the project. We also discussed the best possible timing and duration of the interview, taking into account each participant's tolerance of extraneous stimuli and patterns of fatigue. Paterson and Scott-Findlay (2002) recommended preparing carefully before interviewing people with TBI. The interview agenda for a semi-structured interview consists of relatively small number of open-ended questions to prompt recall (Willig, 2013). For example, one of my questions was 'How do you feel your life has changed since your brain injury?'. Most participants were able to answer this question. However, I adapted the interview for participants with memory impairment and used more direct and straightforward questions. For example, 'What were your main challenges before your brain injury?' and 'What were your main challenges after your brain injury?'. Further questions that were helpful to generate participants' narrative were, 'What would you say to someone who just experienced head injury?' and 'What do people need to know about TBI to understand it more?'.

In qualitative interview research, individuals with expressive language problems have often been less included than people with a clear and articulate style (Lloyd, Gatherer & Kalsy, 2006). One reason for this may be the increased risk of biased perceptions and interpretations of the participants' narratives by the researcher (Goodley, 2001, 1996). However, Lloyd et al. (2006) stressed the importance of including people in

qualitative research who might have problems making their voices heard, as people with expressive language impairment are vulnerable to disempowerment, oppression, and marginalisation within society. Morris (1991) argued that the process of empowerment should begin by providing individuals with a voice and the right to express their own perspectives. Lloyd et al. (2006) suggested that this could be facilitated through the process of qualitative research. In the current study, two of the participants suffered from speech impairment. I needed to be aware of the extent to which my own communication style and interview questions might affect their responses.

Prior to conducting the study, I reflected on what methodological approach would be applicable for the analysis in my study. In determining which approach (or approaches) to use in this study, the research questions, the data and the potential contribution of the study were all key considerations. For example, I considered using interpretative phenomenological analysis (IPA), which is concerned with the detailed examination of individual lived experience and how individuals make sense of these experiences (Eatough & Smith, 2013). IPA endorses social constructionism's view that language, social context, and historical periods all influence how we experience life and our sense of self. In this respect, IPA shares some commonality with FDA. One main difference between FDA and IPA is that FDA aims to examine the *role* of language in describing a person's experience, whereas IPA intends to explore how people may *ascribe meaning* to their experience (Eatough & Smith, 2013). One of the current study's research questions were 'What discourses are used by individuals with TBI to (re)construct aspects of their identity?' My rationale in using FDA and not IPA related to the study's aim to focus on the role of language and discourse. The aim was also to explore relationships between discourses, which is an important aspect of FDA.

I was also interested in using different interpretations of the same data in order to provide a holistic and multi-perspective insight into individuals' experiences (Frost et al., 2010). I considered a psychosocial approach (e.g., Frosh & Baraitser, 2008), which integrates different analytic approaches (e.g. a discourse approach with a psychoanalytic approach). A psychoanalytic approach assumes that people are motivated by unconscious emotional dynamics developed in their childhood (Lemma, 2003). It tries to understand participants' psychological dynamics, including their developmental history, unconscious desires, fantasies, conflicts and defence

mechanisms (Lemma, 2003). After consideration, I decided not to use a psychoanalytic approach because of the nature of the research question, analysis and data collection. Many participants in this study had memory impairments, and it would not have been ethically appropriate to include biographical data that might have been difficult for the participants to retrieve. After long consideration, I chose to use multiple qualitative approach incorporating FDA and Frank's (1995) illness narrative approach. The rationale for using Frank's (1995) illness narratives was to further explore the meaning-making processes within the discourses and positionings identified in the FDA. The emphasis was on how different types of illness narratives could bring a further understanding of participants' discourses.

METHODOLOGY PART TWO

Methods

In this section, I describe this study's research methods including participant ethics, participant recruitment, interview procedures, data handling and ensuring participant wellbeing.

2.11 Design

This research used a qualitative design. FDA (Willig, 2013) was used to analyse the data. The data was also approached with a narrative reading using Frank's (1995) illness narratives. Biographical narrative semi-structured interviews (Potter & Wetherell, 1987) among a purposive sample of eight individuals living with TBI provided text for the analysis.

2.12 Participant ethics and participant recruitment

The study followed ethical considerations to protect its participants from any harm or loss. I maintained complete confidentiality regarding any information about the participants during the research process.

The research proposal for this study is included in Appendix A. Ethical approval was granted from City University Ethics Committee (Appendix B). The study was also approved by the Head Office of a head injury charity from which all the participants were recruited. I approached the charity in November 2013, and following a series of meetings, the charity kindly offered to support this study, acknowledging that it promoted awareness of TBI and its consequences. The charity is independent from the NHS.

The charity agreed to act as the participant identification centre. The participant recruitment method was developed to include ethical considerations such as how to safeguard participants' confidentiality and wellbeing. Potential participants were

identified and approached by the staff at the charity. The staff members informed potential participants about the study. Potential participants then contacted me or a member of staff if they wanted to participate (see Recruitment Leaflet: Appendix C).

2.13 Interview procedure

I interviewed eight participants consisting of five males and three females, with an age range of between 29 and 61 years (mean = 45.9 years). All participants were White British. The participants provided information about the severity of their brain injury themselves; severity ranged from moderate to severe on the Glasgow Coma Scale (GCS, Levin & Eisenberg, 1991). They had all been hospitalised post-injury and had subsequently returned to the community. One participant was employed post-injury. Five of the participants worked as volunteers at the charity.

Four of the participants acquired their head injuries from car accidents, two from motorbike accidents, one from parachute jumping, and one from an assault. They had obtained their injuries eight to 37 years prior to the interviews (see Participant Overview: Appendix D). The participants were all able to read and understand the information sheet (Appendix E) and consent form (Appendix F) in English. There was no exclusion on the basis of sex, gender, ethnicity or religion.

Participants attended one to two face-to-face biographical, narrative, semi-structured interviews. The interviews involved asking open-ended, non-directive and directive questions about participants' lives prior to and post their head injury. My aim was to build a good rapport with the participants to stimulate a 'naturalistic' dialogue rather than a formal interview. I used an interview schedule (Appendix G) that was developed through studying previous qualitative research (e.g., Langdridge, 2007; Smith, Flowers & Larkin, 2009), and through discussions with my supervisor and with staff at the charity. The interviews lasted between 45 and 90 minutes, and included information-giving and a verbal debrief. Some participants preferred to attend two shorter interviews because of fatigue. The interviews were arranged to take place on the day that the participants would usually attend the charity. At the beginning of the interview, I went through the information sheet with the participants before they signed the consent form. The information sheet reiterated the aims of the study in full. I informed

participants that their participation was voluntary and that they could withdraw from the study at any time.

Potter and Hepburn (2005) argue that the most appropriate method of gathering data for discourse analyses is to use the texts of 'naturally occurring conversations', such as tape recordings of medical consultations or conversations between groups of family members or colleagues. They argue that interviews can distort data because it is the interviewer, rather than the interviewee, who guides the situation and influences the ensuing discussion. However, other theorists argue that an interview is a prevalent form of interaction in current Western society (e.g., Atkinson & Silverman, 1997). It can be argued that the interview becomes a 'conversation' within a culturally entrenched communication situation where discourses are reinforced, negotiated and challenged (Taylor & Littleton, 2006). Furthermore, Taylor and Littleton (2006) argue that interviews can be particularly appropriate to use within identity studies. I took these arguments into consideration when carrying out the interviews and the analyses.

The interview procedure for this study was also informed by Potter and Wetherell (1987). They claim that interviews for discourse analyses need to consider both consistency and diversity. Consistency is important as the researcher wishes to identify regular patterns in language use. Diversity and variation will inform the researcher of the full range of discourses that individuals might draw on when constructing the meanings of a topic. Potter and Wetherell (1987) emphasised that interview techniques which encourage diversity are those that result in an informal conversation style. It is also important to acknowledge that the researcher becomes part of the 'conversation' and that the researcher's questions become just as much a topic of the analysis as the participants' answers. The researcher's questions set some of the functional context for the answers, and must be included in the analysis. This means that the linguistic nuances of the questions are as important as the linguistic nuances of the answers.

I did not carry out pilot studies as I wanted to be able to use all the participants' narratives for the analysis and in order that all participants had a voice in the final study. I was particularly struck by the way participants wanted to talk about the consequences of their TBI, in order to inform and educate others who had no experience of a brain injury. I found this vital for the research question. I agree with Taylor (2001) who has suggested that a research interview can increase awareness of

a topic, and that participants want to be interviewed, as through this, their life circumstances are validated. The interview becomes a platform where the participant can tell his or her narrative in a first person context.

2.14 Audio-recordings, transcripts and data handling

The interviews were audio-recorded. The audio-recordings were encrypted and stored electronically. Consent forms and personal details were stored in a locked cabinet separate from the transcripts to ensure participants' privacy. None of the participants' personal details were on the audio-recordings or transcripts. The consent forms and transcripts were kept separately, and all names and identifying details were removed from transcriptions to ensure that participants' anonymity was protected. Pseudonyms were assigned to participants. Transcripts were made anonymous and identifying details were changed. Participants were allocated a number for my identifying purposes only (P1, P2 etc.). All data will be kept secure for five years and then destroyed.

The audio-recordings were transcribed (verbatim). I listened through the audio-recordings and made field notes on the transcripts. I used these as notes later in my coding and analytical work. I adopted the reduced transcription style of Atkinson and Heritage's (1984) original conversational transcription notation. Line numbers were added to transcripts of interviews. I kept the key features of the original transcriptions and the transcripts included my questions and the participants' responses, pauses, delays, laughs or evidence of emphasis, sadness or distress (Potter & Wetherell, 1987).

2.15 Participant wellbeing

I aimed to preserve participants' psychological wellbeing, dignity and confidentiality throughout the process. To receive information for the analyses, I needed to ask questions about the participants' life experiences and relationships. I was concerned that talking about a change of identity or change of behaviour post-injury might evoke difficult feelings. Therefore, I thoroughly explained the interview process to the participants to ensure they fully understood what they were being asked to take part in. I explained that participants did not have to disclose anything they did not want to

share. I only asked questions that were beneficial for the research and I did not ask any questions for my own curiosity. All interviews were held in a room at the charity so participants felt safe in a familiar environment and so that appropriate support was on hand if necessary. The staff were informed when the interviews took place and participants were informed they could contact staff after the interviews if they felt they needed further support. I also gave participants details of resources or organisations working with people who are emotionally distressed (Appendix H).

2.16 Foucauldian discourse analysis

This section will provide a detailed description of how the text was analysed. The analytical method was informed by Willig's (2013) adaptation of FDA, positioning theory (Davies & Harré, 1990) and Potter & Wetherell (1987).

A reminder of the discourse analysis:

1. Foucauldian discourse analysis (Willig, 2013) was used to explore what kind of discourses individuals with TBI used to (re)construct their identity. This part of the analysis was interested in how people with TBI (re)construct identity in their society and culture.
2. Positioning theory (Davies & Harré, 1990) was used to explore how available discourses created different subject positions. It was concerned with the relationship between discourse and subjectivity. The aim was to consider how individuals with TBI are positioned within their context.

The majority of texts offering guidelines on discourse approaches to qualitative analysis tend to caution readers against following their guidelines too rigidly (Potter & Wetherell, 1987). Instead, Potter and Wetherell (1987) claim that the theoretical framework concerning the nature of discourse needs to be understood before the researcher approaches the text for analysis. Therefore, it was important to carry out an analysis that would be appropriate for my research questions and for my understanding of discourse.

A Foucauldian approach to discourse analysis was carried out following Willig's (2013) six stages:

1. Discursive constructions
2. Discourses
3. Action orientation
4. Positionings
5. Practice
6. Subjectivity

Stage 1: Discursive constructions

I began by reading and re-reading the transcripts. I read the transcripts and listened to the audio-recordings several times without any attempt to analyse the text. Reading without analysis allows the reader to become aware of 'what the text is doing' (Willig, 2013, p. 119). I then coded the data. Coding is the stage that involves selecting the material for analysis (Potter & Wetherell, 1987). My aim was to be inclusive, as Potter and Wetherell (1987) have emphasised that coding should be done as inclusively as possible, for instance all borderline cases that seem initially only vaguely related should be included. I went through the text with the question: 'How is the object (identity) constructed?'. I identified all discursive constructions that contained any reference to identity and highlighted these by marking sections. In this stage, both implicit and explicit references needed to be included (Willig, 2013). For example, participants might not have explicitly talked about identity by directly naming it, but they might have referred to identity as being part of functioning in different aspects of their life, for example: 'I was functioning' or 'I was not working properly'.

The following example shows a sample of the identified discursive constructions of identity in the interview of participant P1.

<u>Reference to discursive construction of 'identity'</u>	<u>Line Number</u>
I was practically dead	24
I came out. How I came out, I have no idea.	31
I don't remember that at all.	32
But I didn't know anything about brain injury, who would?	43

When I woke up I thought what am ok what am I doing	46
What was I did was that, in your memory because you are not sure if your memory is working properly you say things as they come in your head	51
Things were easy before	57
You will have to be retrained how to well function	59
The real problem with it is the invisibility	69
Look at me 'do you have brain injury?' No but he has.	70
I went back to work, which was a mistake	
So it was good I actually saw her, that she saw me alive.	91
But things that were easier before all of the sudden became very difficult.	92-93
I thought when I came out of hospital that things that was easy before was a nightmare. Just getting a bill I thought my god it is a bill.	96-98
I had no money that was the thing.	102
So I was living on savings. I was not working.	
I was not capable working.	106-107
I went back to work but I wasn't capable of work.	
So I was volunteering to see if I was functioning.	110-111
I was more aggressive. I am still like it now.	135

Stage 2: Discourses

In this stage, I asked myself: 'What discourses were drawn upon to (re)construct aspects of identity?' and 'What are their relationship to each other?' (Willig, 2013). I used a large sheet of paper to make notes of discursive constructions and discourses. I made a table divided into time phases: 'pre-injury' (referring to time before injury), 'post-acute injury' (hospital and rehabilitation stay and on return home), 'intermediate' (between post-acute injury and current time) and 'current time' (referring to current daily life). This assisted in organising and identifying discourses. I then named the different discourses and wrote a description of these. If the discursive constructions did not fit with an existing discourse, I created a new name to describe it. The aim was to link all participants' references, patterns, differences, contradictions and discursive constructions to the different discourses (Potter & Wetherell, 1987).

Stage 3: Action orientation

I then looked at the 'action orientation' of discourses that were being used (Willig, 2013). Action orientation (or functional orientation) refers to the strategic deployment of talk in order to achieve particular social effects (Willig, 1999). I asked questions including: What is achieved by participants with these discourses? What were the consequences (action orientation)? What is the function and how does this relate to other constructions produced in the text reading? (Willig, 2013). By asking these and other questions, I sought to learn what a participant might gain by (re)constructing identity using a 'disability' discourse when talking about their identity. Through examining a person's action orientation, we gain further understanding of what the various constructions of the discursive object (identity) are capable of achieving in a conversation (Willig, 2013).

Stage 4: Positioning

In this stage, I identified different subject positionings associated with the discourses, as I wanted to explore how discourses and inter-relationships within discourses enabled different subject positionings (Davies & Harré, 1990). The concept of 'positioning' can be related to the idea that a person has multiple identities, which are actively constructed through conversations with others (Davies & Harré, 1990). I was interested in how the participants might form different positionings and identities. For example, a person with TBI might use a 'medical' discourse to (re)construct identity; thus, they might position themselves as 'disabled' and might therefore construct a sense of belonging within this category. I was interested in how participants constructed meaning in different categories (e.g., constructing belonging to being 'disabled' or 'non-disabled'). Positioning involves seeing the world from the perspective of where one is positioned. It also involves the psychological and emotional development within a certain category. Thus subject positions have direct implications for understanding social identity (Davies & Harré, 1990).

Stage 5: Practice

This stage considered the relationships between discourse and practice. It involved exploring the ways in which discursive constructions and subject positionings

contained within them opened up or closed down opportunities for action (Willig, 2013). Thus, when a person constructs a particular view of the world and positions themselves within this view, discourses facilitate, limit, enable and constrain what can be said and done (Willig, 2013). For example, if a person with TBI uses a 'medical' discourse, this may endorse a position of dependency, and can have implications for or limit what they can do. This may also influence how they receive support from the societal and family contexts in which they live.

Stage 6: Subjectivity

This stage explored the relationship between discourse and subjectivity. I explored how participants may have felt, thought and experienced their discourses from within their various subject positionings (Willig, 2013). I approached this stage with tentative interpretations, as I can only speculate what participants felt, thought and experienced.

The six stages were repeated for each of the eight participants. After analysing the interviews, I looked for unifying and differing themes between them.

2.17 Narrative Reading

A narrative reading was used to explore the meaning of participants' (re)construction of their identity in the context of their overall story. The narrative reading drew on Frank's (1995) typology of illness narratives. To guide the reading, I relied on Frank's original descriptions and examples. It was also informed by Hiles and Čermák's (2008) guidelines for narrative analysis.

The first step consisted of multiple readings of the eight participants' transcripts again in order to immerse myself anew in their overall narratives. I asked different questions of the content of the narrative including: 'What type of story is being told?' and 'Who are the protagonists?'. I asked questions concerning the tone of the narrative such as: 'How is the story being told?', 'What kind of language is used?', and 'What might be the rhetorical functions of the narrative?'. Further questions were about the themes of the narratives including: 'What are the key themes?', 'How do they relate to each other?', and 'Do they support or contradict each other?'. Finally, I asked questions that focused on social and psychological functions such as: 'What kind of identities are constructed

in the narratives?', 'How does the narrative position the narrator?', and 'How much agency does the narrative offer the narrator?' (Hiles & Čermák, 2008).

I then read the narratives once more holding in mind Frank's heuristic frameworks. The initial readings and Frank's analytic concepts enabled the identifying of themes and patterns in the data. I explored how Frank's illness narratives related to the discourses, constructions and positionings identified in the FDA. The aim was not to coerce the participants' discourses into one or more of Frank's illness narratives (restitution, chaos and quest) but rather to try and disentangle narrative threads. This involved charting the narratives in terms of words, phrases and sentences that exemplified the narrative types. I was also mindful of the way in which the narratives might combine and interrupt each other within the interviews.

2.18 Validity and reliability

The conventions, standards of conduct and evaluation of qualitative research can be difficult to define (Yardley, 2000). One reason for this may be that the term 'qualitative' embraces such different methodologies and associated epistemologies, and quality is therefore difficult to evaluate. To aid the evaluation, I followed the principles of Yardley (2000) and Elliott, Fischer and Rennie (1999) when assessing the validity and reliability of this study.

Yardley (2000) suggested following these four main principles when assessing the quality and validity of qualitative research:

1. Qualitative research should be 'sensitive to context' [...] This can be established in different ways. The researcher can demonstrate an awareness of existing literature, which should inform and underpin chosen methodology. The researcher can pay attention to the historical period and socio-cultural context, and be aware of how the context may affect any interpretations. The researcher needs to be mindful of the relationship between the researcher and participant and how expectations from the research questions might affect interpretations.

2. The research needs to apply 'commitment and rigour'. The research needs to be thorough in terms of the appropriateness of its participants and data collection, and in terms of the completeness of the analysis undertaken.
3. The research needs to show 'transparency and coherence', which refers to how clearly the stages of the research process are outlined in the write up of the study. The methods must be transparent and subject to a process of reflexivity.
4. Consideration needs to be given to 'impact and importance' of the study and whether it has contributed to anything useful or important that would make a difference. For example, does the study have a possible contribution to make social change or improved practice within mental health care?

Elliott et al. (1999) proposed evolving guidelines for research with the expectation that they would be developed and modified over time. Elliott et al. distinguished guidelines that are appropriate for both quantitative and qualitative research from those specific to qualitative research.

1. The shared guidelines include: explicit scientific context, appropriate methods, respect for participants, specification of methods, appropriate discussion, clarity of presentation and contribution of knowledge.
2. Specific guidelines for qualitative research include: owning one's perspective (to specify theoretical orientations and personal anticipation), situating the sample (good practice would be to provide basic descriptive data), grounding in examples (to provide at least one example of a e.g. a discourse), providing credibility checks (to ask colleague or supervisor to look over the analysis), coherence (to present the write up in a coherent and understandable way), accomplishing general versus specific research tasks (to emphasise that conclusions only apply to the groups studied) and resonating with readers (the material should be presented in such way that readers have expanded their appreciation and understanding of it).

Elliott et al. further suggested that these guidelines were not supposed to be applied as a rigid 'checklist'. In this study, these guidelines have provided a foundation to aim for good practice, validity and reliability.

2.19 Summary

In this chapter I have set out my understanding of a social constructionist position and how this approach argues that identity, personality and subjectivity are constructed through language and discourse. FDA was justified as the primary tool used to explore how people with TBI (re)construct identity in their society and culture. Reasons for applying a supplementary narrative reading were explained (Frank, 1995).

CHAPTER 3 – ANALYSIS - RESULTS

3.1 Overview of discourses

This chapter contains an analysis of discourses participants used to (re)construct aspects of their identity during the research interview. The discursive object of analysis was ‘identity following traumatic brain injury’ (TBI). In this section I will present the identified discourses and a brief review of Frank’s (1995) illness narratives, before presenting extracts from the interviews and the analysis.

The analysis distinguished two overarching discourse themes (‘medical’ discourse and ‘psychosocial’ discourse) and 31 discourses, which were conceptualised, integrated and presented in the following five discourse themes (Appendix I):

1. Identity in relation to disability and invisibility
2. Identity as rebirth and ongoing development
3. Identity in relation to uncertainty and awareness
4. Identity in relation to perceived normality and social belonging
5. Identity in relation to independence, acceptance and recovery.

3.1.1 Medical discourse and psychosocial discourse

I found that ‘medical’ and ‘psychosocial’ discourses integrated and overlapped with all other discourses, and were used by all participants in the study. In this study, a ‘medical’ discourse derives its definition from the medical model that regards a physical disability as a medical illness (Sherry, 2006). It defines illness (e.g., cognitive disability) without involving the individuals’ experiences of the illness within a particular cultural context. A ‘medical’ discourse can often construct a power position, in which a person’s deficiencies only show up when a person is constrained to live in environments designed to suit the needs of others (Mackelprang & Salsgiver, 2009). A ‘psychosocial’ discourse is associated with the psychological effects of TBI considering the social context in which individuals live, for example social disconnection, perceived stigmatisation and social abandonment (Sherry, 2006).

I have chosen to present the discourses in broad themes as this offers a coherent way to interpret the discourses used by the participants. All eight participants drew extensively on at least one of the five discourse themes, and some drew on all of them. Some discourses, including 'loss of identity', 'change of identity', 'survivor' and 'different' overlap with other discourses and are presented in more than one discourse theme.

I am aware that organising the discourses under discourse themes is artificial. It creates labels and categorises the participants' narratives, which may impoverish the complexity of human interactions and resources (Wooffitt, 2005). Therefore, I emphasise that the themes are not rigid but possible constructions amongst the many available. I also want to emphasise that my interpretations of the discourses, positionings and subjectivity are tentative. Wetherell (1998) argued that there is always plurality in the subject positions available to individuals through a discourse. I found that participants often used several discourses, and that these often overlapped and contrasted. The identified discourses aim to incorporate participants' (re)constructions of identity. In cases where I could not find a discourse that I felt represented a participant's (re)construction of identity, I named it using the participants' verbatim interviews and word choices.

3.2 Overview of discourse themes

3.2.1 Identity in relation to disability and invisibility

The first theme presents participants' use of discourses of 'disability' and 'invisibility'. It presents related discourses of 'right and wrong', 'survivor', 'loss of identity', 'loss of professional identity' and 'perceived stigmatisation'.

Several participants drew on a 'disability' discourse and talked about not being able to function physically and cognitively in the same ways as they did before their injury. This was often accompanied with 'loss of professional identity' and 'loss of identity'. The 'disability' discourse seemed to endorse the 'medical' discourse belief that physical impairments are supposed to be 'fixed' to become 'right'. The construction of 'right and wrong' was also represented as an index of what is the 'right' way to be and behave in society. These constructions could offer a position of dependence and

disempowerment. Disempowerment may stem either from an individual's negative self-evaluation or from societal discrimination.

The 'disability' discourse was often accompanied by an 'invisibility' discourse. The 'invisibility' discourse's central point was the invisibility of the brain injury to other people, and their subsequent disregard or under-appreciation of the injury's effects. Constructions of invisibility were sometimes associated with a discourse of 'perceived stigmatisation'. 'The perceived stigmatisation' discourse offered positions of disconnection and disempowerment, which may have been associated with participants perceiving that they were misunderstood, undervalued and rejected by wider society.

The construction of 'disability' could also be linked to a 'survivor' discourse, which created ambiguous positionings. This was possibly associated with a position of 'should feel happy', in which survivors perceive that they *should* feel happy to have survived a potentially fatal injury, but in fact were not so, as a consequence of the TBI. The conflict consequent upon this position appeared to restrict participants' freedom to (re)construct their identity.

3.2.2 Identity as rebirth and ongoing development

The second theme consists of the participants' use of the discourses 'rebirth' and 'ongoing development'. Both discourses refer to the creation of a new identity post-injury with 'rebirth' implying a shorter time-span than 'ongoing development'. These discourses also relate to discourses of 'positive personal growth', 'loss of identity' and 'change of identity'.

Several participants talked about becoming a 'new person' or a 'different person' post-injury. The 'rebirth' discourse was associated with the trauma (traumatic head injury), and was associated with the onset of a 'new' identity. For some participants, this was both a traumatic and positive occurrence, as they were able to create a 'new' identity, but at the cost of the loss of their previous one.

Some participants used an 'ongoing development' of identity discourse; they described a more gradual identity change post-injury. These participants talked about how their

injuries took their lives down unexpected paths, which some described as positive. The 'ongoing development' discourse allowed for an active and independent position, in which the participant had agency over the (re)construction of their identity. The 'rebirth' and 'ongoing development' discourses appeared to sometimes facilitate positive personal growth and the freedom to (re)construct a 'new' identity that some reported feeling 'happier' about than the 'old' identity.

3.2.3 Identity in relation to uncertainty and awareness

The third theme presents participants' use of discourses of 'uncertainty', 'loss of self-knowledge' and 'loss of identity'. These discourses are linked to different aspects of memory to (re)construct identity. The theme also presents discourses of 'awareness', 'awareness of emotional change', 'awareness of difference' and 'change of identity'.

Several of the participants found memory loss frustrating and discussed how they were uncertain about their identity, as they could not retrieve pre- and/or post-injury memories. Participants drew on discourses of 'uncertainty', 'loss of self-knowledge' and 'loss of identity' when talking about the process of adaption. Uncertainty constructions were often used amongst participants with severe memory loss and participants with no or little social support. The 'uncertainty' discourse was often associated with a position of dependency and was a barrier to self-understanding.

Participants drew on a discourse of 'awareness' describing feeling different post-injury. Participants expressed that they were aware of thinking, feeling and behaving differently, but they are not sure in what way. Some participants expressed difficulties in making sense of their 'new' identity and struggled to formulate a clear sense of self-knowledge and their 'new' identity. Some participants saw their 'new' identity as a 'change' as opposed to a 'loss', which might have offered a more 'forgiving' and 'empathetic' position.

3.2.4 Identity as perceived normality and social belonging

The fourth theme presents participants' use of the discourses 'perceived normality', 'social belonging', 'them and us', 'social disconnection', 'social abandonment', 'loss of social identity', 'perceived stigmatisation', 'positive personal growth' and 'different'.

These constructions involved psychological and emotional positions, which underpinned a categorical sense of belonging or not belonging to, and the perceptions of, wider society.

Participants drew on a 'social belonging' discourse and a 'them and us' discourse when talking about themselves and others with TBI. The construction of 'them and us' offered a position of shared social identity. Participants expressed a sense of belonging within a category of people with TBI, but also acknowledged that this category was not homogeneous. The 'them and us' construction seemed to offer a position of exclusion from a trajectory of 'normal' social expectations.

All but one participant lost employment and several experienced relationship breakups post-injury; these participants drew on discourses of 'loss of social identity', 'social disconnection' and 'social abandonment'. The discourse of 'social disconnection' appeared to provide a position of alienation and social isolation. Some participants struggled to accept and (re)construct their social identity.

A few participants used a discourse of 'different' in contrast to 'disabled', which might have enabled them to accept to their physical impairments and body. Also, some participants expressed that the experience of TBI enabled personal growth and allowed them to develop emotional strength.

3.2.5 Identity in relation to independence, acceptance and recovery

The fifth theme presents discourses of 'acceptance', 'recovery' and 'independence'. Related discourses were identified including 'adapting to change', 'responsibility' and 'survivor'. A discourse of 'independence' was often accompanied with a conflicting discourse of 'dependence'. Some participants had physical disabilities that made them dependent on family and health care support. However, for some participants, the 'dependence' discourse developed over a longer time-frame post-injury, and a discourse of 'independence' then became available. This may be associated with improvement of their symptoms or adaption to them. Thus, some of the participants re-positioned themselves towards a more independent and empowered state over time.

Some participants drew on an 'acceptance' discourse, which enabled these participants to accept their disabilities and 'new' identity, as part of their process of 'recovery'. This assumes that 'recovery' was gaining equipoise with their TBI, as opposed to returning to their pre-injury levels of functioning. The 'acceptance' discourse might have allowed the individual to (re)construct their identity in a forgiving and non-judgmental way. However, the concepts of 'dependency', 'independency', 'acceptance', 'recovery' and 'empowerment' have idiosyncratic meanings for individuals and are not inevitably associated with positive or negative values.

3.3 Frank's illness narratives

In this study, Frank's (1995) illness narratives (restitution, chaos and quest) were used to explore identity in TBI, and the role of narrative in helping to (re)construct identity. Frank's (1995) illness narratives were applied to take the analysis and interpretive work in a different direction, by placing participants' account of identity following brain injury within a broader context. The aim of using Frank's three illness narrative approach was to conceptualise and organise the identified discourses and positions identified in the FDA.

The narrative reading revealed a mixture of the narrative types and an intertwining of threads in the participants' illness stories. Restitution, quest and chaos seemed to alternate – identity was therefore permeated with a plurality of meaning. The participants' narratives revealed that a trajectory of narratives was experienced. Some participants' narratives began with chaos, moving to restitution and then transferred to quest narratives. For other participants, a chaos narrative seemed to stay with them through their stories; for some participants, the quest narrative seemed to be dominant through their stories.

The analytic aim was to look at similarities, links and relationships between the discourses and positionings identified in the FDA. The aim was not to 'force' the different discourses to 'fit' into a specific narrative style, but to discuss the discourses further within the framework of the narratives. The reading revealed that some participants' accounts were not dominantly within a chaos, restitution or quest narrative. Their narratives sometimes presented a more ambiguous and contradictory meaning-making.

Restitution

The narrative reading revealed different associations with the three narrative types. For example, the restitution narrative, which has the basic story line: 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again', was the least common amongst the participants. The reason for this may be that living with TBI often involves chronic illness-related symptoms, which are not 'curable'. However, the restitution story can be related to the hope of recovering the body's former predictability. Thus, the restitution narrative can be argued to link with the discourses of 'disability', 'medical' and 'right and wrong'. For example, the 'disability' discourse was associated with a person 'having a disease' and becoming 'fixed'. It could also be related to 'perceived normality' and 'social belonging' in the sense that a 'healthy' body is the socially accepted 'normality' in our society. The restitution narrative seemed more common among individuals who experienced a sense of cognitive recovery, and among those who experienced more congruency with their identity before their injury.

Chaos

Chaos narratives reveal vulnerability, futility and powerlessness of being. Stories are chaotic in their absence of narrative order. Chaos narrative implies a sequence of events connected to each other through time. In this study, the chaos narrative seemed to be related to the discourses of 'loss of identity', 'loss of professional identity', 'uncertainty', 'awareness of emotional change', 'loss of self-knowledge' and 'invisibility'. The findings also suggested that the 'disability' discourse could be also associated with the chaos narrative. This was usually in relation to the onset and the early stages (acute post-injury phase) of their illness. In this early stage of illness, the participants expressed frustration over the newly sustained consequences of TBI. The participants' narratives were sometimes chaotic in structure. A chaotic structure may have been influenced by some participants' memory and speech impairment. However, most narratives were coherent and not chaotic in structure. Therefore, alternative narrative types could be better suited in describing some discourses, for example 'loss narrative', 'powerlessness narrative' or 'despair narrative'.

Quest

In the quest narrative, individuals are more accepting of their illness. Quest stories are defined by the ill person's belief that something is gained through the experience. Frank (1995) describes the quest story as being that of finding a voice: the narrator has

been on a journey and has not been 'cured' but changed. In this study, the quest narratives appeared to be connected with discourses of 'rebirth', 'ongoing development', 'acceptance' and 'positive personal growth'. The quest narratives often displayed an open-mindedness to change, and they showed a disposition to explore 'new' identities post TBI.

3.4 Extracts and analysis

This section will present the analysed extracts within the five discourse themes. Each extract will be followed by an adaptation of FDA (Willig, 2013). For most extracts, several different discourses will be presented. The reason for this is to show the diversity and variation of discourses that individuals drew upon when (re)constructing the meaning of their identity (Potter & Wetherell, 1987). Each of the five discourse themes will be followed by a section on Frank's (1995) illness narratives. These parts of the analysis apply Frank's three types of illness narrative: restitution, chaos and quest.

All participants' names are changed to provide confidentiality. Further, all references made to participants' lives, such as names of significant others or place names, are changed or marked with 'X'. However, demographic information is provided where relevant (Willig, 2013). I believe this to be relevant to how the participants constructed discourses and subject positions, and how these affected interpersonal communication between the participants and myself. For example, when a participant (re)constructed identity referring to the discourse of 'disability', I considered it relevant to include the participant's employment status pre- and post-injury, and information about participants' physical and cognitive problems post-injury.

3.4.1 Identity in relation to disability and invisibility

The first theme presents participants' use of the discourses of 'disability' and 'invisibility'. It presents the related discourses of 'right and wrong', 'survivor', 'loss of professional identity' and 'perceived stigmatisation'.

Extract 1

Rachel: It's really affected, um I'm a lot slower. Um and is that I'm really slow at learning. It's like something about my brain just doesn't...it doesn't click in my brain for so long.

CW: Really.

Rachel: It was like the local hospital. Basically and I was like I just...I want to know

whether I'm meant to be right now or whether...or whether there is something that's always going to be there.

CW: Ah yeah, yeah.

Rachel: Because no-one's really talked about the accident a lot.

CW: Hm, hm.

Rachel: Um and I saw a doctor. He didn't even have my notes basically, he was going off what I said and it was like 'oh yeah, you've got brain damage so you'll always have a part of your brain that's...that's sort of not...not working properly or something.'

CW: This is quite a long after you had your accident?

Rachel: Hm. Yeah this was about ten years after my accident.

CW: Hm, hm. How did you feel about that?

Rachel: I cried for two hours like properly sobbed and um yeah, like, right from the start, I don't know why, I was quite emotional about it and then he sort of quite soon sort of told me, like yeah you're always going to have these problems, you're always going to have problems and yeah, that...yeah...

(Lines 109 - 129)

Rachel is a woman in her late 20s. She sustained her brain injury when she was in a car accident at the age of 16. She said she was in a coma for four days. She reported that she suffered from mild memory impairment and tiredness. She is currently in employment.

Based on Extract 1, it can be argued that Rachel drew on a 'disability' discourse and the contrasting discourse of 'right and wrong' when (re)constructing her identity. Rachel expressed frustration at her inability to learn things quickly post-injury compared to pre-injury. She used words such as 'slow', 'working properly', 'always' and 'problem'. A 'disability' discourse could endorse the belief that physical impairments are 'wrong' and supposed to be 'fixed' and to become 'right'. The physical symptoms of her injury seem to underpin Rachel's (re)construction of an identity: 'I want to know whether, I am meant to be right now', 'it doesn't click in my brain' and 'always going to be there'. The two discursive constructions ('disability' and 'right and wrong') offered a subject position in which she could externalise her disability. This may have represented a position of not recognising the disability as part of herself and an expectation of or hope for improvement. The construction of 'right and wrong' could also represent an index of what is perceived as the 'right' way to be and behave in society. This discourse thus represents how a person 'should' be, as compared to their perception of how society would expect them to be.

The 'disability' discourse is linked to a 'medical' discourse, and this is highlighted by Rachel's interview. For example, Rachel talked about visiting the doctor and being told that her brain would never '[work] properly'. This may have constructed a power relationship between the doctor and Rachel, in which he as an expert states she will never function properly, without considering her personal experience or functioning. A 'medical' discourse suggests a rigid view of identity and largely determines what is held valid in society. The use of these discourses ('disability', 'right and wrong' and 'medical') may be associated with positions of psychological 'stuckness', dependence and disempowerment. These positions might have constrained Rachel's ability to (re)construct a meaningful 'new' identity.

Extract 2

CW: No, so how was it? How was it like when you came out?

George: When I came out, I thought. When I woke up I thought what am ok what am I doing in hospital. I had no idea what on earth what happened to me. I thought what am I doing here. I got to go home but people would say things that I was doing wrong.

CW: What kind of things were they?

George: I was repeating things over and over again. Interrupting people. What was I did was that, in your memory because you are not sure if your memory is working properly you say things as they come in your head. So if someone asks you a question, you do 'bla bla' straight to you before you forget it. So it looks like interruptions that you are not listening to what the other person is saying but all you are thinking I better say it before I forget it. Things like aahh.... things were easy before, like walking up the stairs for example but if you have been lying in bed for four months you will have to be retrained how to well to well function. When I came out of hospital I went back to work, which was a mistake.

(Lines 57 - 71)

George is a man in his late 50s. He acquired his injury from being hit by a car eight years prior to the interview. He was in a coma for around six weeks. He suffered frontal lobe injuries and had a cerebral haemorrhage. He said that he suffered from traumatic amnesia, but also stated that his memory had partially recovered. He stated that he felt that he was almost back to having the memory he possessed prior to his injury.

I asked George what it was like when he came out of hospital. He answered the question by relating it to the acute post-injury period and to the intermediate period when he went back to work. It can be argued that George drew on discourses of 'disability' and 'right and wrong'. He used the terms, 'no idea', 'what on earth', 'doing wrong', 'mistake', 'retrained how to well to well function', which implied that the 'disability' discourse constrains how a person 'should' be and behave. George also

talked about having the self-awareness to recognise that something was 'wrong', even though he was not sure what it was.

In the acute post-injury phase, George was not certain whether his memory was working properly. He described the need to have things repeated to him in order to help him remember what he was saying while in conversation. George seemed to have (re)constructed his identity with the help of interpersonal relationships and conversations with significant others. The discourses of 'disability' and 'right and wrong' might have placed George in a dependent and disempowered position, as he drew on the influences and observations of others when (re)constructing his identity. This position might be associated with a lack of control over forming an independent identity.

The interview took place eight years after his injury. During this time, George seemed to have experienced a cognitive recovery and adapted to his symptoms of TBI. He talked about the acute post-injury phase as something in the past. He had also been able to build up newer memories and a self-narrative following on from the injury, which seemed to have shifted his positioning to a more independent state.

Extract 3

CW: So how did you feel about things after the injury? What...what kind of feelings did you have?

John: Ah I didn't have many really, you know.

CW: No?

John: I just...I had one thing in my head, I'm going to walk properly, you know and um I done a lot of um drinking, you know.

CW: You started to drink?

John: Yeah.

CW: Yeah? Did you drink before?

[...]

John: And...and um...and with not working and I couldn't um...I had to...I tried working ...You know um to get money, you know and um I went to an agency. Gave them a...dodgy name. Said I was a waiter, you know, and that was OK and I started trying it and I... I couldn't do it.

CW: So you went to restaurant to...to try to wait?

John: Yeah, yeah, it was straightforward, it was. I was...there was um...it was one...one day I was on and I had one table. Twelve people on it. So I knew where it was and so I put the starter on. And um I got the main course. Brought them down. You know. Um I got the um the main course, I went through the restaurant and I couldn't find a thing. I couldn't remember.

CW: Oh, that must have been frustrating.

John: And then I put them on... I put them on the wrong table. [laughs]

CW: How long after the injury was this, do you remember?

John: It was about three years. Yeah, yeah, because I was, yeah, walking, yeah and all that, and that was back...I wouldn't be doing it.

CW: But you couldn't ...

John: Yeah, yeah, but I couldn't. It was straightforward, plate-forward, everything was on plates, it just just bang, bang, bang. It's not...if it had have been service...I wouldn't be doing it.

CW: So that was... the...that was the only time you tried to go back to work then?

John: Yeah, yeah, hm, and I couldn't do it.

CW: So how did you feel after that?

John: Oh devastated, you know. Oh, no, I was in a terrible state, you know and I turned to more drink then, you know.

CW: So you then started to drink more?

John: Yeah, yeah, but I haven't drank now for about six years, you know.

CW: So how did you stop?

John: Well I looked at myself and I think, you know, you're going to die and I'd... I'd gone through all that, I'm not going to die through drink, you know, you know. I got through the accident, you know, and um even now...well you don't...I'm over sixty now, right. You don't see a lot of epilepsy over 60 [laughs]...so I'm here you know. That's the way I look at it.

(Lines 840 – 847; 852 – 889)

John is in his early 60s. His brain injuries were caused by an assault 24 years' ago. He reported he was in a coma for two to three weeks and suffered from severe injuries including left hemiplegia (weakness of the left arm and leg). Other physical symptoms post-injury included: amnesia, epilepsy, chronic headaches, tiredness, some cognitive impairment, memory impairment, speech impairment and word finding difficulties. John lives by himself in a rental flat. Prior to the injury, John had a long career as a waiter within the hospitality industry. He cannot work post-injury because of his physical and cognitive disabilities.

John drew on discourses of 'disability' and 'loss of professional identity' in relation to his cognitive symptoms and his difficulty with functioning at work: 'I'm going to walk properly', 'I tried working' and 'I couldn't remember.' He expressed frustration and emotional devastation at not being able to work again: 'terrible state' and 'I turned to more drink then.' Prior to the injury, John seemed to have strongly identified himself with his profession. Following the injury, John had to (re)construct his identity without being able to ground it in the role of a professional waiter. His 'it was straightforward, plate-forward' statement hints at a gap between what he thinks *should* be possible, and

that which *is* possible, perhaps negatively impacting his concept of self. The 'disability' discourse appeared to constrain the (re)construction of a 'purposeful' and 'meaningful' identity. A 'purposeful' identity in the current Western society is often related to working ability. Here, the discourse of disability seems to create a dependent and helpless position.

John also drew on a 'survivor' discourse: 'you're going to die and I'd...I'd gone through all that'. The 'survivor' discourse allowed for ambiguous positions. On the one hand, it appeared to be linked to a position of 'should feel happy'. This position implied that he should feel happy about being a survivor, even though the injury had had a severe negative impact on many aspects of his life – physically, socially, emotionally and economically. Therefore, it might have been difficult for him to find meaning and purpose in his 'new' identity, despite the idea that he was a 'survivor' and that his survival 'should' have been experienced in a positive and grateful way. On the other hand, the 'survivor' discourse might also have enabled him to recognise the fluidity of his own identity. He had moved from attaching great importance to his profession, marking a significant aspect of his identity, to alcohol misuse in association with the loss of this, to the realisation that he had survived brain injury and wanted to live. The statement: 'you don't see a lot of epilepsy over 60...' may reflect a sense of pride and optimism around his construction of identity; he survived an assault with resulting TBI and he perceived that he had lived longer than expected with his diagnosis of epilepsy.

Extract 4

CW: So where did you work then?

George: Financial services in 'X' and they paid for me when I was in hospital. They got by me and I went back there when I came out of hospital and they passed on shorter hours, part time work to get me back into the trunk to get me back into the swing. Some people don't do that. Lots of employers don't adapt. So basically you go back to work to the frontline to the deep-end. Like you don't have any problems at all because the real problem with it is the invisibility thing. Look at me 'do you have brain injury?' No but he has. I think you look at someone in a wheelchair and you say something is wrong with you. There are assumptions all the time.

(Lines 78 - 88)

Here, George (re)constructed his identity through a 'disability' discourse, which he was required to adapt to (e.g., George's work place reduced his work hours so he could adapt). George also (re)constructed his identity using an 'invisibility' discourse. In relation to identity, the word 'invisibility' suggests that a person is socially and emotionally isolated and in some ways absent from the world in which they exist, despite being physically present in that world. George seemed to return to work too soon after his injury, even though his workplace catered for his condition with flexibility. He perceived that his colleagues could not see his injury: 'It is the invisibility thing', 'Look at me 'do you have brain injury? No but he has'. He compared the perception of himself to the concept of someone in a wheelchair; he appeared to argue that there was something visibly wrong with a person in a wheelchair, while the perception was there was nothing visibly wrong with him when others looked at him. He continued, 'There are assumptions all the time', which seemed to imply that there are *wrong* assumptions made all the time. George may draw on an 'invisibility' discourse to take up a position of rationalising his post-injury experiences. However, identity drawn from an 'invisibility' discourse may also create a position where people feel outside the 'normal' of the wider society and therefore feel misunderstood.

It can be argued that the 'disability' and 'invisibility' discourses constructed a power relationship between George and his employers. Even though his employers were actively supportive and aiming to help George return to work, this could have resulted in a position of inequality. The power relationship also resonates with a wider economic discourse, which expects members of society to work and to be productive in order to be part of Western society.

Extract 5

Rachel: As I said, like, for years I didn't meet anybody else with a brain injury and it's like I felt so isolated and that nobody...nobody could understand.

CW: Yeah, yeah.

Rachel: And um like any...because...the other thing is with brain injury is it's...it's not physical, no-one can see it and like X was saying, another young girl here, she was like... she...she walks with a stick and one of her reasons for

carrying the stick, she doesn't need it so much but one of her big reasons for carrying it is because without it, she said people thought I was drunk.

CW: Because the way she was walking?

Rachel: Yeah and it's like because you can't see it and people, when, like even now, like all my new jobs um it takes me so long, as I said, to get it because I'm really slow at learning things. People like 'oh', 'oh' and just think I'm an idiot and I'm like I'm really not, they just don't...don't get it.

CW: Do you feel that you need to tell them that you have a brain injury?

Rachel: it's really...it's like I don't... that's crazy...Yeah and it's like I don't want to and I don't at first, I'm kind of like trying to be balanced and bubbly and pretend that nothing's there and ra, ra, ra and then, like after I've been like this job again, after I'd been going for like a week, two weeks and I'm still not remembering some basic stuff that I got shown the first day I will then sort of mention it and things because I kind of almost...it's like I feel like it's an excuse but it...it's the truth as well but I feel like it's an excuse.

CW: Why would it be an excuse do you think, why would it feel like an excuse?

Rachel: I don't know because...because you can't tell to what degree it's...it's...bad, I can't think...I can't tell whether it's me just being stupid or whether it is the brain injury, I'm not sure which one it is and I never will be so I just kind of, after a while start going 'oh, I've got brain damage.'

CW: How do you...how do you explain that to them... what do you say to them when...

Rachel: I don't really say it so it's if it comes up, I suppose. Yeah. I don't really say it to like a stranger straight away. I don't...I don't talk about it really um but yeah, I don't know how it comes up but um... yeah... never mind...sorry.

(Lines 1082 – 1113)

In extract 5, it appears that Rachel drew on discourses of 'disability' and 'invisibility'. Rachel did not meet anyone else with brain injury until several years after her injury. One could argue that this generated a position of social disconnection and alienation, as she said, 'I felt so isolated' and 'nobody could understand.'

Rachel spoke about the difficulties arising from TBI being a hidden disability: 'not physical, no-one can see it.' The discourse of invisibility seemed to offer a belief that only visible injury could be understood: 'I can't tell whether it's me just being stupid or whether it is the brain injury'. This suggests that Rachel took a position of externalising the disability as something separate from herself and may suggest that Rachel (re)constructed her identity as separate from some aspects of her disability. The subjective experience may be that she had not accepted memory impairment and impaired cognition as part of her post-injury identity. To illustrate her point about the injury being invisible, Rachel compared herself to a peer who attended the head injury charity. The peer had TBI *and* had a physical representation of that injury in the way that she walked. She walked with a stick so as not to appear to be intoxicated ('drunk'). The function of this could be that by walking with a stick, she adopted a physical and visible identity and this achieved some understanding from others.

Rachel also drew on a 'perceived stigmatisation' discourse, which could offer a position of social disconnection. This is highlighted by Rachel's avoidance of disclosing her brain injury to others. There could be different functions for this. One purpose could be to avoid rejection. By not disclosing, she might wish to avoid prejudice and discrimination against disabled people, and perhaps would prefer to be treated like the 'medical' discourse's understanding of 'normal'. Another function could be that she does not want TBI to be her identity in a group (e.g., at work).

Frank's illness narratives in relation to disability and invisibility

One can argue that 'disability', 'medical' and 'right and wrong' discourses can be connected to the restitution narrative as they endorse the belief that 'health' is the normal condition that people ought to have restored ('Yesterday I was healthy/able-bodied, today I'm sick/disabled, but tomorrow I'll be healthy/able-bodied again'). Here, the restitution narrative was related to hope about becoming 'healthy', able-bodied, experiencing cognitive recovery and re-connecting with the identity participants had pre-injury.

Extract 1 illustrates how the restitution narrative is connected to a medical cure and the expertise of health professionals. Rachel's narrative about the doctor serves to describe her expectations of a diagnosis and hope of a restored self. She seemed to seek answers from the doctor as the 'expert' on how to be 'working properly'. As the doctor said, 'part of [her] brain is not [...] working properly', Rachel seemed to consider parts of herself were 'wrong' in a society where 'healthy' is the norm. It can be argued that a restitution narrative actually restrains an individual's freedom to (re)construct a meaningful 'new' identity. The association with 'healthy' as the norm may restrain individuals who are chronically ill to a disempowered position. One part of the participants' narratives could be their own desire for restitution. The narratives might also be affected by the expectation of what other people want to hear.

In extract 2, George's narrative seemed to begin as a chaos narrative. He expressed feelings of powerlessness and vulnerability when talking about his experiences acute post-injury. In extract 4, George used metaphors of danger when talking about returning to employment, 'the front line' and 'the deep end', which implied that he intended to illustrate the emotional fear of going back to his previously familiar context.

However, George's narrative appeared to intertwine with a restitution narrative. George's restitution narrative operated to make sense of how things have changed from the acute post-injury phase until the present (the time of the interview). He talked about his time in hospital and learning to walk again in the past tense, which suggested that his narrative plot was about being partly recovered and partly 'cured'. George's narrative about re-learning implied a desire to restore to a 'healthy' identity and to recover. Narratives of how things have changed from the acute post-injury phase to the present sometimes suggested that participants had experienced a degree of cognitive recovery or adjustment to their disability. This reconciles with the majority of people who tell restitution stories and who describe experiencing that they are currently 'able bodied' and restored to their pre-injury identity. Also a restitution narrative was more common amongst individuals who expressed higher similarity and less discrepancy between their self-concept pre- and post-injury. George's illness stories highlight that the 'disability' discourse can be associated with the chaos narrative and participants' meaning-making during the acute post-injury phase. However, the stories also illustrate that the 'disability' discourse can be related to the restitution narrative, as part of hope of recovery.

In extract 3, John's narrative described significant emotional difficulties about not being able to return to work, with a consequent loss of professional identity. His words suggested a life with no hope of continuing employment. Consequently, John's narrative lacked the hope of becoming 'healthy' and able bodied again. John's narrative suggested that he felt he had not gained anything positive from his illness. Instead it reflected how TBI had caused significant distress in his life. The discourses of 'loss' were associated with an uncontrollable present, and with powerlessness and hopelessness. This was connected to a chaos narrative, and to difficulties in meaning-making and in (re)constructing an alternative identity and work role following TBI.

The 'invisibility' and 'perceived stigmatisation' discourses could also be linked to the chaos narrative. Individuals living in the chaos narrative describe experiencing an 'emotional battering' stemming from their rejection by others (Frank, 1995). In extract 5, Rachel expressed the difficulties arising from TBI being a hidden disability. This seemed to create a position of social disconnection and alienation. In chaos stories, life does not get better, the wound is just too raw and the danger is ever present (Frank, 1995). However, Rachel's narrative expressed the importance of meeting other people with TBI, which could facilitate social integration and help to (re)construct a meaningful identity post TBI.

3.4.2 Identity as rebirth and ongoing development of identity

The second theme presents participants' use of discourses of 'rebirth' and 'ongoing development' of identity. These discourses also relate to discourses of 'positive personal growth', 'loss of identity', 'change of identity' and 'different'.

Extract 6

CW: And how...how do you feel about your life now?

Simon: I'm trying to survive but I have changed, I've got no memory, no.

CW: Hm. So when you say you've changed, is that...

Simon: After my accident I was a very different person but I'm now trying to treat every day like it's a new day.

CW: Hm.

Simon: Be growing up and being an infant, you know.

CW: How do you do that?

Simon: I don't really know, I can't say exactly how I do anything, but I'm trying every day to make a new day and start again, yeah.

(Lines 699 - 708)

Simon is in his mid 40s. Simon's brain injury occurred 12 years prior to the interview. He suffered severe injury to his frontal lobes following a parachuting accident. He reported that he was in a coma for more than seven weeks. Simon suffers from substantial long-memory impairment. Simon said that he could remember main narratives of his life pre-injury but he had more difficulty remembering specific details. Simon also suffers from impaired short-term memory and some cognitive impairment, which stopped him from pursuing his career. He also suffers from some loss of behavioural control, which causes some disinhibiting and impulsive behaviours. He lives with his mother and has the help of a carer.

Simon drew on a 'loss of identity' discourse. He appeared to have lost part of his sense of identity because of his memory impairment: 'I've got no memory, no.' Simon also drew on a 'rebirth' discourse. When I asked about what had changed post-injury, Simon said, 'After my accident I was a very different person but I'm now trying to treat every day like it's a new day.' In this statement, Simon said that he felt different now compared to how he felt in the acute post-injury phase. It seemed that in order to manage the loss of his 'old' identity and adjust to his 'new' identity Simon practiced treating every day as 'a new day'. He continued by saying, 'Be growing up and being an infant, you know', which referred not only to (re)constructing his identity every day, but also metaphorically to going through the learning stages of childhood skill acquisition again during adulthood. Thus using a 'rebirth' discourse might have allowed

him to manage memory loss. This could also have facilitated the formation of new social relationships. For example, by conveying to others that every day is a new start for him, 'I'm trying every day to make a new day and start again', he might have anticipated that people would understand and accept him. By (re)constructing the world from the position of daily 'rebirth', might have helped Simon to adjust and adapt to loss of self-knowledge.

Extract 7

CW: I was going to ask you a little bit about before and after the injury. Did you feel that you were in any way a different person or personality before or after the injury?

Thomas: Yeah. Before my injury I was always, how can I put it, always got in trouble with the law. I had a criminal record before my injury. I done burglary stole cars, before my injury and after my injury I was a different person. I wouldn't think about it.

CW: You wouldn't think about stealing now?

Thomas: No. Totally different person. It was like this...flick a switch.

CW: So why do you think that?

Thomas: I don't know.

CW: How did your personality that change?

Thomas: I think so, yeah. It was just a different person. You know it's like, before my injury I used to be in trouble with the law, fight people, you know there was so much anger and that. You know, towards my family, you know, towards other people. It's just like that other person's gone, you know what I mean? Really gone.

CW: So was it that, the kind of the anger that went or something else that went?

Thomas: After? Almost tranquil. Yes, it's sort of like you've turned the switch and completely gone, you know. It's quite surreal really. It really is.

CW: Did you feel like you kind of missed that person that's gone?

Thomas: No. Definitely not. When I look back at things I've done I think to myself 'why'? Why did I do the things, you know? It's not me, you know. It's really not me.

CW: So you couldn't really recognise yourself from the person that had been before?

Thomas: No. I hardly recognise that person at all. When they do a ASB check and all that thinking no, a criminal record, no. I really can't. It's not me.

(Lines 411 - 436)

Thomas is in his early 50s. He obtained his brain injury 37 years ago as teenager in a motorbike accident. He suffers from memory impairment, seizures and chronic headaches. Post-injury Thomas learned to read and obtained an art degree. He also talked about becoming a Christian post-injury.

Thomas referred to his past and committing petty crime prior to the injury. He appeared not to be able to reconcile who he was pre-injury to the person he became post-injury, and highlighted his different attitude towards crime: 'I wouldn't think about [engaging in criminal activity] now'. Thomas drew on a discourse of 'rebirth' and (re)constructed his identity in terms of beginning a 'new' life post-injury. He used utterances including 'totally different person', 'flick a switch' and 'it's just like that other person's gone' to emphasise the difference in personalities pre- and post-injury. By (re)constructing identity with a metaphor of immediate change, 'flick a switch', his discourse of rebirth was reinforced. It allowed Thomas to describe the powerfulness and the intensity of being a 'new' and 'different' person.

Thomas appeared to use discourses of 'different' and 'change of identity' instead of 'loss of identity' in conjunction with the 'rebirth' discourse. Thomas implied that he was not content with his life prior to the injury, 'When I look back at things I've done I think to myself 'why'?' and perhaps by (re)constructing a 'new' identity, with a clear onset from the date of the trauma, he could re-invent himself into someone different. A 'rebirth' discourse seemed to facilitate an active and independent position, which increased the distance from his 'old' self.

Extract 8

CW: Is there anything that you feel that we haven't talked about that you would like to add about your life after the injury?

Mary: Just, I think it has affected my family the worst.

CW: OK, in what way do you think it has affected your family worst?

Mary: Well I think it has made me a favour. I don't think they think that. They don't see it that way.

CW: Have you spoken about it with them?

Mary: My mother says 'I can see where you are coming from.'

CW: How do you think your mother has been affected?

Mary: Because I am not the same person that I used to be. I used to help about with filling forms in and everything. I can't do that now. And my sister because she is nine years younger than me, I was like a mum to her.

CW: Yeah, has that changed do you think? Are you still like a mum to her?

Mary: No. Every time she had a problem she could call up and talk to me. She can't now.

CW: So do you think your relationships have changed with your family?

Mary: A bit.

CW: In what way do you think?

Mary: I can't pick up the phone and talk how I used to talk to them.

CW: What is different now then?

Mary: I can't give the advice the way I used to.

CW: So how do you think it is different: How did you talk to them before?

Mary: Because before my accident I used to say what I was feeling. I can't say that to them now.

(Lines 727 - 749)

Mary is in her late 40s. She sustained her brain injury from a car accident eight years prior to the interview. She said she was in a coma for over seven weeks. She suffers from right side paralysis, some cognitive impairment and mild speech impairment. In contrast to many of the other participants, she said her memory improved following injury. During the interview, Mary stated several times that the injury did her 'a favour', as prior to her injury, she used alcohol excessively, and her doctor had advised her to stop drinking because of the risk of liver damage. She stated that post-injury she could not drink alcohol because of the risk of brain injury related seizures. She also said that she used to be quite aggressive before the injury, but now described herself as more mellow. She stated that she suffered from depression prior to the injury, and that she had not felt depressed post-injury, although she sometimes felt low.

Mary stated that the injury did her 'a favour'. Although she was aware that her injuries resulted in functional impairments, the injury also instigated a new life and identity that did not seem possible prior to her injury. Here, Mary drew on discourses of 'ongoing development' and 'positive personal growth' in (re)constructing her identity. An 'ongoing development' of identity discourse appeared to enable Mary to accept her

new life. The construction also offered a subject position that distanced her from her identity pre-injury. In practice, this might have given her the opportunity to (re)construct a 'new' identity, which she seemed more content with.

However, despite the development of identity seeming 'positive' for Mary, her change of identity was not always understood by significant others, as they might have felt they lost the person they once knew. Mary appeared to have changed her position and role within her family. Mary said she was aware that her family found it difficult that she has changed, and that she did not want to worry them further by telling them how she felt. One could argue that the position of distance from her 'old' self impaired her to ability to connect and communicate with her family, as they struggled to relate to the 'new' Mary.

Extract 9

George: The [psychologist] in X hospital. She did the test cognitive stuff like you have difficult changing attention, you have difficulties shifting attention. You are very strong in certain areas. I said to her, 'how do you know how, if you didn't know me before, how do you know how different I am now?' Do you know what I mean? She said it is basically based on your CV. You have done this and you done that so the assumption is that you were that level.

CW: Yes, because you can't really know if you haven't been tested before?

George: Yes, I said to her, 'why don't you test everyone at 18 for example.' Not her personally [laughs]. But she said it is basically based on your CV and your life experiences. So I said to her 'How do you reconstruct yourself, if you basically starting from to 'zero', after brain injury? How do you go back to where you were?' Singing, writing, you know, functioning.

CW: Yes, I was wondering if you felt any different?

George: No. After brain injury I was not good at all. I could not see what in earth I was doing this. Everyone was against me. I was just very negative. Post the brain injury, now, I can understand how the world is now. I am back to where I used to be.

CW: Do you think you have a different view of the world now?

George: Not really more that if people moan about this and moan about that.
Hang on a minute I have a brain injury.

(Lines 511 - 539)

George drew on discourses of 'ongoing development' and 'recovery' to make sense of his identity post-injury. He uses words such as 'before', 'different', 'zero', 'go back', 'reconstruct yourself', 'basically starting' and 'functioning'. George referred to (re)constructing his identity from 'zero', which enabled the position of a new beginning from a 'blank slate'. An 'ongoing development' discourse of identity may also allow for a position of independence. The position of independence might have enabled George to (re)construct a 'new' identity, over which he could have agency. However, a position of independence may also produce a subjective experience concerning the responsibility of (re)constructing yourself.

George also drew on the 'medical' discourse when he said that the psychologist based his cognitive level post-injury from his CV and his life experiences. An objective measurement may assess change in cognitive function, but there are many unexplained personality changes that cannot be understood using CVs and reported experiences. George also said he is 'back where he used to be', which implied that he was 'cured' and 'fixed' to what is perceived as 'healthy' in western society. The 'medical' discourse might enable George to attribute a scientific measurement to his change of identity, which could be useful for his recovery. However, drawing on a 'medical' discourse might have positioned George as objectified; he seemed to question the assumption that individuals can be measured in comparison to a CV. He emphasised the importance of 'being known' prior to the injury in order to accept an identity of 'being different'. He said, 'how do you know how, if you didn't know me before, how do you know how different I am now?' This suggested an active, searching and analytic position from which George (re)constructed his identity. George might have been conflicted between wanting a scientific answer that could explain how he had changed, and understanding that human beings are too complex to be described by objective measurement.

Frank's illness narratives in relation to rebirth and ongoing development

Discourses of 'rebirth', 'ongoing development' and 'positive personal growth' appeared to be connected with quest narratives. Several of the participants described how they experienced their injury as a 'favour' or a 'reason', equating with Frank's (1995) notion of quest. Quest narratives are defined by the ill person's belief that something is gained through the illness experience (Frank, 1995). By focusing on a process of adaption, participants emphasised their ability to (re)construct their sense-of-self over time. They often displayed an open-mindedness to change and to exploring new identities.

In extract 7, it appears that Thomas believed his head injury happened to him for a reason. The quest narrative operates to shape Thomas' post-injury experiences and his construction of a 'new' identity. Frank (1995) describes the quest story as being that of finding a voice: the narrator has been on a journey and has not been 'cured' but changed. The person is in possession of a wisdom that (s)he wants to share with others, 'perhaps to make a difference to the unfolding of their stories' (Frank, 1995, p.127). It seems that Thomas experienced that he had been on a journey of change. He was not 'cured' but changed, and he had the desire to share the wisdom of his change. Here, Thomas is not a passive, helpless victim of his fate, but is presented as a 'wounded story teller' (Frank, 1995). Thomas' quest narrative made his head injury part of his journey with new meaning as its destination. One could argue that Thomas' quest narrative was extended to total self-re-invention following his trauma, which was connected to a discourse of 'rebirth'.

In extract 8, Mary's narrative illustrated that she experienced her brain injury as a 'favour', which could relate to the quest narrative. Mary's circumstances post-injury seemed to have instigated a new way of living and identity that did not seem possible before the injury. Mary's quest narrative was related to a 'positive' outlook on her identity change and on her life post-injury.

In extract 6, Simon drew on a 'rebirth' discourse. For Simon the 'rebirth' discourse seemed to serve as making meaning of his identity when living with memory impairment. Here, the 'rebirth' was not related to the quest narrative, but perhaps an alternative narrative, of adapting to loss of self-knowledge.

3.4.3 Identity in relation to uncertainty and awareness

The third theme presents the participants' use of the discourses of 'uncertainty', 'loss of self-knowledge' and 'loss of identity' that were often related to memory loss. Some participants used discourses of 'awareness', 'awareness of difference' and 'awareness of emotional change'. The 'uncertainty' discourse implies an insecure and unclear construction, while the 'awareness' discourse suggests a more certain construction of understanding concerning the new identity in relation to the previous one.

Extract 10

CW: Do you think that anything has changed in your personality?

John: Um yeah, I think so, I don't know what it is but sometimes um I can't even question that, I can't...answer that, you know.

CW: Is it difficult?

John: Yeah. I mean, I'm alive, I mean that's...that's right, um, I mean, why am I alive after all that? You know.

CW: Yeah? Is that what you ask yourself?

John: Yeah.

CW: Do you feel like you're...like you're a survivor?

John: Yeah but um I was change...I've changed, I know I've changed but I don't know, I can't remember.

CW: So would you say you don't remember really how you were before and after or?

John: Um how do you mean?

CW: You know you were saying you think you have changed but you don't remember so do you remember how you were before?

John: No, not really.

CW: No, no?

John: Well I...I don't...there's nothing there really, you know, when I...when I look back, it's like...like I say to myself, I sit down on my own and I say, ah, I don't think.. I have changed, yeah, it's just I've never had that...I remember being really, really happy, you know...and I've never got that since.

CW: Hm.

John: Yeah, I never got that sense back, you know.

CW: Hm. So yeah, you...you remember that you felt happiness that you felt really, really happy about things?

John: Yeah, yeah, I remember going...I never got the buzz since.

(Lines 1100 - 1126)

John drew on an 'uncertainty' discourse when talking about the process of change: 'Um yeah, I think so, I don't know what it is but sometimes um I can't even question that, I can't...answer that, you know.' Impaired memory and loss of self-knowledge appeared to be the critical factors in his uncertainty about his identity. Thus, without a clear recollection of previous and current events, he was less able to (re)construct his identity. It can be considered that this creates positions of dependency, disempowerment and a barrier to self-understanding. During the interview, John said he has no significant other in his life to provide both a sense of continuity with the past, or an ongoing reference for the present. This social and interpersonal void appeared to restrict his opportunities to fill in memory gaps, which could have helped him to (re)construct his identity.

John also drew on the discourse of 'awareness of emotional change' when he described how he used to be more content in life: 'I remember being really, really happy...' Somehow he appeared to remember the experience of happiness and the

associated 'buzz' it gave him, and expressed a sense of loss and bereavement from not feeling happiness any more, even though he could not remember more concrete details or differences. There could be different reasons for the sense of loss, for example, the physical impact of the trauma, but also the physical, emotional and psychological symptoms that John experienced during the years following his injury.

Extract 11

CW: And do you feel any kind of behavioural changes?

Simon: Not really but I'm not an expert, so I don't know. I did a Psychology Degree, but I'm not, you know.

CW: Yeah.

Simon: I don't really know the answers to that, yeah. I mean I've changed but I don't really know how or why, yeah.

CW: So something changed in you?

Simon: Yeah.

CW: But you don't really know how. Hm...and how does it feel?

Simon: I'm now...there are certain... I'm very...I'm governed now by doing things by routines, everything I do is counting to a certain number or sort of, you know, everything is routine-oriented. So I don't waste time and do nothing and just sit there, you know.

CW: Hm. You said, you have your routine with breakfast and Weetabix. So how...was your life not very routine-like before?

Simon: Well I don't know but I don't think as routine as it is now, yeah.

CW: Hm, and um would you say that when you talk about a change and a change as a person would you say that is an identity loss or...or a change?

Simon: I think it's more of a change than an identity loss but, you know, again, I can't really answer those questions.

CW: Hm.

Simon: Exactly because I've got no idea. I mean, nowadays I just float through life.

(Lines 881 - 900)

Simon drew on the discourse of 'uncertainty' to (re)construct his identity: 'I've changed but I don't really know how or why, yeah'. As stated earlier, Simon suffered from substantial memory impairment, which hindered him creating new memories and impaired his analytical capacity. He needed therefore to create his identity from fragments of knowledge. He seemed to draw upon the practices that made up his daily routine, which appeared to allow him to locate himself in the world, but could not provide a deeper level of self-knowledge.

Importantly, Simon stated that he saw his identity as a 'change' and not as a 'loss', 'I think it's more of a change than an identity loss.' He also struggled to answer the questions, stating: 'I don't really know the answers'. Potentially, he was uncertain of what had changed. Using the 'uncertainty' discourse as opposed to a 'loss' discourse in (re)constructing his identity might have enabled Simon to adapt to his identity post-injury. Loss of his previous sense-of-self might be associated with insecurity, whereas a focus on ongoing change might offer a more forgiving and empathetic position.

Additionally, Simon positioned himself as non-expert: 'I'm not an expert, so I don't know' and 'I did a Psychology Degree, but I'm not, you know'. Arguably, Simon positioned me, a psychology trainee, as the expert while placing the position of a 'non-expert' on himself. This position as a non-expert may be associated with uncertainty so hindering the (re)construction of his identity.

Extract 12

Charlotte:knowing that some people have had the same brain injury but aren't the same.

CW: How do you feel about that?

Charlotte: Um. It makes you, I don't know, it makes you realise that because it is hidden, you can't see and for me I can't always... even like I try and analyse myself, why am I feeling like this, or acting like this? I'm different, but not sure how. Sometimes there isn't an answer. So well when you see people that have had similar injuries it's strange, because I only know what I have gone through for my injury. It's like well it sort of opens your mind to the same thing that happens to the same person it could affect them in totally different ways. It made me realise, you know, that it wasn't lucky. It was unlucky that I got hit, but it could have been different.

(Lines 379 – 389)

Charlotte is in her late 20s. Her injuries resulted from being hit by a car eight years prior to the interview. She said that she was in a coma for six days. She stated that she suffered multiple head injuries, a broken neck, a broken pelvis, a broken arm and a punctured lung. She told me that when she was discharged from the hospital, she spent around ten months in a wheelchair. She was medically retired in 2010 and started volunteering at the head injury charity the same year. She stated that she suffered from memory impairment.

Charlotte used the 'uncertainty' discourse to (re)construct her identity: 'I'm different, but not sure how'. She expressed difficulties in making sense of her current identity. Charlotte also drew on the 'awareness' discourse as she revealed that she is aware of being different, but not sure in what way. The 'awareness' and 'uncertainty' discourses appeared to have created ambiguous positions.

The 'awareness' discourse might have provided a position of freedom to (re)construct a 'new' identity around the difference. This subject positioning enabled Charlotte to actively understand her own symptoms: 'even like I try and analyse myself'. On the other hand, the 'uncertainty' discourse might have facilitated a position of acceptance

that she could not always know what had changed: 'sometimes there isn't an answer'. One could argue that these somewhat conflicted and ambiguous positions reflect how individuals struggle to make sense of their identities following brain injury.

Frank's illness narratives in relation to uncertainty and awareness

In the current study, the participants' narratives were often shaped by discourses of 'uncertainty', 'loss of identity' and 'loss of self-knowledge'. These discourses could relate to the chaos narrative, in which the narrator seems frozen in an uncontrollable present, and in powerlessness and hopelessness (Frank, 1995).

One of the chaos narrative's distinguishing features is the absence of narrative sequencing. The participants' narratives in the current study were sometimes chaotic in structure. A chaotic structure may have been influenced by some participants' memory and speech impairment. For example, in extract 10, John expressed: 'Yeah but um I was change...I've changed, I know I've changed but I don't know, I can't remember'. The severity of John's disability and the unlikelihood of improvement could explain why his account conformed to a chaos narrative.

Several participants hesitated often, repeated themselves and searched for words. Their inability to articulate thoughts easily might have affected the words chosen and their constructed identity via language. Thus, they might not have been able to use the words they really would like to use when talking about their lives. This may have restricted their (re)construction of identity as produced by language and through communication with others.

However, most narratives were coherent and not chaotic in structure. Therefore, they might appear better suited to an alternative 'uncertainty', 'loss' or 'powerlessness' narrative. The narratives were sometimes told in the past tense and represented how the participants felt during particularly vulnerable and emotionally difficult periods of their lives. This was usually in relation to the onset and the early stages of their illness. Also chaos narratives were never presented as a single narrative amongst the participants, but intertwined with restitution narratives and/or quest narratives

In extract 12, Charlotte's account was not predominantly a chaos narrative, restitution or a quest narrative. Her narrative presented a more ambiguous and contradictory meaning-making. She drew on an 'uncertainty' discourse, but did not express

hopelessness or use a quest manifesto. She seemed to have adjusted to and accepted feeling different, but did not judge this as a 'good' or 'bad' change.

3.4.4 Identity as perceived normality and social belonging

The fourth theme presents participants' use of discourses of perceived 'normality' and 'social belonging'. This group presents psychosocial constructions of the desire to belong to and feel 'normal' in society post-injury. Participants drew on discourses of 'social belonging', 'them and us', 'loss of social identity', 'social disconnection', 'social abandonment', 'perceived stigmatisation' and 'different'.

Extract 13

CW: What would you want to say to people who don't know anyone with a brain injury?

Thomas: Someone who hasn't got a brain injury?

CW: Yeah, to know about it, or that would be important to know?

Thomas: Someone who hasn't got a brain injury... That's a good question actually. To someone who hasn't got a brain injury ... That's a good question isn't it? God.

CW: Anything that would help to understand.

Thomas: To understand ... I suppose we are just like them, you know, we are no different to them. Because we have a brain injury doesn't mean that we're no different to them, you know what I mean?

CW: Yeah.

Thomas: Are we, we're not.

CW: No.

Thomas: Just because our brains got bashed, it's no different, you know. I've lost a bit of memory but it doesn't make us any different, you know. If anything it makes us stronger, you know. I'm not saying it makes us any better than a person that's got brain injury. If anything it makes us stronger, you know what I mean. I think we've got more zest for life than a person that's got no brain injury. We value life more than a person that's got no brain injury, do you know what I mean?

CW: Yeah. Because you've been through something traumatic, is that what you mean? So you value life a bit more afterwards?

Thomas: I think so, definitely.

CW: And you also said you have a zest for life? More kind of joy for life almost?

Thomas: Yeah. We grasp life more, you know. Much so, yeah.

(Lines 1094 - 1131)

Thomas appeared to (re)construct his identity with a sense of social belonging to a category (i.e., individuals with TBI). He uses the words 'them' when referring to people without TBI and 'us' when referring to people with TBI. The discourse of 'them and us' seemed to enable him to (re)construct his social identity within the norms of a social belonging to individuals within a TBI category. This perspective provided Thomas with a position of shared social identity. Thomas also stated that there was 'no difference' between people with and without TBI. Here, Thomas used the 'social belonging' discourse to construct 'normality' and to belong to a category in the wider social world. He 'minimised' the injury; if the injury is nothing, there is no difference. However, he still used the word 'them' when describing people with no TBI, creating a division linguistically and subjectively. This offered a position of being an 'outsider looking in' at what is perceived as 'normality' in our current society. Even though Thomas discounted the perceived difference between people with and without TBI, he (re)constructed a 'new' identity of being different to 'them' (those without TBI). This suggests a wish to belong to and to be accepted by wider society, an act that in itself

recognises a separation. This could be a source of potential conflict for some participants. Some participants might want to belong to a social world that they used to inhabit but their discourses (e.g. 'them and us') limit them.

Thomas also used a discourse of 'positive personal growth' when describing his 'zest for life', and feeling stronger post-injury. For example, he used the words 'it makes us stronger' and 'I think we've got more zest for life' in describing himself post-injury. He described how the experience of TBI had enabled his personal growth and allowed him to develop his emotional strength. His observation that people with TBI have 'more zest for life' could stem from this described emotional development, or from a perception of the fragility of life that could result from being subject to severe injuries.

Extract 14

CW: What would you say, I mean you have talked about money and other things what would be important for you then and now?

Charles: Then it was all about things, having a good car, a good house, items. Now friends, friends and family it really is. Realising that, you realise who your friends are, that still with you now that were then. That you, people you can rely on. It takes something like this to happen for you to think hold on a minute they are still with me now. [A friend] was by my bedside even when I was not awake. He was there by my side talking to me, chatting to me. My dad was talking to me and I squeezed his hand. It is things like that you think oh my word. I would like to think that I would do the same thing, if God forbid that happened to them, I know I would, I would do the same for them. It is just doing the right thing.

CW: Did you lose any friends though?

Charles: Again my [now ex] girlfriend, I mean all that happened is that they are not with me now so my friends their lives have moved on, they have now got wives or husbands, they have kids, their lives have moved on. Whereas my life is on hold...mine is like on pause. Their lives have carried on so I am on catch-up if you like, I am trying to catch-up. You cannot rush the catch-up.

CW: How do you feel about being on pause or catch-up would you say?

Charles: I am still alive. How can you... it is weird I would rather have this than the alternative of being dead or disabled. So in a way, ok it is bad but it could have been a lot worse.

(Lines 1100 – 1121)

Charles is in his mid 40s. He acquired his injuries from a motorbike accident 13 years prior to the interview. He said he was in a coma for around two weeks. He stated that he suffered from traumatic amnesia following his accident. He stated that his long-term memory was good and he was able to recall events from before and after the accident. However, he suffered from impaired short-term memory and said he had difficulties in recalling daily events (e.g., where he parked his car or what he had for dinner). Prior to the accident he worked in the finance sector. He was currently working as a volunteer at the head injury charity.

Charles seemed to draw on multiple contrasting discourses (discourses of 'work and productivity', 'social belonging' and 'them and us') in order to make sense of his experiences in different contexts and time periods. Prior to the injury it appeared that Charles constructed his identity through discourses of 'work and productivity' as the primary identifying features. His identity was also constructed by belonging to the category of a successful socioeconomic group: 'Then it was all about things...'.

Eight years post-injury Charles seemed to have shifted position regarding what he found important in life; at the time of the interview, he primarily used a discourse of 'social belonging' to (re)construct identity, 'Now friends, friends and family it really is'. Charles also drew on a discourse of 'them and us'. He said, 'their lives have moved on. Whereas my life is on hold'. A 'them and us' construction might have constrained his progress in life, as it offers a position of exclusion from a typical trajectory of a 'normal' life. However, the function of shifting the importance of his social relationships might allow Charles to (re)construct a meaningful identity post TBI.

Extract 15

Charlotte: I feel like I had lost everything.

CW: Hm.

Charlotte: Um even to the extent of in the beginning all of my friends, who I used to socialise with, they would come up the hospital and was always there. Once they knew, it felt to me, that once they knew I was [...] going to survive I didn't see them no more.

CW: Okay, so what happened with your friends they...

Charlotte: Yeah...and then...I started seeing them again but it is hard for me, because they all had children. It wasn't hard for me knowing that they was my friends before and now I can't do the same as them... It was more the fact that you'd be sitting having a conversation but they wasn't putting any effort into listening to your conversation... so they was speaking to somebody else. It was like 'This is getting very stressful.' So they struggled to deal with the change because even though I am Charlotte on the outside, my thought process, my behaviour, none of that was the same as what it used to be. Yeah. I see them in the street now and we speak but I don't actually socialise with them. I don't see any of my friends.

(Lines 283 – 299)

Charlotte said, 'So they struggled to deal with the change', which implied that her friends could not manage or connect with Charlotte's altered personality and behavioural changes, and that this contributed to the breakdown of their friendships. It can be indicated that Charlotte drew on discourses of 'loss of social identity', 'social disconnection' and 'social abandonment' to (re)construct her identity: 'I feel like I had lost everything'. The discourse of 'social disconnection' may offer positions of alienation and social isolation, which enforce difficulties in communicating and connecting with others. Charlotte suggested that she had insight into the changes to her personality and behaviour. This might have facilitated her self-understanding and adaption to her post TBI identity. Charlotte's social isolation could be connected with a perceived devaluation of her social role and perceived stigmatisation. This could have resulted in her withdrawing further, increasing her sense of social isolation.

Extract 16

CW: And one more thing, would you describe yourself as a disabled person?

Mary: No not at all.

CW: So how would you describe yourself?

Mary: Different.

CW: Different Yeah. In what way?

Mary: The way I look and the way I walk. Like I said, it has done me favour. Everything is with my injury. I walk a bit with a limp. My voice and my eyes, one is broader than the other. That is about the only difference. Physically I look the same.

CW: Would you say that is a positive or negative thing for you?

Mary: It is a positive thing.

CW: In what way?

Mary: Because I put myself out and I don't care what people think. I don't mind telling people what happened to me.

(Lines 843 – 856)

Mary did not identify herself as disabled; instead she drew on the discourse of 'different'. The discourse of 'different' appeared to enable Mary to take up an accepting position towards her physical impairments and her body. In contrast to a 'medical' discourse, she seemed to see the injury positively, as 'a favour', and not as a problem that needed to be 'fixed'. This accepting position also appeared to allow her to (re)construct her 'own values' and meaning about her identity post-injury. Mary stated that she did not mind disclosing what happened to her 'because I put myself out and I don't care what people think'. This is in contrast to a discourse of 'stigmatisation' that

other participants described. In adopting a practice of openness about her injury, she could reduce societal stigmatisation.

Frank's illness narratives in relation to perceived normality and social belonging

The discourses of 'perceived normality' and 'social belonging' could relate to a restitution narrative in the sense that individuals have the desire to be 'normal and 'healthy'. This can be associated with how contemporary Western culture treats 'health' as the normal condition that people ought to have restored. Some of the participants reported that they experienced social disconnection and exclusion from the 'normal' trajectory of life. For example, in extract 15, Charlotte expressed that she had experienced difficulties adjusting to her loss of friendships.

In extract 14, Charles, expressed that he felt his, 'life were on hold' and that his friends' lives had 'carried on'. This resonates with the chaos narrative, in the sense that Charles expressed a lack of control of his life. His account also intertwined with a quest narrative in that he had re-evaluated what was important for him in life. His account reveals a social connection with his family and friends. Charles' narrative intertwined regret for what he has lost (chaos) but also the experience of adjusting or finding purpose in life (quest). Thus, Charles might have come to terms with some of the consequences of TBI.

The quest narrative was also present in Thomas' account (extract 13). He described that he had more 'zest for life' post-injury. In extract 16, Mary described her TBI in terms of 'it has done me favour' and herself as 'different' not disabled. The discourses of 'normality' and 'social belonging' illustrate how adjusting and adapting to TBI can take various forms. These include acceptance of feeling 'different' but also the difficulties of experiencing 'social disconnection'. The participants (re)constructed their identity within the norm of belonging to an 'individuals with TBI' social category. This does not imply that these participants were focused on the specific outcome of recovery. Instead it might imply that these participants' adaption and adjustment to TBI took another form.

3.4.5 Identity in relation to independence, acceptance and recovery

The fifth theme presents discourses of 'acceptance' and 'recovery', and the discourse of 'independence' that often conflicted with the discourse of 'dependence'. Related discourses that were identified including 'acceptance of different', 'responsibility', 'adapting to change' and 'survivor'.

Extract 17

CW: So did [the neurosurgeons] see something else then?

George: They said you recovered a lot 70-80 per cent, you know. Some people can't do stuff, some people can. That was what I was saying - brain injury 'A' [starting from the letter A] recover from it. I don't know if it is your old personality or whatever.

CW: Mmm... Talking about personality. Do you feel differently now?

George: Not really. No. I am more like I used to be now after brain injury probably not.

CW: Ok so how was then? Do you remember how you felt different then?

George: What do you mean after the brain injury?

CW: Yes, now you said you feel more as before.

George: Well I was depressed all the time.

CW: Depressed?

George: Anxiety. Depressed. Anything. For example, the hand control of the television went wrong, I go mental. I threw it out.

CW: So you got angry and you said you got depressed as well?

George: Yes a lot, after that because the court case lasted for four years and that was like you have no money coming in from anywhere and you get benefits. You get ATOS [a health care company that conducts assessments for the Department of Work] and you got to talk to the GP. That is a nightmare that is. You see a GP who doesn't know you at all with loads of medical records and say 'you seem ok, go back to work.' You didn't know me before. You don't know me now and then they redrew the benefits. The clinical psychologist at Mile End advocated against and they it got back straight away. They said 'they should never have took it away.' It is a nightmare. At that time you're in panic mood.

(Lines 411 - 434)

In extract 17, George drew on 'recovery' and 'medical' discourses to (re)construct his identity. George talked about recovering and developing from the acute post-injury phase until the current time. The 'medical' discourse appeared to enable George to identify himself with a numerical measure of recovery, 'they said you recovered a lot 70-80 per cent, you know.' As discussed earlier, a 'medical' discourse may constrain individuals to construct only identities that 'should' be flawless or otherwise 'fixed'. The individual might seek answers from health professionals about their recovery and possible identity change. However, a health professional cannot fully understand how individuals experience themselves before or after injury. The 'medical' discourse can also create a power dynamic between the health-professional and patient, which objectifies the individual with TBI. For example, within situations such as applying for healthcare and benefits: 'You see a GP who doesn't know you at all with loads of medical records and say, you seem ok, go back to work'. In this context the 'medical' discourse can create a subjective position of dependence and disempowerment. It can be argued that this may limit the ability of (re)construction of an independent identity and psychological recovery.

Extract 18

Rachel: Yeah, because before that I always thought I'll just get over [cognitive symptoms of brain injury], I'll get over it, I'll get over it and um yeah, now I know that I'm never going to be right and things take me a lot longer to learn and stuff like that but... I just have to accept it and that's just me.

CW: Hm.

Rachel: Um...at first, as I said, I had to have a lot of help from people and I felt amazingly stupid and all this sort of thing um to the fact where, yeah, obviously it upset me a huge amount but I just... and it's got the point now after thirteen years where I can sort of go 'right, yeah, um...it's just me now, I've got to accept that I'm not where I was, I never will be and I've just got to get on with things the best I can.'

CW: Hm.

Rachel: It's...which isn't... to be honest, it's not bad. I can... I can walk, I can get around, I look after myself.

(Lines 135 - 148)

Rachel drew on discourses of 'acceptance' and 'adapting to change' to (re)construct her identity: 'I just have to accept it and that's just me'. The 'acceptance' discourse was a current construction. She referred to accepting her situation 'now', which implied that she was still on an evolving path of 'recovery' during the interview. Rachel seemed to accept that she still had memory impairment and learning difficulties, but she saw herself as recovering because she seemed to have accepted this part of herself and to have incorporated it into her identity. This implies that an adjustment (transformation) period unfolds over a prolonged period of time and that a person's sense-of-self shifts during this period, so allowing the assimilation of this shifting state of being. It might be that an 'acceptance' discourse offers positions of independence and empowerment that are linked with self-understanding.

Extract 19

Charlotte: Then there's times when I am tired, when it doesn't always pan out. It is hard. I went from being independent and going on holidays to places like the Maldives, and stuff like that to then sitting indoors. We didn't get any help, so my Mum was buying me colouring books. She said like 'see if you can colour, [the letter A], without going over the lines.'

CW: Yeah.

Charlotte: That took months. Um and my co-ordination. I try and feel myself and I was missing my head because of my hands. Yeah, I still struggle sometimes with that... move, well it doesn't actually move. [Charlotte's dog], she got me back out into the world.

CW: [Charlotte's dog] is the dog?

Charlotte: Yeah. She got me back out into the world and I think she has helped me take responsibility again for me. Because, yeah, I'm responsible for looking after her which makes me responsible. I have got to ensure that I look after me, cos she can't do anything. So it was hard the first couple of years, thankfully I was on the ground floor and she could go out to do what she had to do but after that she gets walked all the time. Yeah, she did help me a lot. I can do housework and I can walk the dog. I can't do a handstand because my arms aren't level but.

(Lines 216 – 234)

Charlotte used the discourse of 'dependence' in contrast to 'independence'. She talked about her life prior to her injury, when she was independent, in comparison to her life in the acute post-injury period when she found herself dependent: 'I went from being independent [...] to then sitting indoors'. Charlotte's memory of her mother trying to encourage a behavior usually practiced in childhood ('see if you can colour, A, without going over the lines') suggested that Charlotte had a subjective experience of being passive in this relationship. The discourse of 'dependence' was employed as she discussed how she had been limited by the physical and cognitive symptoms of the injury. However, from the acute period post-injury to the time of interview, Charlotte experienced physical and cognitive recovery. At the time of interview, she drew on a more 'independent' discourse: 'I can do housework and I can walk the dog'. Charlotte's construction of identity was not constant and she drew on different discourses pre, acute, post and longer-term post-injury. This is consistent with a social constructionist position, which argues that identity is fluid.

Extract 20

Charles: I just think it was realising that I could have died. That my god I am still here that, I am happy to be here still and that is why I enjoy life so much. Look the old Charles is dead. I am not the same Charles now but I thought about saying that but I might look the same but I am not the same person now. I know that I will be tired and I am aware of my limitations and that is the thing about a head injury, it is inside being aware that if you have a busy day and take it easy for a day or two before that because otherwise you will be mentally fatigued.

CW: How does it feel? Does it feel like you actually have a new personality?

Charles: I do.

CW: How does it make you feel to have that new personality?

Charles: I always wondered if I met the old Charles how we would get on. I don't even know if he would have time for me because he was so busy that maybe he would not have time for me. I don't know, I don't know. Am I a better me or worse me? I am just a different me. I am still me but a different me. I am more jokey, is that a bad thing? I mean I do know when to not joke so I know when to think ok that is not funny and to be serious.

CW: Do you feel any loss of that other person?

Charles: Oh no not really. I can see what I have gained from the injury. Before my injury having free time was limited, I was working all the hours, trying to see my friends and now I have time. I have all the time in world. How can you put a price on time? I could in theory travel the world. I have not done but I could do.

(Lines 648 – 671)

Charles drew on a discourse of 'acceptance of difference'. At the time of interview, his long-term memory was intact and he remembered events, behaviour and feelings from prior to the injury. He had access to a narrative of self that existed prior to his injury,

which appeared to help him to (re)construct his identity. The 'acceptance' discourse seemed to enable him to reconcile that he was different but that this was not necessarily negative: 'Am I a better me or worse me? I am just a different me. I am still me but a different me'. This also implies that although he felt 'different' post-injury, he still had a strong sense of his 'old' identity. The discourse of 'acceptance' might offer a position of freedom to (re)construct his identity with reference to how he used to be. Alternatively, it might simply reduce potential conflict that could arise from the knowledge of two identifiable and different senses of self.

Charles also drew on the discourse of 'survivor' when he said, 'I just think it was realising that I could have died'. Charles experienced significant trauma, but he had a sense of overcoming this trauma, which appeared to make him feel resilient. Here the 'survivor' discourse might enable a position of empowerment.

Extract 21

CW: Is that what you would want... if someone... if you met someone who had just had a brain injury, is that what you want... what would you want to say to them?

Rachel: Um just about like trying... I'd... I'd say, like, yeah about understanding and I yeah I had this and I had that and you're not alone, you're not the only person that suffers with this and I'd probably say something like no... I wouldn't say to them you're not going to get better, there is a section of you that will never get better now. I would... I would say like... I'd probably look at the positive things and be like 'your brain cells regenerate and they do make new connections and I couldn't do this and this and this and now I can do all this stuff' and I wouldn't focus on anything that I still feel I can't do or still feel that is a problem but I would... I would tell them all the positive stuff so hopefully that would make them want to keep going.

(Lines 1700 - 1711)

In Extract 1, Rachel talked about the emotional desolation she experienced when her doctor told her 'you're always going to have problems'. In Extract 5, Rachel (re)constructed her identity through discourses of 'invisibility' and 'perceived

stigmatisation'. In extract 21, Rachel revealed what she would say to people who recently obtained a TBI.

In extract 21, Rachel stated she would include 'the positive things' - that brain cells regenerate, that she had progressed since the acute post-injury period, and that she could now do things that she could not do previously. Here, one could argue that Rachel drew on discourses of 'acceptance' and 'recovery' to (re)construct her current identity. Rachel's awareness and acceptance of her brain injury symptoms seemed to help her adapt to a 'new' identity. The discourse of 'recovery' allowed positions of independence and responsibility, from which Rachel could take up agency in forming her identity. The discourse of 'recovery' can also be associated with an idea of a fluid identity, which develops and changes over time and social context. The conflicting and different discourses from Rachel's different extracts illustrate the complexity of Rachel's (re)construction of her identity.

Frank's illness narratives in relation to independence, acceptance and recovery

In extract 17, George's interview revealed a connection with a restitution narrative. His account was illustrated by his experience of being back to how he was prior to his head injury: 'They said you recovered a lot 70-80 per cent'. George also expressed that he experienced periods of depression and anxiety after his injury. This might illustrate that a person's cognitive ability might undergo recovery, but that psychological adjustment might not be in a parallel process.

In extract 20, the quest narrative was present in Charles' account. Charles drew several discourses, including 'acceptance', 'difference' and 'survivor'. Charles' quest narrative revealed that he had adopted an optimistic attitude towards living with TBI as part of life's journey. He seemed to focus on what he had 'gained' and not what he had 'lost' following his head injury. He appeared to have achieved a balance between accepting the symptoms of his head injury and creating a meaningful life. As with many individuals with TBI, Charles had experienced the trauma of almost dying, 'I could have died', which might have made him feel that he should be grateful for the life he had now. It is possible that Charles' quest narrative operated to express the privilege of being alive, but also served to reduce any emotional difficulties associated with being a 'survivor' and living with a chronic illness.

A quest narrative represents a journey of accepting, reflecting on and understanding change, resulting in a transformation of one's self (Frank, 1995). In extract 18, Rachel's account was not about 'gaining' something from TBI, but about 'adapting' to resulting changes. Rachel drew on an 'acceptance' discourse but not in relation to the quest narrative. Thus, Rachel's 'acceptance' discourse seemed to be accompanied with emotional struggle and disbelief. In this sense individuals with TBI believe they should accept their injury, but are unable to do so. Rachel's words, 'I'll get over it, I'll get over it...' and 'I've just got to get on with things the best I can' might function to reassure herself that she is accepting the person she is now.

Similarly (to Rachel's account) in extract 19, Charlotte's narrative was based on a developing process of adapting, realising and accepting change. Charlotte expressed that adapting to her illness had been difficult and she recognised the damage that the illness has done. She was not solely seeking recovery from illness (restitution) nor did she seem to have lost all hope (chaos); instead she was trying to accept and to adapt. Charlotte's narrative could be connected with a quest narrative, in which the meaning-making was not about 'gaining' something from TBI, but about 'adapting' to resulting changes. Here, Charlotte's quest narrative was linked to a counter-narrative and an affirmative model of disability, where disabled is not seen as a tragedy. This is important as a counter-narrative might help in the process of (re)constructing identities.

Rachel's accounts illustrate how narratives intertwine in threads. Rachel's narratives seemed to have alternated between chaos (extract 5, with connection to the invisibility aspect of TBI) and restitution (extract 1, in relation to a 'medical' discourse). In extract 1, Rachel expressed her own desire to become 'healthy and able bodied again'. However, in extract 21, none of Frank's illness types seemed to be dominant. Her story might be defined by a restitution narrative in the sense that these stories are based on expectations of what other people want to hear. For example, Rachel expressed what she would say to someone who recently acquired TBI: 'I'd probably look at the positive things and be like 'your brain cells regenerate''. One could argue that a quest story was also present here, as Rachel's story had elements of 'accepting' as part of her journey: 'about understanding and I yeah I had this and I had that and you're not alone'. However, the transformation from restitution to quest narrative was not complete. Rachel did not seem to experience that she had gained something from TBI, but perhaps was beginning to accept the TBI.

3.4.6 Summary of analysis

In summary, these findings indicate that participants constructed overlapping and sometimes conflicting discourses including 'medical', 'disability', 'invisibility', 'rebirth', 'ongoing development', 'uncertainty', 'awareness', 'perceived normality', 'social belonging', 'independence', 'acceptance' and 'recovery'. These discourses can be seen as fluid and developing over time. Examples of multiple levels of identity were identified, which is congruent with the social constructionist's view of identity. The identified discourses seemed to create ambiguous and contrasting positions, for example 'empowering' and 'disempowering'. These findings suggest that there is great complexity and variety within the (re)construction of identity following TBI. The reading applying, Frank's illness narratives, found that the participants' stories were fluid and continually developing. Restitution, quest and chaos narratives seemed to intertwine and alternate. Several participants appeared to express a hope to be 'cured' and 'healthy' again. This seemed to be associated with 'health' being the norm in Western society. The narrative reading will be discussed further alongside the results of this discourse analysis.

CHAPTER 4 - DISCUSSION

In this section, the main findings of the study are summarised and discussed in the context of their relevance to counselling psychology, and in the context of the current literature. I will discuss psychological approaches that might be considered for the psychological treatment of traumatic brain injury (TBI), including the process of empowerment (Burr, 1995; Fenton & Hughes, 1989; O'Hara & Harrell, 1991), and acceptance and commitment therapy (ACT) (Hayes, Strosahl, & Wilson, 2003; Hayes & Wilson, 1999). I will discuss the methodological implications and limitations of this study, before making suggestions for future research. Finally, I will offer my reflections.

4.1 Findings in relation to previous literature and unique contribution

Through a careful and methodical Foucauldian discourse analysis (FDA) of interviews with individuals who had sustained TBI, (re)constructions of 'identity' were identified. The analysis distinguished two overarching discourse themes ('medical' discourse and 'psychosocial' discourse) and 31 discourses, which were conceptualised, integrated and presented in the following five discourse themes: (1) Identity in relation to 'disability' and 'invisibility'; (2) Identity as 'rebirth' and 'ongoing development'; (3) Identity in relation to 'uncertainty' and 'awareness'; (4) Identity in relation to the 'perceived normality' and 'social belonging'; and (5) Identity in relation to 'independence', 'acceptance', and 'recovery'.

Frank's (1995) illness narratives were used as a supplementary reading to explore identity further from another interpretative 'lens'. The discourses and positions identified in the FDA were conceptualised and organised by applying Frank's (1995) illness narratives types – restitution, chaos and quest. The narrative reading suggested that the different narrative types might be connected with the different discourses. For example, the restitution narrative could be linked with the discourses of 'disability' and 'perceived normality'. The chaos narrative seemed to relate to discourses of 'invisibility', 'uncertainty', and 'loss'. The quest narrative appeared to be connected with discourses of 'rebirth' and 'ongoing development'. The aim was not to coerce the different discourses into one or more narrative style, but to discuss the discourses further within the framework of the narratives.

4.1.1 Discourses of disability and invisibility

Identity change can have complex implications when dealing with a traumatic life event or a health-related diagnosis (Cohen-Mansfield et al., 2006). The findings in the current study demonstrated that several participants used discourses of 'disability', 'medical', and 'right and wrong' to (re)construct identity. These discourses endorsed the belief that physical impairments are 'wrong' and are supposed to be 'fixed' to become 'right'. These discourses also seemed to offer positions of dependency, disempowerment and psychological 'stuckness'. Disempowered and dependent positions could have implications for action, as such positions appeared to constrain the relevant participants' ability to (re)construct a 'new' meaningful identity. This supports findings by Cloute et al. (2008) who identified 'TBI as deficit' and 'medical model referencing' as two major interpretative repertoires. Cloute et al. (2008) explored the co-construction of identity among individuals with TBI and their significant others, and proposed that 'TBI as deficit' could create positions of dependency, passivity, and disempowerment. This also relates to the wider socio-political view that a disability discourse can be a form of 'social oppression' (Oliver, 1990).

The findings of the current study demonstrated that cognitive and physical symptoms of TBI often underpinned (re)constructions of identity. Due to cognitive impairments, individuals could not always return to previous employment. However, the participants did not always accept the disability aspect of their identity. The rejection of a 'disability' discourse indicated that participants perceived 'disabled' to have a negative meaning in our societal context. This conflict seemed to constrain some participants in making sense of their 'new' identity and in developing a meaningful life post-injury. This resonates with Frank's (1990) review of embodiment, in which he suggested that disability and chronic illness have often been perceived as negative within cultural perceptions. Frank (1990) claimed that the concept of a 'medicalised body' is one of the dilemmas of being chronically ill in the current 'healthist' society. A 'healthist' society requires the body both to perform functionally and to present visually (Kleinman, 1988), and correspondingly the value we attach to 'self' depends on these aspects. When the body fails, medicine is expected to correct the 'wrong'. Those whom medicine cannot cure become double failures, first as selves and then as patients (Kleinman, 1988). Frank's (1995) restitution narrative is related to hope about becoming 'healthy' and able-bodied. It is also linked to the belief that 'health' is the

normal condition that people ought to have restored ('Yesterday I was healthy/able-bodied, today I'm sick/disabled, but tomorrow I'll be healthy/able-bodied again') (Frank, 1995). In the current study, the restitution narrative was connected to participants' hope of becoming healthy again. The analysis also revealed that a restitution narrative seemed more common amongst individuals who expressed higher similarity and less discrepancy between their self-concept pre-TBI and post-TBI.

Importantly, the participants did not only see themselves as a person with TBI or a person with a disability, but also as a person belonging to other categories, for example, a son, mother, husband, volunteer worker, dart player, art student and/or someone living in London. Thus, the participants were not disabled in every social context, suggesting that being 'disabled' or 'non-disabled' is not a static state, and that such categories are constantly refined, progressed and transformed in different social contexts (Barnes et al., 1999; Oliver & Barnes, 1998). This confirms that identity is constructed through multiple levels of self: 'disability' was only part of participants' complex and multi-faceted identity. This idea relates to propositions within both social identity theory (Tajfel & Turner, 1986) and social constructionism (Burr, 1995; Foucault, 1977) that identity is fluid and consists of a combination of different levels of available discourse(s). It also relates to a multi-dimensional construct of identity as changing in different situations (Sabat & Harré, 1992). Finally, the idea of multiple levels and fluidity is reflected in Frank's (1995) illness narratives. Frank (1995) considered narratives to be fluid and continually developing, and again the current study's findings resonated with this. For example, some participants' narratives began with chaos, before moving to restitution and then transferring to quest.

The present study's findings suggested that participants drew extensively on an 'invisibility' discourse when (re)constructing identity. Individuals with TBI often show no physical evidence of their disability (Sinnkaruppan & Williams, 2001). Invisibility was often described as a 'negative' aspect of identity. The 'invisibility' discourse sometimes created a position of 'abnormality' and 'not belonging' to wider society, and appeared to evoke feelings of not being understood and being socially disconnected. The 'invisibility' discourse could also endorse a position of disempowerment, constraining individuals' psychological flexibility in (re)constructing a meaningful identity. The conflict between 'disability' and 'invisibility' discourses might have constructed a power relationship between individuals with TBI and individuals without TBI. Participants

expressed that they felt misunderstood in a society where a person 'should' be able and productive if other people could see no physical impairment. This finding supports the findings of McClure, Buchanan, McDowall and Wade (2006), that the public and non-expert health professionals hold misconceptions about TBI, and overestimate the abilities of those with invisible disabilities more than the abilities of those with visible disabilities. It also resonates with Chamberlain (2006), who found that the invisible nature of TBI had a negative effect on participants' mental health and recovery. Steadman-Pare et al. (2001) found that a lack of recognition of the invisibility of TBI decreased life satisfaction.

4.1.2 Social belonging and social identity theory

The findings of the current study indicated that participants drew on discourses of 'perceived normality' and 'social belonging'. Some participants drew on a dualistic 'them and us' discourse, which enabled a position of shared social identity. The word 'them' created a different division linguistically and subjectively. The discourse 'them and us' sometimes provided for an ambiguous position of belonging to groups that represented 'normality' or 'different'. It suggested a wish to belong to and to be accepted by wider society, which was in itself an act that recognised separation. Within Frank's (1995) illness narrative approach, the discourses of 'perceived normality' and 'social belonging' could be connected with the restitution narrative in the sense that individuals have the desire to be 'normal and 'healthy' again and so belong in wider society.

These findings could also partly be described by social identity theory (SIT) (Tajfel, 1982; Tajfel & Turner, 1986), which aims to explain the psychological processes of belonging and identification within social groups. Social identity theory was initially developed to explain group behaviour relating to inter-group conflict and discrimination (Tajfel & Turner, 1979). It suggests that people define their sense of social identity in terms of group membership (Tajfel, 1982; Tajfel & Turner, 1986). The individual's sense of self derives from membership of social groups (i.e., in-groups), which provide social identity. Individuals define their sense of self in social and not only in individual terms (i.e., us and we, not only I and me) (Jetten, Haslam, & Haslam, 2012). This means that a person's psychology often depends on the state of the groups that define the self. If these groups provide a person with stability, meaning and purpose, then this

will have implications for their mental health (Jetten et al., 2012). If a person's in-group is compromised in some way (e.g., if they leave or change a group, or are perceived to be rejected from an in-group), then this may have negative psychological consequences. These changes can both be positive or negative, with individuals often experiencing a sense of loss that requires an adjustment process (Jetten et al., 2012). Therefore, it is important to reflect on how membership of groups has an impact on wellbeing post TBI. It also important to reflect on how narratives could be components of social change and to address people's attitude towards individuals with TBI.

Patterns of 'perceived stigmatisation' were identified in relation to conflicting discourses of 'disability', 'invisibility' and 'social belonging'. 'Perceived stigmatisation' could also be linked the chaos narrative. Chaos stories reveal vulnerability, futility and powerlessness (Frank, 1995). Chaos narratives also describe fear of rejection by others (Frank, 1995). Stigmatisation is a social construction, and is influenced by the shared beliefs, values and norms within a specific culture, ethnicity and historical period (Abdullah & Brown, 2011). Crocker, Major and Steele (1998, p. 505) proposed that 'stigmatisation occurs when a person believes they possess some attribute or characteristic that devalues their social identity and marks them as different within a particular social context'. Nochi (1998) found that diagnostic labels, such as TBI, were associated with an image of abnormality, craziness or stupidity.

In the current study, the discourse of 'perceived stigmatisation' provided a position of social disconnection and disempowerment. Participants expressed that they did not always disclose their injury to others. The purpose of this may have been to avoid prejudice, discrimination and rejection. However, this behaviour appeared sometimes to lead to further social isolation. Perceived stigmatisation may have compromised participants' ability to (re)construct social identities. Crocker et al. (1998) proposed that stigmatisation increases experiences of threats and leads to uncertainty about social identity. Tajfel and Turner (1986) indicated that belonging to a devalued social group could impair the reconstruction of identity. Furthermore, Perlick et al.'s (2001) study of stigmatisation among patients with mental illness demonstrated high rates of avoidance of social interactions with non-family members and subsequent psychological isolation. Stigmatisation could be addressed through education and interaction between individuals with TBI and members of the public (Corrigan, Druss, & Perlick, 2014). From a therapeutic perspective, ACT has been shown to have a

moderate impact on self-stigmatising attitudes (Louma, Kohlenberg, Hayes, Bunting, & Rye, 2008). ACT will be discussed in more detail below.

4.1.3 Social connectedness and wellbeing

Stigmatisation and social disconnectedness could also be addressed through social support and social connectedness within rehabilitation. In the current study, several of the participants drew on discourses 'social disconnection' and 'social abandonment' to (re)construct their identity. The discourse of 'social disconnection' might offer positions of alienation and social isolation, which could enforce difficulties with integration in society. Several of the participants' narratives demonstrated social isolation, disconnectedness, lack of communication with others and not feeling understood: '...for years I didn't meet anybody else with a brain injury and it's like I felt so isolated and that nobody...nobody could understand' (Rachel, extract 5). There is a growing evidence that social connectedness is associated with wellbeing among individuals with chronic illnesses. Haslam, Jetten, Postmes, and Haslam's (2009) paper reviewed research examining the relationship between social identity, health and wellbeing within a number of different disciplines. The authors presented five core themes relating to social identity and wellbeing that can help to shape health-related policy and practice. These themes addressed the relationship between social identity and (a) symptom appraisals and response; (b) health-related norms and behaviour; (c) social support; (d) coping resources; and (e) clinical outcomes. The review evidenced the positive impact of social connectedness on health and wellbeing. For example, Jones et al. (2008) explored the relationship between social support and social identity among individuals who experienced TBI and acquired brain injury (ABI). Jones et al. revealed a paradoxically small but significant correlation between severity of TBI and life satisfaction. A follow-up analysis indicated that this relationship could be explained by the fact TBI tended to increase the strength of individuals' sense of social identity through the social support and social connectedness they experienced from significant others and social networks as part of their rehabilitation.

In the context of 'social identity and clinical outcomes', Haslam et al. (2009) found associations between life satisfaction and group membership. For example, one study among individuals who had had a stroke showed a relationship between membership of multiple groups and increased ability to maintain valued social identities (Haslam et

al., 2008). Haslam et al. (2009) related this to the 'rejection-identification' model (Branscombe, Schmitt, & Harvey, 1999), which argues that perceived stigmatisation may lead to increased in-group identification, so maintaining psychological wellbeing in the face of social devaluation. Haslam et al. (2009) emphasised that shared identity (i.e., when we define ourselves as having a group membership) can help individuals to address issues that affect them collectively, for example, by promoting awareness, disseminating information, and challenging stigmatisation. Haslam et al. (2009) argued that shared social identity can be the basis for all forms of productive social interaction between people, including motivation, cooperation and empowerment. Based on their review, Haslam et al. (2009) concluded that a key point in published research was that group life, and the social identities that underpin it, is central to individuals' psychological wellbeing and capacity to engage in wider society. One critique with Haslam et al.'s (2009) review is that although the authors promoted group work, they made no suggestions on how to apply this clinically.

Jetten, Haslam and Haslam (2012) conducted a social analysis of identity, health and wellbeing. Their analysis provided a theoretical framework based on a social identity approach to health and wellbeing across a range of contexts and conditions. The authors underlined the importance of social identity networks as a resource. They suggested that focusing on entire social identity networks as opposed to single identities could be relevant in determining people's response to stressors. To understand how people respond to challenges such as life transitions, identity loss, and trauma, it is important to explore how a person's salient identity (their potentially accessible identity) is affected, how rich a person's identity network is, and how different identities stand in relation to each other (e.g., whether their norms and values are compatible or incompatible). For example, individuals generally appear to be much better equipped to cope effectively with various challenges if they have more than one social identity to fall back on (Haslam, Jetten, Haslam, & Knight, 2012). Jones, Jetten, Haslam and Williams (2012) researched the advantages and disadvantages associated with disclosure and non-disclosure of ABI. Their findings indicated that individuals who expected to encounter discrimination as a result of having ABI were more reluctant to disclose their injuries. They also found that individuals who were more willing to disclose their injury to others reported higher levels of self-esteem and life-satisfaction. The authors emphasised the importance of psychological interventions that might help to rebuild social relationships and communication with others. In the

current study, several of the participants' accounts illustrated difficulties with alienation and disconnectedness. For some of the participants their relationships and closeness with significant others were compromised following TBI. This highlights the importance of community integration and the requirement to support both the individuals with TBI and their families, to enable social connectedness and rebuild social relationships. The participants' narratives also illustrated the positive influence of social connectedness on psychological wellbeing. For example, several participants reported increased social connectedness through their engagement with 'the head injury charity'. The charity both enabled shared social identity and social participation through different social activities.

4.1.4 Uncertainty and awareness

The current study identified that some participants drew on an 'uncertainty' discourse. This 'uncertainty' was often associated with severe memory impairment. Memory impairment limited participants' self-narrative and self-knowledge. Thus, without a clear recollection of autobiographical or daily events, participants struggled to (re)construct their identities confidently. Some participants' memory and cognitive impairments hindered their analytical capacity to recover. This was sometimes accompanied by feelings of loss and bereavement. These findings confirm Nochi's (1998) previous findings, which suggested that impaired retrieval of long-term memory interferes with autobiographical memories and self-narratives. Another study by Nochi (1997) found that participants carried a 'void' in their understanding of their past and current self. The current study also support the findings of Cloute et al. (2008), who identified a pattern of passive positioning in relation to 'medical model referencing', with impaired memory as a factor. Cloute et al. suggested that without clear recollection of events, participants could not 'own' their experience and this therefore created a position of disempowerment. The 'uncertainty' discourse was also linked to a chaos narrative. These narratives were sometimes told in the past tense and represented how the participants felt in particularly vulnerable and emotionally difficult periods in the early stages of their illness.

It has been suggested that individuals with TBI lack awareness of and insight into changes in their identity (Crisp, 1994). In the current study, eight participants were interviewed. I perceived that participants did have a sense of awareness of change,

loss and uncertainty in relation to their identity. Some participants were aware of their identity change and aware that their current identity felt different to their pre-injury identity, while some were uncertain how they had changed. This finding can be related to the findings of Tyerman and Humphrey (1984), which demonstrated that individuals with TBI have awareness of their identity change. I presumed that there are many different levels of awareness and that the participants had subjective experiences, including the capacity to talk about their (re)construction of identity, which integrate into constructions of identity (Prigatano, 2000). In the current study, awareness could provide an active and analytic position, which had ambiguous consequences. For some participants a discourse of 'awareness' provided confidence of the process of (re)constructing identity. For one participant the awareness of emotional change exacerbated feelings of loss.

4.1.5 Loss and bereavement work

The current study identified different discourses of 'loss', for example, 'loss of social identity' and 'loss of professional identity', 'social abandonment' and 'social disconnection'. This is consistent with previous TBI studies that have reported several types of loss, including loss of work, friends and partners, and social disconnection (Levack et al., 2010; Prigatano, 1992; Wood & Yurkakul, 1997). In the current study, loss of occupation and profession were associated with difficulties in (re)constructing a purposeful identity. This is in keeping with a qualitative study by Klinger (2005), which reported that occupational loss and adaption were critical for reframing self-identity post-TBI. Loss and social abandonment could be connected to the chaos narrative. One of the chaos narrative's distinguishing features is absence of narrative sequencing, and that the narrator seems frozen in an uncontrollable present, full of fear, powerlessness and hopelessness (Frank, 1995). However, most participants' narratives were coherent and not chaotic in structure. Participants' stories were also often reflected on and considered the past and the future. Therefore, the narratives about loss and social disconnection may appear better suited to an alternative 'loss', 'powerlessness' or 'despair' narrative.

Psychological therapy, including bereavement work (Worden, 2010), may help clients heal their loss of identity and build on ongoing identity change. Worden's 'tasks of mourning' model suggests that grief is work, which involves learning and adjusting to loss. Realistic goals of grief work include regaining an interest in and recreating a

purposeful life. Worden claimed that time itself does not heal loss and one does not recover from loss over a set time period. Worden's model comprises four phases of grief - not stages - as grief is not considered a linear process. Worden's 'tasks of mourning' are grief processes for someone mourning a deceased person. However, the phases may be translated for individuals who experience a loss of identity following TBI. The first phase is to actualise and accept the reality of the loss. Coming to an acceptance of loss involves an intellectual and emotional process. Many individuals need to review the events of loss before they can actually come to full awareness that it has happened (Worden, 2010). The second phase is to process the pain of grief. Not processing the pain results in 'not feeling' and people in mourning often cut off their feelings by avoiding painful thoughts (Worden, 2010). Denial of change is a common response amongst individuals with TBI who experience loss (Myles, 2004). Other feelings that individuals often experience through loss are anger, guilt, anxiety, helplessness, and loneliness (Worden, 2010). Anger can often be turned inwards and experienced as depression, anxiety, or low self-esteem. The third phase is to adjust to the world without the deceased (Worden, 2010). In relation to a loss of identity post-TBI, this could translate to coming to terms with loss of previous identity and function. The fourth phase involves progressing towards a meaningful and purposeful life without the 'old self'.

4.1.6 Identity reconstruction and information processing

Ylvisaker and Feeney (2000) reviewed intervention procedures developed to help individuals with TBI to reconstruct an organised, meaningful and reasonably realistic identity. These interventions are relevant to several participants in the current study who struggled to (re)construct a meaningful identity, integrate into society, and develop fulfilling activities and work roles. For example, some of the participants drew on the discourses 'disability' and 'loss of professional identity', and seemed to have strongly identified themselves with their pre-injury level of functioning and profession. These discourses seemed to create positionings of helplessness and psychological 'stuckness', which hindered the identification and development of values, goals and action to (re)construct a meaningful identity post-injury.

Ylvisaker and Feeney (2000) describe the interacting cognitive subsystem approach to information processing (ICS, Teasdale & Barnard, 1993) and the self-as-metaphor hypothesis (Lakoff & Johnson, 1980), as these theories provide a conceptual

framework to interventions facilitating reconstruction of identity. ICS includes nine cognitive sub-systems, each specialised in handling a specific type of information (Teasdale & Barnard, 1993). Ylvisaker and Feeney (2000) emphasised the ICS's distinction between the two sub-systems - 'propositional meaning' and 'implicational meaning'. The former is expressed by potentially true or false statements and stores objective biographical information about identity. 'Implicational meaning' is conveyed by metaphor, symbol or narrative, and stores knowledge of sense of self, including self-evaluations, emotional associations and related action strategies. Implicational meaning has multiple connections to other sub-systems, including 'sensory meaning'. For example, a particular tone of voice from a significant other may trigger a belief about 'self as a victim' (Teasdale & Barnard, 1993). Teasdale and Barnard (1993) suggested that a vicious cycle of depression could occur when depressogenic mental models (e.g., a sense-of-self as unworthy or a failure) are stored as implicational meaning, and maintained by propositional-level negative facts (e.g., 'I did yet another task poorly'). Psychotherapy within an ICS framework explores situations that elicit maladaptive emotions, and helps to identify alternative schematic models that do not produce dysfunctional emotional reactions (Teasdale, 1997).

The self-as-metaphor hypothesis (Lakoff & Johnson, 1980) suggests that construction of self, including the social self, is metaphorical. For example, 'he is pushing himself too hard', 'I'm feeling very scattered today', or 'you need to nurture yourself'. Lakoff and Johnson (1980) suggested that the metaphorical self is developed early in life and that parents help their children construct a positive sense-of-self ('you are such as big, good boy just like daddy') or a negative sense-of-self ('you're such as loser') through metaphor. A critical component of rehabilitation for individuals with TBI is the process of facilitating the construction of an alternative metaphoric identity and schematic model of self, which are associated with positive emotional states and socially functional action strategies (Ylvisaker & Feeney, 2000).

Ylvisaker and Feeney (2000) reviewed the ICS and the self-as-metaphor theories, and applied these to the rehabilitation of young adults with TBI who had behavioural difficulties and difficulties with community reintegration. Three case studies were presented. Psychotherapy within an ICS framework was used as intervention for clients and therapists to construct alternative identities collaboratively. The therapist's role was to facilitate the identification of a compelling metaphor that might help to organise reflective thinking about long-term goals, and strategies that might achieve

these goals. The authors revealed mixed results from the intervention. One case showed positive and enduring effects, the second was positive but may have required further intervention, and the third case showed no lasting effects. However, one limitation of this study was that the interventions were not specified. For example, details such as the duration of the intervention and the number of sessions were not included. Additionally, outcome measures used to evaluate positive or negative outcomes were not provided. It is therefore difficult to evaluate the effectiveness of this intervention. However, outcome measurements might not always be an appropriate, reliable or valid method to understand complex discourses around identity change. Levack et al. (2010) suggested that further research and in-depth analysis of identity was needed to develop outcome measures to evaluate experiences of loss of identity and satisfaction with reconstruction of identity. Ylvisaker and Feeney (2000) highlighted that the interventions might not be appropriate for individuals who are extremely concrete in their thinking style and therefore would have difficulties to construct an alternative metaphoric identity. In the current study, participants sometimes used 'negative' value-laden metaphors, in association with their identities post-injury, including: 'I'm a lot slower', 'not working properly', 'it doesn't click in my brain for so long', 'go back to work to the frontline to the deep-end' and 'I'm never going to be right'. A therapist working within the framework of the self-as-metaphor could work with the client in facilitating more compelling metaphors and use these to develop values and goals. This could be a relevant psychological intervention for individuals who struggle to (re)construct a meaningful identity and work role post-injury. It is important to highlight that different metaphors may have idiosyncratic meaning for individuals and is not always related to positive or negative emotional values. Therefore, it is important that the therapist facilitate the identification of an alternative metaphoric identity tailored to the client's meaning-making and social context.

4.1.7 Rebirth and gaining 'something' through illness

An interesting aspect of the current study is participants' use of 'rebirth' and 'ongoing development' discourses. Some participants experienced an immediate 'shift' and 'rebirth' of a 'new' identity after their injury. One participant used the metaphor 'flip a switch' to explain the immediate change of identity following injury. For some participants a 'rebirth' discourse might have been a strategy to manage the difficulties resulting from memory loss. Some participants took a position of accepting loss of self-

knowledge. This may have enabled these participants to take agency over their identity and so re-establish their social relationships.

Several participants drew on a slower 'ongoing developmental' discourse in (re)constructing a 'new' identity. Their narratives described the more gradual development of a post-TBI identity that would not have been feasible pre-injury. The (re)construction of identity did not necessarily mean a 'better' or 'worse' self, but a 'different' version of self. An individual who experiences a life-changing trauma that disrupts their identity must adapt to a new view of themselves (Charmaz, 2002). This often is a gradual and long-term process when chronic illness disrupts the self-concept that a person has previously taken for granted (Charmaz, 2002). This self-concept includes habits of thinking and behaving that are defining characteristics of an individual, distinguishing them from others. The changes in identity necessitated by TBI may be challenging to accept. Charmaz (2002) stated that chronically ill individuals sometimes avoid viewing themselves as chronically ill and resist reconstructing an altered self around illness until they exhaust other explanations and gain knowledge of how their daily life has changed.

An interesting contribution of the current findings was that several participants described their experience of TBI as positive in terms of personal growth represented by their 'new' identity. 'Rebirth' and 'ongoing development' discourses sometimes provided the ability and freedom to (re)construct a 'new' identity that participants reported being 'happier' about than their 'old' identity. These discourses connected with participants' use of quest narratives. A quest narrative could include an illness (TBI) as part of a person's journey with new meaning as its destination (Frank, 1995). For example, one participant used a discourse of 'positive personal growth' when describing his 'zest' for life, feeling stronger post-injury, and subsequently developing a different attitude to life. These findings indicate that positive personal growth was associated with this participant's understanding and acceptance of the new reality. Similarly, Nochi (2000) proposed a categorical narrative of 'the grown self' in which the experience of TBI had contributed some positive characteristics to participants' selves.

The 'positive' narratives from some participants concerning the change of identity could be used to justify the transition towards becoming a 'new' person. It is important to consider that factors such as declaiming an undesirable social identity, justifying an

action or attributing blame may be part of participants' responses. It might be difficult to admit to oneself and to others that it can be very challenging to become 'someone else'. Any change in identity may also be difficult for family or friends to understand, as they may feel they have lost the person they once knew. The position of distance could create interpersonal conflicts, communication difficulties, and feelings of disconnection. Landua and Hissett (2008) defined loss of a family member with TBI as being physically present but psychologically absent.

In the current study, one participant did not identify herself as disabled and used a 'different' discourse to (re)construct her identity, which enabled her to take an alternative and empowered position towards her physical impairments and body. A 'different' discourse suggests that 'health', 'illness' and 'identity' can be constructed through language (Foucault, 1977). Thus, this participant chose to use the word 'different' to describe herself, which implies an act of freedom in (re)constructing an identity.

4.1.8 Independency and acceptance

An important finding in the current study was that 'dependent' and 'independent' discourses were fluid. The discourse of 'dependence' changed over time, and according to situation and interpersonal dynamics. Some participants re-positioned themselves towards a more independent state over time. Some participants experienced cognitive and physical recovery, which allowed them to lead more independent lives. The 'responsibility' discourse might have been associated with independence. For example, the responsibility of working as a volunteer or taking care of a dog could facilitate a shift of positioning to a more empowered and independent construction. This corresponds with a fluid and multi-dimensional identity, and implies that people undergo many changes throughout their lifetime (e.g., Sabat & Harré, 1999). This is in line with Frank's illness narratives (1995), which considers narratives as fluid, continually developing and overlapping.

Another finding in the current study was that an 'acceptance' discourse appeared to enable positions of empowerment and independence. Importantly, the concept of 'acceptance' had an idiosyncratic meaning for individuals and was not inevitably associated with positive or negative values. The 'acceptance' discourse was often

constructed over a period of years and allowed participants to assimilate a shifting state of being. The 'acceptance' discourse seemed sometimes connected with a quest narrative, in which the meaning-making was not about 'gaining' something from TBI, but about 'adapting' to resulting changes. Acceptance of a 'new' post-TBI identity does not imply 'better' or 'worse' than the 'old' identity, but it does imply acceptance of the fluidity of change. This offers an opportunity for ongoing cognitive and emotional development, and psychological flexibility for rehabilitation. Ben-Yishay and Prigatano's (1990) considered acceptance an important part of recovery and rehabilitation for people with TBI.

4.2 Relevance for counselling psychology and clinical implications in enabling patients with TBI

This study provides a further understanding of the discourses individuals with TBI use and of the relationships between dominant discourses, available positions and illness narratives. It provides further knowledge about the needs of clients with TBI, so as to assist counselling psychologists with assessment and interventions. A discourse analysis can highlight the dominant discourses used and challenge their status as 'truth' (Burman & Parker, 1993). For example, the understanding that a 'dependent' discourse may change into a more 'independent' discourse, and that this is often accompanied with acceptance, highlights the importance for a psychologist to work towards acceptance with clients who experience psychological inflexibility. This study highlights the importance of working with re-positioning of a subject to an alternative perspective. For example, a 'disability' discourse created a disempowered position. A therapeutic goal would then be to facilitate access to more empowering subject positions.

The findings may also potentially inform counselling psychologists working within other populations, including clients with other neurological disorders such as dementia (Cohen-Mansfield et al., 2006), with chronic illnesses (Baumgarten, 2007), or with mental health issues where clients have similarly reported the experience of loss of sense-of-self (Wisdom, Bruce, Saedi, Weis, & Green, 2008). It also may inform psychologists working with a range of physical and psychological issues about how dominant discourses (e.g., the 'disabled' discourse, the 'mental illness' discourse, or

the 'addiction' discourse) can limit individuals' psychological flexibility and recovery. Below, I will discuss how the findings from this study can be applied to clinical practice.

4.2.1 Rehabilitation

Long-term recovery of TBI is influenced by variables including severity, age at injury, time since injury and pre-morbid psychological or physical factors (Redpath et al., 2010). Neuropsychological rehabilitation is recognised as a 'complex health care intervention', which involves multidisciplinary health care professionals (Gracey & Wilson, 2014). These interventions include techniques to improve motor symptoms, memory, language, cognition and compensatory techniques (Gracey & Wilson, 2014).

There is growing evidence that community-based outpatient holistic rehabilitation has demonstrated improvement in perceived quality of life, cognition and self-sufficiency (Cicerone et al., 2004). Yates (2003) argued that community-based rehabilitation programmes based around a biopsychosocial model may improve psychosocial functioning and social role outcomes for survivors of TBI. The World Health Organisation's, International Classification of Functioning, Disability and Health (WHO ICF, 2001) is based on the biopsychosocial model of disability, and considers both health factors and contextual factors. The ICF provides a more flexible framework than the two major conceptual models of disability, the medical model and the social model. As discussed in the introduction, the medical model views disability as a physical phenomenon resulting in functioning that is seen as limited and deficient (Fitzgerald, 2006; Mitra, 2006; Palmer & Harly, 2012). The social model argues that society imposes disability on individuals with impairments (Bingham, 2013; Mitra, 2006; Sherry, 2006).

The way in which disability is defined is important because the language people use to describe disabilities influences the identities, interactions, expectations and positionings of those with disability within society (Barton, 2009). In this context, it is important to consider that ICF has become an important conceptual framework in rehabilitation services, and has provided a global and collective language for health and disability. The core components include: 'body functions and structures', 'environmental factors and personal factors', 'activities and participation'. The concept of participation has become a source for better understanding the possible impact of impairments that a disabled person may experience (Fisher & Howell, 2016). The ICF

(WHO, 2001) defines participation as 'involvement in a life situation' or 'the lived experience of people in the actual context in which they live'. Social participation can be described as a way to contribute to a broader society by working with empowering communities (WHO, 2001). Rehabilitation concepts, such as social participation, serve as a basis for a deeper understanding of clients' lives, assist in problem solving and form a basis for measuring quality of life. However, there is still no agreement on what 'quality of life' is, and how it should be measured. Wade and Halligan (2003) argue that the ICF framework needs to include quality of life assessments. Wade and Halligan's (2003) definition of quality of life includes the person's own evaluation of their capacities at all levels, taking into account contextual matters, and based on their expectations and values.

A holistic model of neuropsychological rehabilitation emphasises the importance of psychotherapy as part of the treatment package (Coetzer, 2008). Different psychological approaches have been used to care for clients with TBI, including psychodynamic psychotherapy (Prigatano, 1999), relational approaches (Bowen, Yeates & Palmer, 2010), and cognitive behavioural therapy (CBT) (Anson & Ponsford, 2006; Bradbury et al., 2008). CBT has been studied more than other approaches. The highly structured content of a CBT approach has been shown to be useful in treating emotional distress post-TBI (Bradbury et al., 2008). However, some research has found that CBT may have limited therapeutic effectiveness in individuals with certain neuropsychological impairments (King, 2002; Lincoln & Flannaghan, 2003). The potential limitations of CBT include its emphasis on treating symptoms, and its focus on thought challenging, which may be an unhelpful process among individuals with chronic disabilities and cognitive impairments (Sherer et al., 1998).

I will discuss two psychological therapeutic approaches that could be considered part of a holistic and integrated neuropsychological rehabilitation programme. They are 'the process of empowerment' (Burr, 1995; Fenton & Hughes, 1989; O'Hara & Harrell, 1991) and acceptance and commitment therapy (ACT, Hayes, Strosahl & Wilson, 2003; Hayes & Wilson, 1999).

4.2.2 The process of empowerment

The reason for highlighting ‘the process of empowerment’ as important for TBI rehabilitation is derived from the findings of the current study and existing TBI research (e.g., Cloute et al., 2008). The findings in the current study suggested participants drew on a ‘disability’ discourse and a ‘medical’ discourse, which may have provided a position of dependence and disempowerment. This appeared to hinder participants in creating an identity that included positive self-worth, and in having the confidence to produce a meaningful life. A restitution narrative could also be considered disempowering, as the narrator desires to return to a former healthy body, which might not be possible for someone with a chronic illness. The ‘process of empowerment’ is not a formulated psychological therapeutic approach per se. However, a clinical application for services and organisations working with TBI might be to incorporate empowerment as part of neuropsychological rehabilitation (O’Hara & Harrell, 1991).

Yates (2003) highlighted the importance of integrating the concept of ‘empowerment’ into interventions and into rehabilitation programmes, particularly the elements of ‘personal power’ (the power of the individual to influence their environment) and ‘power with’ (social power where people come together as equals) (Neath & Shriner, 1998). Empowerment originated from political awareness movements in the late 1960s and 1970s (Ryles, 1999), and is a key concept in disciplines such as community psychology, multicultural and feminist research, and social work (e.g. Freire, 2000; Gutiérrez, 1990; Solomon, 1987). WHO (1998, p.6) defines empowerment as ‘a social, cultural, psychological process through which individuals and social groups are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and achieve political, social and cultural action to meet those needs’. Segal, Silverman and Temkin (1993) define empowerment as a process in which individuals gain control over their lives and influence the organisational and societal structure in which they live. Cattaneo and Chapman (2010) propose a model of the process of empowerment that could be applied across different contexts and population groups. The model’s main components include personally meaningful goals, self-efficacy, knowledge, competence, action towards pursuing a goal, and impact (a review of what happened as a result of the person’s action).

O’Hara and Harrell (1991) developed ‘the empowerment rehabilitation model’, which is a holistic, integrated approach to enhance enablement and empowerment processes

for people with TBI. The model serves as a guide to treatment, and includes several components: enhancing motivation, the enabling of patients with information and skills, empowering patients with self-awareness, acceptance, and self-respect. It works towards acceptance of a redefined personal identity, a redefined sense of meaning in life, and a newly defined future. O'Hara and Harrell (1991) emphasised that a crucial part of the empowerment process is that the client needs to be involved in treatment decisions. Another aspect is to provide the client with information concerning their injury and to facilitate skills development including physical task mastery, independent living skills, vocational skills, academic skills, problem solving, interpersonal skills, goal setting, and skills in stress management. Similarly, Zimmerman (1995) views the identification of skills deficits, learning new skills and gaining knowledge as key elements of the psychological empowerment process within rehabilitation programs for individuals with disability. A study by Sit, Yip, Ko, Gun and Lee (2007) on community-based stroke prevention demonstrated that educational interventions by health professionals helped clients to integrate their learned knowledge into their real-life experiences. The opportunity to integrate learned knowledge in daily life empowered clients to develop self-care and responsibility.

One important goal of O'Hara and Harrell (1991)'s empowerment model is to replace a 'victim' discourse with the construction of a 'survivor' discourse, to progress the client from a helpless, powerless position to a more empowered one. This process is intended to help the participant resume a sense of internal control and responsibility for decision-making. This may be helpful in promoting change towards a more powerful position for some clients with TBI. However, the findings in the current study suggested that a 'survivor' discourse presented ambiguous positionings. For one participant, a 'survivor' discourse created a position in which he should feel happy and a sense that survival 'should' be experienced in a positive and grateful way. This position restricted the participant in how he should feel and behave. In contrast, for another participant who also drew on a 'survivor' discourse, it created a position that allowed for resilience, empowerment and agency. It is therefore important for the therapist to try to understand the underlying causes of what a 'survivor' discourse means for a client and if they are psychologically ready to shift position. There may also be alternative discourses that could facilitate the progress of psychological change for some clients better, such as the 'acceptance' discourse. A 'survivor' discourse may refer to that survivors (of TBI) 'should' feel happy to have survived a potentially fatal injury, but in

fact are not so as a consequence of the TBI. An 'acceptance' discourse refers to an individual accepting their disabilities as part of their process of adjustment. Acceptance may have idiosyncratic meaning for individuals and is not inevitably associated with positive or negative values.

Findings from the current study showed that some participants with memory impairment (re)constructed their identity through a discourse of 'uncertainty', which sometimes allowed for positions of dependence and disempowerment. O'Hara and Harrell (1991) proposed that information about change, talking about one's history, brain injury, and pre-injury goals, may help to re-establish identity. Part of therapy could be assessing the client's need to gain self-knowledge. Subsequently, the therapist could facilitate this by gathering information about pre-injury personality, life history, prior health problems (such as substance misuse or low self-esteem), family and relationship role(s). The authors proposed that pre-existing issues could complicate recovery if left unaddressed or unacknowledged. For some clients with severe memory impairment, this process may help them 'fill in the memory gaps' and facilitate the reconstruction of identity (Nochi, 1997). Additionally, for some clients with clear memory and attachment to pre-injury identity, the re-definition of self may provoke a profound grief response, which then needs to be addressed, for example with Worden's (2010) 'tasks of mourning', as discussed above.

There are some concerns with the process of empowerment, for instance, if an 'empowerment' discourse becomes a dominant construction it may lead to negative implications. In a discursive study of smoking addiction, Gillies and Willig (1997, p. 298) stated that 'replacing a discourse of addiction with a construction of self-determination is not necessarily a positive step, in that it can foster guilt and self-blaming and thereby actively impede health promotion objectives'. Similarly, replacing a 'disempowerment' discourse with a construction of 'empowerment' or 'self-efficacy' may cause individuals with TBI to feel personally blamed or responsible for their difficulties. Thus, I suggest an 'empowerment' discourse may have a negative effect if individuals do not have a positive subjective experience of becoming empowered, and this may evoke feelings of failure and may hinder recovery. An empowering therapeutic approach can therefore risk producing another level of power relationship between the client and health professional. This may discourage clients from expressing thoughts

around all elements of their disability, including experiences such as frailty, pain and illness (Morris, 1991).

A brief critique of the risks of empowerment demonstrates how health professionals need to develop their awareness of how dominant discourses can have implications within a therapeutic relationship (Burr, 1995). This can be established by being aware of the impact of language and constantly analysing the impact of our discourses.

Dominant discourses privilege those versions of social reality that legitimate existing power relations and social structures. Some discourses are so entrenched that it is very difficult to see how to challenge them. They have become 'common sense'. At the same time, it is in its nature of language that alternative structures are always possible and that counter-discourses can, and do, emerge eventually (Willig, 2013, p. 130)

Other authors have also highlighted the importance of language within the process of empowerment. For example, Fenton and Hughes (1989) suggested that a change of power constructions could evolve by creating an empowering system within a practice or organisation, and by encouraging self-empowerment through language. Self-empowerment is a process of becoming increasingly more in control of oneself and one's life, and consequently increasingly independent. Fenton and Hughes argued that this could be achieved by actively working on attitudes and beliefs with reflection and sensitivity. If a system encourages an individual to develop their input into that system, it encourages individual growth.

4.2.3 Acceptance and commitment therapy, ACT

One important finding in the current study was that participants who drew on an 'acceptance' discourse reconciled their disabilities with their 'new' identity, and that this seemed to enable positions of empowerment and independence. However, it seemed that the 'acceptance' discourse was not available to all participants, and positions of helplessness sometimes constrained psychological flexibility. Frank (1995) described the quest story as being that of finding a voice: the narrator has been on a journey and has not been 'cured' but changed. For some participants in the current study, the quest narrative was not about 'gaining' something from TBI, but about adapting to resulting

changes. A quest narrative represents a journey of accepting, reflecting on and understanding change, resulting in a transformation of one's self (Frank, 1995). This narrative journey of accepting can be vital in the process of (re)constructing a meaningful life post-TBI. It has also been suggested that acceptance is key for clinical, rehabilitation and recovery work. For example, Ben-Yishay and Prigatano (1990) suggested that TBI patients must work through stages of engagement, awareness, mastery, control, acceptance, and identity, as part of rehabilitation. Thus, specific psychological therapeutic approaches aimed at facilitating acceptance and psychological flexibility could be considered part of a holistic neuropsychological rehabilitation programme.

The principles of ACT have been applied to a diverse range of populations including individuals with chronic illnesses (Kangas & McDonald, 2011; Pull, 2008). For example, Risdon, Eccleston, Crombez, and McCracken (2003) reported that important factors in accepting chronic pain were patients' acknowledgement that a cure for pain might be unlikely, shifting focus away from pain to non-pain aspects of life, and overcoming resistance to the idea that acceptance is a sign of weakness.

ACT (Hayes et al., 2003; Hayes & Wilson, 1999) is one of the 'third wave' behavioural therapies. It is derived from behavioural theory (Skinner, 1945) and Eastern meditative practices (Williams, Teasdale, Segal, & Kabat-Zinn, 2007). Functional contextualism (Hayes & Wilson, 1999) is the underlying philosophy of ACT, and this shares common philosophical roots with social constructionism (e.g., Burr, 2003). ACT views psychological events as on-going actions, which interact with historical and situational contexts. Harris (2009) defined functional contextualism's perspective as:

...no thought, feeling or memory is inherently problematic, dysfunctional, or pathological. In a context, which includes cognitive fusion and experiential avoidance, our thoughts, and feelings and memories often function in a manner that is toxic, harmful, or life distorting. However, in a context, of defusion and acceptance, those very same thoughts, feelings and memories function very differently: they have much less impact and influence over us. They may still be painful, but they are no longer toxic, harmful or life distorting and more importantly they do not hold us back from valued living (p. 34).

ACT aims to improve functionality within psychological events (thoughts, beliefs, perceptions), rather than only to reduce symptoms. As the premise of ACT-based interventions is facilitating functional change, the approach may have particularly utility for helping distressed TBI individuals to re-engage in living a meaningful life despite their neurological and physical disabilities (Kangas & McDonald, 2011). Psychological flexibility and functional change are established through six key core processes: acceptance, cognitive defusion, being present, self as context, values, and committed action (Hayes, Louma, Bond, Masuda & Lillis, 2006). Acceptance is the first process, and is defined as learning to accept both positive and negative thoughts and feelings, particularly relating to events and circumstances one has no control over or cannot change (Hayes, et al., 2006).

Recent studies support the role of ACT and other mindfulness-based approaches for improving quality of life and emotional functioning in individuals with ABI and TBI (Bédard et al., 2003; Kangas & McDonald, 2011; Soo, Tate, & Lane-Brown, 2011). Kangas and McDonald (2011) reviewed the literature on ACT as a treatment for a range of psychological problems related to TBI and other chronic illnesses. These authors suggested that ACT may assist individuals with TBI in moving forward with their lives by accepting their cognitive and physical changes. The authors emphasised the significance of acceptance, arguing that it improved functionality and meaningfulness, regardless of the level of disability. No published study to date has tested the efficacy of an ACT intervention that incorporates all six key processes in a TBI population. Kangas and McDonald (2011) recommend that some of the ACT core processes may not necessarily be suitable for all clients with TBI, as clients require a level of awareness and flexibility to engage in this type of behavioural therapy.

A study using three of the core processes in ACT with clients following TBI found evidence of improved quality of life and reduced depressive symptoms (Bédard et al., 2003). In Bédard et al.'s study, 10 participants with mild to moderate TBI received a 12-week programme including acceptance, contact with the present moment, and self-as-context. Therapeutic techniques included insight meditation, breathing exercises, guided visualisation, and group discussions. Facilitators also encouraged participants to use self-exploration as a tool to identify the transformative resources present in themselves, empowering participants to exert control over their situation. Three types of outcome measure were collected: quality of life, psychological processes, and function. Depressive symptoms were measured with the Beck Depression Inventory

(BDI-II, Beck, Steer & Brown, 1996). The study revealed reduced depressive symptoms following the intervention. It also indicated improved quality of life on the Short Form Health Survey (SF-36, Ware & Kosinski, 2001). Participants' functioning, as assessed via the Community Integration Questionnaire (CIQ, Sander, Fuchs, High, Kreutzer & Rosenthal, 1999), showed no sign of improvement. There were some limitations with this study, including the small sample size and consequent under-powering. One other limitation was that the majority of men and younger participants did not enrol or dropped out of the programme. Further research should involve engaging male participants and younger participants, as well as longer-term follow-up, as the duration of the effect was not measured.

Soo et al. (2011) carried a systemic review of ACT for managing anxiety in population with ABI. The inclusion criteria for studies included in the review were: studies using the ACT intervention; that the target was an anxiety disorder or anxious symptomology; and that the intervention used randomised control trials (RCTs) or single case experimental designs (SCEDs). The review found no published studies of ACT for management of anxiety following ABI. However, there was evidence that through an ACT intervention, acceptance of disability was associated with improved quality of life and community integration post TBI (e.g., Snead & Davis, 2002). Based on this review, Soo et al. suggested that acceptance-based approaches to managing anxiety might also be applicable to an ABI population. The authors suggested that the behaviourally based components of ACT, such as values and committed action, would help to identify and attain goals for a meaningful life. One limitation of this review was that the heterogeneity of the studies identified meant that it was therefore not possible to conduct a meta-analysis.

ACT has been criticised as offering relatively minor differences from traditional CBT (Beck, 1976) and as Eastern meditative approaches are considered a theoretical practice in their own right (Hofmann & Asmundson, 2008). It has also been criticised for the lack of research to validate its effectiveness (Öst, 2008). However, studies in this area may be less prolific as outcomes are focused on acceptance rather than reducing symptoms, which may be more difficult to measure.

4.3 Methodological implications

4.3.1 Evaluation, strengths and limitations

An evaluation of this study requires a critical appraisal of the extent to which I have been able satisfactorily to analyse and to interpret my findings using a multiple qualitative approach. In this study, the main approach was to use FDA (Willig, 2013) to explore how people with TBI (re)construct identity in their society and culture. The study explored how available discourses facilitated, limited, enabled and constrained what participants could do or say (Willig, 2013). The focus on subject positionings (Davies & Harré, 1990; Harré & van Langhove, 1999) enriched the findings by adding another level to the analysis. Positioning theory considers the power dynamics that shape interaction and positioning processes. Additionally, Frank's (1995) illness narratives were applied to conceptualise and organise the identified discourses and positions identified in the FDA. The narratives were used to explore the data further, in particular, to investigate identity in TBI and the narratives' role in helping to (re)construct identity.

I believe that the multiple qualitative approach provided more depth and richness to the findings than a single discursive analysis would have accomplished. As a multiple qualitative approach offers a more holistic view of people's experience and provides insights that cannot be gained by using one method alone (Chamberlain, Cain, Sheridan, & Dupuis, 2011; Frost, 2011). I believe that the FDA and the narrative reading helped to inform each other. The FDA was focused on the language used while the narrative reading offered a greater freedom of interpretation. The FDA provided a framework for understanding participants' available discourses while the narrative reading was particularly sensitive with respect to interpreting subjective meaning-making and social processes (Murray, 2003). In other words, the narrative reading made it possible to explore participants' stories and how they made sense of their experience. The different methodological approaches revealed several commonalities. For example, participants' narratives changed and intertwined and this was in line with discourses that were fluid and changeable over time and dependent on social context. The different narrative types, restitution, chaos and quest, were connected to the discourses identified in the FDA. However, I did not want coerce the discourses into the different narratives types but rather tried and disentangle narrative

threads. This required a high level of reflection. The use of multiple qualitative approaches requires the researcher to reflect on the relationship, commonalities and incongruities with one another (Frost, 2011). For example, the use of multiple interpretative 'lenses' to view and analyse data changes the researcher's perspective, which in turn informs the researcher when making meaning of the data from a different 'lens' (Willig, 2012).

The aim of this study was to explore the data using different qualitative methods: FDA (Willig, 2013), positioning theory (Davies & Harré, 1990) and Frank's (1995) illness narratives. On reflection, I think the positioning theory (Davies & Harré, 1990) was applied separately as a theoretical framework in the methodology but was merged into the FDA in the analysis and the discussion. I think the reason for this process was that 'positioning theory' informed and helped to conceptualise 'positioning'; the analytic stage four of Willig's (2013) six-stage adaption of FDA. In addition, I also found that the 'positioning' stage, within the FDA, informed and clarified the concepts of 'positioning theory'. For example, in the current study, positioning theory (Davies & Harré, 1990) was applied as the theoretical framework in association with how individuals with TBI (re)construct identity. Positioning theory proposes that people's identities are formed through their positioning within a discourse (Davies & Harré, 1990). Once having taken up a particular position as one's own, a person inevitably sees the world from the vantage point of that position (Davies & Harré, 1990). In the current study, FDA (Willig, 2013) was used to explore what kind of discourses individuals with TBI used to (re)construct their identity. I was interested in and identified the participants' available discourses and positionings. In the stage 'positioning', I focused on what subject positionings the available discourses offered. For example, some participants used a 'medical' discourse to (re)construct identity, which might have offered a subject positioning of disempowerment. In this context the positioning of disempowerment becomes the individual's viewpoint of the world and is also part of forming their identity, which is part of positioning theory's (Davies & Harré, 1990) concept of identity. I hope this illustrates how 'positioning theory' and the 'positioning' stage intertwined and informed each other in this study. I am aware that the 'positioning theory' merged into the FDA in the analysis and the discussion, however the 'positioning theory' underpinned and strengthened the theoretical framework of the 'positioning' stage in the FDA.

I needed to reflect on how the multi-faceted layers of understanding could be used for clinical application. I think it is important that theory and research integrate with clinical practice in order to instigate debate, potentially leading to the subsequent developments in patient care. A multiple qualitative method can be applied on pragmatic level. For example, a multi methods analysis could facilitate counselling psychologists to understand a client's subjective experience from different perspectives (Hollanders, 1999). This may assist tailoring the therapeutic work to the unique needs of each client (Cooper & McLeod, 2011; Palmer & Woolfe, 2000).

There are limitations in using a multiple qualitative approach, for example, how to do justice to the depth and breadth of the data. I therefore needed to reflect on my own knowledge and on the analytical approaches I used – discourse and narrative. I also adopted a reflexive position to acknowledge my own interests in relation to the topic and how this could lead to potential biased interpretations. I wish to highlight some concern I experienced with one stage of FDA. The process of identifying, naming the discourses and categorising them into groups risked creating unnecessary labelling (Wooffitt, 2005). The names and the categorisation were also subjected to my available discourses. However, categorisation is necessary to conduct a comprehensive report of the findings. Wetherell (1998) argued that there is always plurality in subject positions available to individuals through a discourse. Therefore, it is important to be aware that the researcher's identified discourses are possible constructions amongst many available interpretations.

The considerations of using a language-based methodology for individuals with cognitive and language impairments are recognised (Lloyd et al., 2006). One implication is that language impairment might have compromised some of the participants' narratives. For example, they might not have been able to source the words they felt corresponded to their thoughts. Consequently, using a language-based research methodology with people for whom language itself is impaired risks that participants might not be able to express their thoughts and feelings. If a person struggles to express themselves through language it might also create an unequal power positioning between the participant and the researcher. This could lead the participant to feel misunderstood and socially disconnected. This might also influence the perceptions and interpretations of the researcher. In this study, I therefore considered and adjusted my interview and communication style to facilitate these

issues. I endeavoured to create a non-judgmental and safe interview environment. I needed to take a cautious position when analysing the words and language of the text. I wanted to highlight the importance of including people with speech impairment in qualitative research who might have problems making their voices heard in everyday life. Consequently, it was a strength of this study that participants were individuals with TBI and that they were able to voice their subjective experiences. I agree with Morris (1992), who suggested that the process of empowerment should begin by providing individuals the right to express their own perspectives. To enable empowerment and decrease stigmatisation of disabilities, it is important to continue conducting research with and by disabled individuals.

A strength of this research is that it meets Yardley's (2000) criteria for validity in qualitative research, and Elliott, Fischer, and Rennie's (1999) guidelines for qualitative and quantitative research, which are both outlined in the methodology chapter. For example, one of Yardley's criteria is that the researcher needs to be mindful of their relationship with the participant, and how expectations of the research questions might affect interpretations. My literature review of FDA studies and methodology (e.g., Willig, 2013) highlighted the risk that a 'research discourse' in an interview situation could offer myself as a trainee counselling psychologist a subject position of an 'expert' and the participant a subject position of a 'client'. I needed to be mindful and reflective of my use of language and non-verbal communication to constrain this process. My aim was also to build good rapport with the participants to stimulate a 'natural' dialogue rather than a formal interview.

A limitation of this study was the small number of participants that compromises its generalisability (Howitt & Cramer, 2005). The eight participants were all members at the same head injury charity and therefore comprised a fairly homogenous group. They were all White British and so represented a limited racial and cultural background. It is therefore doubtful whether this study sufficiently represented the differences and commonalities of discourses and narratives for the broader population with TBI. On the other hand, there was a high level of heterogeneity within the sample (Howell, 2007) across injury-related variables, including aetiology, severity, age at injury and time post-injury. For example, one of the participants was in paid employment and five were volunteers at the head charity at the time of the interviews. Their duties as volunteers included a range of different tasks such as preparing lunch and washing up in the

kitchen, facilitating and helping out in the art room or supporting other members visiting the charity. The fact that some participants were volunteers might have increased the level of heterogeneity within the sample. However, this qualitative research sampling did not aim to produce a statistically representative sample, but aimed to reflect the diversity and patterns of participants' constructions and narratives (Howell, 2007).

Another limitation was not having access to participants' medical files to obtain information from Glasgow Coma or Outcome scales that would have enabled an accurate determination of participants' injuries. Participants self-reported their length of coma without further validation from medical records. However, one could consider that access to participants' medical files could produce a power situation in which the participants might feel exposed and vulnerable. Details of rehabilitation and psychological treatments were also self-reported and may not have been accurate. Some participants disclosed experiences of psychological care and rehabilitation, but because of injury-related memory impairment, details of therapy could not always be recalled. Secondly, participants may not have wished to disclose these details. It would have been valuable to explore whether the length and/or type of rehabilitation influenced different kinds of discourses, and this could be an area for future research. However, as discussed earlier, TBI is associated with complex and wide-ranging symptoms, so differences might be difficult to distinguish. Another limitation of this research was that psychological disorders such as depressive disorders, anxiety disorders or post-traumatic stress disorder (PTSD) were not accounted or screened for. Participants self-reported information about experienced psychological problems. The fact that I am a trainee psychologist may have affected their answers, either by a desire to disclose or to feel understood, or not to disclose because of a fear of self-disclosure. Moreover, participants' discourses and subject positionings might also have been influenced by potential psychological disorders such as PTSD.

4.3.2 Proposals for future research

Further research is needed with individuals who have severe injuries and symptoms, (e.g., speech impairments) in order to gain deeper understanding of individuals who usually do not have a voice in a wider societal context. Other methodologies might be appropriate, such as a visual methodology, which use materials such as photographs, films and drawings to explore the world of participants (Willig, 2013).

I also suggest conducting long-term studies to investigate the fluidity of identity (re)construction and re-shifting of positionings of individuals with TBI. For example, a qualitative research design could involve completing interviews with the same participant group over a longer period of time, for example, over 10 to 20 years, with interviews completed every one to three years. This would explore the continuum of recovery in relation to identity (re)construction. However, this kind of longitudinal study would be logistically difficult to complete.

There is a need to better understand how individuals with TBI (re)construct their life and integrate into broader society. For example, future studies could use a different integration of qualitative analyses. This might develop other perspectives on this topic. There is also little research involving individuals with TBI and the outcome of different psychology therapies, for example ACT (Hayes, 2004).

4.4 Final Reflections

The process of working with this thesis has been an enriching journey. I gained a deeper understanding of TBI. I have developed my skills in theoretical research methods. I have experienced the entire process of research from conceiving of the idea, carrying out the literature review, identifying the study's participants, developing the methodology, learning how to apply the methodology, interpreting the findings, and finally discussing these in light of previous studies and psychological therapies. The process has deepened my understanding of research and the strengths and limitations that are part of it. My knowledge and understanding of both the topic matter and research methodology have continued to evolve during this process and I will alter several aspects of my work as a result.

Within my role as a counselling psychology trainee, I had no previous experience of the neuropsychological rehabilitation of brain injury. This may have been a disadvantage, for example in evaluating appropriate psychological therapies for this population. However, I have professional experience of working with individuals suffering from complex and enduring psychological problems, including depressive disorders, anxiety disorders, personality disorders, post-traumatic stress disorder, bereavement, substance misuse and individuals diagnosed with HIV. Many of these

conditions evoked feelings of loss and uncertainty among clients about their identity. Many of these issues also interacted with discourses of 'mental health' or 'chronic illness', which could allow for positions of disempowerment, dependence, stigmatisation, and social disconnection. Therefore, I could use this multi-faceted experience of working with a diverse range of individuals and psychological problems to inform my suggestions for developing therapeutic interventions. I also suggest that it might be an advantage to conduct research with a population group that the researcher has not worked with, as this allows for a more open-minded approach to the research posed.

I learned that research can cross boundaries of both care and care groups such as ABI, dementia and other chronic illnesses. The understanding of relationships between discourses and positions within one participant group (e.g., individuals with TBI) can help to inform psychological interventions for other care groups. This could underpin the understanding and facilitation of clients across many physical and psychological health issues to replace a disempowered position with an empowered position.

I have gained better understanding about the social constructionist view of health and illness. Considering beliefs about and attitudes towards health and illness available in a culture enables a more holistic understanding of experiences of chronic illness. Discourse analysis enabled me to understand how available discourses such as the 'medical' discourse limited or constrained individuals in what they could do or say. However, I found that discourse analysis was challenging due to the intense focus on language. Frank's (1995) illness narratives offered a connection between language and subjective experience within discourses. I therefore think the narrative reading assisted me to take the analysis a step further, enabling me to gain an understanding of participants' experience and link this to clinical practice. The aim of trying to understand another person is vital to my role as a counselling psychologist, and a deeper understanding has

4.5 Conclusion

A multiple qualitative analysis provided further understanding of the (re)construction of identity of individuals with TBI. The study has contributed to the qualitative literature concerning the needs of clients with TBI. This multi-level analysis explored identity from different perspectives, and so contributed to a richer knowledge and

understanding of these constructions. FDA (Willig, 2013) was used to explore how people with TBI (re)construct their identity within their society and culture. Frank's (1995) illness narratives were used to explore meaning-making and identify relationships among these discourses. I propose that a multiple qualitative approach needs to be considered in a qualitative study to facilitate a complex and holistic understanding of a person and the society in which they live. The findings identified overlapping and sometimes conflicting discourses. Discourses of 'disability' and 'medical' were common (re)constructions of identity amongst the participants. These findings need to be considered within current understanding of 'norms' and 'health' in Western society. This reflects how these discourses offered positions of dependency and disempowerment. 'Process of empowerment' (O'Hara and Harrell, 1991) could facilitate shaping attitudes towards individuals with disabilities within the community. An interesting aspect of the findings was that the discourses of 'dependence' and 'independence' were fluid and shifting. These findings supported the social constructionist view of a multi-level and fluid identity. The findings suggest that 'acceptance' discourse appeared to enable positions of empowerment and independence. Specific interventions including ACT (Hayes, Strosahl & Wilson, 2003) aimed at facilitating acceptance could be considered to assist in adjusting to both positive and negative parts of identity post-TBI.

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Appendix A: Research proposal

Working Title: The impact of traumatic brain injury on perception of self

Literature Review and Problem Statement

Background

In the UK around 700,000 people attend emergency departments for traumatic brain injury (TBI) each year. The vast majority of brain injuries are categorised as minor brain injuries (Barrow, Ndlkum & Harris, 2012). TBI is brain injury caused by trauma to the head, such as falling, car accidents or assault. TBI occurs at the time of injury but may be worsened by poor treatment and may progress in the days post injury. The effects of a brain injury are wide ranging and depend on a number of factors such as the injury type, location and severity (Barrow et al., 2012). Individuals with TBI may experience cognitive, physical, behavioural and emotional symptoms. An unknown proportion of individuals experience long-term problems such as pain, confusion, persistent headaches, memory problems, mood changes and sensory problems (Daisley, Tams & Kischka, 2009). TBI mainly affects young people (72%) with an average age of 35 years and can have visible (scarring, deformity) and invisible (cognition, memory loss, behaviour, emotional lability) consequences (Sinnakaruppan & Williams, 2001).

TBI can be classified as mild, moderate or severe based on the person's level of consciousness at initial presentation using the Glasgow Coma Scale (GCS) (based on verbal, motor and eye-opening reactions to stimuli). The GCS is scored from 3 to 15. Mild TBI is classified as a GSC 13-15, moderate as 9-12 and severe as 3-8 (Barrow et al., 2012). Other methods to classify severity of TBI are changes that are visible on neuroimaging, such as brain swelling and focal lesions (Daisley et al., 2009). However, a recent critical review by Saatman et al. (2008) suggests that while GCS is extremely useful in the clinical management of TBI it does not provide specific information about pathophysiologic mechanisms, which are responsible for neurological deficits and targeted by interventions. Pathophysiologic mechanisms are defined as the functional changes associated with or resulting from disease. The classification of TBI has recently been reviewed by the national Institute of Disorders and Stroke of America

(Saatman et al., 2008) and a new multidimensional classification proposed for use in clinical trials into TBI. This new classification has not yet been established and therefore this study will use GSC to classify TBI. Mild TBI can be difficult to assess. Initial computed tomography scan results may be normal and patients may initially be free of symptoms, however symptoms may develop in the days or weeks subsequent to injury causing these patients to then seek medical assistance (Stoler & Hill, 1998).

Ego, self and identity

Different psychological approaches propose varied and occasionally contradicting ways to define the concepts of self and identity. This introduction will describe some of the theories used to define identity. Freud's (1923) structural model of the mind conceptualises the human psyche as an interaction of three concepts the id, ego and the superego. The id is entirely unconscious. It is present from birth and contains human drives including sexuality and aggression. The ego is believed to develop around six months of age. It has both conscious and unconscious aspects. The conscious ego is what we refer to as 'self' (Freud, 1923). The ego and self are often used interchangeably (Lemma, 2003). The mental approaches are responsible for mediating with the external world. The superego is developed around four to five years of age. It incorporates the values and morals of society and is learnt from parents and others. The superego is divided into two parts: and ego ideal (ideal self), what the ego aspires to be; and the conscience, that punishes the ego when it fails. Intrapsychic difficulties arise because of the potential conflicts between the id, ego and superego Freud's (1923). Hartmann (1939) used the term ego for mental agency and self for the individual self. This theory suggests that ego includes innate capacities that facilitate an individual's ability to adapt to his or her environment. These include perception, memory, concentration, motor coordination and language.

Erikson's (1980) theory of psychosocial development suggests that identity develops in a series of stages and is affected by social experiences throughout life. One of the main factors in this theory is the development of ego identity. According to Erikson ego identity is the conscious sense of self that individuals develop through social interaction. Our ego is constantly changing due to new experiences and in our daily interactions with others. Each of the stages is concerned with becoming competent in an area of life. These include trust versus mistrust (0 – one year), autonomy versus shame and doubt (two to three years), initiative versus guilt (three – five years), industry (competence) versus inferiority (six to twelve years), identity versus role

confusion (thirteen – eighteen years), intimacy versus isolations (young adulthood), generativity versus stagnation (middle adulthood) and ego integrity versus despair (old age).

Kohut's (1977) self psychology developed in response to his work with patients diagnosed with narcissistic disorders, but was subsequently applied to all forms of psychopathology. People with narcissistic disorders often have a sense of weak or unstable sense of self. Kohut suggested that self-cohesion is the primary motivation guiding human behaviour. The reason for anxiety is the individual's lack of cohesiveness and permanence in the sense of self. Kohut used the term self to refer to all of the personality and emphasised the role of empathy in the development of self. Suggesting that human maturation involves differentiation within empathetic relationships. Kohut used the term self-object, which is one's experience of another person. Individuals need self-objects throughout their lives to help with emotional survival. However, Lacan (1953) stated that sense of identity is an illusion and that we are constructed solely in and through language.

In relational frame theory (Hayes 1995), there exist three distinct senses of self. These are firstly, 'the conceptualised self', which is the ability to evaluate, explain and predict one's own behaviour. Secondly, 'self as an ongoing process of verbal knowing', which is what a person linguistically knows, such as emotions, thoughts and memories. Thirdly, 'self as context', which, allows the person to distinguish her perspective from others.

Loss of sense-of-self

Loss of sense of self is a common experience among individuals with TBI. It involves conscious awareness that part of the individual is, in some way, not the same person as pre-injury. This is associated with emotionally distressing negative self-evaluations of the post-injury changes and functioning (Myles, 2004). Loss of self after a brain injury can be understood as the effects of a 'crisis of the conceptualised self'. From this perspective, loss of self sense is largely a verbal and relational process. This may be expressed as 'I am not the same person' (Myles, 2004). The person post-injury may also experience behavioural changes, such as being aggressive towards others or acting impulsively. A person who pre-injury conceptualised herself as being a gentle person but who post injury acts aggressively towards others may feel that they are no longer the same person (Myles, 2004). Some people with TBI and loss of sense of self,

use denial as a strategy to cope with the loss of their pre-injury concept of self. However, long-term denial and avoidance of thoughts and feelings can lead to increasing psychological distress. Nochi (1998) describes people's experiences of loss of sense of self as non-monolithic and able to take various forms. Nochi suggested that the diverse nature of loss of self reflects the complexity of self and that the self is constantly generated and modified by the person's interaction with the world.

Previous research on traumatic brain injuries

In this literature search most papers addressing TBI and mental health issues were quantitative research. However some qualitative research was identified and is discussed below. Nochi (1998) used grounded theory to explore how interactions with society affect the sense of self of individuals with TBI. The main theme expressed by participants was that society attached both negative and positive images that often contradicted their own self-perception. Participants often felt that negative diagnostic labels such as TBI were associated with an image of abnormality, craziness or stupidity. A systematic review on the care needs of people with TBI by Jennekens, De Dierckx and Dobbles (2009) showed that we know very little about the precise needs of people with chronic mild TBI. The aim of the review was to gain insight into neuropsychological care needs on cognitive, emotional and behavioural issues for people with mild TBI. The review included three large-scale American surveys involving people with mild, moderate or severe traumatic brain injury. None of these focussed on minor brain injuries. The authors suggest that more qualitative research is needed to understand the experiences of people living with mild TBI and their needs. Neimeyer

Morris et al. (2005) interviewed individuals who had sustained TBI one to ten years previously and from which they had residual difficulties. These individuals all suffered from moderate to severe disability. Most of the interviewees reported social, cognitive, physical, behavioural and emotional difficulties. They reported several types of loss, including loss of work, friends and partners. Emotional difficulties reported included apathy, anxiety, depression, frustration, irritability and avoidance of crowds. Some participants reported concerns about loss of both sense of self and sense of identity. Others reported that they felt they had lost the person they were prior to the trauma. Participants also described changes in physical appearance, such as scars or weight change with resulting concerns about self-image. Another issue was not to be understood by others, for example friends and relatives may not understand that the

participants were depressed or exhausted in the absence of external signs of injury (Morris et al., 2005). One criticism of this study is that while the authors identified themes, it is not clear what method of analysis they used. The authors state that a person centred outcome measure has been developed from this study, however this is not fully explained.

The loss of self and identity can have significant impact on families and relationships. Wood and Yurkakul (1997) observed the changes in marital status of 131 people with traumatic brain injuries. All the participants had been in a relationship for at least one year prior to the injury. The study found that 48% of these couples divorced in the subsequent eight years. The authors did not explore the factors that contributed to relationship breakdown. Landua and Hissett's (2008) study explored the combined impact on mild TBI on loss of self, ambiguity identity and relational breakdown. The authors interviewed individuals suffering from mild TBI and their families. This study demonstrated that the symptoms experienced by the patients changed how they related to themselves and the people closest to them. Many of the interviewed patients expressed a sense of loss of self. This was expressed in boundary ambiguity and ambiguous loss. Boundary ambiguity can be defined as a family member being physically present but psychologically absent. This is different from experiencing death of a family member, which is a stressful event but it is validated through socio cultural processes and allows the family to move on. The study identified relationship conflicts such as alienation, guilt, blame and rejection as common themes. The authors suggest that early recognition of these issues and early therapeutic intervention may prevent relationship breakdown and unnecessary stress to both patients and their families.

Severe TBI may also alter the way the patient perceives their physical and emotional environments. A case study on a patient who was in coma for 63 days and suffered from post-traumatic amnesia reported loss of autobiographical memory, self-image and emotional bonds to family and others. The patient experienced identity self-change, which manifested as 'clinging' to identity of others and 'borrowing' their identity (Pachalska et al., 2011). Depending on the complexity of the head injury and nature of trauma, patients with TBI may develop post-traumatic stress disorder (PTSD) (Resick, 2005). Giles (2009) reviewed studies made on PTSD following TBI and found strong correlation between PTSD and identity self-change. Brewin's (2011) study on military service men diagnosed with PTSD showed that trauma was associated with altered perception of self, which could be either positive or negative. However many patients

with TBI do not have PTSD and still have diverse problems with cognition, emotional lability and self-sense and change of identity. This has not been well explored. The relationship between pre-TBI identity and subsequent mental health issues is also not well studied. Kroupa (1996) carried out interpretative phenomenological analysis on interviews with ten adults with TBI. The participants found it difficult to take on the commitments and responsibility associated with adulthood. A recurrent theme was that they often 'felt forced to the edge of self' as they had lost their previous relationships with the environment and people around them. Some of the participants attempted to maintain their pre-injury assumptions regarding self, while others adapted these to their current (post-injury) abilities and limitations. Weingarten's (2012) case study on four women with chronic illness showed that they all experienced self-loss and had developed a chronic sorrow. Weingarten (2012) uses narrative therapy and describes the chronic sorrow as a painful gap between who they have been and who they are now. The sadness is related to ongoing losses associated with illness and disability.

Statement

This study will use qualitative methodology using semi-structured interviews to develop knowledge about how people with TBI experience sense of self. It will investigate participants' experience of loss of sense of self. It will explore whether they have reconstructed their reality of sense of self, changes in identity and behaviour post-injury. It will explore change of behaviour post-injury. The findings will have implications for counselling psychologists working with this large client group by providing new knowledge concerning the psychological suffering experienced by these people.

In this study a psychosocial approach will be used. A narrative analysis will be followed by a psychoanalytic formulation of the interview transcripts. A psychosocial approach is used to provide a multidimensional understanding of the research questions. The study will integrate the narrative analysis with a psychoanalytic approach. Narrative analysis will be used to explore individuals' stories and experiences following TBI. It will investigate individuals' experience of loss of sense of self, changes to identity and in behaviour. It will explore how individuals with TBI construct and may reconstruct sense of self.

A psychoanalytic approach will also be used to explore the individuals' experience of perceived identity change and loss of sense of self, post TBI. The psychoanalytic

approach is concerned with the emotional dynamics that originate in childhood. This psychoanalytic analysis will draw from psychoanalytic interpretative strategies and expand on the initial narrative analysis. The interpretations will be drawn from autobiographic information of the participants and from psychoanalytic theory. This study will focus on how identity and self is shaped within a psychoanalytic framework. The focus will be to deepen the understanding of how individuals may reconstruct their identity following TBI. It aims to enrich our understanding of the psychological (conscious and unconscious) processes involved in constructing identity and sense of self. The main research questions are - How do people with traumatic brain injury (TBI) describe their sense of self post-injury? Can a psychoanalytic framework provide further understanding of emotional subjective processes post TBI?

Research Strategy

Qualitative methodology

The study will apply qualitative methodology using semi-structured interviews as the method of data collection (Willig, 2008). Qualitative research is concerned with the meaning of how people make sense of their experiences and the world around them. It aims to explore 'what is it like' to experience certain conditions or situations, for example how people experience and cope with chronic illness (Willig, 2008). In this study I (Cecilia Wolfenstein, the researcher) have chosen a qualitative approach to explore the experiences of how individuals with TBI experience of self. I am interested in the impact of identity change and loss of sense of self post TBI. I also seek to develop an understanding of how current experiences of living with brain injury are linked to identity development. I believe that a qualitative approach is the appropriate method to explore these questions. I will use a psychosocial approach and will conduct a narrative analysis followed by a psychoanalytic formulation of the interview transcripts.

Psychosocial analysis

A psychosocial approach aims to identify psychological structures and processes that can provide deeper understanding of the interview data. This approach suggests that both psychological and social processes can inform the researcher about the participants' thoughts and experiences (Willig, 2012). This study will use a psychosocial approach to attempt to integrate narrative analysis with a psychoanalytic approach and hence develop a multidimensional understanding of the research

questions. The rationale behind this is that different interpretations of data can provide a holistic and multi-perspective insight to individuals' experiences (Frost et al., 2010). Psychosocial approaches require the researcher to take a critical realist position and seek multivariate information from the data. The critical realist position can vary in the extent of certainty of psychological theory and knowledge (Willig, 2012). Operating from this position I will present my interpretations with caution, emphasising that they represent possibilities rather than certain knowledge. The study aims to explore the complex intrapsychic and interpersonal dynamics that construct identity within a framework that also holds the social context of developing identity.

Narrative analysis

Narrative analysis is based on the premise that individuals use stories to make sense of themselves and their world, and to present themselves to others. It is often at times of change or incoherence in people's lives that stories are particularly useful to make sense of changes in their identities and relationships (Sarbin, 1986). Narrative researchers have interest in the structure and form of the stories that people tell. They are concerned with participant's life stories but is also interested in the social and cultural context of the stories (Langdridge, 2007). Narrative researchers vary in the way they interpret text and are interested in different features of the narrative. They apply a range of interpretative perspectives to the narrative. This consists of working through the text repeatedly asking different questions (Willig, 2008). In this study data will be collected through semi-structured interviews using open questions. In this study I will use critical narrative analysis (CNA), after Riceour (1987). This analysis strives for explanation beyond the narratives and is defined as hermeneutics of suspicion. The researchers are interested in the underlying psychic and social processes underpinning the narrative (Josselson, 2004). CNA is a process that consists of six stages (Langdridge, 2007). It begins with stage one, 'a critique of the illusion of the subject', which is a reflexive engagement. I need to think through my background and experience, and the impact this might have on analysing the data. Next is stage two, 'identifying narratives, narrative tone and rhetorical function', which consists of reading the text through to define and identify clusters of the narratives. There could be one narrative or several narratives. There may be a main narrative that is framed by research aims, but within it there may be other stories. In this study I will focus on the participants' narratives about identity. This is followed by stage three 'identities and identity work', where I look at the particular 'self' being brought into the narrative. I will

revisit the transcripts and asks questions such as 'who is this person?', 'what kind of person does this narrative construct and how does this relate to the topic discussed?'. It will be a very relevant stage in the current study as the topic concerns the participant's loss of sense of self and identity change. Stage four 'thematic priorities and relationships' requires that I go through the transcripts systemically, looking for themes. Stage five 'destabilising the narrative' involves engaging with critical social theories. Finally, stage six 'critical synthesis' is the production of a synthesis of the findings (Langdridge, 2007).

Psychoanalytic approach

A psychoanalytic approach assumes that people are motivated by unconscious emotional dynamics developed in their childhood and explores 'why' people experience something. In this approach the researcher goes beyond the text (interview) and looks at factors such as the individual's biographical information, childhood development, relationships with significant others and the psychosocial context (Willig, 2012). A psychoanalytic theory focuses on individuals' unconscious thoughts, fantasies, and conflicts (Lemma, 2003). Psychoanalytic interpretation applies concepts and perspectives that are informed by psychoanalytic theory to try to understand and demystify the participants' narrative. In this study a psychoanalytic perspective will explore the relationship between current experiences and how the person makes sense of identity and sense of self. It will draw from theories of identity including Erikson's (1980) theory of psychosocial development and Hartmann's (1939) ego psychology. I will draw from further psychoanalytic theories, however, which ones are not established at this point. Psychoanalytic approaches are concerned with something hidden and the task of the researcher is to uncover hidden material. The approach is therefore defined as suspicious interpretation. It interprets surface level manifestations such as un-reflected descriptions of experience and non-verbal expressions of emotions (Willig, 2012). It tries to understand the participants' psychological dynamics, including their developmental history, unconscious desires and defence mechanisms. Psychological mechanisms such as distortions and displacement of meaning are identified. A successful psychoanalytic analysis is therefore relative to the researcher's interpretative skills and ability. The training, theory and culture of the researcher will have an impact on the interpretation (Willig, 2012). Therefore, in this study I need to take a cautious and realist position and draw my interpretation on sufficient information and link it to human psychology and theory. I need to be tentative and critically

reflective about my interpretations, as these are just possibilities and not facts. Another aspect is the use of relationship between the researcher and participant. My own presentation and experience of the interview must be concerned. The unconscious dynamic, such as transference and countertransference, may also have an impact on the interview (Willig, 2012). Countertransference is shortly described as the therapist's emotional reaction towards the participant (Lemma, 2003). However, it is important to highlight that I am not trying to help the participant therapeutically but are concerned with knowledge production (Kvale, 2003).

Interviews

I will conduct semi-structured interviews to elicit data. The interviews will be completed face-to-face and be 60 minutes long. They will be conducted at a room at [REDACTED] [REDACTED] For the semi-structured interviews I have developed a set of questions. The questions in the interview schedule will be initially used in a pilot study and then edited if required. I will initially analyse the transcripts with a narrative analysis and secondly with a psychoanalytic approach. Therefore the interview questions need to gather relevant information for the two subsequent analyses. For the narrative analysis I am interested in the individual's experience of living with TBI. I am focussed on how individuals with TBI construct their loss of self of sense, identity and behaviour change. The focus is on encouraging the production of narrative data. This will involve asking the participants open-ended and non-directive questions about particular aspects of their life (Langdridge, 2007). For the psychosocial analysis I need to ask questions around autobiographical information, psychosocial context and personal history. Sample of question include: "How would you describe your childhood?", "How do you feel that your life has changed since the brain injury?", "How do you think your behaviour changed since the brain injury". I have to be aware that it can be a challenge to conducting the interviews in an empathic manner and keeping elicit data, without priming the participants (Smith, 2009). A pilot interview will be conducted with the first recruited participant. The pilot will be conducted in order to develop the interview questions. I will inform the participant prior to the interview that they are taking part in a pilot and will not be included with the subsequent data as analyses as this interview is intended for refining the interview schedule.

Sampling Considerations

The target number of participants will be eight. The participants will be members of the organisation [REDACTED], the brain injury association. The participants will be people with traumatic brain injury (TBI). The participants will have symptoms of TBI at least six months post-injury. If hospitalised they should have subsequently returned to their home environment. The participants will be male and female with age range from 18-70 years. The nature of this study and the lack of funded translator services mean this study will only seek to recruit participants with conversational English. The participants must also be able to read and understand the information sheet and consent form in English. There is no exclusion on basis of sex, gender, ethnicity and religion.

I will recruit and identify the participants through members of staff at [REDACTED] [REDACTED]. Members of staff at [REDACTED] will inform potential participants about the study verbally. They will also give them a recruitment flyer. The recruitment flyer will inform the potential participants about the research. The participants will be informed that they can contact me or staff at [REDACTED] if they would like to participate in the study. The recruited participants will be required to attend one to two (depending of outcome of pilot study) 60-minute face-to-face semi-structured interview with me. This meeting will last maximum 90 minutes including information giving and verbal debrief. They will have to travel to [REDACTED]. Prior to the interview the participants will read and sign the consent form at their own time. The information sheet will inform them about the full aim of the study. I will inform them that participation is voluntary and that they may withdraw from the study at any time. After the interview they will be able to ask questions about the study. The interview will be audio recorded by an audio device. The audio recordings will be transcribed by an authorised transcription agency. The authorised transcription agency will follow safeguarding measures to secure confidentiality of the data. The transcripts will be transferred to an encrypted Word document. I will analyse them on a password-protected computer. Audio-recordings and transcripts will be encrypted and stored electronically. The consent form and personal details will be kept in a locked cabinet separate from and the transcripts to insure the participants' privacy. None of the participants' personal details will be on the audio-recordings or transcripts. All data will be kept secure for five years and then destroyed. Participants will be allocated a number for my identifying purposes only. As the consent forms and transcripts will be

kept separately and names/identifying details removed from transcriptions, the participants anonymity will be protected completely.

Ethics and Permissions

Ethical approval has been obtained from City University. I will follow ethical considerations to protect the participants from any harm or loss. I will aim to preserve the participants' psychological wellbeing and dignity throughout the process. Before the interviews an informed consent form will be given to all participants to ensure that the participants are fully informed about the research procedure. The participant will read it and give their consent by before proceeding. There will be no deception of the participants e.g. withholding any information about the study. The participants will be informed that they have the right to withdraw from the study at any time without being penalised. This will inform the participants the full aim of the research. I will maintain complete confidentiality regarding any information about the participants during the research process. Further, it will be agreed that pseudonyms will be used in all future publications.

There may be a moderate risk that the participants will experience psychological distress while talking about their experiences. It may be that talking about loss of sense of self and change of behaviour post-TBI will evoke difficult feelings. The study will use narrative and psychoanalytic analyses. To receive information for the analyses the researcher will need to ask questions about the participants' life experiences, relationships and childhood. This may also bring up difficult emotions. Therefore, I will explain the interview process to ensure that the participants fully understand what they are being asked to take part of. The interviews are semi-structured so the participants' stories will guide the direction of the interview. Participants do not have to disclose anything they do not want to share. I will only ask questions that are beneficial for the research and she will not ask any questions for my own curiosity. I will give the participants a list with contact details of resources to counselling services and organisations that are working with people with TBI. The list will also include counselling services for people who are emotionally distressed. In the situation of a participant becoming visibly upset. I would stop the interview. I would contain the situation by using my counselling skills. I have five years of clinical experience of working in varied mental health settings including IAPT; HIV; sexual health; drug; personality disorder services. I have worked with clients presenting with a range of emotional and psychological problems including anxiety, panic attacks, depression,

addictions, personality disorders, childhood trauma, PTSD, HIV related problems, loss and bereavement. I have MSc in counselling psychology from City University and a postgraduate diploma in low intensity Cognitive Behavioural Interventions from University College London. I will also make sure that I have informed a member staff at [REDACTED] that would be able to assist me containing a difficult situation.

Furthermore, I will inform that participation is voluntary and that they may withdraw at any time reason without needing provide an explanation. They do not have to disclose anything they do not want to share. I will give the participants a list of contact resources to counselling services and organisations working with people with TBI. All participants will be offered to ask questions about the study after the interview. I will also give the participants my and my supervisor's contact details in the case they would require help with signposting to support services post interview. The participants will not be given a written debrief, however the participants will have the opportunity to ask questions about the research and offered to view the final report. I will give my and my supervisor's contact emails if they would like to ask any further questions.

Reflexivity

Personal reflexivity is concerned with the researcher's own values, ideas, experiences, beliefs and social identification and how this has an impact on the research. It also involves reflecting on how the research may influence or change the researcher (Willig, 2008). I (the researcher) need to reflect on different concerns such as the risk that I may be subjective and biased when analysing the interviews. I have to be aware about my own motivations for conducting the research. My motivations are not solely academic and I do have a personal interest for this topic. I think this will help me completing the study as I feel passionate about it. It also helped clarify why I chosen qualitative methodology. My personal interest drives me to ask how people with mild to moderate brain injury experience their life. I think it is important to be aware and reflect on what I, as a person will bring to the research. For example, I am a Swedish woman living in London with influences of different cultures and psychosocial background.

Epistemological reflexivity is concerned with the assumptions and implications that the researcher makes during the process of conducting the research (Willig, 2008). I need to reflect on the choice of methods used in the study. My epistemological position is the study of nature of knowledge and how we come to know world of things (Burr, 2003). My epistemological position is most in line with social constructionism. Social

constructionists suggests that human experience including perception is understood in a social, historical, cultural, environmental and linguistic context (Burr, 2003). Research from a social constructionist perspective is concerned with identifying various ways of constructing social reality (Willig, 2008).

Psychosocial perspective has been criticised for being unethical because it deviates from the original meaning from the original text (Willig, 2008). My interpretations will draw on biographical information and psychoanalytic theory. In order to conduct ethically sound psychosocial analyses, I will need to take on a realistic critical and tentative position. My interpretations will be cautious and possibilities rather than certain knowledge. During the analysis, I need to be aware about my subjective position and it is important to bring myself into the analytic process as necessary. The participants may want to read the final paper and the psychoanalytical interpretations may have an impact on them. They may feel misrepresented. I need to be clear and state in my written work that I am aware of reflexivity issues and that the interpretations are drawn from psychoanalytic theory and from my subjective position.

Research Materials

I will cover the cost for any correspondence including stamps, printing of letters and envelopes. I will generate all research material. This includes the recruitment letter, informed consent form, interview protocol, list of support services for potentially distressed participants and debrief. These will be generated with advice from my supervisor.

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Appendix B: City University Ethics Form

Ethics release form for student Research projects	
Ethics Release Form for Student Research Projects All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, together with their research proposal clearly stating aims and methodology, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study. This form should be completed in the context of the following information: - An understanding of ethical considerations is central to planning and conducting research. - Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc. - The published ethical guidelines of the British Psychological Society (2009) <u>Guidelines for minimum standards of ethical approval in psychological research</u> (BPS: Leicester) should be referred to when planning your research. Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative. Section A: To be completed by the student Please indicate the degree that the proposed research project pertains to: BSc M.Phil M.Sc D.Psych X n/a Please answer all of the following questions, circling yes or no where appropriate: 1. Title of project The impact of traumatic brain injury on perception of self 2. Name of student researcher (please include contact address and telephone number) Cecilia Wolfenstein [REDACTED] Email: [REDACTED] Mobile: [REDACTED] 3. Name of research supervisor Julianna Challenor 4. Is a research proposal appended to this ethics release form? Yes X No 5. Does the research involve the use of human subjects/participants? Yes X No If yes, a. Approximately how many are planned to be involved? Six to eight participants. b. How will you recruit them? I will recruit and identify the participants through members of staff at [REDACTED], the brain injury association. Members of staff at [REDACTED] will inform potential participants about the study verbally. They will also give them a recruitment flyer (appendix 2 of research proposal). The recruitment flyer will inform the potential participants about the research. The participants will be informed that they can contact me or staff at [REDACTED] if they would like to participate in the study.	

c. What are your recruitment criteria?

(Please append your recruitment material/advertisement/flyer)

Recruitment flyer: Appendix 2 of research proposal.

The participants will be people with TBI. The participants will be male and female with age range from 18-70 years. The participants will be members of the organisation [REDACTED], the brain injury association. The participants will have symptoms of TBI at least six months post-injury.

If hospitalised they should have subsequently returned to their home environment. The nature of this study and the lack of funded translator services mean this study will only seek to recruit participants with conversational English. The participants must also be able to read and understand the information sheet and consent form in English. There is no exclusion on basis of sex, gender, ethnicity and religion.

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent? Yes No X

d1. If yes, will signed parental/carers consent be obtained? Yes No

d2. If yes, has a CRB check been obtained? Yes No

(Please append a copy of your CRB check)

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? (If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).

The participants will be required to attend one to two 60-minute face-to-face semi-structured interview(s) with myself (the researcher) (Appendix 1 of research proposal: Interview schedule). The session will take maximum 90 minutes including information giving and time for any questions. They will have to travel to [REDACTED] to attend the interview. Prior to the interview they will be given an information sheet and a consent form (Appendix 3 and 4 of research proposal: information sheet and consent form) to read and sign at their own time. I will go through the information sheet and consent form with them and ask if they have any questions before continuing. After the interview they will be able to ask questions about the study. The interview will be audio recorded by an audio device.

7. Is there any risk of physical or psychological harm to the subjects/participants? Yes X No

If yes,

a. Please detail the possible harm?

There may be a risk that the participants will undergo psychological distress while talking about their experiences. It may be possible that talking about identity change and loss of sense of self post-brain injury will evoke difficult feelings. The study will use narrative and psychoanalytic analyses. So some of the questions will be asking about their relationships and childhood experiences. This may also bring up difficult emotions.

b. How can this be justified?

The aim of this study is to explore how people who suffered TBI experience 'loss of sense of self', 'behavioural changes' and 'identity change'. The study will use narrative analysis and psychosocial analysis. To receive information for the analyses I will need to ask questions including their life experiences, relationships and childhood (Appendix 1 of research proposal: Interview schedule). This may be emotionally difficult for some participants to talk about. Prior to the interview I will explain the interview process and the aim of the study to ensure that the participants fully understand the research procedure. The interviews are semi-structured so the participants' stories will guide the direction of the interview. The participants do not have to disclose anything they do not want to share. I will only ask questions that are beneficial for the research and she will not ask any questions for her own curiosity.

c. What precautions are you taking to address the risks posed?

I will inform them that participation is voluntary and that they may withdraw at any time without needing provide an explanation. They do not have to disclose anything they do not want to share. I will stop the interview if any of the participants will become visibly upset. I would use my counselling skills to contain the situation. I will also make sure that I have informed a staff member at [REDACTED] that would be able to assist me containing a difficult situation. I would not let the participant leave the interview in an upset state. All participants will be offered to ask questions about the study after the interview. The participants are members of [REDACTED] that offers support to people with TBI. I will also give the participants a list of other contact resources to

counselling services and organisations (Appendix 6 of research proposal: Support services for potentially distressed participants).

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes **X** **No**

They will be given an information sheet providing the aims and the procedure of the research.

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

For information sheet and consent form see appendix 3 and 4 of research proposal: information sheet and consent form.

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

No of the participants' treatment or care will be compromised in anyway if they choose to participate, discontinue with the study or not participate in the study.

Yes No **X**

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes **X** **No**

If no, please justify

If yes please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

All participants will be required to read and sign an informed consent form (see appendix 4 of research proposal).

1. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

The interview will be audio recorded by an audio device. The audio recordings will be transcribed by me or an authorised transcription agency. I and the authorised transcription agency will follow safeguarding measures to secure confidentiality of the data. The transcripts will be transferred to an encrypted Word document.

12. What provision will there be for the safe-keeping of these records?

Audio recordings and the transcripts will be kept by [redacted] me (Cecilia Wolfenstein). Audio-recordings and transcripts will be encrypted and stored electronically. No of the participants' personal details will be on the audio-recordings or transcripts. Paper copies of transcripts will be kept in a locked cabinet. The transcripts will be identified with a participant number. The consent form and personal details will be kept separate in a locked cabinet (at [redacted] a locked cabinet in my home) from the transcripts to insure the participants' confidentiality. Personal details will be kept 6- 12 months and then destroyed.

13. What will happen to the records at the end of the project?

The transcripts and the audio recordings will be kept for 5 years and then destroyed, which is in line with the City University data storage policy.

14. How will you protect the anonymity of the subjects/participants?

No data recorded in the study will identify your name or personal details. The consent form will be kept separate from the audio-recordings and the personal details.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

Participants are members with [REDACTED] which can provide support. I will also give the participants a list of other contact resources to counselling services and organisations (Appendix 6 of research proposal: Support services for potentially distressed participants).

There will be no written post research debrief, however the participants will be encouraged to ask questions about the research and offered to see the final report. They will be given my contact details and my supervisor's contact emails if they would like to ask any further questions or see the final report (Appendix 5 of research proposal). I will offer the participants a follow up de debrief when the transcripts are analysed.

(Please append any de-brief information sheets or resource lists detailing possible support options)

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation her

Signature of student researcher Cecilia Wolfenstein Date 13.12.13

CHECKLIST: the following forms should be appended unless justified otherwise

Research Proposal	X
Recruitment Material	X
Information Sheet	X
Consent Form	X
De-brief Information	X

Section B: Risks to the Researcher

1. Is there any risk of physical or psychological harm to yourself? **Yes X** No
If yes,

a. Please detail possible harm?

There may be a risk of physical and psychological harm to oneself when one are meeting and interviewing a previously unknown participant.

b. How can this be justified?

I anticipate that risk of physical and psychological harm to myself is small. The participants will be identified by the team at [REDACTED], thus the participants are known to the team.

c. What precautions are to be taken to address the risks posed?

I will conduct the interviews in a room at [REDACTED]. I will let a member of the staff know that she will be in a certain room for 90 minutes to insure safety. I will inform a staff member of the timing of the interview and contact them after completed to reassure them that I did not come to harm.

Section C: To be completed by the research supervisor

(Please pay particular attention to any suggested research activity involving minors or vulnerable adults. Approval requires a currently valid CRB check to be appended to this form. If in any doubt, please refer to the Research Committee.)

Please mark the appropriate box below:

Ethical approval granted

Refer to the Department's Research and Ethics Committee

Refer to the School's Research and Ethics Committee

Signature J. Challen Date 31/1/14

Section D: To be completed by the 2nd Departmental staff member *(Please read this ethics release form fully and pay particular attention to any answers on the form where underlined bold items have been circled and any relevant appendices.)*

I agree with the decision of the research supervisor as indicated above

Signature Jessica J. Dabson Date 31/01/2014

Appendix C: Recruitment Leaflet to Participants

Research about experiences of living with TBI

The Impact of Traumatic brain injury on perception of self

My name is Cecilia Wolfenstein and I am a trainee counselling psychologist at City University, London.

I am interested in how you experience sense-of-self and identity following traumatic brain injury (TBI). The aim of the study is to explore how people experience and construct identity after TBI. This will be a chance for you to tell your story. I hope that from conducting this research it will improve awareness and understanding of living with TBI.

It will be completely anonymous to protect your privacy. You will only be asked to discuss experiences you are happy to share and will not be pressed to reveal anything you are uncomfortable with.

A total of 8 people will be recruited for this study and this will be on a 'first come, first served' basis. If you are interested in taking part I would invite you to a face-to-face interview with me.

The interview will be held at a room at [REDACTED] This will be part of my doctoral research in counselling psychology at City University.

Your contribution to the study will be voluntarily and confidential. No data recorded in the study will identify your name or personal details. Participating in the study will have no bearing on your medical care.

If you think you may be interested, or would like more information, please talk to:

Ben Graham or [REDACTED] at Headway East London

or call or text me on my mobile: [REDACTED]

or email me at following email: Cecilia.wolfenstein.1@city.ac.uk

Contacting us does not mean you are committed to anything!

Cecilia Wolfenstein
Researcher and Trainee Counselling Psychologist

Julianna Challenor
Supervisor
Email: Julianna.challenor.1@city.ac.uk

Appendix D: Participant Overview

Table 1: Demographic information for participants

<i>Participant</i>	<i>Gender</i>	<i>Age</i>	<i>Years since injury</i>	<i>Cause of injury</i>	<i>Length of coma</i>	<i>Employment Pre-injury</i>	<i>Employment Post-injury</i>
George	Male	58	8	Car accident Pedestrian	Six weeks	Employed	Unemployed
Simon	Male	46	12	Parachute Accident	Estimated more than 7 weeks	Employed	Unemployed
John	Male	61	24	Assault	2-3 weeks	Employed	Unemployed
Mary	Female	46	8	Car accident	Estimated 8 weeks	Unemployed	Unemployed
Charles	Male	44	13	Motorbike accident	1-2 weeks	Employed	Unemployed
Charlotte	Female	29	8	Car accident Pedestrian	6 days	Employed	Unemployed
Rachel	Female	29	13	Car accident	4 days	Employed	Employed
Thomas	Male	53	37	Motorbike accident	Estimated 2-3 weeks	Employed	Unemployed

Appendix E: Participant Information Sheet



**School of Arts
and Social Sciences**
CITY UNIVERSITY LONDON

31.01.14

PARTICIPANT INFORMATION SHEET

The Impact of Traumatic brain injury on perception of self

Introduction

You have been invited to take part in a research study, which explores the experience of sense of self after Traumatic brain injury (TBI).

The Researchers

My name is Cecilia Wolfenstein and I am a Trainee Counselling Psychologist at City University, London. I am conducting this research as part of my Doctorate in Counselling Psychology. The research is being supervised by Dr Julianna Challenor (Chartered Counselling Psychologist and Academic researcher at City University).

The research is in collaboration with [REDACTED]

What is the purpose of the research?

The purpose of the study is to explore people's experience of change of self and identity post TBI. The aim is to explore how people re-construct identity after TBI.

Why have I been invited?

You have been invited to take part as you have been diagnosed and experience symptoms of TBI for at least 6 months. A total of 8 people will be recruited for this study and this will be on a 'first come, first served' basis.

Do I have to take part?

You are under no obligation to take part in the study; it is completely up to you to decide. We will describe the study and go through this information sheet with you.

What will happen to me if I take part?

Nothing will happen directly to you. Instead, you will be interviewed about your experience of sense of self and identity post TBI.

What will I have to do?

You will be asked to attend one to two interviews with the researcher at [REDACTED], which will last a maximum of 90 minutes.

You will not be required to bring anything with you on the day. The interview will be audio recorded by myself (Cecilia Wolfenstein).

A verbal and a written debrief will be provided at the end of the interview where there will be an opportunity for feedback and support. You will also have the option to attend a separate second session to discuss the themes raised in your interview.

What are the possible risks or disadvantages of taking part?

The interview schedule will require you to talk about your personal experiences, which may cause some distress. This however, will be managed appropriately and you may pause at any time during the interview or take a short break. Additionally, if you do not feel comfortable to answer a particular question you can skip this.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help the understanding of TBI. The research will give you the opportunity to talk openly and honestly about your experiences. I hope that from conducting this research it will improve awareness and understanding of living with TBI.

What will happen if I don't want to carry on with the study?

Participation is entirely voluntary, and you can decide not to participate, or withdraw at any time, without giving a reason, and without your medical care or legal rights being affected.

If you withdraw from the study I will destroy all identifiable information

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researcher or my supervisor who will do their best to answer your questions. You can also speak to a member of staff at [REDACTED]

Will my taking part in the study be kept confidential?

All identifying data such as names/places will be removed or changed to preserve anonymity. Should you disclose anything that indicates potential harm to either yourself or others, I have a statutory obligation to break confidentiality.

How will the transcripts and the results be kept confidential?

All information that I collect about you during the course of the research will be kept strictly confidential by me Cecilia Wolfenstein. Audio-recordings and transcripts will be encrypted and stored electronically. None of the participants' personal details will be on the audio-recordings or transcripts. The transcripts will be identified with a participant number. Paper copies of transcripts will be kept in a locked cabinet. The consent form and personal details will be kept separate in a locked cabinet from the transcripts to ensure the participants' confidentiality.

The transcripts and the audio recordings will be kept for 5 years and then destroyed, which is in line with the City University data storage policy.

What happens when the research study stops and to the results?

Once I have conducted all of the interviews, I will analyse the data in order to examine your experiences in close detail. This analysis will then form part of the research thesis, which will be reviewed by an academic group of people at City University. I will write up a report, which will include the anonymous extracts of the transcripts.

My research supervisor will look at the anonymous information from the interview. Professional and academic committees to examine the quality of the doctoral research will also look at this information.

Part of transcripts may be published in academic journals, web forums or other publications. It will be agreed that pseudonyms will be used in all future publications.

Contact Details

Ms Cecilia Wolfenstein

Trainee Counselling Psychologist

T: [REDACTED] (City University)

(Telephone messages can be left through the course administrator Alison Peach)

E: [REDACTED]

Dr Julianna Challenor

Chartered Counselling Psychologist

Research Supervisor, City University

E: [REDACTED]

[REDACTED]

Appendix F: Participant Consent Form

PARTICIPANT CONSENT FORM

The Impact of Traumatic brain injury on perception of self

Patient Identification:

Title of Project: [*The Impact of Traumatic brain injury on perception of self*]

Name of Researcher: [**Cecilia Wolfenstein**]

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that my information will be stored in a locked cabinet and that the information I provide will be anonymised. ☐
4. I give consent for the interview to be audio recorded, transcribed and for direct quotes to be included in the research report which I understand will be anonymous. ☐
5. I understand that relevant sections of my data collected during the study, may be looked at by individuals from [**CITY UNIVERSITY LONDON**], where it is relevant to my taking part in this research. I give permission for these individuals to access my records. ☐
6. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Person
taking consent.

Date

Signature

Appendix G: Semi Structured Interview Schedule

Interview Schedule

Injury

- Could you tell me how and when you acquired your brain injury? (Prompt- What were the circumstances that led up to injury?)
- What were your injuries?
- What happened in hospital/the days/weeks/months after?
- Did you receive any rehabilitation/Support?

Life after injury

- Could you describe your life now?
- What do you do? Family? Work? Social life?
- How do you feel about your life now?
- How do you feel about yourself? Physically/mentally/ emotionally?
- How do you feel that your life has changed since the injury? (Prompt - Could you describe how you feel different?)
- What were your main challenges after your injury?
- What is the thing you loved/cared about most?

Life before injury

- Could you describe your life before your brain injury?
- What did you do? Family? Work? Social life?
- Tell me about your family and what it was like growing up?
- How did (do you remember how?) you felt about yourself? Physically/mentally/ emotionally?
- What were your main challenges before your injury?
- What was the thing you loved/cared about most?

Identity

- Do you feel as a different person after the injury?
- How would you describe yourself as a person now?
- How have other people (family/friends/colleagues) behaved towards you post injury?
- What would you say to someone who just experienced a brain injury?
- Do you tell people about your injury? (Prompt – What do you tell them? How does it make you feel?)

Mental health in relation to change pre and post injury

- Are you receiving any current psychological (counsellor, psychologist) therapy?
- Have you received psychological therapy, previously in life?
- Would you think it would be helpful to talk to someone?

General

- Is there anything I haven't asked that you would like to talk about?

Appendix H: Participant Debriefing Including Support Service Information

Research project: The Impact of Traumatic brain injury on perception of self

Dear,

Thank you for taking part in the research interview today. I am grateful for your time and contribution.

Talking about some subjects may evoke difficult emotions for a few days afterwards. This is normal and will usually get better after a day or two. However, if you feel that the interview has affected and you need support or talk to someone, there are several things you could do:

1. Following the interview, you can contact me if you need to talk anything through that the interview may have raised for you (please see my contact details below).
2. You can also contact [REDACTED] or [REDACTED] at [REDACTED]
3. You can contact your GP for emotional support or information how to get help.
4. You can also contact organisations that support people with traumatic head injuries and organisations that support with people with emotional support:

Headway
Web site: Headway.org.uk
Helpline: 0808 800 2244

Mind
Web site: Mind.org.uk
Helpline: 0300 1233393

Samaritans
Helpline: 08457 909090
Web site: www.samaritans.org

If you would like to discuss anything about this research and your participation further or if you would like to see the final report. Please do not hesitate to contact me:

Email: [REDACTED]
Telephone: [REDACTED] (City University)
Telephone messages can be left through the course administrator

Yours sincerely,

Cecilia Wolfenstein Trainee Counselling Psychologist,

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Appendix I: Overview of Discourses

Table 2: Overview of discourses

<i>Discourses</i>					
Discourse Themes	Medical			Psychosocial	
	Identity in relation to disability and invisibility	Identity as rebirth and ongoing development	Identity in relation to uncertainty and awareness	Identity in relation to perceived normality and social belonging	Identity in relation to independence, acceptance and recovery
	Right and wrong	Loss of identity	Loss of identity	Them and us	Acceptance of difference
	Perceived stigmatisation	Change of identity	Change of identity	Social disconnection	Adapting to change
	Loss of professional identity	Positive personal growth	Awareness of emotional change	Social abandonment	Responsibility
	Survivor	Different	Awareness of difference	Loss of social identity	Dependence
			Loss of self-knowledge	Different	Survivor
				Perceived stigmatisation	
				Work and productivity	
				Positive personal growth	
Overview of discourses. This table lists the 33 overlapping discourses ordered by the five discourse themes, as described in the text. The themes are (overarching) discourses and serve to bind the remaining discourses for analysis. Some discourses appear in more than one theme. All discourses are conceptualised within the overarching medical and psychosocial discourses.					

SECTION B – PUBLISHABLE PAPER

(Re)Constructions of identity following traumatic brain injury: A discourse analysis

This paper is written in accordance with Neuropsychological Rehabilitation's guidelines for the authors (Appendix J).

This study was conducted in affiliation to City University, London, as part of a Professional Doctorate in Counselling Psychology (DPsych)

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Abstract

A multiple qualitative methodology was used to explore how people with traumatic brain injury (TBI) (re)construct identity. Eight individuals who sustained moderate to severe TBI were interviewed. Different interpretative “lenses” were used to analyse the data: Foucauldian discourse analysis (FDA) was used to explore how individuals with TBI (re)construct identity in their society and culture. The study also focused on the role of subject positionings within discourses. Frank’s illness narratives (restitution, chaos, quest) were applied by placing the participants’ account of identity following brain injury within a broader meaning-making process. The analysis distinguished discourses of “disability”, “medical”, “invisibility” and “dependence”, which appeared to result in disempowered subject positionings. Discourses of “independence” and “acceptance” appeared to enable empowered subject positionings. An interesting aspect of the findings is that the “dependent” and “independent” discourses are of a fluid and shifting nature. The findings support the social constructionist view of identity as a fluid and multidimensional construct. The findings of this study may inform how clients with TBI adjust and accept “new” identities following their brain injury. Clinical implications are discussed in the context of neurological rehabilitation. Opportunities for accessing alternative and more empowering discourses are considered.

Keywords: Traumatic brain injury, multiple qualitative analysis, Foucauldian discourse analysis, Frank’s illness narratives, disability, process of empowerment.

Introduction

In the UK, around 700,000 people attend emergency departments with traumatic brain injury (TBI) each year (Barrow et al., 2012). TBI is the result of an external source coming into forceful contact with, or rapid acceleration/deceleration movements of the head (Kushner, 1998). The acquired injury results in variable alteration of cognitive and behavioural functioning. These effects may be transient, long-lasting or permanent, depending on injury specifics and severity (Roebuck-Spencer & Cernich, 2014). Individuals with TBI are at high risk of developing psychological issues, including depression, anxiety, post-traumatic stress disorder (PTSD), loss of motivation and difficulty controlling anger (Brown, 2014). Individuals with TBI also frequently experience somatic symptoms including headaches, dizziness, fatigue, muscle rigidity, paralysis, seizures, speech impairment, sensory problems and loss of sight (Sheerer & Sander, 2014). Physical disability often leads to serious social problems. Many individuals never recover full social independence and remain largely dependent on family and health care support (Wood, 2013). Cognitive symptoms include memory impairment, slow processing speed, poor attention and concentration, and loss of insight, awareness and initiative (Sheerer & Sander, 2014). TBI may result in physical scarring, however, many individuals with TBI have few or no visible sequelae and the consequences of the injury are often invisible (Sinnakaruppan & Williams, 2001). The invisibility of their disability can have an impact on relationships and psychological wellbeing (Kendall & Terry, 1996). Steadman-Pare, Colantonio, Ratcliff, Chase and Vernich (2001) found that the lack of recognition of the participants' invisible injuries was a major factor influencing their life satisfaction.

5.1 Changes in identity following TBI

Individuals with TBI have reported experiences of personality disturbance, loss of sense-of-self and changes in identity (Prigatano, 1992). Loss of sense-of-self involves conscious awareness that part of the individual post-injury is, in some way, not the same as pre-injury (Nochi, 1997). Morris et al. (2005) interviewed individuals who had sustained TBI one to ten years previously. Many participants reported concerns about loss of sense-of-self and sense of identity. Following TBI, changes in the biological state of the brain can result in temporary or permanent changes in

emotional and motivational responses (Prigatano, 1992). When these changes are more permanent, they can manifest as personality changes. For example, psychosocial changes related to brain injury may cause increased irritability, agitation, anger or apathy (Prigatano, Pepping & Klonoff, 1986). Because of the complexity and multiple causes, it is very difficult to conceptualise or measure changes of personality (Prigatano, 1992).

Qualitative research exploring how people with TBI subjectively experience altered identity and loss of sense-of-self has increased since the 1990s. One reason for the absence of research prior to this is that individuals with TBI were considered lacking in self-awareness due to their enduring neuropsychological impairments and its emotional and social consequences (Crisp, 1994). Thus, researchers have not always trusted that self-reports directly reflect the subjective experiences of the participants (Crisp, 1994). However, Tyerman and Humphrey (1984) proposed that individuals with TBI might have more awareness than was typically appreciated. Prigatano (2000) suggested that by making the presumption that individuals with TBI have subjective experiences including the capacity to comment on their sense-of-self (even of lost or altered), it is possible to develop a deeper understanding of the phenomenological experience of brain injured clients. During the last three decades, researchers have begun to develop a deeper understanding of subjective experience and sense-of-self among individuals with TBI (e.g., Nochi, 2000).

Levack, Kayes and Fadyl (2010) conducted a meta-synthesis of 23 qualitative studies published between 1965 and 2009 investigating lived experiences of recovery from TBI acquired in adulthood. The review highlights some important issues, including mind and body disconnection, disconnection with pre-injury identity, social disconnection, emotional sequelae, internal and external resources, reconstruction of identity, and reconstruction of a place in the world. Levack et al. suggested that further research and in-depth analysis of identity was needed to develop outcome measures to evaluate experiences of loss of identity, satisfaction with reconstruction of identity, and sense of connection with one's body and one's life following TBI. Myles (2004) studied loss of self from the perspective of relational frame theory (Hayes, 1995), which defined three distinct senses of self: conceptualised self, self as an ongoing process of verbal knowing, and self as context. Loss of sense-of-self following TBI can be understood as the effects of a

“crisis of the conceptualised self” (Hayes, 1995). From this perspective, loss of sense-of-self is largely a verbal and relational process. This may be expressed as “I am not the same person” (Myles, 2004). Myles suggested that this is associated with emotionally distressing negative self-evaluations of the post-injury changes and functioning.

Nochi’s series of psychosocial studies examined the self-narratives of individuals with TBI. Nochi (1997) found that the participants carried a “void” in their understanding of their past and current selves. Nochi suggested that the “void” manifested in various ways. First, the “void” was associated with participants’ sense of loss from changes in physical and cognitive functioning after sustaining TBI. Second, there was a “void” in memories of the past, which made it difficult for participants to build a consistent narrative of their past. Finally, there was the “void” within present self. Nochi (1998) identified three areas of “loss of self” following TBI: “loss of self in relation to pre- and post-injury comparison”, “loss of self in the eyes of others”, and “discontinuity of identity through lost disrupted memories”. Nochi suggested that the diverse nature of loss of self reflects the complexity of self and that the self is constantly generated and modified by the person’s interaction with the world. In a further study, Nochi (2000) found that participants reconstructed certain self-narratives in coping with their changed self-images and daily lives. The common narratives included: “the self better than others”, “the grown self”, “the recovering self”, “the self living here and now”, and “the protesting self”. Nochi concluded that successful developments of self-narratives needed to occur in interaction with other people, society and culture, as opposed to in the context of isolated rehabilitation.

Gracey et al. (2008) conducted a thematic analysis of identity pre-injury, current identity post-injury, and the ideal post-injury self. The authors concluded that with an acquired brain injury (ABI, a term that includes TBI, strokes and brain tumours), people make sense of themselves in terms of the meanings and felt experiences of their social and practical activities. The researchers endorsed the need for rehabilitation to focus on skills in the domains of cognitive, physical, sensory and social functioning. A recent study by Freeman, Adams and Ashworth (2015) used thematic analysis to explore the experience of perceived changes in sense-of-self relating to the social identity of men with TBI. Some major themes identified were

“perceived stigmatisation”, “a sense of abnormality”, “TBI being an invisible injury”, “being treated differently”, and “loss of social status and shame”. Yeates, Henwood, Gracey and Evans (2007) explored awareness of disability following ABI, within a family context, interviewing individuals with ABI and their relatives. The authors found that both individuals with ABI and their relatives struggled to make sense of changes in identity. Cloute, Mitchell and Yates (2008) used discourse analysis to explore the co-construction of identity with family members. The analysis identified four overarching interpretive repertoires including “medical model of referencing”, “dependence as intrinsic to TBI”, “TBI as deficit and progression”, and “productivity as key life-defining features”. Their analysis showed a common pattern of passive and disempowered positions in relation to the “medical model of referencing” (Cloute et al., p. 664). The authors proposed that understanding identity as occurring in conversational discourse might be clinically useful in helping individuals co-constructing a more empowered self-narrative. Cloute et al. proposed further research into discursive ways of understanding TBI and identity, as social constructionist interpretations are rare within brain injury literature.

5.2 Combined research methodologies in relation to chronic illness

In recent years, psychological researchers have begun to use a combination of qualitative research methodologies. Frost (2009) argued that multiple research methodologies within the context of a single study allows for a multi-layered understanding of the data. The literature search identified a limited number of studies using multiple methodologies in brain injury studies. Todres and Galvin (2005) and Galvin, Todres & Richardson (2006) completed a qualitative study, combining narrative and descriptive phenomenological analyses to explore the experience of caring for a significant other with Alzheimer’s disease. The authors conclude that the two methodological approaches complemented each other in terms of gaining knowledge of “breadth” (narrative identity) and “depth” (lived experiences). A study by Godwin, Chappell and Kreutzer (2014) used a multiple research methodology to explore how couples adjusted following one of the partners sustaining TBI. Firstly, grounded theory was used to explore lived experiences and analyse narratives written by individuals with TBI and their partners. A second analysis was conducted of clinician-authored literature. Triangulation and constant comparative analysis of the data was then performed

through substantive and theoretical coding. Two grounded theories were developed: relational coring and relational recycling. Relational coring included themes that impacted the couples, such as ambiguous losses. Relational recycling refers to the process of emotional healing and an evolving couple identity. Godwin et al. (2014) suggested that rehabilitation professionals need to construct treatment plans that include patients coupled relationships.

5.3 Social context of identity

Different psychological approaches propose varied and occasionally contradictory ways to define the concepts of identity. This study is underpinned by social constructionism (Burr, 2003; Foucault, 1980) and positioning theory's (Davies & Harré, 1990; Harré & van Langhove, 1999) view of identity. Research from a social constructionist perspective is concerned with identifying multiple ways of constructing identity and social reality (Willig, 2013). According to social constructionism, all that accounts for human experience is constructed through language. Thus, identity is constructed in daily life by drawing on available discourses and in communication with others; language is part of identity construction (Burr, 2003; Gergen, 2001). A "discourse" refers to a coherent set of meanings, metaphors, representations, images, stories and statements that together construct a particular version of events (Wiggins & Potter, 2013). This suggests that there may be a variety of different discourses surrounding any individual, each with a different narrative and representation of the world (Burr, 1995). It is argued that identity is constructed continuously, meaning that is considered unstable and fluid (Burr, 2003). All social and psychological phenomena, such as identity, memory and subjectivity, are constructed through language. Therefore, identity is not perceived as "inner reality" but as a socially constructed psychological phenomenon (Potter & Wetherell, 1987).

5.4 Rationale and objective of present study

There is a growing body of literature exploring subjective experiences following brain injury (Gracey et al., 2008; Nochi, 2000). However, some authors have concluded that there remains a need for more in-depth qualitative analyses that

focus on TBI in relation to identity, psychological therapies and experience (Levack et al., 2010; Yeates et al., 2007).

The aim of this study was to add to Cloute et al.'s (2008) discursive research and to facilitate further understanding of the use of discourses when (re)constructing identity following TBI. The aim was also to gain a multi-layered understanding of the data using a multiple methodology. The rationale for combining different theories and methodologies is that this offers a more holistic view of people's experience and provides insights that cannot be gained by using one method alone (Chamberlain, Cain, Sheridan & Dupuis, 2011; Frost, 2011). To facilitate this, an analysis combining different interpretations was applied, to answer the following research questions: (1) what discourses are used by individuals with TBI to (re)construct aspects of their identity? (2) What subject positions are made available by these discourses? and (3) What narratives are used within the identified discourses and positionings?

5.5 Method

5.5.1 Background

There has been a tendency to interview caregivers of individuals with TBI rather than the individuals with TBI themselves about their experiences. This suggests an underlying assumption that people with moderate to severe TBI do not have the ability to communicate in meaningful ways about their subjective experiences (Paterson & Scott-Findlay, 2002). However, some authors argue that populations with disabilities represent a unique culture in which memory and recall are cultural representations. Therefore, it is important that these people are included in research that investigates living with their disabilities (Crowe, 1998; Paterson & Scott-Findlay, 2002). In this study, the researchers took into consideration that several participants suffered from impaired short-term memory and/or long-term memory. Some participants also experienced attention deficits and became fatigued during the interview. Two suffered from speech impairment. The researchers used strategies from the literature to mitigate and attend to these challenges. For example, Paterson and Scott-Findlay (2002) recommended preparing carefully before

interviewing people with TBI. The researchers adapted the interview for participants with memory impairment by using direct and straightforward questions.

The conventions, standards of conduct and evaluation of qualitative research can be difficult to define (Yardley, 2000). To aid evaluation, the researchers followed the principles of Yardley (2000), and Elliott, Fischer and Rennie (1999) when assessing the validity and reliability of this study. The researchers needed to adopt a reflexive position to acknowledge their own interests in relation to the topic and how this could lead to potentially biased interpretations.

5.5.2 Participants

All participants were clients of a head injury charity in London. Data were obtained by interviewing eight participants consisting of five males and three females, with an age range of between 29 and 61 years (mean = 45.9). All participants were White British. The participants provided information about the severity of their brain injury themselves; severity ranged from moderate to severe on the Glasgow Coma Scale (GCS, Levin & Eisenberg, 1991). They had all been hospitalised post-injury and had subsequently returned to the community. Only one participant was in paid employment post-injury. Five of the participants worked as volunteers at the charity. Four of the participants acquired their head injuries from car accidents, two from motorbike accidents, one from parachute jumping and one from assault. They had obtained their injuries eight to 37 years prior to the interviews. The participants were all able to read and understand English. There was no exclusion on basis of sex, gender, ethnicity or religion. Participants' demographic information is presented in Table 1.

The participant recruitment method was developed to give consideration to ethical issues such as how to safeguard participants' confidentiality and wellbeing. Potential participants were identified and approached by the staff at the charity, who informed them about the study. Potential participants then contacted by the researchers or by a member of staff if they wanted to participate.

5.5.3 Data collection

Biographical narrative semi-structured interviews (Potter & Wetherell, 1987) were conducted to elicit conversation around lived experience prior to and post injury. Participants attended one or two face-to-face interviews, which lasted in total between 45-90 minutes. Some participants preferred to attend two shorter interviews. The best possible timing and duration of the interview was chosen, taking into account participants' tolerance of extraneous stimuli and patterns of fatigue (Paterson & Bramadat, 1992). The interview procedure for this study was informed by Potter and Wetherell (1987). They claim that interviews for discourse analyses need to consider both consistency and diversity. Consistency is important as the researcher wishes to identify regular patterns in language use. Diversity and variation will inform the researcher of the full range of discourses that individuals might draw on when constructing the meanings of a topic. It is important to acknowledge that the researcher becomes part of the "conversation", and that the researcher's questions become just as much a topic of the analysis as participants' answers. The interviews were audio-recorded. The audio recordings were transcribed verbatim. A reduced transcription style, Atkinson and Heritage's (1984) original conversational transcription notation, was adopted. All the data will be kept secure for five years and then destroyed.

5.5.4 Data analysis

The aim of this study was to explore the way in which individuals with TBI (re)construct identity using a multiple qualitative approach. This approach combines methods, analysis or interpretations to seek multiple perspectives on human experience (Frost, 2011).

5.5.5 Foucauldian Discourse Analysis (FDA)

FDA (Willig, 2013) was used to explore how people with TBI (re)construct identity in their society and culture. In the current study, FDA was carried out following Willig's (2013) six analytic stages including discursive constructions, discourses, action orientation, positionings, practice and subjectivity. (1) Discursive constructions: this stage involves identifying discursive constructions by reading through the data with

the question: “How is the object (identity) (re)constructed?” In this stage, both implicit and explicit references (to identity and to TBI) needed to be included. (2) Discourses: in this stage, the researchers asked: “What discourses were drawn upon to (re)construct aspects of identity?” and “What is their relationship to each other?” The aim was to link all participants’ references, patterns, differences, contradictions and discursive constructions to the different discourses. (3) Action orientation: action orientation refers to the strategic deployment of talk in order to achieve particular social effects (Willig, 1999). The researchers asked questions including: “What is achieved by participants with these discourses?” and “What were the consequences (action orientation)?” Through examining a person’s action orientation, researchers may gain further understanding of what the various constructions of the discursive object (identity) are capable of achieving in a conversation. (4) Positionings: here the researchers identified different subject positionings associated with the discourses, to explore how discourses and inter-relationships within discourses enabled different subject positionings. This part of the analysis was informed by positioning theory, which proposes that people’s identities are formed through their positioning within a discourse (Davies & Harré, 1990). (5) Practice: this stage considered the relationships between discourse and practice. It involved exploring the ways in which discursive constructions and subject positionings contained within them opened up or closed down opportunities for action (Willig, 2013). Thus, when a person constructs a particular view of the world and positions themselves within this view, discourses facilitate, limit, enable and constrain what can be said and done (Willig, 2013). (6) Subjectivity: this stage explored the relationship between discourses and subjectivity. It explored how participants may have felt, thought and experienced their discourses from within their various subject positionings (Willig, 2013). The six stages were repeated for each of the eight participants. After analysing the interviews, the researchers looked for unifying and differing themes between them.

5.5.6 Frank’s illness narratives

A narrative reading was used to explore the meaning of participants’ (re)construction of their identity in the context of their overall story. Frank (1995) identified three types of narratives told by people who have experienced illness: restitution, chaos and quest. The restitution narrative has the basic story line:

“Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again”. The narrator of the restitution story wants the body’s former predictability back again. In the chaos narrative, the plot is that life will never improve and no one is in control. Quest stories are defined by the ill person’s belief that something is gained through experience. In the current study, the aim of using Frank’s illness narratives was to conceptualise and organise the identified discourses and positions identified in the FDA. The aim was not to coerce the participants’ discourses into one or more of Frank’s illness narratives (restitution, chaos and quest) but rather to try and disentangle narrative threads.

5.6 Analysis

The analysis of the interviews distinguished two overarching discourse themes (“medical” discourse and “psychosocial” discourse) and 31 discourses, which were conceptualised, integrated and presented in five discourse themes: (1) identity in relation to “disability” and “invisibility”; (2) identity as “rebirth” and “ongoing development”; (3) identity in relation to “uncertainty” and “awareness”; (4) identity in relation to the “perceived normality” and “social belonging”; and (5) identity in relation to “independence”, “acceptance” and “recovery”. An overview of these discourses is presented in Table 2. In this paper, the following discourses are presented and discussed: “medical”, “disability”, “invisibility”, “perceived stigmatisation”, “dependence”, “independence” and “acceptance”. The reasons for choosing these discourses were: (1) that these were highly prevalent discourses; (2) discourses of “disability”, “medical” and “invisibility” often appeared to offer positions of dependency and disempowerment, and to construct physical impairments as “wrong” and needing to be “fixed” to become “right”; (3) “invisibility” and “perceived stigmatisation” are likely to be associated with social isolation; and (4) discourses of “acceptance” and “independence” were drawn upon to (re)construct alternative and “new” identifications. “Acceptance” and “independence” discourses were often part of an adjustment period, which unfolded over a long period of time. A person’s sense-of-self seemed to shift to allow them to assimilate their “new” identity. The researchers are aware that organising the identified discourses under themes is artificial. It creates labels and categorisation of the participants’ narratives, which may impoverish the complexity of human interactions and resources (Wooffitt,

2005). Therefore, it is important to emphasise that the themes are not rigid but indicate possible constructions amongst many available.

In the next section, extracts from the analysis are presented. The analysis integrates FDA (Willig, 2013), positioning theory (Davies & Harré, 1990), and Frank's (1995) illness narratives.

5.6.1 Disability and medical discourses

Several participants drew on a “disability” discourse (re)constructing identity. The “disability” discourse could endorse the belief that physical impairments are “wrong” and can be corrected with medication and medical treatment. This discourse was often accompanied with a loss of professional identity and a loss of social identity. Several participants drew on a “disability” discourse and talked about not being able to function physically and cognitively in the same ways as they did before their injury.

“It’s really affected, um I’m a lot slower. Um and is that I’m really slow at learning. It’s like something about my brain just doesn’t... it doesn’t click in my brain for so long.”

The disability often appeared to not be recognised as part of self; participants seemed to want to become “right”. The “disability” discourse offered an expectation of hope for improvement. The construction of “right and wrong” was also represented as an index of what is the “right” way to be and behave in society. The discourse represents how a person “should” be as shown by the following extract.

“It was like the local hospital. Basically and I was like I just... I want to know whether I’m meant to be right now or whether... or whether there is something that’s always going to be there.”

The “disability” discourse is linked to the “medical” discourse. For example, one participant talked about visiting the doctor and being told that her brain would never “[work] properly”. This may have constructed a power relationship between the

doctor and the participant, in which he as an expert states that the participant will never function properly, without considering her personal experience or functioning.

“Um and I saw a doctor. He didn’t even have my notes basically, he was going off what I said and it was like “oh yeah, you’ve got brain damage so you’ll always have a part of your brain that’s... that’s sort of not... not working properly or something.”

A “medical” discourse suggests a rigid view of identity and largely determines what is held valid in society. The use of these discourses (“disability” and “medical”) may be associated with positions of psychological “stuckness”, dependence and disempowerment. These positions might serve to constrain participants’ ability to (re)construct a meaningful identity following TBI.

One can argue that “disability” and “medical” discourses can be connected to the restitution narrative, as they endorse the belief that “health” is the normal condition that people ought to have restored (“Yesterday I was healthy/abled-bodied, today I’m sick/disabled, but tomorrow I’ll be healthy/able-bodied again”). The restitution narrative is also connected to a medical cure and the expertise of health professionals. The narratives describe the participants’ expectations of a diagnosis and hope of a restored self. In the above extracts, the restitution narrative was related to hope about becoming “healthy” again, that is, able-bodied, and about re-connecting with the identity participants had prior to their injury.

The association with “healthy” as the norm may constrain individuals who are chronically ill to a disempowered position. One part of participants’ narratives could be their own desire for restitution. The narratives might also be affected by the expectation of what participants think other people want to hear. The restitution narrative seemed to be a more common narrative among participants who had experienced a sense of cognitive recovery, and among those who had experienced becoming more like they experienced themselves to be before their injury.

5.6.2 Invisibility and perceived stigmatisation

The “disability” discourse was often accompanied by an “invisibility” discourse. The “invisibility” discourse’s central point was the physical “hiddenness” of the brain injury to other people, and other people’s subsequent disregard for or under-appreciation of its effects. The “invisibility” discourse offered positions of disconnection and disempowerment, which may have been associated with participants perceiving that they were misunderstood, undervalued or rejected by wider society.

“And um like any...because...the other thing is with brain injury is it’s...it’s not physical, no-one can see it...”

“Like you don’t have any problems at all because the real problem with it is the invisibility thing. Look at me ‘do you have brain injury?’ No but he has. I think you look at someone in a wheelchair and you say something is wrong with you. There are assumptions all the time.”

Participants seemed to use invisibility as a negative metaphor to describe a sense-of-self. In relation to identity, the word “invisibility” suggests that a person is socially and emotionally isolated, and in some ways absent from the world in which they exist, despite being physically present in that world. The invisibility discourse appeared to create a position of disempowerment, which may have constrained participants’ progress and the psychological flexibility needed to (re)construct a “new” meaningful identity.

Interviewer: Do you feel that you need to tell them that you have a brain injury?

Participant: It’s really... it’s like I don’t... that’s crazy... Yeah and it’s like I don’t want to and I don’t at first, I’m kind of like trying to be balanced and bubbly and pretend that nothing’s there and ra, ra, ra and then...

Constructions of “invisibility” were sometimes associated with a discourse of “perceived stigmatisation”, which offered positions of disconnection and disempowerment, and may have been associated with participants perceiving that they were misunderstood, undervalued and rejected by wider society. This is highlighted by some participants’ avoidance of disclosing their brain injury to others. There could be different functions for this. One function could be to avoid rejection. By not disclosing, participants might wish to avoid prejudice and discrimination, and perhaps would prefer to be treated like the “medical” discourse’s understanding of “normal”. Another function could be that participants do not want TBI to be their identity in a group (e.g., at work).

The discourses of “invisibility” and perceived stigmatisation can be linked to the chaos narrative. Individuals living in the chaos narrative describe experiencing an “emotional battering” stemming from their rejection by others (Frank, 1995). In the above extracts, participants expressed the difficulties arising from TBI being a hidden disability. This seemed to create a position of social disconnection and fear of rejection. In chaos stories, life does not get better, the wound is just too raw and the danger is ever present (Frank, 1995).

5.6.3 Independence and dependence

A discourse of “independence” was often accompanied by a conflicting discourse of “dependence”. Some participants had physical disabilities that made them dependent on family and health care support. However, for some participants, the “dependence” discourse developed over a longer time-frame post-injury, after which, a discourse of “independence” became available. This may have been associated with improvement in participants’ symptoms or adaption to them. Thus, some participants shifted themselves towards a more independent and empowered position over time.

For example, one participant used the discourse of “dependence” in contrast to “independence”. She talked about her life prior to her injury, when she was independent, in comparison to her life following the acute injury, when she found herself dependent.

“Then there's times when I am tired, when it doesn't always pan out. It is hard. I went from being independent and going on holidays to places like the Maldives, and stuff like that to then sitting indoors. We didn't get any help, so my Mum was buying me colouring books. She said like ‘see if you can colour [the letter A], without going over the lines’.”

The discourse of “dependence” was employed as she discussed how she had been limited by the physical and cognitive symptoms of the injury. However, from the acute period post-injury to the time of interview, the participant experienced physical and cognitive recovery. At the time of interview, she drew on a more “independence” discourse.

“Yeah. She got me back out into the world and I think she has helped me take responsibility again for me. Because, yeah, I'm responsible for looking after [her dog] which makes me responsible.”

The participant's construction of identity is not constant and she referred to different levels of identity pre-injury, following the acute injury and at the time of the interview. This suggests that different discourses have been available during different times in her life and is consistent with research that argues identity is fluid. Similarly, restitution, quest and chaos narratives seemed to alternate – identity was therefore permeated with a plurality of meaning. Some participants' narratives began with chaos, moving to restitution and then transferred to quest narratives. For other participants, a chaos narrative seemed to stay with them. For some participants, the quest narrative seemed to be dominant throughout their story.

5.6.4 Acceptance

Some participants drew on an “acceptance” discourse, which enabled them to accept their disability and “new” identity, and which was part of their process of recovery. This suggests that “recovery” was gaining equipoise with their TBI, as opposed to returning to their pre-injury levels of functioning. The “acceptance” discourse might have allowed the individual to (re)construct their identity in a forgiving and non-judgmental way. However, the concept of “acceptance” has

idiosyncratic meanings for individuals and is not inevitably associated with positive or negative values.

One participant who drew on the “acceptance” discourse expressed: “I just have to accept it and that’s just me” and “it’s just me now, I’ve got to accept that I’m not where I was”. She referred to accepting her situation “now”, which implies that she was still on a path of adjusting during the interview. In other words, she was aware she had memory impairment and learning difficulties, but she saw herself as adjusting because she seemed to have accepted this part of herself and to have incorporated it into her identity. This implies that an adjustment or recovery (transformation) period unfolds over a prolonged period of time, and that a person’s sense-of-self shifts during this period. Thus, it might be that an “acceptance” discourse offers a position of independence and empowerment.

“Yeah, because before that I always thought I’ll just get over [cognitive symptoms of brain injury], I’ll get over it, I’ll get over it and um yeah, now I know that I’m never going to be right and things take me a lot longer to learn and stuff like that but... I just have to accept it and that’s just me.”

For one participant his long-term memory was still intact and he remembered events, behaviour and feelings prior to the injury. He had access to a narrative of self that existed prior to his injury, which appeared to help him to (re)construct his current identity. The “acceptance” discourse seemed to enable participants to reconcile to the possibility that changes in identity and feeling “different” were not necessarily negative.

Interviewer: How does it make you feel to have a new personality?

Participant: I always wondered if I met the old me how would we get on. I don’t even know if he would have time for me because he was so busy that maybe he would not have time for me. I don’t know, I don’t know. Am I better me or worse me? I am just different me. I am still me but a different me...

The above extract illustrates that although the participant felt “different” post-injury, he still had a strong sense of his “old” identity. The discourse of “acceptance” might offer a position of freedom to (re)construct his identity with reference to how he used to be. Alternatively, it might simply reduce potential conflict that could arise from the knowledge of two identifiable and different senses of self.

The above narratives were based on a developing process of adjusting to, adapting to and accepting change. Participants expressed that adapting to their illness had been difficult, and they recognised the damage that the illness has done. They were not solely seeking recovery from illness (restitution), nor did they seem to have lost all hope (chaos); instead they were trying to adjust and to accept. The “acceptance” discourse could be connected with a quest narrative, in which the meaning-making was not about “gaining” something from TBI, but about “adapting” to resulting changes. A quest narrative can be linked to a counter-narrative and an affirmative model of disability, where being disabled is not seen as a tragedy. This is important as a counter-narrative might help in the process of (re)constructing identities. A quest narrative also represents a journey of accepting, reflecting on and understanding change, resulting in a transformation of one’s self.

5.7 Discussion

Through careful and methodical FDA of interviews with individuals who had sustained TBI, discourses of “identity” were identified. The findings in this study demonstrated that participants used discourses to (re)construct identity including “disability”, and “medical”. Cognitive and physical symptoms often underpinned (re)constructions of identity. A “medical” discourse endorsed the belief that physical impairments were “wrong” and were supposed to be “fixed” to become “right”. These discourses seemed to offer positions of dependency and disempowerment. Disempowered and dependent positions could have implications for action, as such positions appeared to constrain some participants’ ability to (re)construct a “new” meaningful identity. This supports findings by Cloute et al. (2008) who identified “TBI as deficit” and “medical referencing” as two major interpretative repertoires. Cloute et al. proposed “TBI as deficit” could create positions of passivity and disempowerment. This finding also relates to the wider socio-political view that a disability discourse can be a form of “social oppression” (Oliver, 1990).

Frank's (1995) illness narratives were used as a supplementary reading to explore identity further from another interpretative "lens". The narrative reading found that different types of narrative could be connected with different discourses. For example, the restitution narrative could be linked with "disability" and "medical" discourses. The quest narrative appeared to be connected with an "acceptance" discourse. The aim was not to "force" the different discourses to "fit" in a specific narrative style, but to discuss the discourses further within the framework of the narratives.

The present study's findings suggested that participants drew extensively on an "invisibility" discourse when (re)constructing their identity. Individuals with TBI often show no physical evidence of their disability (Sinnkaruppan & Williams, 2001). Invisibility was often described as a "negative" aspect of identity. The invisibility discourse sometimes created a position of "abnormality" and "not belonging" to wider society, and appeared to evoke feelings of not being understood and being socially disconnected. An "invisibility" discourse could also endorse a position of disempowerment, constraining individuals' psychological flexibility in (re)constructing a meaningful identity. The conflict between "disability" and "invisibility" discourses might have constructed a power relationship between individuals with TBI and individuals without TBI. Participants expressed that they felt misunderstood in a society where a person "should" be able and productive if other people could see no physical impairment. This finding supports the findings of McClure, Buchanan, McDowall and Wade (2006), that the public and non-expert health professionals hold misconceptions about TBI, and overestimate the abilities of those with invisible disabilities more than they overestimate the abilities of those with visible disabilities. It also resonates with Chamberlain (2006), who found that the invisible nature of TBI had a negative effect on participants' mental health and recovery.

Both discourses of "invisibility" and of "perceived stigmatisation" could be linked with the chaos narrative. Chaos stories reveal vulnerability, futility and powerlessness. Chaos narratives also describe fear of rejection by others (Frank, 1995). Crocker, Major and Steele (1998, p. 505) proposed that "stigmatisation occurs when a person believes they possess some attribute or characteristic that devalues their

social identity and marks them as different within a particular social context". Participants in the current study reported that they did not always disclose their injury to others. The purpose of this may be to avoid prejudice, discrimination and rejection. Stigmatisation could be addressed through education and interaction between individuals with TBI and members of the public (Corrigan, Druss & Perlick, 2014). Stigmatisation could also be addressed through social support and social connectedness within rehabilitation. There is a growing evidence that social connectedness is associated with wellbeing among individuals with chronic illnesses (Haslam, Jetten, Postmes, & Haslam, 2009). Haslam et al. (2009) suggested that a shared identity (i.e., defining the self as having a group membership) could help individuals to address issues that affect them collectively, for example, by promoting awareness, disseminating information, and challenging stigmatisation. Jones et al. (2008) explored the relationship between social support and social identity among individuals who experienced TBI and ABI. Jones et al. found a paradoxically small but significant correlation between severity of TBI and life satisfaction. A follow-up analysis indicated that this relationship could be explained by the fact TBI tended to increase the strength of individuals' sense of social identity through the social support and social connectedness they experienced from significant others and from social networks as part of their rehabilitation.

An important finding in the current study is that "dependence" and "independence" discourses are fluid and changing. The discourse of "dependence" changed over time, situation, and with interpersonal dynamics. Some participants shifted themselves to a more independent and empowered position over time. Some participants experienced cognitive and physical recovery, which allowed them to lead more independent lives. For example, the responsibility of working as a volunteer could facilitate a shift of positioning to a more empowered and independent construction. This corresponds with the concept of a fluid and multidimensional identity and implies that people undergo many changes throughout a lifetime (Davies & Harré, 1990). This is also in line with Frank's illness narratives (1995), which are considered to be fluid and continually developing.

5.7.1 Clinical implications

This study provides further understanding of the discourses individuals with TBI use and of the relationships between dominant discourses, available positions and illness narratives. It provides further knowledge about the needs of clients with TBI. For example, the findings suggest that participants drew on “disability” and “medical” discourses, providing positions of dependency and disempowerment, which may have hindered them in creating an identity involving self-worth and the confidence to produce a meaningful life. These discourses were also related to the restitution narrative and the idea that “healthy” is the (Western social) norm (Frank, 1995). This finding highlights that services and healthcare professionals working with individuals with TBI need to consider opportunities to access alternative and empowering discourses and subject positionings, in order facilitate the (re)construction of an alternative identity. This could be addressed through psychological interventions within community-based outpatient holistic rehabilitation.

There is growing evidence that community-based outpatient holistic rehabilitation leads to improvements in perceived quality of life, cognition and self-sufficiency (Cicerone et al., 2004; Coetzer, 2008) among patients with TBI. Yates (2003) argued that community-based rehabilitation programmes based around a biopsychosocial model may improve psychosocial functioning and social role outcomes for survivors of TBI. The World Health Organisation’s International Classification of Functioning, Disability and Health (ICF WHO, 2001) is based on the biopsychosocial model of disability, and considers both health factors and contextual factors. Its core components include body functions and structures, environmental factors and personal factors, activities and participation. Participation can be described as a way of contributing to a broader society by working with, consulting and empowering communities (WHO, 2002).

Yates (2003) highlighted the importance of integrating the concept of “empowerment” into intervention and rehabilitation programmes, particularly the elements of “personal power” (the power of the individual to influence their environment) and “power with” (social power where people come together as equals) (Neath & Shriner, 1998). These forms of power could facilitate the shaping of flexible and community-enabling interventions as part of long-term rehabilitation

for individuals with TBI. The WHO (1998, p.6) defines empowerment as “a social, cultural, and psychological process through which individuals and social groups are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and achieve political, social and cultural action to meet those needs.”

O'Hara and Harrell (1991) developed “the empowerment rehabilitation model”, which is a holistic and integrated approach to enhancing enablement and empowerment processes among individuals with TBI. The model serves as a guide to treatment, and includes several components: enhancing motivation; enabling of patients with information and skills; and empowering patients with self-awareness, acceptance and self-respect. It works towards patients' acceptance of a redefined personal identity, a redefined sense of meaning in life, and a newly defined future. A study by Sit, Yip, Ko, Gun, and Lee (2007) on community-based stroke prevention demonstrated that educational intervention by health professionals helped clients to integrate their learned knowledge into their real life experience. The opportunity to integrate learned knowledge in daily life empowered clients to develop self-care and responsibility.

The current study also highlights the importance of working with re-shifting positionings to an alternative perspective. A therapeutic goal would then be to facilitate access to more empowering subject positions. Fenton and Hughes (1989) suggested that a change of power constructions could evolve by creating an empowering system within a practice or organisation, and by encouraging self-empowerment through language. Self-empowerment is a process of becoming increasingly in control of oneself and one's life, and consequently increasingly independent. Fenton and Hughes argued that this could be achieved by actively working on attitudes and beliefs.

There are some concerns with the “process of empowerment”, for instance, if an “empowerment” discourse becomes a dominant construction, it may lead to negative implications. In a discursive study of smoking addiction, Gillies and Willig (1997, p. 298) stated that “replacing a discourse of addiction with a construction of self-determination is not necessarily a positive step, in that it can foster guilt and self-blaming and thereby actively impede health promotion objectives”. Health

professionals need to develop awareness of how dominant discourses can have negative implications within a therapeutic relationship (Burr, 1995). This can be established by being aware about the impact of language and constantly analysing the impact of our discourses. Willig (2013) argued that some discourses are so entrenched in society that it is very difficult to see how to challenge them. However, “it is in the nature of language that alternative structures are always possible and that counter-discourses can, and do, emerge eventually” (Willig, 2013, p. 130).

One important finding in the current study is that an “acceptance” discourse appeared to enable positions of empowerment and independence. The “acceptance” discourse could also be connected with a quest narrative, in which meaning-making was about adapting to changes post-TBI. Importantly, the concept of “acceptance” has an idiosyncratic meaning for individuals and is not inevitably associated with positive or negative values. The “acceptance” discourse was often constructed over a period of years and allowed the participants to assimilate this shifting positioning of being. This offers an opportunity for ongoing cognitive and emotional development, and psychological flexibility for rehabilitation. However, it seemed that the “acceptance” discourse was not available to all participants, and positions of helplessness sometimes constrained psychological flexibility.

It has been suggested that acceptance is a key process for rehabilitation work. Ben-Yishay and Prigatano (1990) suggested that stages of engagement, awareness, mastery, control and acceptance are vital processes of rehabilitation. Thus, specific psychological therapeutic approaches aimed at facilitating acceptance and psychological flexibility could be considered part of a holistic neuropsychological rehabilitation programme. One example is acceptance and commitment therapy (ACT, Hayes, 2004; Hayes, Strosahl & Wilson, 2003), which aims to improve functionality within psychological events (thoughts, beliefs, perceptions) rather than only to reduce symptoms. As the premise of ACT-based interventions is facilitating functional change, the approach may have particularly utility for helping individuals with TBI to re-engage in living a meaningful life despite their neurological and physical disabilities (Kangas & McDonald, 2011). Psychological flexibility and functional change are established through six core processes: acceptance, cognitive defusion, being present, self as context, values, and committed action (Hayes, Louma, Bond, Masuda & Lillis, 2006). Acceptance is the first process, and

is defined as learning to accept both positive and negative thoughts and feelings, particularly relating to events and circumstances one has no control over or cannot change (Hayes, et al., 2006).

Recent studies support the role of ACT and other mindfulness-based approaches for improving quality of life and emotional functioning among individuals with TBI and ABI (Bédard et al., 2003; Kangas & McDonald, 2011; Soo, Tate, & Lane-Brown, 2011). In Bédard et al.'s (2003) study, participants with mild to moderate TBI received a 12-week programme including acceptance, contact with the present moment, and self-as-context. Therapeutic techniques included insight meditation, breathing exercises, guided visualisation, and group discussions. The study found that depressive symptoms improved and quality of life improved among participants following the intervention. Kangas and McDonald (2011) reviewed the literature on ACT as a treatment for a range of psychological problems related to TBI. These authors suggested that ACT might assist individuals with TBI in moving forward with their lives by accepting their cognitive and physical changes. Soo et al. (2011) carried a systemic review of ACT for managing anxiety in population with ABI. The review found no published studies of ACT for management of anxiety following ABI. However, there was evidence that through an ACT intervention, acceptance of disability was associated with improved quality of life and community integration post TBI (e.g., Snead & Davis, 2002). Based on this review, Soo et al. suggested that acceptance-based approaches to managing anxiety might also be applicable to an ABI population. Further evaluation with outcomes or process research could improve our knowledge of the effectiveness, suitability and safety of ACT in the treatment of individuals with TBI.

5.7.2 Limitations

Several interpretative lenses allowed for a multifaceted exploration and understanding of the participants' (re)constructions and meaning-making around identity. A limitation in using a multiple qualitative approach is in giving justice to the depth and breadth of the data. The researchers needed to reflect on their knowledge and on the analytical approaches. The use of multiple qualitative approaches requires the researcher to reflect on the relationships, commonalities and incongruities within and between each approach (Frost, 2011).

The eight participants were all members at the same head injury charity and therefore comprised a fairly homogenous group. They were all White British and so represented a racial and cultural background limited in its diversity. It is therefore doubtful whether this study sufficiently represented the differences and commonalities of discourses and narratives for the broader population with TBI. On the other hand, there was also a high level of heterogeneity within the sample (Howell, 2007) across injury-related variables including aetiology, severity, age at injury and time post-injury. Despite these limitations the findings can still add understanding, provide an opportunity to consider further research, and inform clinical understanding.

5.7.3 Proposals for future research

Further research is needed with individuals who have severe injuries and symptoms, (e.g., speech impairments) in order to gain deeper understanding of individuals who usually do not have a voice in a wider societal context. Other methodologies might be appropriate, such as a visual methodology, which use materials such as photographs, films and drawings to explore participants' world (Willig, 2013).

It may also be important to conduct long-term studies to investigate the fluidity of identity construction and re-shifting of positionings of individuals with TBI. For example, a qualitative research design could involve completing interviews with the same participant group over a longer period of time. This would explore the continuum of recovery in relation to identity construction.

5.8 Conclusion

This multiple qualitative analysis has provided further understandings of the (re)construction of identity among individuals with TBI. The study has contributed to the qualitative literature concerning the needs of clients with TBI. The findings showed that participants presented with complex and varied psychological concerns. Discourses of “disability” and “medical” were common constructions of identity amongst participants. One consideration implied by these findings is the current understanding of “norms” and “health” in Western society. In our current society, there is the belief that physical impairments are “wrong” and are supposed

to be “fixed” to become “right”. This reflects how these discourses offered positions of dependency and disempowerment. Hence it is important to consider “the process of empowerment” as part of holistic community-based rehabilitation. A “process of empowerment” (O’Hara & Harrell, 1991) could facilitate the shaping of attitudes towards individuals with disabilities within social communities. Empowerment is also a process in which individuals gain control over their lives and the societal structure in which they live. Invisibility and perceived stigmatisation are difficult problems amongst individuals with TBI that can produce positions of social disconnectedness. There is growing evidence that social connectedness (Haslam et al., 2009) is associated with wellbeing among individuals with chronic illnesses. This leads again to the importance of a community-based rehabilitation model, which can help individuals to address the issues that affect them collectively, for example, by promoting awareness and disseminating information. The findings suggest that an “acceptance” discourse appeared to enable positions of empowerment and independence. Specific approaches including ACT (Hayes, 2004; Hayes, Strosahl & Wilson, 2003), aimed at facilitating acceptance could be considered to help individuals adjust to both positive and negative parts of identity post-TBI. Finally, health professionals need to develop their awareness of how dominant disempowering discourses are entrenched in society and how to shift these to alternative discourses.

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