THE EXPERIENCE OF NEUROPSYCHOLOGICAL ASSESSMENT, VIEWS OF CLIENTS WITH TRAUMATIC BRAIN INJURY

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A thesis submitted in partial fulfilment of the requirements of the University of East London for the Degree of Doctor of Clinical Psychology.

May 2012

(27,516 words)

Abstract

It is estimated that every year in the UK, more than one million people attend Accident and Emergency following a head injury. Neuropsychological assessment to detect impairments after a traumatic brain injury is a primary aspect of care. There is little information on how the neuropsychological assessment is experienced. This study captures the experience of undergoing a neuropsychological assessment from the viewpoint of clients with traumatic brain injury. Semi-structured Interviews were conducted with eight clients with traumatic brain injury, who had recently undergone a neuropsychological assessment. These were analysed using Interpretative Phenomenological Analysis.

Overall, the experiences of undergoing a neuropsychological test were variable, with reports of positive and negative experiences. Participants valued being treated as equal partners during the assessment process while also respecting that the assessor held the knowledge and expertise to aid their understanding of the injury. Assessor qualities and the relationship with the assessor affected participants' assessment experiences. Familiarity with the assessor allowed participants to relax, whilst an unfamiliar assessor lead to uncertainty and anxiety. Participants had mixed views for the reason for the assessment. They approached the assessment with determination and a need to try their best. Feelings of anxiety, confusion, anger and frustration were reported. Participants also described feelings of relief and an eagerness to complete the tests. There was an overall sense that the assessment provided awareness about their difficulties after head injury, from which they could progress. Participants spoke about the fatigue experienced during the assessment which they felt negatively impacted on their assessment experience, as did a poor assessment environment. The analysis has demonstrated that undertaking a neuropsychological assessment is not a neutral experience for clients with a TBI.

The results of the study are considered in the light of existing research and its clinical implications.

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Acknowledgment

I would like to express my sincere appreciation to the participants in my study and Headway East London and The Queen Elizabeth Foundation for helping in the recruitment of study participants.

I would also like to thank my thesis supervisor Dr Matthew Jones Chesters for his valuable advice and support.

I also extend my thanks to my family for their encouragement throughout this study.

Chapter 1: INTRODUCTION

1.1. Overview

Neuropsychological assessment to detect impairments after a traumatic brain injury (TBI) is a primary aspect of care (Sherer, Novak, Sander, Struchen, Alderson & Thompson, 2002). Traumatic brain injury (TBI), 'an injury to the brain caused by a trauma to the head' (Headway, 2012), can have varied effects on the person depending on the type, location and severity of injury, leading to physical, cognitive, behavioural and emotional impairments. Research in other clinical populations has highlighted that, although some persons find undergoing an assessment a positive experience (Bennett-Levy, Klein-Boonscahte, Batchelor, McCarter & Walton 1994; Westervelt, Brown, Tremont, Javorsky & Stern, 2007), there are feelings of uncertainty, anxiety and insecurity in others (Coniff, 2008; Keady & Gilliard, 2002). The perspective and experiences of the person with TBI has been neglected in the literature, research tending to focus on more objective accounts from carers and relatives (Howes, Benton & Edwards, 2005). The small number of qualitative studies that have been conducted with survivors of TBI have provided valuable information about their experiences. (Paterson & Scott-Findlay, 2002; Nochi, 1998). To my knowledge, no study has specifically focused on the experience of undergoing a neuropsychological test from the viewpoint of a client with TBI.

Currently, there is little research exploring the experience of undergoing a neuropsychological assessment in any clinical population. Westervelt et al*.* (2007,p 1) point out, "current trends in mental health care, including increased provider accountability and an emphasis on consumer satisfaction, underscore the need for exploration into the perceptions and satisfaction of the patient undergoing neuropsychological assessment".

The aim of this study is to find out about the experience of being neuropsychologically assessed from the viewpoint of a survivor of TBI.

This chapter will first describe the process of neuropsychological assessment and then lead into its application to clients with TBI. Descriptions of types of TBI, prevalence rates and injury sequelae will follow. I will then discuss the inclusion of clients with TBI in research. The existing literature on the experience of undergoing a neuropsychological assessment in other clinical populations will be reviewed and evaluated. Finally, study rationale, aims and research questions will be outlined.

I will write throughout in the first person in keeping with epistemology of qualitative research and to sustain transparency and reflexivity (Webb, 1992). The term client, survivor and participant will be used interchangeably throughout the study.

1.2. Literature search terms and search engines

I conducted an electronic literature search using medical and psychological databases: ScienceDirect, MEDLINE, OneFile, Directory of Open Access Journals, Bentham Science, Adis International, PLoS, PsychINFO.

The search terms used included:

- TBI
- Head Injury
- Brain injury
- Neuropsychological assessment
- Qualitative research
- Subjective experiences
- Sequelae of head injury

I used these terms in various combinations. As there is very limited qualitative literature in this area, I have included both qualitative and quantitative research articles throughout the study. My search strategy also included searching for current guidelines via widely used internet browsers. I also reviewed reference lists in order to locate relevant books and journal articles.

1.3. Neuropsychological assessment

‘Clinical neuropsychology is an applied science concerned with the behavioural expression of brain dysfunction’ (Lezak, 1995, p.7). Neuropsychological assessment addresses the cognitive processes associated with different areas of the brain via the administration of psychological tests. Typically, tests are administered to assess functions such as attention, perception, memory and learning, language, visuo-spatial, motor and executive functions (Lezak, 1995). The neuropsychological assessment is unique in terms of breadth of information obtained regarding the integrity of higher brain functions (Prigantano, 2003).

The British Psychological Society's Division of Neuropsychology (2004) has established guidelines to assist neuropsychologists in maintaining professional standards. These guidelines address issues such as clinical practice, use of neuropsychological tests, medico-legal practice, research, professional description and insurance. Only those with the appropriate training should offer clinical services and practice within the area of clinical neuropsychology. Additionally, all clinical neuropsychologists should have regard to their competence and experience when offering services to clients, taking consideration of the age and ethnicity of the client, the diagnosis and the clinical problem. The guidelines state that care should be taken in gaining consent of the client before discussing the client with family members, carers or other agencies. With regard to the use of neuropsychological tests, the guidelines state that administration should take place by an individual who has received appropriate training and experience in administration, scoring and interpretation of the tests.

Clinicians have an ethical responsibility to constantly update their knowledge. Lezak (1995) has noted that clinicians cannot help but bring their own biases and preconceptions to the diagnostic process which may be out of date. In addition, experiences and views may be relevant to another population and life events.

Sundberg and Tyler (1970, as cited in Wilson, 2009, p195) define neuropsychological assessment as including 'the systematic collection, organisation and interpretation of information about a person and his (her) situations and the prediction of his (her) behaviour in new situations'.

The prevalence and persistence of neuropsychological deficits after TBI emphasises the importance of neuropsychological evaluations, particularly given the relationship between cognitive disability and outcomes. Such information is valuable to those who have sustained the TBI, their families and those providing the treatment.

1.3.1. Neuropsychological assessment after TBI

Neuropsychological assessment for adults with TBI is useful for assessing changes over time, monitoring treatment and detecting disturbances in higher cerebral functioning. It can also assist patients to make practical decisions about care regarding their ability to function independently (Prigantano, 2003). The neurobehavioral impairments following a TBI are considered important as they have a significant impact on day-to-day functioning. Although physical impairments often appear most significant after a TBI, it is the cognitive, behavioural and emotional impairments that predict long term outcomes. Neuropsychological evaluation of TBI assesses multiple areas of cognitive function, sensory and motor abilities and behaviour, and also considers emotional and psychiatric outcomes.

The tests used by neuropsychologists are generally selected according to the referral question, issues pertinent to the client and clinician’s preference. Many neuropsychologists use a core battery of tests that investigate major dimensions of cognitive domains (attention, visuoperception and visual reasoning, memory and learning, verbal functions and academic skills, construction, concept formation, self regulation, motor ability and emotional status) and can discard or add tests as the examination proceeds. The neuropsychological assessment also includes a review of pre-injury functioning, review of medical background and an interview with the client to assess behavioural and emotional functions. Following the assessment, the outcome is delivered in writing to the client’s GP, referrer and to the client and significant other in the form of a feedback session. In some cases psycho education may be necessary. This includes recommendations and a plan for managing rehabilitation.

Lezak (1995) emphasises the importance of using examination techniques specifically designed for eliciting impairments that are common in head injury survivors. Many tests used for general cognitive assessment measure abilities that are likely to withstand head trauma. After an acute stage, a TBI survivor can perform close to average on the Wecshler Adult Intelligence Scale (WAIS) but continue to suffer executive and memory deficits (Lezak, 1995). Test performance is usually evaluated by comparison to average scoring for the normal population.

While test scores can identify cognitive profiles, useful information can be gained from the manner in which a person approaches the tests.

The timing of administration of a neuropsychological assessment differs between clinicians (Sherer et al., 2002). Early testing will reflect acute processes and might not be a reflection of stable functioning. It has been suggested that intensive neuropsychological examination may be rendered invalid if undertaken in acute or post-acute stages (Lezak, 1995). Lezak (1995) recommends baseline evaluation of a client with TBI after Post Traumatic Amnesia (PTA) has resolved with a follow up assessment of cases of severe TBI at 6 and 12 months after injury.

The way in which individuals learn of their referral for neuropsychological assessment can affect how they view the examination. This can lead to diverse responses such as good or poor cooperation, anxiety and distrust that may modify test performance. Some neuropsychologists send a letter to a new client explaining, in general terms, the kinds of problems dealt with in the assessment and the procedures the client can expect. Hartfield, Cason and Cason (1982) report that anxiety is negatively correlated with the accuracy of patients' expectations about medical procedures.

Feedback is an important component of the neuropsychological assessment process. The neuropsychologist must translate results into a format that can be communicated to the survivor of TBI, family and anyone else involved in their care. The provision of feedback can be an intervention in its own right. However, many people who undergo neuropsychological assessment comment that they have never received any feedback about their performance (Gass & Brown, 1992). This can lead to feelings of confusion, distress and uncertainty for the person being assessed and family, especially in the light of sudden onset of challenges that the brain injury brings (Gass & Brown, 1992). They suggest a general approach to providing feedback which includes seven steps that they have found helpful to use with many brain injured survivors.

The testing situation is set up to obtain the best level of performance (Lezak, 1995). The examiner may spend the entire first session preparing the client for the assessment. Lezak (1995) recommends that, in this session, the examiner should cover: the purpose of the examination; the nature of the examination; the use to which the examination will be put; confidentiality; feedback information; a brief explanation of the tests procedures and discussions about how the client feels about taking the tests.

The assessment process can be demanding and time consuming. Many head injured clients fatigue easily and consequently, performance levels drop, concentration weakens and failure rates increase (Paterson & Scott-Findlay, 2002). Both fatigue and awareness of poor performance can feed the depressive tendencies experienced by many neuropsychologically impaired patients. Ideally neuropsychological testing should be undertaken in quiet conditions with no distractions. In most cases, this environment is an examination room with adequate ventilation, sufficient artificial light and at a comfortable temperature.

Both optimal and standard conditions can prevail in an ideal testing situation. Optimal conditions allow clients to do their best, free from distraction and fatigue. Standard conditions, prescribed by the test maker, ensure that each administration of the test is similar to every other administration, so that scores can be compared with those obtained on other tests. Many tests contain detailed directions on presentation, including specific instructions on word usage and handling the material. It is necessary to administer the test in a highly standardised manner when norms of tests have a statistically well standardised scoring system. The standardisation of testing procedures also enables the examiner to discover the individual characteristics of each client's response (Lezak, 1995).

“Nowhere is the conflict between optimal and standard conditions so pronounced or so unnecessary as in the issue of emotional support and reassurance of the patient” (Lezak, 1995 p. 141). To adhere to standard conditions, the examiner must maintain an attitude that appears emotionally impassive. The strict rules dictating adherence to wording of the test manual and non disclosure of a single success have often created a cold, mechanical procedure. This can be anxiety provoking for the client. Confronted by an examiner with no warm facial expression, a toneless voice and curt responses, a client may assume he is doing something wrong, failing or displeasing the examiner, anxiety increases and test performance is compromised (Bennett-Levy et al., 1994). The assessor must be a competent practitioner, have interview and counselling skills and appreciate social and cultural variables. He should be aware of any potential anxiety and distress, prepared to intervene in a supportive manner, such as asking a simple question to raise self esteem (Lezak, 1995).

The above literature indicates that client experience is important, influenced by the qualities of the assessor and assessment environment, potentially impacting on performance on the assessment. The neuropsychological assessment can be viewed as unique and has a relational component, in contrast to a medical assessment (e.g. an MRI scan). A sensitive examiner can improve a situation, putting the client at ease, giving continual encouragement and support. ‘Examiners who distribute praise randomly and not just following correct responses are no more giving away answers than if they remained stonily silent throughout’ (Sharpio, 1951. Cited in Lezak, 1995. p131). This in turn will create a comfortable, interested client able to provide information about functioning that may have been forgotten. A relaxed client will also be more receptive to explanations and recommendations regarding difficulties, enabling the examination to become a mutual learning and shared experience.

Lezak (2004) points out that some clients may experience the neuropsychological assessment as threatening to self esteem and a painful reminder of their cognitive deficits. She emphasised the importance of making the assessment as ‘patient-focused’ as possible by controlling the examination to enhance understanding while minimising negative examination experience. Genevay (1997) advocates a need for the reduction of ‘power’ held by the assessor, suggesting if practice is to improve, subjective experiences must be valued and seen as an integral part of the assessment process.

It is also important to remain mindful of limitations to the neuropsychological assessment. Most neuropsychological tests have been developed in Western, English speaking normative cohorts. The construct validity of neuropsychological tests may vary according to ethnic group (Brickman, Cabo & Manly, 2006). Ecological validity, the degree to which performance on the neuropsychological tests corresponds to real-life everyday function, is of major importance. Referrals are now more focused on clients' everyday cognitive abilities and suitability for rehabilitation, rather than for diagnosis. However the tests themselves have not been changed accordingly (Chaytor & Schmitter-Edgecombe, 2003).

The powerful rhetoric of the purpose of the assessment (to make things better and find out about the person's strengths and weaknesses) along with a sense of professional 'ownership' of diagnostic testing, may explain the lack of focus on the social context of the person and subjective experiences.

1.4. Traumatic Brain Injury

1.4.1. Prevalence of TBI

A traumatic brain injury (TBI) is defined by the Brain Injury Association of America (1986):

"Traumatic brain injury is an insult to the brain, not of degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in impairment of cognitive abilities or physical functioning. These impairments may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment".

The prevalence of TBI has not been reliably determined (Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006). This is partly due to the lack of universally accepted criteria of TBI. The majority of epidemiological studies have examined TBI prevalence in the United States. The United Kingdom Acquired Brain Injury Forum (UKABIF, 2012) draws attention to some of the difficulties in obtaining true prevalence of TBI in the UK. Firstly, statistics are often based on the primary presenting problem within an Accident and Emergency (A&E) department; a secondary head injury may therefore not be taken into account. Secondly, Primary Care Trusts have different classification systems regarding brain injury. Thirdly, there is a lack of coordinated care in the

NHS when the person moves through the system, information can be lost or mis-recorded. In response to these weaknesses, some epidemiological studies have suggested attendance at A&E departments as a more reliable measure of prevalence of TBI in the community (Jennett, 1981).

It is estimated that every year in the UK, more than one million people attend A&E following a head injury (Teasdale, 1995). Of these, 135,000 people will be admitted to hospital as a consequence of a brain injury. (Headway, 2012).

The age groups most at risk from TBI are under 5's, the 15 to 29 year group and the over 65's (Headway, 2012). With TBI there is a clear gender difference in incidence rates. Males are 2 to 3 times more likely than females to sustain a head injury; this rises to five times more likely in the 15-29 year group (Headway, 2012). Men are more likely to be involved in road traffic accidents and also have increased exposure to recreational and sports injuries. Older people form the other 'at risk' group, being susceptible to falls and more also likely to die from brain injury.

There has been a decline in the number of deaths from TBI over time due to improvements in medical care of head injuries and rapid emergency transport (Miller, Jones, Dearden, & Tocher, 1992). The rate of death from TBI is now estimated to be 0.2% (NHS choices, 2012). The increasing numbers of survivors means a greater increase in the prevalence of TBI leading to substantial societal costs (Ghajar, 2000). It is estimated that across the UK there are around 500,000 people (aged 16 - 74) living with long term disabilities as a result of TBI (Headway, 2012).

The leading causes of TBI are road traffic accidents (50%), falls, assaults, sporting or recreational activities. Sporting injuries are thought to account for 300,000 TBI's every year (UKABIF, 2012).

1.4.2. Causes of head Injury

TBI can be viewed as a dynamic process, evolving over hours and days following the injury, continuing over weeks, months and years.

The neuropsychological assessment approach depends on the time since injury, the nature and location of the trauma, severity of brain injury and secondary effects. I will outline the prominent injury types and classifications of severity of injury.

Closed head injury

A closed head injury occurs when an external mechanical force causes the brain to be moved violently, for example, in a car accident when the head hits the windscreen. The brain tissue is not penetrated and membrane of the brain is intact, but the skull can be fractured. The most common mechanisms of closed head injury are rotational injuries, a rotational movement of the brain within the skull, and acceleration-deceleration injuries, involving impact between the brain and the inner surface of the skull. The differential movement of the skull and the brain when the head is struck results in shear, tensile and compression forces, impacting on axons and blood vessels, resulting in diffuse axonal injury, contusion and brain swelling, leading to diffuse injuries (Headway, 2012). Where the stationary head is hit by a moving object, there is a local injury under the site of impact (coup injury). Conversely, when a stationary object is hit by a moving head, the brain collides with the skull interior, causing damage on the opposite side to site of impact (contra-coup injury). Both of these injuries are considered focal brain injuries.

Moderate to severe closed head injury produces a high incidence of orbito-frontal and anterior temporal lobe contusion and can produce attention deficits, slowed cognitive processing, impaired learning and retrieval of new information, deficits in auditory or visual processing and frontal lobe damage (e.g. planning and organisation, perseveration, impulsivity).

Penetrating head injury

A penetrating or open head injury involves trauma in which the skull is crushed or penetrated by a foreign object. Missile, bullet injuries and road traffic accidents can be penetrative, with the central nervous system membrane lining being pierced. Damage is usually localised. Impairment or loss of abilities controlled by parts of the brain that are damaged can occur after a penetrating head injury.

Secondary injuries

Head injury usually involves a combination of the primary injury (e.g. closed and penetrating injuries), secondary injury and a combination of focal and diffuse injury. Secondary injury occurs over time after the primary injury, this can include ischemia, oedema, infection, subdural haematoma, hypoxia, intracranial pressure and post-traumatic epilepsy. There are regions of the brain that are more vulnerable to injury such as the frontal cortex, temporal lobes and hippocampi, which results in specific neurobehavioral problems. (McAllister, 2008).

1.4.3. Injury Severity

Consequences of TBI can range from mild effects to prolonged coma, persistent vegetative state or death. There are three measures used to categorise severity of the brain injury during the acute stage.

- The Glasgow Coma Scale (GCS, Teasdale & Jennett, 1974) rates the depth and duration of altered consciousness and is the most commonly used clinical method. This is a scale ranging from 3 (most severe) to 15 (less severe), used to identify how severely the person is concussed and how severe the injury is. Three parameters are used to assess consciousness; eye opening, verbal response and motor response.
- Post-Traumatic Amnesia (PTA) refers to a disturbance of memory for events after the injury. The longer the period of PTA, the more severe the injury. The typical PTA grading system is:
  Mild injury: PTA < 1hour
  Moderate injury: PTA 1-24 hours
  Severe injury: PTA >24hours
- The Loss of Consciousness (LOC) refers to the duration of unconsciousness. Time taken to regain consciousness is an indication of injury severity, the patient may not always be able to describe the length of LOC so other sources (e.g. witness, police reports) are consulted. There are several systems of grading of LOC. One includes:
  Mild injury: LOC for 30 minutes or less
  Moderate injury: LOC > 30 minutes, <24 hours
  Severe injury: LOC for > 24 hours.

A universally accepted definition for the severity of brain injury does not exist (Petchprapai & Winkelman, 2007) leading to conflicting inclusion criteria in literature sources. However, injury has been classified as mild, moderate and severe as follows:

Mild Injury

A mild head injury is defined by a GCS score of 13-15 points, a LOC of less than 30 minutes and post traumatic amnesia of less than one hour Teasdale,1995). De Kruijk, Leffers, Manheere, Meerhoff, Rutten and Twijnstra(2002) point out that mild brain injury can result in problems in the long term that affect daily functioning and as a result should not be underestimated. Sequelae of mild head injury can include diffuse reductions in attention and information processing, mild executive dysfunction and problems in verbal learning and retrieval.

A group of symptoms has been described in post concussive syndrome including headache, dizziness, memory difficulties, fatigue, depression, impaired concentration, visual and auditory complaints and insomnia. Some survivors of TBI patients have reported symptoms of post concussive syndrome 1 year after their injury (Deb, Lyons and Koutzoukis, 1999).

Moderate Injury

A moderate brain injury is defined by a GCS of 9-12 points, a LOC of more than 30 minutes and less than 24 hours and PTA between 1 and 24 hours. The most commonly reported cognitive symptoms include difficulties with memory planning, thinking, attention, organising, concentration and word-finding problems. Physical sequelae include tiredness, headaches and dizziness. Emotional and behavioural sequelae can include lack of motivation, depression and irritability.

Severe Injury

A severe head injury is defined by a GCS of less than 8 points, a LOC of more than 24 hours and PTA of more than 24 hours.

Patients with severe head injury can display the full spectrum of impairments across all cognitive domains. Consequences of severe head injury may include significant physical disabilities, personality changes, long term cognitive deficits and emotional and behavioural changes. Only a minority of TBI's are severe. Those who survive may remain in a persistent vegetative state or suffer severe disability for at least 6 months (Teasdale, 1995).

1.4.4. Sequelae of traumatic brain injury

TBI can result in impaired physical, cognitive, emotional, behavioural and social functioning (Kersel, Marsh, Havil & Sleigh, 2001).There is considerable variation in sequelae following TBI depending on the type of injury sustained. It has been estimated that a quarter of TBI survivors present significant residual complaints (Giles & Clark-Wilson, 1993). Brooks, Campsie, Symington, Beattie and McKinlay (1986) agree that cognitive and behavioural impairments are of the greatest significance for both the person with the TBI, family adjustment and long-term functional outcome.

Physical sequelae

Physical impairments resulting from a brain injury can include movement, balance and coordination problems, dyspraxia, headache, loss of sensation, epilepsy and bladder and bowel control (Headway, 2012). Physical impairments may be permanent or resolve with time (Brooks et al., 1986). Extent of physical disability has been found to correlate with the severity of brain trauma (McKinlay, Brooks, Bond, Martinage & Marshall, 1981). The mobility of many brain injured survivors is affected by severe musculoskeletal injuries (Campbell & Parry, 2005). Many people make a good physical recovery after a head injury. There may, therefore, be few visible effects of the injury but the impact of these can still have a significant effect on everyday life. A further common difficulty faced by survivors of TBI is tiredness or fatigue. Fatigue comprises both physical and mental tiredness, a limiting symptom impacting on everything undertaken. It can also be caused by extra effort required to process information after the onset of neurological damage (Ouellet & Morin, 2006). A study by Middelboc, Andersen, Birketsmith & Friis (1992) reported fatigue present soon after injury even with those with a mild head injury. Nearly all (95%) of the 460 adults surveyed in one study reported being more fatigued since their injury (Ouellett & Morin, 2006). Fatigue, as a subjective concept, creates problems in its definitions and consequently makes it hard to measure quantitatively.

Cognitive sequelae

Cognitive impairments are a common after TBI. Global cognitive impairments have been reported following both moderate (Rimel, Giordani & Barth, 1982) and severe TBI (Lezak Howieson & Loring, 2004). Hellawell, Taylor and Pentland (1999) point out that the extent and duration of cognitive deficits experienced by survivors of TBI are related to injury severity. Schretlen and Sharpio (2003) found those with moderate to severe brain injury had cognitive deficits that were three times more serious than those with mild brain injury. Additionally, those with severe brain injury had pronounced long term impairments, even if cognitive functioning improved during the two years following injury. The cognitive impairments following brain injury include difficulties in: memory, attention, perception, planning/organisation, problem solving, insight, learning and communication (UKABIF, 2012).

Memory impairment is the most common cognitive impairment following TBI (Headway, 2012). This is an enduring impairment and difficult to treat. Retrograde amnesia and anterograde amnesia are two types of memory impairment observed. Amnesic syndrome, an inability to hold information in mind long enough to carry out a sequence of behaviours, may occur in the most severe forms of brain injury. This inability to encode, attend or recall information leads to the incapacity to plan, form actions and learn information.

A reduced concentration span and inability to apply attention to more than one task at a time are common difficulties in survivors of TBI, becoming worse when tired or stressed. Sohlberg and Mateer (1987) define attention as being able to focus on particular stimuli over time and flexibly manipulate information.
A variety of visuo-spatial and perceptual disorders can result from a TBI. Among these are agnosia, inattention to particular parts of the surrounding environment (neglect disorders), difficulty performing actions (apraxia) and sensory losses. Some of these perceptual deficits may resolve over time, others may not (Headway, 2012).

Language difficulties are often observed after TBI. Survivors and their relatives have reported long-term difficulties with word finding, reading and writing (McKinlay et al., 1981). Problems with language loss (aphasia) can be either receptive, in that no sense can be made of what is heard or read, or expressive, the inability to find the right words. Global aphasia occurs when language problems are both receptive and expressive.

Frontal lobe injuries may result in clients having difficulty in higher level processes that underlie executive functioning. Executive functioning incorporates a set of cognitive abilities that controls and regulates behaviours and other cognitive processes such as working memory, planning and sequencing and mental flexibility.

Individuals with executive functioning deficits may have difficulty regulating their behaviour. Frontal lobe damage can lead to neurobehavioral sequelae that may be perceived by to be a fundamental personality change, consequently impacting negatively on relationships (Headway, 2012).

Neurobehavioral sequelae

Chronic neurobehavioral sequelae changes occur in many survivors of moderate and severe TBI, reflecting regional brain damage (McAllistar, 2008). Seventy percent of moderate to severe brain injury survivors demonstrate personality changes up to 10 years post trauma. These can be due to frontal lobe changes. Excitability in this area can lead to impulsivity, emotional lability or mood swings, socially inappropriate behaviours and hostility (Kersel et al., 2001). A reduced activation of the frontal lobes can result in apathy, decreased spontaneity, lack of interest and emotional blunting. Behavioural changes can be especially distressing, particularly for the relatives of TBI survivors. Research findings have reported difficulties in survivors of TBI with: depression (Bowen, Neumann, Conner, Tennant, & Chamberlaim 1998); anxiety (Kersel, Marsh, Havill, & Sleigh., 2001); obsessional behaviours (Childers, Holland, Ryan, & Rupright, 1998) and post traumatic stress disorder (Bryant, Marosszeky, Crooks, Baguley & Gurka, 2000). Research into the emotional/behavioural sequelae of TBI indicate that these changes can persist for a very long time, in some cases permanently. A lack of awareness or insight is often noted in TBI survivors (Headway, 2012). The mental ability to monitor and adjust personal behaviour is a sophisticated skill contained in the frontal lobes of the brain. There may be little awareness of the impact of personal actions, or a full understanding of the impact of the injury.

From this information, it is evident that the sequelae following a TBI vary between individuals, depending on the type, severity and location of the head injury. Consequently, the range of different cognitive sequelae resulting from injury require extensive and in-depth neuropsychological assessment.

1.4.5. Survivors of TBI as participants in research

The majority of research concerning brain injury has focused on objective, third person accounts (Howes, Benton & Edwards, 2005). The justification for this is the client's lack of insight and awareness of difficulties which warrants seeking the opinion of a relative or other informant (Thomsen, 1974). Lezak (1978) points out that the capacity for self awareness decreases as the severity of brain injury increases and this, along with a tendency for patients to minimise dysfunction has contributed to the more 'objective' views of relatives being used in research. Paterson and Scott-Findlay (2002) point out that many researchers only select participants that can express their experiences reflectively, with meaning, as they consider that this will provide an objective view of these experiences.

Literature has neglected to consider the perspective of clients with a TBI. Tyerman and Humphrey (1984) suggest that even if the person's self appraisal is limited, the subjective impairment is the reality for these clients. This information provides important guidance for both therapist and researcher, guiding therapy and facilitating adjustment. Tyerman and Humphrey (1984) discuss that research should be seen through the eyes of the head injured client as well as their closest associates.

Paterson and Scott-Findlay (2002) conducted an interview based study with 6 survivors of severe or moderate TBI to determine the allocation of rehabilitation services after injury. They suggest that many of the aspects of interviewing clients with TBI are similar to those that observed when interviewing any clinical population. However they noted that most researchers have avoided the complexity that clients with TBI present and little is known about the challenges in interviewing such a unique population. They discounted the fact that clients with TBI are unsuitable as interviewees in qualitative research. Paterson and Scott-Findlay (2002) discussed the effort and frustration and other challenges this group experience at times, but believe the data contributed significantly to the findings. The authors noted the survivors of TBI often became fatigued or distracted, participants fed back about the effort it took for them to focus on the interview questions, particularly if there were distractions in the environment. An interesting observation from this study was that when participants were presented with questions that prompted free recall, their responses contained limited descriptors or affective components. An explanation provided for this was that participants may have felt the need to present the image as one who has recovered.

A study by Nochi (1998) investigated how clients with TBI experience themselves. Participants were selected who appeared to have insight into loss-of-self experience related to TBI. Nochi (1998) postulates that the subjective view of self image of clients with TBI has not been fully explored, with studies focusing mainly on a medical or neuropsychological aspect. It is important to understand how survivors of TBI interpret themselves as well as experiences from their own unique perspective. They actively interpret their symptoms and are not just passive recipients. Listening carefully to clients with TBI and viewing the world from their standpoint constitutes a basis for future research (Nochi, 1998)

1.5. Existing research on the experience of neuropsychological assessment

Research into the experience of undergoing neuropsychological assessment is limited.

Bennett-Levy et al’s. (1994) study involved 129 adult outpatients/clients from 5 centres (2 hospitals and 3 Commonwealth Rehabilitation Service Branches) located in Australia. Participants had a variety of diagnoses, including head injury and stroke.

All had undergone a neuropsychological assessment 0-6 months previously and their memory and other cognitive skills (e.g. reading) were deemed adequate enough by the neuropsychologist to recall the assessment and complete the Neuropsychological Assessment Questionnaire. The questionnaire explored how the procedure of neuropsychological assessment was experienced. Participants had the opportunity to provide qualitative statements in accordance with each question. Forty eight questions were answered, covering outcome measures, expectation and preparation, testing and discussion and feedback. Bennett-Levy at al. (1994) reported total percentages for each question. Participants reported the neuropsychological assessment positive (56%) with the majority (91%) as positive or neutral. Between 40% and 60% reported that they felt adequately prepared and most found it interesting and relevant. Half the participants found it tiring and frustrating and a minority found it too long and suffered a headache. In terms of discussion and feedback, 32% of participants did not receive feedback but indicated they would have liked to. When feedback was given, half found it useful but it was not always remembered and understood. Three quarters of the participants reported little or no anxiety about the assessment. The authors concluded that a positive assessment experience was dependent on whether they found the feedback and discussion useful. Bennett-Levy et al. (1994) suggest that having a neuropsychological assessment is not considered a neutral experience and has an effect on thoughts and emotions. However, absolute levels of satisfaction with the assessment are likely to differ significantly between client populations. They provide suggestions for ways neuropsychologists can improve practice to improve the quality of their service. These include: adequately preparing the client for the assessment; provision of an adequate rationale for the assessment; provision of understandable and memorable feedback; sensitivity to anxious clients and provision of a comfortable assessment environment. This is the first study to have investigated the experience of neuropsychological assessment. The study, quantitative in nature, used closed questions which did not allow for rich descriptions of participants experiences to be explored and may have produced analytic and synthetic responses. Participants were not asked about the character of the neuropsychologist who undertook the assessment or details of the examination procedure (e.g. length of session, nature of feedback). The omission of these important components of the assessment process have impacted on experience reported.

Westervelt, et al. (2007) assessed perceptions of the neuropsychological evaluation of 129 clients and 80 significant others presenting to an academic medical centre neuropsychology service. The diagnoses of participants included; dementia, cerebrovascular disease, developmental disorder, epilepsy, TBI and tumour. The surveys were sent to participants one month after they had received assessment feedback. Nine questions were included regarding the scheduling of appointment, assessment environment, the assessor, feedback session, general impressions and recommendations. The participants were provided with the opportunity to comment on each item. Responses to each question were calculated as a percentage to answers falling in categories of 'very much, mostly, somewhat and not at all'.

Overall, patients and significant others reported satisfaction with interview, testing and feedback sessions. Negative comments were about the conditions of the setting (e.g. room too hot/cold) and length of assessment. Positive response concerned sufficient time spent by the neuropsychologist reviewing findings and detailed understanding of strengths and weaknesses. In terms of recommendations, most participants reported having followed these or had plans to do so, describing them as very helpful. Overall findings suggest that the neuropsychological assessment experience is generally well received by those assessed. Due to a low return rate of surveys a potential bias may exist in the sample. The surveys were not anonymous, therefore, patients with less positive experiences may not have responded. In addition, the study, based only on a single neuropsychology practice, may not be generalisible to other settings.

The two studies cited above (Bennett-Levy et al.,1994; Westervelt et al., 2007) present with a number of limitations. Many are retrospective and consequently rely on the memory of participants, influencing the reliability of the data. These studies have taken a quantitative perspective, results of which may be potentially limited, omitting in-depth questions about the experiences of being assessed. The use of standardised tools assumes areas of importance about the assessment process for participants but does not allow other, possibly more relevant, areas for them to be raised (Nevonon & Broberg, 2000).

Donofrio, Piatt, Whelihan & DiCarlo (1999) examined the experience of neuropsychological assessment and feedback in persons with brain dysfunction. The primary focus of this paper was experience of feedback. Sixty participants referred to an outpatient neuropsychology clinic were asked to complete a one page questionnaire relating to their experiences of assessment and feedback. Participant views of the assessment were unaffected by the training level of the assessor. They found feedback was very helpful, as was receiving a written summary of the findings. The findings from this study indicated overall satisfaction with the assessment experience and the importance of the provision of feedback , including recommendations, in a written summary form,. Unfortunately this study was an abstract presentation and only a summary format was available. Consequently there is uncertainty about the quality of the study.

Keady and Gilliard, (2002) interviewed 15 clients (12 women, 3 men) recently diagnosed with Alzheimer's disease about their experience of being cognitively assessed for dementia. Grounded theory and the constant comparative method were used. A major area of concern arising from this study was a sense of 'insecurity' and 'uncertainty' around the assessment process. The interviewees reported the assessment room as being "cold and unfriendly"; one lady remarked about "pictures of brains on the wall" which served to increase her anxiety. The formal part of the assessment involved assessors reading instructions from charts, with little or no information about the test purpose given. One man described the testing experience similar to "being back at school". The authors observed a number of coping responses developed in reaction to such perceived levels of threat. These included making excuses, relying on others for clarification and being confrontational. More notably, the coping response of strategic resistance was highlighted, as it was thought to be responsible for unresolved feelings of anxiety and distress over the performance.

The authors suggest a number of important conditions required for the assessment process. These include a good prior relationship with the participant, a trusted supporter,the absence of strategic resistance during the neuropsychological assessment and information about diagnosis being shared with the client. Further recommendations include the assessor holding an awareness of the client’s unique biography and shifting focus away from problems to important themes for the client. They also recommend placing the client in a position of greater control, allowing a fuller picture of circumstance to emerge, advocate partnership in the diagnostic process and allowing for a more transparent and open practice. This idea has been endorsed by Chester and Bender (2005), suggest guidelines to establish a person-focused form of neuropsychological assessment. Keady and Gilliard (2002, p24) further draw attention to the fact that we are ‘at the beginning of our knowledge base’, explaining that their work ‘only scratches the surface regarding what it is like to be on the receiving end of a neuropsychological assessment’. The qualitative nature of this study and the use of open ended questions has allowed for more elaboration and richer descriptions about experiences to be given in comparison to the above quantitative studies. The focus of grounded theory is to generate a model of social processes (Willig, 2008) and use of a phenomenological qualitative analysis may have generated more subjective experiences of participants. The sample size was small, non-homogenous and the exploratory nature of the studies suggest that generalisations should not be made to all persons being assessed for dementia.

Within the context of the neuropsychological assessment of possible dementia, Cheston and Bender (2005) suggest that the assessment process is by no way emotionally neutral for the person being assessed. In addition, Shoham and Neuschatz (1985) comment on the demeaning aspect of constant memory tests for people who may have dementia. The constant reminder of memory failure may serve to reinforce inadequacy. Chester and Bender (2005) discuss that the client’s role, by definition, is a position of lower prestige and power than that of the assessor. An individual’s anxiety and uncertainty may increase in the presence of a person with greater power, with the patient experiencing a sense of loss of control over the situation, accentuating fears of dependency and incompetence. These implications can be frightening. Many clients are not told the reasons for assessment. The assessor may give a vague explanation about the real aims of the assessment, leading to the client forming their own ideas about the purpose of the assessment, adopting a position in relation to what they think is being measured. Many neuropsychological tests initially appear childish or patronising, becoming increasingly harder, resulting in the client either giving up or providing a wrong answer. Repeated failure can reinforce feelings of incompetence. Chester and Bender (2005) advocate a need for changes to be made in the process of neuropsychological assessment. These begin with the person concerned and their family offered pre-assessment counselling and an ongoing, long-term supportive relationship. They have raised the need for openness and honesty and an understanding of the social and biographical context in which such problems are occurring.

Conniff (2008) explored children's' views and understanding of cognitive assessment. Eight children were interviewed and responses analysed using Interpretative Phenomenological Analysis. It emerged that their understanding of the process of testing was that it is benign, to help with a problem or discover something wrong. Children had mixed experiences of the testing, describing it as unusual and hard to manage. There was a sense of uncertainty of the content of the test, undergoing the test and the effect the results may have on their lives. Conniff (2008) suggests that it would be beneficial to explore these feelings with children prior to testing. Negative experiences related to being tested for long time periods. Positive experiences related to qualities of the person assessing them and the test room. Children appeared to view the tests as an isolated experience and felt they had learnt from it. Conniff (2008) recommended that a pre-assessment meeting takes place in order to prepare children for cognitive assessment, exploring their thoughts and understanding about the referral and process of assessment. Other recommendations suggest taking the timing of the assessment into account and allowing children the opportunity to be involved in the feedback process. Conniff's (2008) study sample was small and included a large proportion of children from minority ethnic groups. Consequently, it is hard to make claims about *all* childrens' experiences of cognitive assessment.

1.6. Summary and rationale

The existing literature on the experience of undergoing a neuropsychological assessment presents some important findings. A commonality in the findings is that the assessment process is not experienced as being neutral. Adequate preparation for the assessment, both verbal and written, emerges as an important element for inclusion in the assessment process. Feelings of anxiety, uncertainty and confusion about assessment purpose were prevalent (Keady & Gilliard, 2002; Bennett-Levy et al., 1994; Coniff, 2008). The assessment environment, length of assessment and fatigue also had a marked effect on experience of testing (Keady & Gilliard, 2002; Bennett-Levy et al., 1994; Westervelt et al., 2007).

It is clear that there is paucity in literature about experiences when undergoing a neuropsychological assessment in any clinical population. To my knowledge, there is no known study that has specifically explored how a person who has sustained a TBI experiences the assessment process. Paterson and Scott-Findlay (2002) discuss how survivors of TBI can make a significant contribution to qualitative research projects involving interviews. By including these experiences, involvement can progress beyond that of merely being 'the client' so that this particular group has its voice and opinion valued and heard, with potential clinical implications. As Keady and Gilliard (2002, p.24) discuss, it would be beneficial to treat the client as 'a partner in the diagnostic process rather than as subjects'.

Consideration of such an experience is important, not only for the general needs and welfare of those people being assessed but also as feedback to help neuropsychologists improve the quality of the service they provide (Westervelt et al., 2007).

1.7. Study aims

The aim of the current study is to contribute significantly to the current research base which examines the experience of a client with TBI when undergoing a neuropsychological assessment.

More specifically, the research aims to:

- explore each TBI survivor's understanding of the reason for the neuropsychological assessment.

- examine TBI survivor’s reports of having a neuropsychological assessment and how they describe these experiences.
- examine the perceived usefulness of the assessment.

1.8. Research title and questions

Based on the background literature and the aims of the study, the research study title is:

The experience of neuropsychological assessment, views of clients with traumatic brain injury.

The study will use a qualitative approach to examine the often unheard voice of a survivor of TBI. Moustakas (1994) states that quantitative approaches cannot encompass the studies of human experience. He suggested that meaning could be obtained through descriptions of experiences from first person accounts in informal conversations and interviews. Nochi (1998) recommends that listening carefully to clients with TBI themselves and viewing the world from their standpoint constitutes an important basis for future research. The study will extend the idea of evidence based practice by including qualitative methods of researching.

Research questions:

1. What do clients with TBI say about their experience of being neuropsychologically assessed?
2. How do they describe this experience?
3. How did the experience make them feel?
4. What was their understanding of why they were assessed?
5. Is the process of testing perceived as useful?

Chapter 2: METHOD

2.1. Overview

Tyerman and Humphrey (1984) suggest that the head injured person's own perspective has been neglected in research. Howes et al. (2005) discuss that it is generally the relative or carer's more objective and apparently more accurate opinion that is sought. Researchers have a tendency to select participants who can reflect on their experiences in a meaningful manner and articulate their points of view (Paterson & Scott-Findlay, 2002). However, many qualitative studies carried out with survivors of TBI (Nochi 1998, Paterson & Scott-Findlay, 2002 Howes. et al., 2005) have demonstrated that information provided is valuable and meaningful to research.

This chapter will describe my epistemological position, the rationale for choosing Interpretative Phenomenological Analysis (IPA) as the preferred qualitative methodology, highlight and consider the research design and procedure followed. The analysis of the interview data will be discussed and issues of reflexivity considered.

2.2. Epistemological Position

As discussed in the Introduction, there has been limited research exploring the experience of undergoing a neuropsychological assessment. To my knowledge, no study has examined the experiences of neuropsychological assessment in survivors of TBI. The aim of this study is to capture in-depth accounts of such experiences.

The origins of qualitative research lie within the realm of non-positivist or post positivist approaches to exploring and explaining human behaviour. The continuum extends from positivism to relativism. Positivism recognises that reality exists independently of our own representations. A relativist approach considers there to be no observable realities or truths, the world being socially constructed. Psychology has traditionally moved from being based in positivist epistemology to gradually adopting epistemological positions that suggest data can give information about reality, it does not mirror it directly (Harper, 2012). In using IPA I have taken a critical realist perspective, located midway along the continuum. Critical realists take the position that the information we gain about a participant's experience and reality from qualitative data must not be viewed in isolation. The importance of broader cultural, historical and social contexts must also be considered.

IPA, with roots in phenomenology, attempts to gain meanings from participants to understand what it is like to 'live' a particular experience. However, it is also acknowledged that, "while one attempts to get close to the participants' personal world, one cannot do this directly or completely" (Smith, 1996, p264). The current study, in employing IPA as a qualitative framework, provides a detailed examination of experiences of being neuropsychologically assessed while also taking into consideration the social context of these experiences. This is in keeping with my own epistemological position as a critical realist.

I felt IPA was a more suitable approach than other qualitative approaches such as Grounded Theory (GT), Discourse Analysis (DA) and Narrative Analysis (NA) due to the nature of the current study. IPA is focused on providing an understanding of a person's lived experience (Willig, 2008), DA has its emphasis on exploring how language construes social reality. Smith et al. (2009) point out that IPA acknowledges the role of language, due to its subscription to social constructionism, but it also argues that people are not simply discursive agents as they attribute meaning to their lived experiences. IPA was deemed more appropriate to use than GT in the current study as GT aims to generate theoretical explanation for psychological phenomena rather than trying to capture a personal experience (Willig, 2008). IPA on the other hand, is more focused on providing a more detailed psychological account of the personal experiences of a smaller sample. NA was deemed unsuitable as I felt the emphasis on pre-existing narrative structures might impose limits on the data and potentially exclude novel aspects of the neuropsychological assessment experience. I considered IPA was more suitable as it allowed greater flexibility and fitted most appropriately with my research question. In relation to using quantitative research, Nevonen and Broberg (2000) point out that although it has its strengths, it has limitations. They argue that only a fragmented picture is produced through the use of structured questionnaires as the participants only provide information on what they are asked.

Barker, Pistrang and Elliott, 2002) suggest that a qualitative approach allows for the emergence of anticipated themes and is suitable to exploratory research. I held this in mind when considering my research question and how the aims of my study may best be addressed.

2.3. Interpretative Phenomenological Analysis

IPA (Smith & Osborn, 2003; Smith et al., 2009) draws on phenomenology in seeking an ‘insider perspective’ of the lived experience of the person (Smith & Osborn, 2003; Smith et al., 2009). IPA is also interpretative as it draws awareness to the fact that the researcher’s personal assumptions, beliefs and standpoint will influence interpretation and understanding.

IPA’s primary concern is to explore how meanings are constructed by individuals from their experiences (Smith, 1996). Willig (2008) points out that it is impossible to gain access to participants’ life worlds, therefore, the researcher’s interpretative activity is also required. This process has been described by Smith & Larkin (2009) as a double hermeneutic process where the researcher is trying to make sense of the participant, who is trying to make sense of his world. Larkin, Watts and Clifton (2006) acknowledge that the researcher’s own assumptions, values and opinions will influence the process of co-construction and interpretation. The concept of reflexivity is therefore crucial in aiding transparency.

IPA is consistent with the epistemological nature of the research focusing on lived experience. IPA allows the opportunity for exploration of new areas of research and previously unheard voices to be gathered (Willig, 2008). The current research questions, examining clients with TBI experiences of neuropsychological assessment, are suited to this type of exploration following IPA’s requirement that questions are non-directive and open-ended in order to obtain the experiences of the individual (Willig, 2008).

As a ‘novice’ researcher within the qualitative field, I find the process of conducting a study using IPA methodology helpful and appealing following guidelines outlined by Smith et al. (2009). I have been drawn to IPA’s inductive nature, exploring individuals’ complex experiences and enjoy the position it gives me as a researcher, not limited to working within the field of existing knowledge. Through sustained engagement with the data and interpretation, IPA enables meanings to emerge that may not be obvious (Smith & Osborn, 2003).

2.4. Design

The study employed a cross-sectional qualitative design. A restricted sample of eight participants was used, in keeping with IPA requirements to have a small homogenous sample. I used semi-structured interviews, each was audio-recorded, transcribed verbatim and analysed using IPA (Smith & Osborn, 2003; Smith et al., 2009).

2.5. Participants

2.5.1. Recruitment

Interviews conducted in qualitative research generally produce a large amount of verbal information, requiring extensive and detailed analysis. It is therefore appropriate to use a small number of participants when employing a qualitative approach; interviewing more may have lead to individual voices being lost (Larkin et al., 2006). In order to fulfil the requirement for a small number of participants who have had experiences of a similar life event, several brain injury charities and support groups for TBI survivors were contacted by email and telephone (see Appendix 1).

The professionals who had been contacted by myself, approached potential participants, discussed the study and, with permission, passed on their contact details to me. Potential participants were then contacted via email, telephone or in person (at the charity base) and screened according to the inclusion criteria. If appropriate, a participant information sheet (see Appendix 2) was sent and an interview date arranged at the University site, charity base or participant’s home. The participants had the opportunity to ask any questions about the study after receiving the information sheet.

2.5.2. Inclusion criteria

In line with IPA requirements (Smith et al., 2009), I aimed to recruit a reasonably homogenous sample of participants. Although the aim of this study is not generalisability, I recognise that the types of experiences are likely to be shared by other TBI survivors in a neuropsychological assessment.

- Adults of working age (18-65 years) who have sustained a TBI.
- Participants who have undergone a neuropsychological assessment after TBI (>6months, <2 years since assessment)
- Participants should be able to verbally express themselves sufficiently to answer the research questions.
- Participants were required to speak and understand English in order for the interview to be conducted and understood.

2.5.3. Study sample and demographic data

The study sample consisted of seven males and one female. All had sustained a TBI and had undergone a neuropsychological assessment. Ages ranged from 28 to 63 years. Seven of the participants were white British, one participant was Asian. Participants talked for an average of 40 minutes.

Participant	Age	Ethnicity	Gender	Time since head Injury (years)
P1	50	White British	Male	3
P2	35	White British	Male	5
P3	20	White British	Male	3
P4	43	White British	Male	5
P5	63	White British	Male	6
P6	53	White British	Male	6
P7	32	Asian	Female	6
P8	30	White British	Male	8

2.6. Ethical Issues

2.6.1. Ethical Approval

Ethical approval for this piece of research was granted by UEL's Ethics Committee. (see Appendix 3)

2.6.2. Informed consent

Informed consent was sought from each participant prior to conducting the interview. This was achieved by providing an information sheet specifying the reasons for conducting the research and study aims. The information sheet also provided details of the intended method, confidentiality and the right to withdraw from the study at any time. Each participant had the opportunity to ask the researcher any questions about the study prior to the interview. Each participant was asked to give written consent and the consent form was also signed by myself (see Appendix 4).

2.6.3. Confidentiality

The information sheet provided details about confidentiality and its limits, I took time to discuss this with participants. Participants' names and any identifying information were removed for the write up of the study. To ensure anonymity, each participant was assigned a code. I had sole knowledge of the participant identity, both during the process of research and during study write up. All consent forms and codes identifying the participants were stored separately to the digital recordings, transcribed materials and participant demographic data. These were stored securely in a locked filing cabinet at the University of East London. I was responsible for the transcription of all interviews with only myself, my academic supervisor and examiners having access to transcribed material. Each transcript was anonymised and then stored on a computer which was password protected.

Participants were informed that audio recordings and any paper work relating to participants' identity would be destroyed after the doctorate research has been examined. Any anonymised data will be kept for three years after research submission, after this time it will be destroyed.

2.6.4. Potential distress

It was not anticipated that the study would cause any distress to participants. However, should participants feel uncomfortable or distressed, they were verbally reminded by the myself in addition to written instructions on the information sheet, that participation was voluntary and they could withdraw at any time. Prior to commencing each interview, I informed participants that they could take a break when required. The staff at the charity were informed after the interview if the participant had shown any signs of distress. The psychologist of the participant interviewed at home was informed accordingly. At the end of each interview, participants were given the opportunity to discuss and reflect on the interview. It has been suggested that the process of reflecting on experiences can have a therapeutic element (Birch & Miller, 2000).

2.7. Data collection

2.7.1. Semi-structured interviews

A semi-structured interview schedule was developed based on discussions with my supervisor, relevant literature and guidance on interview schedule development (Smith et al., 2009), (Appendix 5). I used the schedule flexibly and the prepared questions prompted the participants to talk and provided a focus towards the research topic. I prepared my questions in an open and expansive format, with minimal verbal input from myself, following guidance from Smith et al. (2009). I chose to ask questions which did not make too many assumptions about the experience of the assessment or may have led participants towards particular answers (Smith et al., 2009). Paterson and Scott-Findlay (2002), in conducting qualitative research with survivors of TBI, found that some traditional qualitative interviewing techniques are unsuitable for this population. Participants struggled with the open ended questions, unless they were questioned in the context of a story they re-encountered. However, Paterson and Scott-Findlay (2002) suggest that survivors of TBI, through interviews, can make an important contribution to qualitative research. I remained mindful of this during my interviews. Holsteing and Gubrium (1995, p.19) suggest that the 'participants' competence as interviewees is determined not as the ability to recount the details of their experience but, the way in which they organise the meanings they convey'. There may be challenges to researchers in obtaining full and active participation, calling for the researcher to be innovative, creative and flexible. I was inspired by these suggestions and also the fact that other studies have been conducted using IPA with groups who may be considered unable to provide 'rich' accounts such as Williams et al. (2004) who investigated autobiographical writings of individuals with high functioning autism using IPA.

2.7.2. Number of questions

I reflected on the fact that many survivors of TBI experience attention deficits (Lynch & KosiuIek, 1995) and can become fatigued and distracted. It has been suggested that these factors should be taken into account and that interview questions should be selected economically (Paterson & Scott-Findlay, 2002). Smith et al. (2009) suggest an IPA interview schedule for an articulate adult should contain between six and ten open questions along with prompts and last between 45 and 90 minutes. I initially developed a schedule which, after discussion with my thesis supervisor, was considered to contain too many questions. I re-drafted, dropping the more detailed and potentially more closed questions. Paterson and Scott-Findlay (2002) suggest that the researcher should determine which questions are more important in answering the research questions and ask them first. I decided to prepare an interview schedule containing four main questions and more prompts than may be typically used in an IPA study for participants who may have difficulty speaking for long periods of time about their experience. I had not planned to ask all of these prompt questions, as it may have been too much for the participant. Many of the questions were also simply different ways of asking the same thing. I remained mindful of one critique of IPA which suggests the interview schedule can drive the analysis (Smith et al., 2009). To avoid this, I intended to guide and encourage my participants to talk about their experiences as openly and honestly as possible.

My interview schedule consisted of four areas:

1. **I asked participants to tell me about the neuropsychological assessment they underwent.**

   This was a general evaluation to find out about their experience of being neuropsychologically assessed and to introduce the topic. I was interested in their understanding of the purpose of the assessment, what they had been told prior to the assessment and whether they had found it useful.

2. **I asked participants to tell me what they remembered about the assessment.**
   I was interested in finding out how they viewed the experience, how it made them feel, if there were parts they particularly remember and views around the assessor and assessment environment.

3. **I asked about the feedback of results and how this was delivered.**
   I was interested in the implications of these results and how this made them feel.

4. **I asked the participants about the outcomes of the assessment.**
   I wanted to determine if they found it to be a useful process and whether it changed their views of themselves.

2.7.3*.* The interview process

The participants were given a choice about the interview location. It took place in a quiet room either at the charity base or the University of East London. On one occasion, I visited a participant at home to conduct the interview due to the distance from either the charity base or University. Each interview lasted approximately 40 minutes. The interview was audio-recorded on a hand held digital recorder and then transcribed verbatim, omitting any identifiable information. Each interview followed the pace of the participant and a break(s) was offered. Participants were given the opportunity to ask questions immediately after each interview. I asked for suggestions about how I could improve my interview. I did this as a measure to reduce the power differential between researcher and participant, appreciating any feedback. Meyer (1998, as cited in Paterson & Scott-Findlay, 2002, p 407) discusses the importance of debriefing, allowing participants the opportunity to discuss their thoughts about the interview experience. None of the participants became distressed in the study.

2.8. Data analysis

2.8.1. Memo writing

After each interview, I wrote down any thoughts, observation and reflections about the interview. I included ways in which I felt my interviewing style could be improved and how well my interview schedule flowed. I noted down any ideas I had regarding emerging themes.

2.8.2. Transcription

I transcribed all interviews. All identifying data were removed and transcripts anonymised. The data were analysed using IPA, following guidelines set out by Smith et al. (2009).

The first stage of analysis involved reading and then re-reading through the transcripts several times. During this process, I made notes in the left hand column relating to possible themes in the text and anything I found interesting or significant in relation to the language and descriptions used. (see Appendix 6).I then read each individual transcript, in a more systematic manner and at a deeper and more conceptual level. My aim was to identify specific ways the participant talked about, understood and thought about the issue (Smith et al., 2009). I made inferences about the nature, meaning and context of experiences from the transcript. I started thinking about what it meant for the participant to have these concerns, making notes of these inferences in the right hand margin. Using different coloured pens, I noted down *how* participants described their experiences and noted discursive devices used when talking. I tried to interpret what the participant was trying to communicate and why they have certain concerns. The transcripts were re-read and, by working through the text line by line, the right hand column was used to note down emerging themes. The emerging themes guided reading of subsequent transcripts, although I continually looked for new or contradictory themes.

The next stage involved constructing a list of potential themes and making connections between them. Some of the themes identified shared reference points and some of them constituted different manifestations of a particular concern. On examination of the themes for each individual transcript, I began clustering and naming each group as ideas for subordinate themes. In keeping with the phenomenological nature of IPA, phrases used by the participants themselves were used as much as possible. I typed themes in chronological order into a list, moving the themes around to form clusters or related themes, as suggested by Smith et al., (2009). I then printed this list and cut it up so each theme was on a separate piece of paper. I moved the themes around, placing those themes that represented similar understandings together. I returned to the transcripts and cut and pasted quotes from each word file, grouping them under potential subordinate and superordinate themes. I then produced a table of emergent themes, including the superordinate and subordinate themes with corresponding text extracts. This was done for each transcript. I continually checked that my themes were viable by moving between the names of themes and quotes that were meant to illustrate them (see Appendix 7).

After all 8 interviews had been analysed, a number of superordinate themes were amalgamated to created six final superordinate themes, each encompassing a number of minor themes.

2.9. Reflexivity of the researcher

Reflexivity is seen as a means through which rigour in research can be increased (Polgar & Thomas, 1991). It refers to an awareness of how both the researcher and the research process can influence the analysis and data (Spencer et al, 2006). The research process will be affected by the professional, personal, cultural and political beliefs, values, assumptions and experiences of the researcher. Reflexivity is the process by which these are taken into account.

Malterud (2001, p. 483-484) states that “a researcher’s background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and then framing and communication of conclusions’.

I have described how I came to be personally interested in this research in my Introduction chapter. I will further elaborate below my own assumptions for the purpose of reflection.

I am a 31 year old white British female, undertaking research for the purpose of the clinical psychology doctorate programme at the University of East London. The course follows a social constructionist perspective, with systemic and narrative approaches purveying rather than the focus being on individualistic approaches. This particular course has allowed me to reflect on my own epistemological position and has no doubt influenced my values and assumptions. I affiliate myself with light social constructionist ideas, taking into account the reality of individual experience but at the same time acknowledging that the social context shapes the way in which an individual's experiences are constructed. This could be viewed as taking as critical realist perspective.

I have not had any experience in working with clients with a TBI but have a keen interest in the neuropsychological assessment process. Prior to training, I had extensive experience working within a memory clinic, administering neuropsychological assessments, for the purpose of assisting in diagnosing possible dementia. Through observation of the conduct of assessment, as well as my own administration of tests, I was struck by how different each person's experience of these tests appeared to be. I was aware of the medically orientated feedback sessions that clients and their families attended and how many appeared lost in this world of professional, medicalised language. I recall feeling frustrated at the lack of support or information following feedback. These experiences have had a lasting impact on me.

In addition to my professionally related experience, my personal experience with a family member undergoing a dementia assessment further fuelled my concerns in this area. The professionals encountered tended not to treat her as the intelligent person she was, instead addressing the person accompanying her, with limited information provided pre and post-assessment.

After discussion with my supervisor about my area of interest and my desire to investigate this process further, he pointed to the limited pool of qualitative research in this area within the TBI population. The co-construction of meaning with participants in this study will have inevitably been influenced by my own experiences and interests. Webster (1998) suggests that the issue involved is knowing how emotional involvement influences the research. My emotional responses were identified in a personal journal, containing personal reflection about the research process.

Chapter 3: RESULTS

3.1. Overview

Interpretative Phenomenological Analysis (IPA) of the eight semi-structured interviews resulted in the emergence of six superordinate themes:

- Professionalism
- Relationship with assessor
- Ideas about assessment
- Approach to assessment
- Results of Assessment
- Limitations of assessment

In the Results section, each superordinate theme and their subordinate themes will be illustrated with verbatim extracts taken from the interview transcripts. Ideas related to one theme are not exclusive and may resonate with other themes.

The themes I have chosen were relevant to the research questions and reflected the participants' reports of neuropsychological assessment. I am aware that a different researcher may have focused on different aspects of the accounts so the themes discussed represent a personally subjective interpretation. These themes represent only one possible account for the experiences described. They do not cover every possible aspect of each individual's experience.

The verbatim extracts that have been presented to illustrate themes have, in some cases, been changed in minor ways in order to improve readability. In places where the recording was inaudible, it is represented in the text as [inaudible]. Where information has been added to explain what a person is referring to in the text, a square bracket has been used. Each participant has been assigned a code P1-P8 to maintain anonymity.

3.2. Superordinate and Subordinate Themes

Table 1: Summary of superordinate and subordinate Themes

Table 1 contains the superordinate and subordinate themes developed from the interview transcripts. Results for each theme are presented subsequently.

Superordinate	**Subordinate**
PROFESSIONALISM	• Expertise and power • Qualifications of the assessor
RELATIONSHIP WITH ASSESSOR	• Familiarity/Unfamiliarity • Style of assessor
IDEAS ABOUT ASSESSMENT	• 'To find out the problem' • Recovery
APPROACH TO ASSESSMENT	• Trying my best • Determination • Mixed emotions
RESULTS OF ASSESSMENT	• Understanding of differences • Awareness of differences • Everyday difficulties • Comparing current to previous self
LIMITATIONS OF ASSESSMENT	• Fatigue • Feedback Setback • Impact of the environment

3.3. Professionalism

This theme captured the importance participants placed on the way they viewed the assessor, whether a clinical psychologist, trainee or technician, within the context of knowledge and level of professionalism held. The qualifications held by the assessor had particular importance for some participants. The assessor as a professional expert emerged as an important subordinate theme with recognition of the assessor being in a more powerful position than the person being assessed. The following sub themes highlight the main ways in which participants discussed this.

3.3.1. Expertise and Power

This subordinate theme captured the ideas that participants expressed about a differential in power and expertise between themselves and assessor. This difference either had a positive or negative impact on the individual. The theme reflected the powerlessness experienced by some of the participants in relation to the assessor during the process of assessment.

P1 talked about positive experiences in relation to the assessment. P1 recognised the assessor as having the expertise to help make sense of difficulties as part of a positive and reassuring experience.

The results from the assessment helped [psychologist] *to understand me and because* [psychologist] *could understand me more she taught me about me. (P1: 241-242)*

The communication was outstanding and it comforted me to know that she understood what was going on inside my head and helping it make sense to me (P1: 233-235).

Although P1 referred to a ‘them and us’ (professional and client) situation, there was no sense of power imbalance. If anything, a feeling of comfort and trust prevailed in the relationship.

P3 and P8 inferred they would have preferred a more informal relationship with the assessor.

I tried to make it as informal as possible without being rude just so I can form a relationship as well as that client, tutor [psychologist]. *(P3: 105-107)*

He told me about his life and he was having a laugh and that so that made me feel more relaxed rather than locked up. (P8: 517-519)

P3 referred to the psychologist assessor as a ‘tutor’, suggesting a pupil-teacher relationship mindset held and anxieties felt at school reverberating through to other situations that entail differences in power. P3 also spoke about having a more balanced relationship with the assessor which may have reduced anxiety and feelings of being under pressure and reduced the power differential within the assessment. Similarly, P8 explained feeling more relaxed after learning about the assessor’s life, perhaps allowing P8 to be viewed on a more equal level.

P4 appeared to view the assessor in a different way.

They say I have to do that and if that’s the rules that’s the rules. I will never say no. I’m not going to as that’s not in my manner. (P4: 318-319).

P4’s comment suggested views about the assessor holding power and authority, setting rules which must be followed. ‘*I’m not going to as that’s not in my manner*’, suggested that P4 held respect for professionals. The way P4 spoke about the assessor was suggestive of a teacher-pupil relationship, with the teacher holding the power due to the formality of the assessment,

It was like being in school doing your exams and you feel nervous regardless I think, anybody would. (P4: 160-163).

P5 held a negative view of professionals and questioned their expertise and knowledge.

If people with brain damage were able to write down and talk about their own personal experiences and the person listening wrote down their words not the words they think fit because then you’re getting true dictation of what the person is saying that shall tell more truth rather than, excuse my language, some *hoodwink putting down their own words and going this is what you mean. (P5: 333-342)*

P5 talked about the value of information obtained from survivors of TBI and that professionals might hear this, ignore it and write down what they ‘think fits’. This marginalises the subjective experience of the person and favours the views of the professional. P5’s mistrust of professionals is demonstrated by referring to them as ‘hoodwinks’.

P6 felt that the feedback of assessment results was written for professionals to read, using technical language and was difficult to make sense of, reflecting the power differentials that may exist between professionals and client. However, earlier in the interview, P6 had reported how useful the assessor had been in talking through results.

The report actually structured, different things with all the tests, lots of it was technical stuff that I wouldn’t really understand, it was saying in this area P6 is weaker or stronger.(P6: 296-298)

P4 reported that he had no feedback about the assessment until it was requested. P4’s experience of having to request the feedback letter led to feelings of being forgotten, not prioritised and, in asking the nurse about the feedback, demonstrates a need to know. This again reflected the needs of professionals being prioritised and the needs of the client marginalised.

I can’t remember the place, I can’t remember who needed that letter, who needed to know the facts about me so, they sent the letter to them but not sent the letter to me so I said to the nurse, I haven’t received the letter have they sent it to the wrong address. He said, no, no, no but what happened with it, he told me and he goes, what I’ll do I’ll get the letter sent through to your address so I’ve actually got the letter (P4: 244-249).

3.3.2. The qualifications of the assessor

Participants spoke about the qualifications held by the assessor.

I was given a student psychologist unfortunately, she wasn’t a fully qualified one and so I didn’t feel she was very professional with her approach. (P7: 5-8)

I tend to think outside the box and I tend to try deliberately to be different...being passed onto students and trainees makes me feel like I'm not important, that I don't matter'. (P7: 291-293)

P7 expressed anger during the interview when considering the tester qualifications in the allocation of what was considered an under qualified professional. The professionalism of the assessor was bought up again later.

The assessor was incompetent', I was showing distress', 'it came across as unprofessional'. (P7: 366-371)

P7 held strong views about treatment during assessment. P7 felt that the assessor did not recognise distress and, coupled with the fact that the assessor was a student and was considered to have no authority to have positive changes, yielded negative experiences of the assessment.

She didn't attempt to change the environment, to try and make me feel more comfortable, everything was discussed over a coffee table... I was thinking this is very confusing because you've done nothing to resolve the situation and I felt she possibly didn't have the authority to change the situation.(P7: 9-15)

However, P1 respected the qualifications the assessor possessed and had faith that this well qualified person would help.

I also appreciate that the people doing these tests are highly intelligent people and highly skilled. (P1: 165-166)

3.4. Relationship with assessor

This theme reflected the relational aspects of neuropsychological assessment. The participants' reports were influenced by how well they knew the assessor. Some participants felt more involved in the assessment process and feedback than others, regardless of whether or not they knew the assessor. Participants discussed the assessor's behaviour throughout the assessment.

3.4.1. Familiarity/Unfamiliarity

Participants said that it made a difference to the experience when the assessor was familiar.

I don't want to be there if I have to go and meet a person and he seems like he's not my type. I suppose it's not even, even the tests, you've got a new job and you go in and the guy is rude and goes and makes himself a coffee and doesn't ask if you want one and you know I just always pull back from people like that. (P8:501-506)

P8 had not previously met the assessor. P8 likened the experience of meeting an unfamiliar assessor to a new work situation when rude, unfamiliar people show no consideration. P8 pointed out that it was not the actual test procedure that was important, but the qualities of the assessor, preferring to be assessed by someone familiar. This demonstrated the importance of the relational component of the neuropsychological assessment. The neuropsychological assessment requires an intense time period of interpersonal contact in an environment with an assessor requesting the participant to carry out tasks, unlike a medical procedure (such as an MRI scan), where the person has limited contact with the professional.

P4 and P2 also did not know their assessors.

My sister was with me I mean cause we were in a little kind of a room, I mean I think, I do think that the lady said to my sister 'you're better off staying outside' because if she had been in there she might have been helping me if you know what I mean. I would feel, I would feel calmer, I would feel a little bit calmer. (P4:105-113)

The lady I'd never seen before, that's quite scary. (P4: 162)

P4, found the idea of an unfamiliar assessor daunting and, feeling anxious prior to the assessment, had brought a relative for support. The repetition of the word 'calmer' reflected anxiety about being in the room with an unfamiliar person.

For P2, the experience was positive even though the assessor was unfamiliar. P2 reported that the assessor recognised the participant's qualities, shared a sense of humour and did not simply view P2 as a person to be assessed, thus creating a more relaxed atmosphere.

Um yeah, the guy who tested me, he seemed like a nice young guy, he seemed to appreciate my sense of humour, I have nothing bad to say about him um he did his job pretty well (P2: 273-274).

P1 was familiar with the assessor and throughout the interview, spoke about how supportive she has been.

I think so yeah, yeah, it's like I said, before it's almost like my guard is brought down a little bit as I know she's trying to help me as opposed to the insurance company. (P1: 271-273)

Communication was outstanding and it comforted me to know that she understood what was going on inside my head and helping it make sense to me (P1: 233-235).

This familiarity acted as a reassurance to P1, allowing a feeling of being valued. P1 talked about 'my guard being brought down', suggesting trust in the assessor, considering her to be 'on my side', an ally rather than an enemy.

P6 and P1 appeared to benefit from the assurance that the familiar assessor, who they liked and trusted would make the assessment worthwhile.

P6 found it useful to view the assessment as a usual 'appointment' with the psychologist and was given the opportunity to discuss clinical concerns and questions about the assessment afterwards.

I was absolutely fine because [psychologist] *knew me, reason* [psychologist] *did it was cause she'd done the other ones and she knew what I was capable of and how I'd improved. (P6: 445-447)*

It's not only the assessment it's also like an appointment as well you know. (P6: 586-587)

P3 also knew the assessor. Frequent use of the word 'relationship' suggests this was an important element of the assessment for P3, something he actively created. It may have served to reduce anxiety, positioning the assessor as more of an equal.

Yeah they're both cool [psychologists] *I got quite a good relationship, like when I come here I did my best to make the relationship, not necessarily swearing and stuff but to make it as informal as possible without being rude just so I can form a relationship as well as that client, tutor. (P3: 103-107).*

3.4.2. Style of assessor

Connected to the issues above, the manner in which the assessor approached and communicated with the participants impacted on their experience, both positively and negatively.

P7 was dissatisfied with the manner in which the examiner conducted the assessment. The comment 'ticking boxes' implies that the examiner had no interest in making the assessment a more personal and individual experience, wanting to complete the assessment as quickly as possible.

She was quite young, she didn't exactly make me feel comfortable. (P7:23-24)

Annoyance at myself and annoyance at her even though I was expressing the sort of distress and I didn't really want to carry on with the tests. She was just doing box ticking as I call it. (P7: 70-73)

P4, on the other hand, felt respected and comfortable considering that the assessor had created a relaxed flexible environment, treating P4 as an adult..

She was calm and gentle. You know, she said to me 'if you can't do this at the moment then leave it and you can come back and do it' rather than say 'look it has to be done, do it now, do it now. There are some I've been around who treated me like I'm a child and I don't like that. (P4: 65-71)

The approach of P5 and P8's assessor also enabled them to feel relaxed and comfortable.

He told me about his life and he was having a laugh and that so that made me feel more relaxed rather than locked up. (P8: 517-518)

He was very polite and hospitable and quite warming. (P5:102)

In P8's case, the sharing of personal information functioned to reduce any power differential, consequently allowing a relaxed atmosphere. The term ‘locked up’ suggests a sense of feeling trapped with no control over the assessment situation.

According to P2 and P6, a collaborative approach evoked feelings of being respected by the assessor.

Yes, after the assessment was completed, um, I was able to sit with a copy of the report with the neuropsychologist and I was able to suggest changes and I was happy that I was able to do that. (P2: 382-386)

But she showed it to me first [the feedback report] to make sure I was happy with what she was saying. (P6: 302-303)

P2 and P6 were pleased to have their viewpoint valued. P2 mentioned a positive experience about being consulted on the feedback report. However, not all participants experienced such a positive feedback style from the assessor. P4 described feeling under no pressure and comfortable during the assessment but later reported that the assessor approached a relative after the assessment, rather than put the participant at ease first. This appeared to have increased P4’s concern and worry. P4 did not feel an active participant in the feedback process.

I asked her ‘how was I, how did I do? ‘She went, oh, you know she said it was kind of ok, she didn’t tell me it was bad. Once I’d left there, I mean I think she had a conversation with my sister...... you know I don’t know what’s been said to my sister but I do know my sister wasn’t pleased about what happened, you know I made mistakes. (P4:168-172)

3.5. Ideas about the assessment

This theme addressed the beliefs participants held about the purpose of neuropsychological assessment. Participants spoke about what they thought the test was trying to find out and how the test could help professionals to help them.

3.5.1. ‘To find out the problem’

Participants were clear that the assessment was to help find something out about their difficulties following the head injury.

The assessment for P2 served to confirm or prove the existence of a head injury. The presence of such a physical injury was not detectable by medical examination but the associated difficulties were very real. P2 reported relief at undergoing the neuropsychological assessment as it confirmed pathology and associated difficulties experienced.

I am actually very grateful for them even because I have a mild to moderate brain injury that didn’t show on MRI scans um, so it showed on ECG scans but the primary diagnostic method for me was neuropsychological assessments, so they have been extremely helpful to me. (P2: 69-73)

P2 had an understanding of the tests assessing both strengths and weaknesses. It is interesting that P2 reflected on the successful areas of the tests, comparing it to pre-morbid ability. Emphasising strengths that may serve as a coping strategy, holding on to previous abilities that hold importance.

I recall there being many different tests, testing different parts of the brain but um interestingly the tests that tested parts of my brain that were functioning normally still, I still did very well compared to pre-morbid estimates. (P2:104-108)

Different understandings regarding assessment purpose were reflected in the language used by participants. Descriptions were given about finding out ‘problems’, to test parts of the brain and to assess different cognitive domains.

Think they’re to do with my memory. (P8:63)

They want to find out what type of brain injury I have basically. (P8: 198-199).

They’re just trying to find out about the problem that I’ve got. (P4: 371-372)

The assessment was to see, if I have it right, to assess and test the various parts of my brain. (P1:24-25)

P6 talked about understanding the assessment as finding out what cognitive functions are intact or lost after head injury.

They explained it, it was basically my level of cognitive impairment, you've lost. Or still have, there's still things you can actually do. (P6: 25-27)

The purpose of the assessment in P3's opinion was to enable the psychologist to ascertain ability levels. P3 referred to present difficulties and viewed the assessment as a means of comparison to pre-injury abilities.

*I think I was being tested cause I think when I came in here [*rehabilitation unit] *I wasn't your A star human being I don't think I was. (P3: 141)*

Um, but I think they just want to see where I'm at if there is an actual scale from where you measure someone with a brain injury to how they could have been before. (P3:149-150)

P5 was confused about the purpose of the assessment and thought the tests were very ordinary tests of 'common sense' perhaps unlike tests completed within other contexts.

The intriguing side is why am I doing this? What is it achieving? Cause to me it's like common sense but now I know it was a neuropsychological assessment it was seeing what common sense I've still got! (P5:21-24)

3.5.2. Recovery

Participants reported that they had approached the assessment with ideas that it would help professionals to find out how to help them.

P2 and P7 discussed the assessment within the wider context of allowing them to access the services they required. P7 spoke about the professionals gaining a new understanding of difficulties in order to help. P2's assessment allowed a positive outcome in terms of acting as a gateway for support.

So that they know what my difficulties are'; 'so they can offer me the right service' (P7:117)

The primary diagnostic method for me was neuropsychological assessments, so they have been extremely helpful to me as without them I wouldn't had got the support I needed' (P2 72-74)

P1 viewed the purpose of the assessment as providing information for the psychologist so she could feed it back and provide knowledge in lay terms.

The assessment helped [psychologist] *to understand me and because* [psychologist] *could understand me more she taught me about me. (P1: 240-242)*

P8 talked about the assessment revealing areas that need 'fixing'. This implies the deficit is considered as something that can be mended. The term 'find your limit' suggests a need to reach a level of understanding of difficulties in order to progress further. The assessment will create a new path for progress.

I like to know what my problems are cause you can then try to fix them, if possible. (P8: 426-427)

Because to get progress you have to find your limit and then go over it. (P8: 282-283)

P8 also showed determination to do well in other areas of life and indicated that there was now a clearer picture of possible achievements.

Yeah basically, I started realising I had a brain injury so then when I got that result I thought 'yeah I want to start aiming for that' instead of that sort of thing, (P8:273-274).

Similarly P4 expressed hope about making recovery and portrayed an understanding of this improvement being measured by future assessment.

That's it when I did that [assessment] *I hope that I've progressed and hopefully when I go back in a couple of years for another one they'll say 'cor you know that's amazing, you were bad at the beginning and now you're really good at it.' (P4: 272-275)*

3.6. Approach to assessment

This superordinate theme encompassed the ways in which the participants approached the assessment. Participants spoke about feeling the need to do well and try their best, in terms of fulfilling self expectations and also a desire to please professionals. They spoke about having mixed emotions and anxiety about what the tests may show, leading to anxiety when undertaking the assessment.

3.6.1. 'Trying my best'

Participants spoke about their expectations when undertaking the assessment and a need to please and impress the assessor as well as achieve self fulfilment.

P3 wanted to do well on the assessment, considering it a personal challenge, alluding to the fact that perceived poor performance on the assessment would lead to worry afterwards.

I tried hard to make them really good scores. It's not like I'd leave out of here and be like don't worry, I'm such a try hard when it comes to anything. Yeah, so I just want to do well on everything. (P3: 162-164)

P1 reported approaching the assessment in a competitive manner. P2 compared the assessment to past academic challenges and enjoyed the stimulation of the tests.

No I wasn't really worried, I'm a competitive person and up until injury have always been a sports person, always involved in leisure development , sports centres and all that so, as soon as that test was put in front of me it was a competition (P1:138-142)

Well my experience of being assessed, I actually quite enjoyed the assessment because I enjoyed the challenge (P2:97-98)

P1 expressed a desire for positive feedback about performance. P1 demonstrated an understanding about standardised assessment procedures acknowledging that the assessor has to be ‘objective’ and not give approving comments throughout the test. In recognising this, P1 may have approached the assessment as a means of gaining personal achievement.

I suppose I wanted the praise and approval off the person doing the test like ‘that was good, that was quick’ but of course they were very objective about it [both laugh] *so it was a bit like that you know, it was more for my own satisfaction the fact that I could do that. (P1: 154-158)*

3.6.2. Determination

Participants reported a sense of determination when completing the assessment. They said that they wanted to try to assert some control over their injury, this was reflected in terms relating to ambition.

P4 spoke about his determination to do well on the assessment within the context of personal progress achieved since injury.

I always want to progress because when I was first in the [hospital name] I had trouble remembering everything and anything. So, when I go to [Hospital] I do want to impress myself. (P4: 6-10)

I thought ‘I’m gonna be better, I’m gonna be better’. (P4:99-100)

P3 also expressed a strong determination to succeed and receive acknowledgement for undergoing the rigours of the assessment situation. P3 suggested the assessment was not a privileged situation for a personal sense of determination but a strategy applied to all aspects of life.

I think when I leave here, I think they’ll say like yeah, he has passed with flying colours on some of the things we put him under. Um, I’m an achiever and I will not leave until that’s the case (P3:144-147)

3.6.3. Mixed emotions

This subordinate theme captured emotions the participants experienced during the assessment.

P3 talked about having mixed emotions during the assessment, related to feelings of being unsure about test performance. P3 reported more positive feelings after the assessment was complete and also expressed a sense of achievement at having completed the assessment.

Um, during, a bit on and off cause you're never one hundred and ten percent about anything. But then afterwards I was kind of confident that I done it I actually think, yeah, you're so smart P3 don't worry about it. (P3:243-244).

Um, I tried to go quickly [laughs] through some of the questions just so I can't look back..... I need to just get through it, I would just start ticking unnecessary boxes or saying silly things] (P3: 267-270)

P3 continued to talk about trying to complete the questions quickly. There appeared to be a sense of panic and worry, perhaps reflecting time pressures of the assessment and an overwhelming need to complete the assessment.

P1 has developed strategies for use in day-to-day life to manage such time pressures, however, the assessment environment did not allow these to be employed, leading to feelings of stress and tension.

One of the strategies that JJ gave me was to write things down. Right so I used to write things down when I did X,Y,Z but when I'm under time pressures, so if I haven't written things down or I've run out of time to do something, I get very stressed and feel really tense. *(P1:196-200)*

P6 also experienced feelings of stress during the assessment and relief after it was completed.

Well I felt better afterwards, after it was done I was trying to get rid of it, it's a stressful thing. (P6: 456-457)

P4 expressed nervous feelings during the assessment relating to the unfamiliarity of the situation and the similarity to a school situation when taking a test. As previously noted, P4 further recognised that having a familiar person present during the assessment would be calming and reassuring. Repetition of the word 'calmer' emphasises the need for this.

The lady I'd never seen before, that's quite scary and you know when it was like, it was like being in school doing your exams and you feel nervous. (P4:178-181).

In relation to his sister being allowed into the room] I would feel, I would feel more calm, I would feel a little bit calmer. (P4:112-113)

Both P7 and P1 described feelings of anger during the assessment. P7 was panicked and frustrated due to time constraints of the tests and an awareness of having difficulty recalling information. The emphasis on feeling 'very angry' illustrates the power of this emotion for P7 (within the context of personal weaknesses being bought up again).

I was running out of time for things cause it took so long to remember what was going on and I knew I couldn't remember (.) it all boiled up to me becoming very frustrated and leaving very angry. (P7: 77-80)

Annoyance, annoyance at myself and annoyance at her even though I was expressing the sort of distress and I didn't really want to carry on with the tests. (P7:70-73)

P1's feelings of anger are directed at the person who caused the head injury, reflecting blame for lower level scores on the accident.

The lower ones it made me feel angry and aggressive towards the person that did it [hit and run driver]. *(P1: 327-329)*

P4 and P2 expressed annoyance within the context of abilities prior to the head injury. Comparisons were made between present competency and ability at school.

P2's feelings during the assessment also related to academic abilities prior to the injury. Embarrassment at an inability to answer the questions resonated, as later in the interview P2 discussed looking up these answer on the internet.

It was a bit annoying to be honest because I remember how I would have done it easily in school. (P4: 32-33)

I just remember my embarrassment when I was asked to name the five continents and I couldn't do that and I thought someone with my educational background should be able to do that. (P2: 452-455)

Other emotions described by P1 were dependent on perceived test performance and these positive and negative feelings were experienced for sometime afterwards.

Well I think um in some respects they made me feel better and in another they made me feel worse....If I thought I'd done well then I would have been quite positive about it, If I thought it was a poor performance I would have been down about it. Yeah so it's one of them really, if it felt good, like I'd performed well great I'd feel positive. (P1:422-426)

P3 experienced different emotions throughout the assessment relating to perceived performance on the different tests. P5 reported no change in feelings with regard to the assessment indicating a sense of coping with the pressures of the assessment. However, P5 did express feelings of eagerness to complete the tests, continuing the sense of intrigue and curiosity expressed by P5 throughout the interview.

Mixed [feelings] *there were some things I'd come across and feel not too sure and others where I'd think yeah I know this. (P3: 280-281)*

My feelings before the assessment were exactly the same as my feelings after the assessment because it kind of didn't matter. (P5:51-53)

My feelings were eagerness, I was eager to do it. (P5: 121)

At the time of assessment, both P6 and P1 were undergoing court cases related to the accidents that caused their head injuries. During the interviews, they both described not wanting to perform too well on the assessment for fear that they may appear 'better' than they were and would consequently receive less compensation for their injury. However, the assessment was personally meaningful to them as they wanted to ascertain their strengths and weaknesses. P1 had a dilemma with trust in the assessor but then worry about performing well in case the opposition's insurance company saw the results. P6 also experienced similar feelings of stress and conflict during the assessment.

It was a very difficult position to be in, when I was being assessed because I didn't know how far those reports were going to go you see. Now I know there's confidentiality there but I'm also a little bit paranoid. (P1: 77-80)

It was very um very stressful Because the case was going on anyway you know so it's a very hard thing because you well, you don't want to be seen to be doing too well because these things are for the case. (P6:276-277)

However, at a later point in the interview, P6 disclosed that the assessment overall had helped in that it had decreased overall stress.

I must be honest I've been ok with it, they've helped me they've bought less stress rather than more. (P6:577-579)

3.7. Results of Assessment

Participants talked about the ways in which the assessment and feedback outcomes gave them insight into the difficulties they experience as a result of their brain injury. Some had no understanding of cognitive impairments prior to assessment. Others reported some awareness, but the assessment added to their understanding. Participants spoke about themselves prior to injury, drawing comparisons to their current view of self.

3.7.1. Understanding of differences

Participants spoke about how the assessment enabled them to gain further knowledge of their difficulties in relation to their brain injury.

P5 spoke positively about becoming more aware of difficulties since injury, with an awareness that something was different, the assessment provided confirmation for this. P1 spoke about the assessment 'confirming' the head injury.

I know I'm not fully all there in certain ways so it's nice to know when you're not. (P5:44-45)

It made me more aware of what I'm lacking up here. (P5: 64-65)

It confirmed that I had a head injury. (P1:174)

P1 continued to discuss how the assessment increased personal confidence levels. It is possible that P1 thought that, prior to the assessment, the brain injury had more of an impact than it actually did, affecting personal views of abilities and confidence.

I think it gave me some more confidence in the knowledge that I'm not as bad as what I possibly, thought. (P1:188-189)

P7 however, appears to have had a very different experience in terms of gaining awareness from the assessment. P7 was already aware of the difficulties caused by the head injury and the confirmation received from the assessment held negative connotations as it reinforced awareness of difficulties.

I didn't like my weaknesses being bought up again after so many years of knowing and having the tests, finding out what the problems are, finding strategies to deal with them and then all of a sudden having them brought back up again. (P7:61-65)

P3 was aware of the head injury impacting on cognitive or 'classroom' abilities, but chose not to concentrate on them, placing more importance on physical recovery. P3 discussed how the tests allowed an understanding of the areas that needed improvement in terms of cognitive ability. It is important to mention P3's comparison of mental abilities to 'classroom things'. As noted earlier, throughout the interview this participant compared the assessment to the classroom and referred to the psychologist as a 'tutor'.

I concentrated so much on my body actually physically repairing I noticed I didn't concentrate so much on the classroom things and, but I'm at that stage now where my legs are strong again and I'm trying to concentrate a bit more on one or the other (P3: 336-340).

P3 may have been so intent focusing on the physical aspect of injury, unable to face the impact of the injury on cognitive abilities as well. This suggests the cognitive impact of the injury was ignored, either because the physical injury was easier ‘to fix’ or P3 may have not wanted others to be aware of these difficulties.

The assessment enabled P5 to recognise the impact the head injury had on cognitive abilities. The understanding of a head injury as a ‘hidden injury’ comes to mind. P5 described being more aware of lacking physical skills, being constantly reminded of this in day-to-day activities. The assessment findings allowed an understanding of the severity of the brain injury to develop.

It made me more aware of what I’m lacking up here [points to head] *I’m aware of more what I’m lacking physically because I have to cope with that everyday but mentally you don’t have to cope with everything everyday so it was because of that I found it intriguing. (P5: 64-68)*

P5 used an example of chairs in a row, as markers of a scale of severity of disability, providing a context in which to understand the level of impairment following the injury.

It enabled me to say, if there were six chairs there labelled one to six, which one to sit in, it gave me a slot. If the chairs are numbered one to six, six is the worst and one is the best, on disabilities with brain damage, it enabled me to see roughly where I was in that aspect. (P5:75-82)

3.7.2. An awareness of differences

Within this subordinate theme, participants described how the assessment had provided a means of understanding how the head injury had affected them.

P3 discussed receiving feedback about strengths and weaknesses following the assessment, perhaps only processing it on a superficial level. The comment suggests P3 needed time to reflect on the results after they had been delivered, indicative of the personal impact of the results and realisation of the impact of the head injury. Similarly, the assessment enabled P6 to recognise the presence of difficulties.

P6 described the assessment as being a ‘reality check’. This placed P6 in a new and different reality to that prior to the assessment.

Personal feedback probably is always a good one, like its ok being told that you're not great at this, you are good at this but when you actually realise yourself its like, it hits home a lot harder because you're like wow, something that happened to me has actually changed a lot of things. (P3:311-315)

It's only actually when you do the assessment you think well, actually I can't do that, it's a reality check you know. (P6: 87-89)

P2 and P8 spoke about not realising what difficulties they were experiencing. Prior to the assessment, P2 was not aware of difficulties experienced. This must have been confusing and provoked anxiety. The knowledge provided by the assessment allowed a clearer understanding about the participant within the context of their difficulties. In P2's second quote, feelings towards the assessment results were mixed, feeling upset about difficulties since injury but also relief at receiving proof of injury. Perhaps this 'evidence' provides P2 and others with a concrete reason for behaviours since injury.

'*I'm really glad they* [neuropsychological assessments] *exist as without them I would not have known what was wrong with me or why'. (P2:78-80)*

It's quite disheartening, other one is relief as it proves that I have a brain injury. (P2: 61-62)

It brought my attention for the first time to a problem, which when I look back has been an obvious problem since my brain injury. (P2:137-138)

P2 reflected on the fact that now this 'problem' seems obvious. This suggests that prior to gaining this insight, a belief may have been held that cognitive functioning was intact as P2 described surprise at discovering difficulties as a result of the head injury.

Similarly, P8 appeared completely unaware of difficulties due to injury. The assessment has provided an important mechanism for insight into current difficulties.

I didn't realise until doing tests like that, that I can see what my problem was sort of thing. (P8: 70-71)

3.7.3. Everyday difficulties

Linked to the above theme, participants spoke about how the assessment findings helped them to gain an understanding about their everyday level of functioning. They were able to use the results and apply them to more personally meaningful situations.

P6 was aware of experiencing difficulties in everyday living, with attention, an area of weakness identified in the assessment.

Attention that was where I was having difficulties with originally. Yeah, the ability to switch between one thing and another. That showed up in the tests. (P6: 202-205)

For P2, the assessment provided useful information in a wider context. P2 gained understanding into various areas of cognitive functioning in which difficulty was experienced. These have then been applied in a meaningful way to everyday functioning, providing information about the most suitable types of work.

The neuropsych assessments, in terms of my inability to work and thus my entitlement to a pension, the neuropsychs, all they show is that the type of work that I could chose because of multi-tasking impairments, organisational impairments, executive functioning and all of that. (P2:292-297)

Something I found particularly helpful in the report was that with every observed neuropsychological deficit, they er coupled it with an example of my subjective experience of day to day living. So they said for example this test shows that he has problems with divided attention and then they gave examples that I gave from my day to day living like can't have a conversation and cook a meal at the same time and I found that really good (P2:336-343)

The assessment feedback was placed within a personally meaningful context for P2 leading to the ability to relate assessment findings to difficulties experienced on a daily basis.

It boosted my self esteem to know that [referring to his IQ] was intact cause it means I can go into the pub and have a conversation with people and sound intelligent. (P2:156-160)

P2 was further encouraged by the fact that aspects of intellectual ability were unaffected by the brain injury, giving confidence to enable interaction with peers. In contrast, P7 had a more negative view and felt some aspects of the assessment were demeaning, had difficulty in connecting them with personally meaningful situations and consequently could not see the relevance of the tests. P4 also found it difficult to see how the tests related to real life and repeatedly remarked that the test materials were out of date. Certain pictures were unfamiliar due to the fact that some of test materials was very old. P4 considered they would not apply to current situations and was led to question test relevance.

I didn't feel that I needed to know what percentage of brown chocolate bars had been eaten by sally or had pink spots on, it had no relevance to real life. (P7:48-50)

The pictures that I had were old, old and tacky that's the way I saw them, I thought well these aren't going to help really are they. (P4:338-340)

Because they show you a picture of a car that was on the road in 1960 and that does affect me a bit cause I think why don't they do something now, something new. (P4:16-18)

3.7.4. Comparing current to previous self

This subordinate theme aimed to capture participants' reflections on the comparison between their current capabilities, (as measured by the assessment) and those before the injury. The assessment provided a new understanding of difficulties for some participants, leading to engagement in favourable comparisons with past and future selves.

The assessment has given P3 an understanding about where difficulties lie. The contrast between the terms 'strong' and 'good' suggested a distinction between memory as being 'weaker' than before, but accepting that it is functioning on a personally acceptable level.

Obviously my memory will never be as strong as what it was but I found ways for it to as good as it was before. (P3: 23-24)

So, but once I understood P3, you're not that person I was before, not a bad person, but you're not him it became much easier, a hell of a lot easier. When this bar wasn't so high I could set my own bar again. (P3: 41-419)

P3 talked in character terms about the potential differences in personal attainment following the injury.

P2 reiterated personal high achievement throughout the interview. This comment suggests that the assessment, in examining intellectual functioning, has highlighted differences between pre-injury self and current self.

Before my er brain injury I got a 2:1 in law from a top university in the UK and um so my intellectual functioning would have been at the top. Um and so the difference between then and now is actually very noticeable. (P2:16-19)

P1 talks about competing against self during the assessment as a reason for completing the tasks.

Well I got to do it, it was a competition against myself. (P1:153)

P6 was hopeful of making a full recovery from the injury and return to pre-injury level of ability. It appears that P6 was dependent on the physical side of his brain to 'fix' itself, this may be a coping strategy employed in order to provide hope for a full recovery.

I've tried to improve myself and that's the thing yeah try to get back to where I was....Things are still in your head so you have to get back to them I think your brain re-wires itself, I think it really does. (P6: 370-378)

3.8. Limitations of assessment

This superordinate theme reflects the limiting factors about the assessment, as reported by participants and questions the validity of the neuropsychological assessment. Fatigue during testing was a topic reported by a number of participants. Participants spoke about the fact that it had not been directly asked about in the interview, was a consequence of the long testing session and impacted on their performance. Participants conveyed that they were unaware of poor performance on various tests and negative feedback regarding this reinforced the impact of their head injury. Assessment environment contributed to a negative assessment experience.

3.8.1. Fatigue

Fatigue was reported as affecting the neuropsychological assessment and as a consequence of the assessment.

P2 discussed this ‘symptom’ of brain injury experienced but was disappointed that it had not been assessed. P2 chose not to discuss this with the assessor, even though it is obviously a major negative consequence of the injury, considering it ‘disabling’.

It would be good if they had that component of that test in the neuropsych assessment because that’s the one thing I felt was missing from the assessments the er any form of testing of my fatigue which is actually one of the most disabling factors of my brain injury. (P2: 315-320)

P2 suggested a measure for fatigue in the assessment. The assessment lasted two hours, during which P2 experienced fatigue. P2 acknowledged that not everyone experiences fatigue after two hours and can continue the assessment for longer time periods. In drawing comparisons to the average working day P2 suggested an assessment should last half a day, maybe trying to understand the injury in terms of functioning in everyday life.

But I guess that maybe one reason is that some people get fatigued after four hours and you can’t really keep someone in the room for four hours, there should be a cut off point a half day at work lasts maybe three hours so I’m sure that could be tested. (P2:292-294)

P1 questioned the validity of assessment in terms of the fatigue experienced. P1 further questioned the effect the fatigue had on the results. P1 also emphasised the impact fatigue had on the experience, both mentally and physically affecting concentration after only a short time.

Well the specific tests or the tests per se I don't think they um, I don't think they proved much because they were very draining after an hour or so, you know, the concentration factor. (P1: 175-177)

Without a doubt I noticed it was draining, without a doubt I was drained, mentally exhausted....Yeah yeah and also when you're mentally drained you feel physically drained as well. (P1:184-185)

P4 talked about the brain as an entity over which there is limited control, accepting that it is not working as well as desired. P4 could not distinguish between normal fatigue and fatigue due to brain injury, emphasising this by qualifying the time period over which he has experienced this problem.

I don't know whether it's because I was tired, or you know some days my brain is a lot more better than it is other days you know that's how the brain works and I mean I do know, I've been like this for four and a half years. (P4:127-130)

P3 reflected on reaching an understanding of fatigue, coping with it and accepting it as part of the injury. P3 further suggested that prior knowledge of the length of the assessment would impact on perception and level of fatigue.

At first, well with the levels of fatigue and things I was like I hate them I want to take running jump but now like I'm alright, I'm not alright, but I can actually enjoy them and just take from the experience as well. (P3:359-361)

I think it's the principle of fatigue, I think if I knew there was a half hour exam I would really die down near the end, but if you say it's an hour one I would probably work for a lot longer than a half hour one and start dying down like, that's why I say fatigue is psychological but I think there's a lot more to it than just getting tired like. (P3:375-380)

P3 described the fatigue experienced when playing football, accepting a need to recognise limits and likened the football experience to assessment experience of fatigue. P3 acknowledged the element of fatigue but had determination not to be beaten by it.

So with the tests it was that same element [as playing football] of (.) get fatigued, who cares, you've had a brain injury and you're going to work even *harder on the next one and be even tireder on the next one and kept on going and going. (p3:396-399)*

3.8.2. Feedback Setback

Some participants had limited awareness and understanding of difficulties following head injury. Some participants felt they were performing well on tests, only to be told later on that this was not the case. This would have negatively reinforced the impact of the head injury.

P7 was aware of the difficulties experienced as a result of the injury. Although P7 was under no illusion that performance was good, a process of negative reinforcement occurred in that weaknesses were bought up again. This bought back negative feelings, such as feeling ‘rubbish’ and of little use.

Um, I had some reassurance from B [assessor] *that they just needed to see what my weaknesses were but I definitely didn’t feel comfortable having my weaknesses brought out again. (P7:287-290)*

Yes but because I know my short term memory cannot handle more than one two or three bits of information at a time, I didn’t actually feel very useful and felt quite rubbish. (P7: 55-57)

P6 anticipated feeling worried at failing on tasks, considering that simply being able to complete the test, whether correct or incorrect, pointed to a good performance, as a buffer/ protective mechanism. The use of ‘perfect’, suggests that P6 did not think any mistakes were being made during the assessment. Any negative feedback would therefore have had a significant impact on sense of achievement and confidence. Similar to P6, P2 displayed a lack of awareness in capability that was revealed during feedback of test results.

Well I assumed I think when I was doing the tests the first time around I just thought I was getting it right, I’m doing it so I’m getting it right. It’s all perfect don’t worry about that. It’s only when the, somebody said to me afterwards, oh actually, you were good in this and bad in. (P6 92-94)

You have to cross the ones that are identical and I'm convinced I've seen them all but when they show me the test results a few weeks later I had missed loads of them and it always surprises me how completely unaware I am of not doing things as well as I should. (p2: 24-28)

3.8.3. Impact of the environment

Participants talked about the importance of the assessment environment. However, due to the extensive negative comments concerning this, I have considered it a limitation, further affecting validity, positively or negatively.

P7 had particular strong views regarding the assessment environment.

She wasn't, didn't attempt to change the environment, to try and make me feel more comfortable, everything was discussed over a coffee table. (P7: 9-10)

Yes and it wasn't, I couldn't see what I was doing because I couldn't focus and concentrate. Yes and she propped her briefcase underneath it. (P7: 30-34)

Ok, the last time I did the test in this room I was desk to eye waist level, doing everything at an eye level but this time there was no eye level table it was just a low down coffee table um so yeah i didn't' feel very comfortable. (P7:28-31)

P7 drew comparisons of the current test environment to previous assessment environments, highlighting the inadequacy of this one. P7 clearly had a negative experience of the assessment room. The low table on which tests were presented affected concentration and, the fact that the assessor tried to amend this in a makeshift manner, added to the impression of the assessor as unprofessional. Similarly, P4 was aware that the conditions of the assessment environment were not optimal.

It was tiny so she <assessor> could sit in front of me and I could sit behind her but that was the only room I mean that was in the summer as well so it was quite hot as well so I mean (P4:38-42)

I mean when I was in there, she had one of these going [points to a fan] *and I thought because that's the trouble, that's the way that I am, I mean if it's hot it affects me, if its cold it affects me. (P4:417-420)*

Brain injury impacts on the person’s ability to sustain concentration and they are easily distracted, which appears to have happened in this situation. The temperature, size of the room and the noise from the fan may have affected P4’s ability to concentrate, increasing anxiety and impacting on test performance. During the interview, P4 spoke about wanting a relative to sit in the room, however this was impossible due to the small size of the room.

Although P2’s overall experience of the assessment room was positive, P2 felt it important to mention that the assessment was interrupted. This distraction may have had implications for performance on the tests, with noise affecting concentration and the interruption and re-schedule affecting continuity.

We had to interrupt one session because there were roadwork’s outside so I just carried on the following week. (P2: 286-287)

Chapter 4: DISCUSSION

4.1. Overview

This chapter provides a brief summary of the main findings, discussing these in further detail within the context of the literature and relates this to the research questions. I have critically appraised my research and discussed the implications of the findings for future research and clinical implications.

4.2. Brief Summary of Analysis

Analysis of the data generated six superordinate themes: professionalism; relationship with assessor; ideas about assessment; approach to assessment; results of assessment and limitations of assessment.

The experiences of participants undergoing a neuropsychological test were variable, with reports of positive and negative experiences.

It was important to the participants that they be treated as equal partners in the assessment process. However, others viewed the process akin to being at school, considering the assessor being in charge and the person who ‘sets the rules’. Participants expressed views on the feedback process, reflecting feelings of professionals having priority over the person assessed.

Participants’ experiences were dependent on the relationship they held with the assessor, in particular, whether or not they were familiar with the person assessing them. Feelings of anxiety and confusion were expressed in cases where the assessor was unfamiliar. Familiarity with the assessor generated feelings of being comfortable, trusting and relaxed and, in some cases, provided a positive experience related to feeling respected with their viewpoint valued. However, this was not always the case and there were negative experiences related to dissatisfaction with the assessor’s approach to assessment.

There was a sense that participants thought that the rationale for the assessment was to find out about cognitive difficulties experienced after TBI. Participants spoke about the assessment confirming or diagnosing their brain injury. Others appeared confused about the purpose of the assessment and some thought it was for professionals to help understand the injury better and help in their recovery.

Certain self expectations were held in approaching the assessment. Participants found it a personal challenge, approaching it in a competitive manner. A sense of determination to do well in the assessment emerged. They talked about different emotions that they experienced throughout the assessment process. Time pressures during the assessment evoked feelings of anxiety and stress. Participants discussed feelings of anger and embarrassment, not only in relation to the conduct of the assessor, but also due to inability to complete certain tasks.

Participants spoke about the assessment providing a new awareness or a further understanding of the difficulties experienced after their injury. Many found this to be positive, giving them a better understanding of themselves and their injury. They were now able to relate difficulties experienced within the context of their injury and relate them to everyday tasks.

Several limitations of the assessment experience were reported by the participants. They spoke about experiencing fatigue during the assessment and the impact this had on their performance. The participants had mixed experiences of the assessment environment which impacted on their emotions and assessment performance. They held a belief that they were performing well on the tests, to find out this was not always the case, negatively reinforced the impact of the head injury.

The analysis has clearly demonstrated that being neuropsychologically assessed is not a neutral experience for clients with a TBI.This in contrast to Bennett-Levy et al. (1994) who suggested that the literature pointed to neuropsychological assessment experience being a neutral quasi-medical procedure, likening it to having a CT scan.

The points raised by the analysis have deep implications for the practice of neuropsychological assessment. This study suggests that opinions about the assessment process are strong and must be listened to. The main research question was:

The experience of neuropsychological assessment, views of clients with traumatic brain injury.

The following areas were explored in relation to the main research question:

Research questions:

- What do clients with TBI say about their experience of being assessed
- How do they describe this experience?
- How did the experience make them feel?
- What was their understanding of why they were assessed?
- Is the process of testing perceived as useful?

In this Discussion I will consider the first two research questions describing experiences of the assessment together.

4.3. What do clients with TBI say about their experience of being assessed and how do they describe this?

Although there was an overall sense of testing being a useful and positive experience, participants held diverse views about the assessment experience and outcomes.

4.3.1 The relationship with the assessor*:* familiarity/unfamiliarity

Participants' experiences were influenced by the degree of familiarity with the assessor, indicating that familiarity may have been a more important factor than the test procedure itself. A good previous relationship with the assessor was associated with feelings of trust, reliance and comfort. Where rapport between participant and assessor already existed, it did not need to be established at the beginning of the assessment, reducing possible anticipatory anxiety. As Cheston and Bender (2005) advocate, an assessment is the first step in a collaborative relationship that may be long term. Similarly, Keady and Gilliard (2002) advocate the need for a good prior relationship between the assessor and participant.

However, an unfamiliar assessor did not necessarily produce negative experiences for participants. This was dependent on whether the assessor attempted to build rapport, creating an informal and relaxed atmosphere. It proved particularly beneficial for participants to have their individual qualities recognised by the assessor consistent with the importance that Genevay (1997) places on an assessor in considering the participant as an intelligent human being, leading to feelings of empowerment. The main point that emerged from lack of familiarity with the assessor was associated with anticipatory anxiety, both prior to and at the beginning of the assessment. Conniff (2008) also discusses this anxiety in children feeling nervous about meeting a new professional when undertaking a cognitive assessment.

4.3.2 Style of assessor

Positive experiences were linked to feelings of respect, treatment as an adult and a lack of ‘pressure’. It also proved beneficial when the assessor was polite and hospitable. Lee (2012) notes the possibility that clients undergoing assessment may be apprehensive about being assessed. They need to know the context of the process, feel at ease and be regarded as individuals rather than as ‘statistical groups’. This is consistent with the existing literature from the medical context. Bensing (1991, p1307) suggested that the “patients’ assessment of the benefits of their physicians’ medical treatment (and therefore satisfaction) will be based on the perceived practitioners’ *affective* behaviour (rather than *instrumental* behaviour) and on attitude to the patient as a human being”.

Participants valued their own opinion being considered by the assessor and time taken to explain the process of assessment. Westervelt et al. (2007) supports this, observing that participants reported feeling pleasantly surprised that the assessor took time to talk them through the results.

Genevay (1997. p.16) discussed the importance of the assessor taking notice of the participants' contributions and not merely "the slice of me they are currently assessing". This is consistent with reports from participants in the current study appreciating the assessor building a relationship and treating them as a partner rather a 'subject' being assessed.

Lack of rapport may have been a contributing factor to negative experiences leading to feelings of dissatisfaction. Dimatteo, Taranta, Friedman & Prince (1980), in a medical setting, describe the relationship between physician and patient as containing a highly charged affective component. The authors point out the importance of establishing rapport and effective communication to ensure patient satisfaction.

4.3.3. Expertise and Power

Participants spoke about power differentials between themselves and the assessor. In most cases, they recognised the assessor as an 'expert' but experienced this in different ways.

Positive experiences of the assessment prevailed when participants perceived a small power imbalance. Although the participants placed the assessor in a position of power and expertise, others tried to establish a more collaborative relationship by attempting to create an informal atmosphere. Participants accepted the difference, perhaps viewing the assessment as yet another interaction with services in a powerless, passive role.

This sense of lesser power was particularly evident in the feedback process. Clients discussed how feedback was directed at professionals (or significant others), with little or no feedback being provided to them. They were left with feelings of confusion and this perhaps served to maintain the feelings of disempowerment and marginalisation. Similarly, Bennett-Levy et al. (1994) reported that participants could not remember, understand or did not receive any feedback, leading to feelings of concern about how they had performed. As Griffin and Christie (2008) point out, the intended audience for the report must be held in mind and unexplained expert terms will distance clients and disempower them.

4.3.4 The qualifications of the assessor

The negative experience of one participant relating to the qualifications of the assessor was reflected strongly. The assessor, a student, may not have the perceived level of expertise and authority that the participant assumed a professional should hold. Although this is a subjective view about qualifications held by the participant, it added to negative feelings. This individual situation appears to contradict findings from Bennett-Levy et al's. (1994) study in which it was found that the degree of satisfaction from patient and significant others did not differ as a function of level of training of the examiner. They suggest that the assessor's qualification level is less important to the client than the ability to establish good rapport.

4.3.5. Approach to assessment: determination and trying my best

Participants employed different attitudes in the tests, such as motivation to do well, competitiveness and determination. This may have helped participants to deal with the uncertainty and anxiety of the testing experience. Conniff (2008) reported that children employed coping strategies to manage the challenges of the test, such as distraction. In further support of current findings, Keady and Gilliard (2002) observed that perceived levels of threat during the assessment process led to the development of coping strategies such as 'making excuses' and 'strategic resistance'. These gave participants time to 'step back' from the assessment process, allowing them to work out the meaning of what was happening and maybe reflect on the consequences poor performance.

4.3.6. Limitations of assessment: fatigue

Many of the participants described feeling tired and mentally drained throughout the assessment. Fatigue was considered a negative consequence of their assessment. The duration of the assessment added to the difficult experience of testing. This is consistent with the findings of Conniff (2008) and Bennett-Levy et al. (1994) who reported participants finding the assessment long and tiring.

There was a sense of uncertainty about the reason for fatigue during the assessment. Fatigue is common in patients with TBI and, according to recent studies, it is one of the most disabling symptoms, regardless of severity of injury

(Fry, Greenop & Schutte, 2010). However, the fatigue may also be due to the assessment being long and mentally demanding. Belmont, Aga, Hugerton, Gallais and Azouvi (2006) suggest that fatigue after TBI is a complex and subjective phenomenon and has multifactorial origins such as sleep problems, depression and endocrine disorders.

Fatigue in TBI patients, according to Van Zomeren and Van Den Burg (1985) may be a result of the high mental effort to perform cognitive tasks. Belmont et al. (2006) further supports this with findings of an association between a number of mistakes in attention tasks and subjective fatigue scores, suggesting higher effort is required to maintain performance on tasks over time.

4.3.7. Limitations of assessment: feedback setback

Participants discussed being informed of poor performance during feedback. This served to negatively reinforce the impact of brain injury and associated cognitive difficulties. This is consistent with Cheston and Bender's (2005) view that repeated failure can strengthen a feeling of incompetency. The assessment procedures exist to examine areas of loss, with the tests situated within a professional knowledge base. Repeated failures on the assessment may reinforce feelings of uncertainty and confusion around test performance (Keady & Gilliard (2002). Similarly, Bennett-Levy et al. (1994, p1) suggest that the assessment may leave a person feeling "depressed at repeated failures". It is important to maintain a balance between the participants' sense of integrity and undertaking an assessment highlighting areas of weakness as the way in which it is delivered is crucial in determining how participants viewed themselves. This is illustrated by a participant in Bennett-Levy et al's.(1994 p 227) study "because it was my third session, the only feedback I got is faults I have, no wonder I went home with a negative frame of mind".

4.3.8*.* Limitations of assessment*:* the assessment environment

Strong views were held about the negative aspects of the assessment environment. Environments were reported as distracting, the room being too small and overly warm. Clients with TBI frequently report feeling distracted and experience difficulty attending to more than one thing at a time (Cicerone, 1996). An environment containing distractions may therefore impact on neuropsychological assessment performance.

Keady and Gilliard (2002) reported problems with the assessment room as being unfriendly, cold, medicalised with “pictures of brains on the wall”. This served to maintain levels of anxiety along with uncertainty about purpose of the visit. This was also evident in Westervelt et al’s. (2007) study with criticisms about the setting for assessment (too hot/cold, room too small). In contrast, Bennett-Levy et al. (1994) reported that most were content with physical surroundings, although a sizable minority would have preferred more breaks or drink during the assessment.

4.4. How did the experience make them feel?

Participants spoke about feeling pressured due to the timed aspect of some of the tests. This pressure led to experiences of anxiety, panic and anger, and a sense of needing to complete the tests as quickly as possible. Behavioural slowing is a common characteristic of brain injury (Lezak, 1995)**.** This slowing, coupled with the time pressure of the assessment, may lead to frustration at both the self and the assessor**.** In support of this, Bennett-Levy et al.(1994) reported that participants expressed uncomfortable feelings of being timed, commenting that they would feel more relaxed without time pressure. Participants were angry that previously developed strategies to deal with consequences of brain in everyday life (e.g. the use of a list, pen and paper) were not permitted during the assessment. I questioned whether the rationale of the assessment was fully understood or had been explained to these participants.
Bennett-Levy et al’s. (1994, p.225) study outlines negative comments about the testing: “I was forced to jump through hoops and it was dammed well obvious that the hoops were out of my reach”. This was also evident in Keady and Gilliard’s (2002) study where participants described feeling confused, anxious and uncertain of the purpose of the tests.

Anger was expressed by participants at their inability to complete tasks, drawing negative comparisons to their ability prior to the injury. Anger towards the person who caused the injury led to anger at the assessment confirming the seriousness of what has happened. Nochi (1998) postulates that difficult emotions emerge after injury, perhaps due to circumstances surrounding the loss. Clients involved in ongoing litigation, resulting in unresolved circumstances, can experience feelings of persecution and helplessness. This was also echoed by participants in the current study undergoing court processes.

Participants reported feelings of nervousness and fear during the assessment. Some commented on the similarity to that of a school situation. I reflected on whether one of the participants in particular had not experienced any form of test since leaving school, hence the reason for making reference to this. The children in Conniff's (2008) study found the test confusing, puzzling and difficult. They also framed their experience by making reference to something familiar, in this case, school.

Feelings of confusion and anxiety were evident which related to the difficultly of tests and performance outcome. For some, anxiety lifted once the assessment process was complete but, for others, remained for some time afterwards causing them to ruminate on perceived poor performance. One participant suggested a short conversation with the assessor immediately afterwards may have proved beneficial.

4.5. What was their understanding of why they were assessed?

4.5.1 Ideas about assessment: 'Trying to find out the problem'

Overall, there was a sense that the assessment was attempting to 'find out' about cognitive difficulties or how 'their brain' functioned after injury and that this information would enable professionals to help them. The explanation participants gave on why they were assessed was overall vague and mostly related to professionals 'trying to find out' their problems.

The participants' reports of rationale for assessment reflected either what they previously had been told by their psychologist or a personal understanding they had formulated themselves. Bennett-Levy et al. (1994) reported that many people were told nothing about the assessment or given very vague information "It was to assess my mental state". Others were under the misapprehension "I understood it was going to be a discussion not a series of tests". There was a relationship between degree of preparation for the assessment and overall experience of the assessment. Webster (1992) found that sending information sheets prior to initial interview increased satisfaction.

The participants held faith that the professionals would discover and explain their difficulties and they were happy to undergo a rigorous battery of tests without a clear picture of the reason. I am led to wonder if they liken it to yet another medical procedure they have been 'told' to undergo, with limited understanding. However, perhaps some participants chose to have a limited understanding in order to protect themselves from the consequences of their performance on the assessment, reducing any anticipatory anxiety. Chester and Bender (2005) hypothesise that people dismiss preliminary explanations and reach their own conclusions in assessment situations. Similarity, Keady and Gilliard (2002) suggest that clients place their own meaning and interpretation on reasons behind assessment if the rationale is not made clear.

4.5.2. Recovery

The idea of recovery within the context of the assessment was different for each participant. Participants spoke about the results allowing them to access appropriate services and support. They also spoke about the assessment results enabling a clearer understanding of their difficulties after TBI, creating a path along which they could progress. Additionally they spoke about the assessment enabling them to understand progress made since the TBI. This new knowledge about the head injury may have resulted in feelings of increased control, individuality, self awareness and self acceptance, having the potential for views of progress and moving forwards, rather than a restricted view of the future.

4.6. Is the process of testing perceived as useful?

The assessment was considered useful by participants because it allowed them to reach an understanding or new awareness about their difficulties after their head injury and this helped them to further understand and make sense of everyday difficulties experienced since brain injury. The assessment process led them to draw comparisons between their current self and self prior to injury.

4.6.1 Understanding of differences

Participants felt the assessment had enabled them to gain further understanding of their cognitive difficulties following brain injury. This was expressed in terms of confirmation of injury, an increased awareness of own abilities and as a baseline from which they could progress. The process of testing proved useful for the participants, providing some relief in ‘knowing’ why they had been experiencing particular difficulties. In support of these findings , Westervelt et al. (2007) reported that although the assessment was merely a confirmation of what participants knew, it was still helpful.

Not all participants in the current study perceived the assessment as useful and, for some, weaknesses were made obvious to confound a sense of coping with the impact of the injury.

The participants discussed focusing primarily on the physical aspects of injury as these were ‘most obvious’. It may be that it was more important to outwardly appear ‘ok’ or ‘fixed’ after the injury thereby coping in the eyes of others. I reflected on the fact that physical disability alone has dramatic effects on a person, with ramifications on personal and social life. However, the head-injured person has additional problems to face in psychological, emotional, cognitive and social impairments (Tyerman & Humphreys, 1984). The assessment had proved useful because it allowed them recognition of associated cognitive deficits. This is supported by Howes et al’s. (2005) study of brain injured women talking about their physical changes as something tangible but with cognitive difficulties seeming less real. Cognitive changes can be more problematic as a ‘hidden disability’ (Headway, 2012).

4.6.2. An awareness of differences

The assessment was a means for the participants to gain a new awareness of themselves in relation to the difficulties experienced after brain injury. Although a sense of initial surprise prevailed, the participants spoke about this awareness in a positive sense indicating they found the process personally meaningful and useful. Nochi (1998) suggests that, in addition to this, the assessment enables individuals with TBI to communicate and legitimise their changes to other people, proof that they are ‘not making it up’. Bennett-Levy et al. (1994) also reported the assessment useful to legitimise the problem. In support of the current study, Bennett-Levy et al. (1994) reported that the majority of participants considered the assessment to be useful, learning about their strengths, problem areas and gaining insight into what the results mean for them in their everyday life. In a study by Callaghan et al.(2006) participants reported a period during which they noticed problems in daily living but were unaware the cause of these were the brain injury, leading to feeling of distress, disbelief and confusion.

As previously discussed, unawareness may have been a coping strategy after the brain injury. Goldbeck (1997) cites unawareness as a coping strategy to the stress of physical illness. Callaghan et al. (2006) carried out a study exploring the experience of gaining awareness of deficit in people who have suffered a TBI. They reported that feelings of loss and fear accompanied understandings about deficits. In contrast, participants in my study expressed a sense of relief to find out about their deficits.

4.6.3. Everyday difficulties

Participants found it useful to have an understanding of how their cognitive difficulties affect daily functioning and that the feedback was placed within personally meaningful contexts. Bennett-Levy et al. (1994) provide a recommendation that feedback should be “memorable, understandable and useful to the person who was assessed”. They suggest feedback should include the application of results for everyday life and ways to get around the problem areas. This is further emphasised by Gass and Brown (1992) indicating that assessment findings should relate to their practical implications.

However, several participants found the tests to be far-removed from their own worlds, and questioned the usefulness of the tests. Participants commented on the test materials appearing old fashioned and they were therefore unable to identify with them. Cheston and Bender (2005) commented on a similar situation where the material used in tests appeared ‘patronising’ or ‘childish’.

4.6.4. Comparing the self with previous self

Participants gained a new awareness of their difficulties from the assessment. This was generally seen as a positive and useful experience, accepting and comfortable of their new self-concept. They acknowledged that they had experienced a number of changes, differences and difficulties since the injury.

Participants talked about the changes in a positive way. They spoke of the assessment as enabling them to understand and accept themselves as a different person since the injury allowing them to move on. Others engaged in comparison to pre-injury self, not necessarily in a negative way, but emphasising retention of ability and personal qualities. Nochi (1998) described hope of recovery as a strategy employed to prevent negative comparison of the future of pre-injury self to future of current self. People with TBI can minimise the negative influence of their self-changes on their sense of well being when they have a story of eventual recovery in their self-narratives. One participant demonstrates this: '*I think your brain re-wires itself, I think it really does' {P6:370-378).* It is possible that current status is viewed as being temporary with recovery to come, reporting changes after injury and an optimism to return to pre-injury state. This can also be considered under the previous section of Recovery with hopes of recovery reflected in the sense of returning to pre-injury level of functioning..

Conversely, some participants discounted their past, focusing on negative aspects of pre-injury life. One participant had been a heavy drinker prior to injury and appeared to have re-interpreted the accident as a means of becoming a better person.

4.7. Methodological considerations

This section provides a critical review of methodological issues within the study. I have used guidelines proposed by Elliott, Fischer and Rennie (1999) to critique the methodology and findings.

4.7.1. Owning one's perspective

In disclosing my own values and assumptions within this research, I have explicitly owned my own perspective (Elliott et al., 1999). I have documented my epistemological position in Chapter 2, where I also specified why IPA is, in my opinion, a suitable method for analysis.

In describing my own experiences with the neuropsychological assessment process, both personal and professional, I have explained how I reached the decision to undertake this particular piece of the research. By engaging in self reflexivity, I have tried to put my views and assumptions to the back of my mind in order to understand and represent the experiences of participants (Elliott et al., 1999).

I became aware, as part of the reflexive process, of particular experiences that emotionally affected me. Certain interview questions brought up previously unexplored patterns of thought and emotion for participants. I was moved by the way participants' expressed anxiety and confusion, not only emerging from the assessment experience but from their experience of brain injury itself. I developed a sense of personal responsibility towards these clients to ensure that their voices are heard through the research. In discussing potentially distressing experiences with participants, I drew on my experience of dealing with sensitive issues in a clinical setting. However, I was aware that I may have avoided further exploration in areas which may cause the participant to feel uncomfortable and potentially disengage. In defence of this, researchers have an 'ethical responsibility towards the participant' (Smith et al., 2009, p66) and in keeping with this, certain lines of questioning should not be pursued.

I was mindful that the interview schedule may have impacted on the themes generated in the analysis. However, efforts were made to avoid using leading questions during the interview and further questions arising from participants' answers were generated. The interview schedule was used flexibly. At the end of the interview, participants were allowed to comment on areas that had not been covered in the interview. I was mindful not to encourage or discourage responses through questioning and body language (e.g. nodding), or to pay more attention to accounts that I found more interesting.

4.7.2. Situating the sample

Participants and their life circumstances (TBI) were described to create meaning in context (Willig, 2008). The representation of voices from clients with a TBI, in the current research, was a strength as there is limited literature from this group's perspective.

The current recollection of the past may not be fully representative of actual experience. Callaghan et al. (2006) suggest a process of 'reinterpretation' may have occurred. Nochi (1998) further elaborates that experiences recalled may present a qualitatively different perspective to that which really occurred. However, IPA focuses on the 'perspective' not on 'true' statements of fact.

In order to explore ways that participants perceive and respond to shared experiences, IPA studies attempt to draw participants from a homogenous sample. (Smith & Osborn, 2003) It could be argued that my sample lacked homogeneity in terms of demographics (e.g. sex, ethnicity), however they all held the similarity of having had a TBI and undergone a neuropsychological assessment. I believe this was sufficient to analyse my interviews together. The generalisability of the results could also be questioned, but, by including in-depth analysis of all participant interviews, a richness of themes was generated and accounts from all perspectives have been allowed to show through. The concept 'generalisiability' can be seen to support a positivist epistemology, therefore controversial in qualitative research in which an emphasis is placed on in-depth accounts from small samples. However, It is the availability of these experiences to others, both socially and culturally, that can help inform knowledge held about them (Willig, 2001).

The majority of clients were recruited from the same charity, even though I had invited participants from many London-based charities. Recruitment was much harder than I had anticipated. I sent numerous letters and emails to charities, accompanied by my information sheet, but received limited response. The difficulties I experienced with recruitment made me reflect that this may be one reason why this group's voices are not heard.

All but one participant was white British. Culture impacts on awareness (Prigatano et al., 1999), it is therefore important to replicate these findings with participants from other cultural backgrounds. I would have liked to have broadened the study, had there been more time, using a more gender balanced study population (e.g. eight males and eight females) to try to capture the diversity in experiences and views.

4.7.3. Grounding in examples

To enable the reader to understand the fit between my interpretations and the data generated, I included verbatim quotations, word constraints permitting, allowing the participants’ voices to be heard.

4.7.4. Providing credibility checks

In order to support the validity of process, my analysis followed a rigorous and transparent IPA procedure (see appendix; Smith et al., 2009). My supervisor, who has experience of using IPA, examined sections of my analysis and audited an interview transcript. He followed the analysis through to the generation of master themes, to gain an assessment of face validity. Similar themes were identified and codes highlighted which required modification (Smith et al., 2009). My supervisor added to the richness of my analysis in providing opinions and ideas, still respecting the double hermeneutic inherent to IPA. I aimed to be as transparent about my thinking as possible because IPA is based on interpreting participants’ narratives. Due to time constraints of the study, respondent validation has not been achieved at this point.

4.7.5. Coherence

The checking of themes by my supervisor enabled achievement of coherence to ensure that the analysis stayed close to the data and individuality was not lost. Within the context of coherence, referring to whether research fits with underlying theoretical and epistemological assumptions of the approach (Yardley, 2000), I considered IPA the best methodological fit with the research question. In addition, I found the structure offered by this methodology appealing and approachable as this was the first piece of qualitative research I had undertaken.

4.7.6. Accomplishing general versus specific research tasks

I would like to have expanded and replicated the current study using a larger and more homogenous sample in order to broaden the claims that can be made from the findings. In research, there is a potential selection bias between those people who choose to participate in the studies and those who do not. IPA uses a purposive sample in order for the research question to be answered, the limitation in generalisation of findings is recognised (Smith et al., 2009). There is no literature on experiences of neuropsychological assessment for clients with TBI to allow comparison with this study. Some findings from this study appear to be consistent with previous results of experiences in other clinical populations.

4.7.7. Resonating with readers

I believe the readers will find my material stimulating and that it will increase the understanding of subjective experiences of this clients with a TBI through greater awareness of how these experiences are connected in a phenomenological manner.

4.8. Personal reflections on the research process

I reflected on possible assumptions being made based on my gender, appearance, status as a clinical psychology doctoral student and someone who had not experienced either a TBI or neuropsychological assessment. I wondered whether this may have influenced the way participants responded to my questions, whether they may have chosen not to share certain aspects of their experiences with me, or, conversely maybe shared more due to my experience within the psychology field.

This study was a new experience for me, undertaking research rather than therapy interviews. I have previously not conducted any qualitative research. In terms of my identity as a psychologist, I stated clearly, at the start of each interview, the purpose of the meeting, my role and how it may differ from meetings with other psychologists. I had to use considerable effort to ensure that I asked questions based upon a research focus and did not begin to act like a therapist. This was particularly difficult when clients asked for opinions about their TBI or asked questions about the meaning of their assessment findings. In these cases, I advised that they spoke to their psychologist or professional at the charity centre.

Gender differences between myself and the male participants may have had an influence on their accounts. The men may have found it easier to discuss their views, emotions and difficulties with a male interviewer. It is possible that they did not give an accurate description of the difficulties experienced after TBI due an awareness of established male stereotypes, not wishing to appear weak, exaggerating or downplaying certain elements. However there was no evidence to corroborate this issue.

Yardley (2000) emphasised that it is difficult to overcome power imbalances that exist between participant and researcher. I remained mindful of this throughout the interviews, attempting to diminish any potential power imbalance. I informed the participants that I considered them as the expert and I was interested in hearing about their experiences. At the end of the interview, I checked that participants were happy for me to transcribe the entire interview.

4.9. Future research

This study may serve as a platform for future qualitative research examining experiences of neuropsychological assessment.

The study could be replicated within other clinical populations who undergo neuropsychological assessment, for example, persons with degenerative diseases such as Parkinson's or Multiple Sclerosis who undergo repeated neuropsychological assessment. It is important in these cases, as the neuropsychological assessment presents with increasing difficulty as conditions progress and may further consolidate any negative experiences for the client. In taking time to understand experiences of the assessment process, there is scope for improvement.

Although IPA recognises that individuals' accounts are governed by the contexts in which they live, I wondered whether the use of discourse analysis would have enabled an understanding about the discourses (social, political, medical and psychological) participants drew upon in describing their experiences. This may be an idea for future research. Grounded theory may have been another alternative approach to use, aiming to facilitate the process of 'discover' or 'theory generation' (Willig, 2008). I would interview three to four participants, explore the data establishing tentative links between characters, returning to the field to interview further participants informed by an emerging theory. This would allow me to respond to questions raised by participants.

4.10. Clinical implications: recommendations

Each theme generated from the data reflects a different aspect of the experience of the neuropsychological assessment. These themes, with a significant impact on the outcome, have implications for clinical practice in all areas of neuropsychological assessment.

The way the assessor related to the participant emerged as a major influential factor in the assessment experience. The participants valued a collaborative approach, feeling respected and being an equal partner in the process. In clinical practice, the therapeutic alliance, a collaborative and affective bond between therapist and patient (Martin, Garske & Davis, 2000) has been argued by some to be more important for successful outcome than type of treatment. Rogers (1973 p.176) suggests “it is the quality of the interpersonal encounter with the client which is the most significant element in determining effectiveness”. Although the neuropsychological assessment does not require the same amount of therapist-patient contact as therapeutic work, this study suggests that the therapeutic alliance must be just as established and effective to maintain a positive experience.

Where possible, clients should be assessed by a professional familiar to them in order to reduce anxiety, allowing the client to feel comfortable before the assessment has commenced. When this is not possible time should be spent before the assessment establishing rapport with the client. It may be useful for the assessor to reflect on the client’s beliefs about help and explore how these beliefs may affect the engagement process. Client’s beliefs about being helped are likely to influence their contacts with all workers, in addition to the professional’s interaction being influenced by his or her own professional contexts (Reder & Fredman, 1996). In some cases client-professional interactions in one part of the network impact on relationships elsewhere, the results of which produce conflict in the helping process (Reder & Fredman, 1996).

Study participants displayed uncertainty regarding the purpose of the assessment. As some participants had limited or no insight into difficulties experienced since injury, they were confused by the referral for neuropsychological assessment. It may be beneficial to send a leaflet to the client prior to the neuropsychological assessment detailing its purpose, what it will entail, who will conduct the assessment, where it will be conducted, approximate length and details regarding a feedback session of the results. The option should be available to bring a carer, relative or significant other to the assessment and feedback session.

Clients undergoing a neuropsychological assessment may be involved with large numbers of professionals and it is important that this is not the 'latest in a long line of unsuccessful interventions' (Reder & Fredman, 1996. p. 465). Prior to meeting the client, the assessor may benefit from speaking to the referrer in order to map the network of professional relationships. It may also be beneficial to obtain a history of the client's relationship to gain an understanding about the referrer's and client's attitude to the referral. This may help understand complexities in the referrer-client relationship and ascertain who may be a useful resource for the client (e.g. in terms of implementing recommendations).

The assessor should spend time, at the beginning of the session, exploring the client's understanding of the referral for neuropsychological assessment. Reder and Fredman (1996) suggest using circular questioning techniques with the client, such as: whose idea was it for you to come and see us? What did you think [that person] hopes for when suggesting you come here? What were you hoping would happen here? Who else knows you have been referred here? Furthermore, questions regarding contacts with other helpers could be asked ('who has been helpful to you and who has not?'). Mapping current relationship to help by exploring client's beliefs, can make a significant difference to the contact with the assessor (Reder & Fredman, 1996). Conversations will no doubt evolve from questions raised on the reasons for an assessment and the client's hopes arising from the assessment. This may make way for a less expert position held by the assessor and a move towards co-participation, exploring collaboratively to solve their problems (Fredman, 2006). Adopting this approach is likely to result in a more positive working alliance and, in turn, a more positive assessment experience.

In response to reports of an inadequate assessment environment and its impact on overall experience and test validity, a recommendation is to consider the conditions necessary to obtain optimal performance. The assessment experience must be as comfortable as possible, including: low distraction; adequate space; ergonomically sound furnishings and good ventilation and temperature. The client should be offered a rest break.

Participants were concerned and confused about fatigue and its impact on their assessment performance. It is important for the assessor to distinguish between fatigue as a symptom of TBI and fatigue as building up over a long assessment period. In considering the former, it is important to assess this during interview prior to the neuropsychological assessment, considering how it may limit performance on the tests. Fatigue due to assessment length should be considered in relation to impact on results; affecting client satisfaction and interaction with the assessment.

In view of this study's findings about the uncertainty and confusion about the process of assessment, clients should be more involved in the feedback process. Although the assessor does need to assert an expert stance in administering and interpreting test results, a collaborative approach could be taken with the client and family in developing recommendations, taking the views and thoughts of clients into account. Feedback should not be delivered indirectly via carers or family members. The client being assessed must be involved in deciding who receives the assessment results. It is important to invite members of the client's system, at their request, to the feedback session. Ley (1982) suggests that when anxious, clients will not absorb everything that is related to them by professionals. Gass and Brown (1992) make suggestions for provision of feedback in a step by step approach. However, there are no official guidelines for feedback of the neuropsychological assessment, so consequently the success of the feedback is dependent on the person delivering it. UK NHS guidelines (Department of Health, 2000) now require copies of reports to be sent to the person who undertook the assessment, delivered in a legible and understandable manner. Feedback of the assessment results must also be delivered in a sensitive manner with empathic understanding (Cheston & Bender, 2005). Sufficient time for individuals to explore the meaning and implications of the results must be considered and, when necessary, appropriate psycho-education provided, both to client and significant other. It is Important that these points are considered in every neuropsychological assessment situation, regardless of time pressures due to service requirements.

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Appendix 1: Recruitment Email

Dear

I am a second year Clinical Psychology trainee and as a part of my doctorate I am required to carry out a piece of clinically relevant research. I am particularly interested in researching the experiences of people who have sustained a TBI.

I am currently trying to recruit participants for my research project and wonder if you would be able to help. If possible, it would be really great to come along to one of your support groups to see what sort of support you offer and to introduce myself to the people at your group and tell them about my research.

In addition, do you know of any other ways that I might be able to meet with any TBI clients who may wish to participate in the research? I have information sheets for anyone who might be interested.

Below, I have attached a brief summary of my research project for your consideration.

Summary of research

My name is Louise Owen and I am currently training to be a Clinical Psychologist. I am conducting a piece of research examining the experience of neuropsychological assessment in people who have sustained a traumatic brain injury (TBI).

Many people who sustain a TBI undergo a neuropsychological assessment to determine areas of skill and weaknesses, such as memory and concentration, using specifically designed tests. To my knowledge, no research has been undertaken to understand this experience in people with a TBI.

I would like to talk to people who have sustained a TBI and have had a neuropsychological assessment within the last two years. I am hoping to find out about their experiences and understanding of having a neuropsychological assessment and how the testing made them feel. These conversations should take approximately 40 minutes and can take place either in a room at the University of East London or at their local support group.

Greater understanding of the experience of being neuropsychologically assessed will help health professionals improve the assessment procedure for the benefit of future clients.

We would very much appreciate your advice and ideas on how best to recruit. Please would you let me know if it would be possible to visit a support group?

Many thanks and best wishes,

Louise Owen

Appendix 2: Participant Information Sheet

‘The experience of neuropsychological assessment, views of clients with traumatic brain injury’

Louise Owen-Trainee Clinical Psychologist

Email: XXXXX

University of East London- Clinical Psychology Department

Water Lane, London, E15 4LZ

School of Psychology Research Ethics Committee Chair: XXXX

- ***Have you recently had a neuropsychological assessment?***
- ***What was this experience like for you?***

My name is Louise Owen and I am currently training to be a Clinical Psychologist. As part of this course, I am required to carry out a piece of research. I have chosen to look at the experience of having a neuropsychological assessment, from the viewpoint of someone who has sustained a traumatic brain injury. I am asking for your help with my research.

Why is this study being done?

Many people undergo neuropsychological testing for a variety of reasons. There has been limited research into experiences of being tested from the viewpoint of a person who has sustained a traumatic brain injury (TBI). The aim of this research study is to learn about the experience of having a neuropsychological assessment in order to improve clinical practice and experiences for other people in the future.

What will participating in the study involve?

I would like to meet with people who have had a neuropsychological assessment within the last 2 years.

If you decide you would like to take part in the study, I will meet with you and have a conversation about your experience of being neuropsychologically assessed. I will tape record our conversations (with your consent) to remember what has been said in order to write this up at a later date as an anonymous report. The conversation will last approximately 40 minutes. This interview will take place in a private and quiet room, either at your home or at your local support group centre.

There are no hazards or risks in taking part in this research. If you feel you want to stop the interview, you can withdraw from the study at any time and it will not affect the care you are receiving.

Confidentiality of the Data

Your confidentiality will be protected at all times and only I will be aware of the identities of people taking part. All personal information and contact details will be kept separate from the interview transcripts and kept in a locked filing cabinet. This will be in accordance with the Data Protection Act. The interviews will be recorded and transcribed by the researcher, the tapes will be then be erased. All the interview data will be anonymised and, 5 years after study completion, will be destroyed. Confidentiality will be broken only if the researcher feels that you are at risk of harming yourself or another person.

Remuneration

There will be no financial reward for taking part in this research. However, we feel it is an opportunity to explore how people with a TBI think and talk about their experiences of neuropsychological testing, in order to benefit others in the future.

I will offer those who take part in this study a summary of the results and the opportunity to discuss any points made during the tape-recorded conversations.

Disclaimer

You are not obliged to take part in this study and are free to withdraw at any time during tests. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to provide a reason.

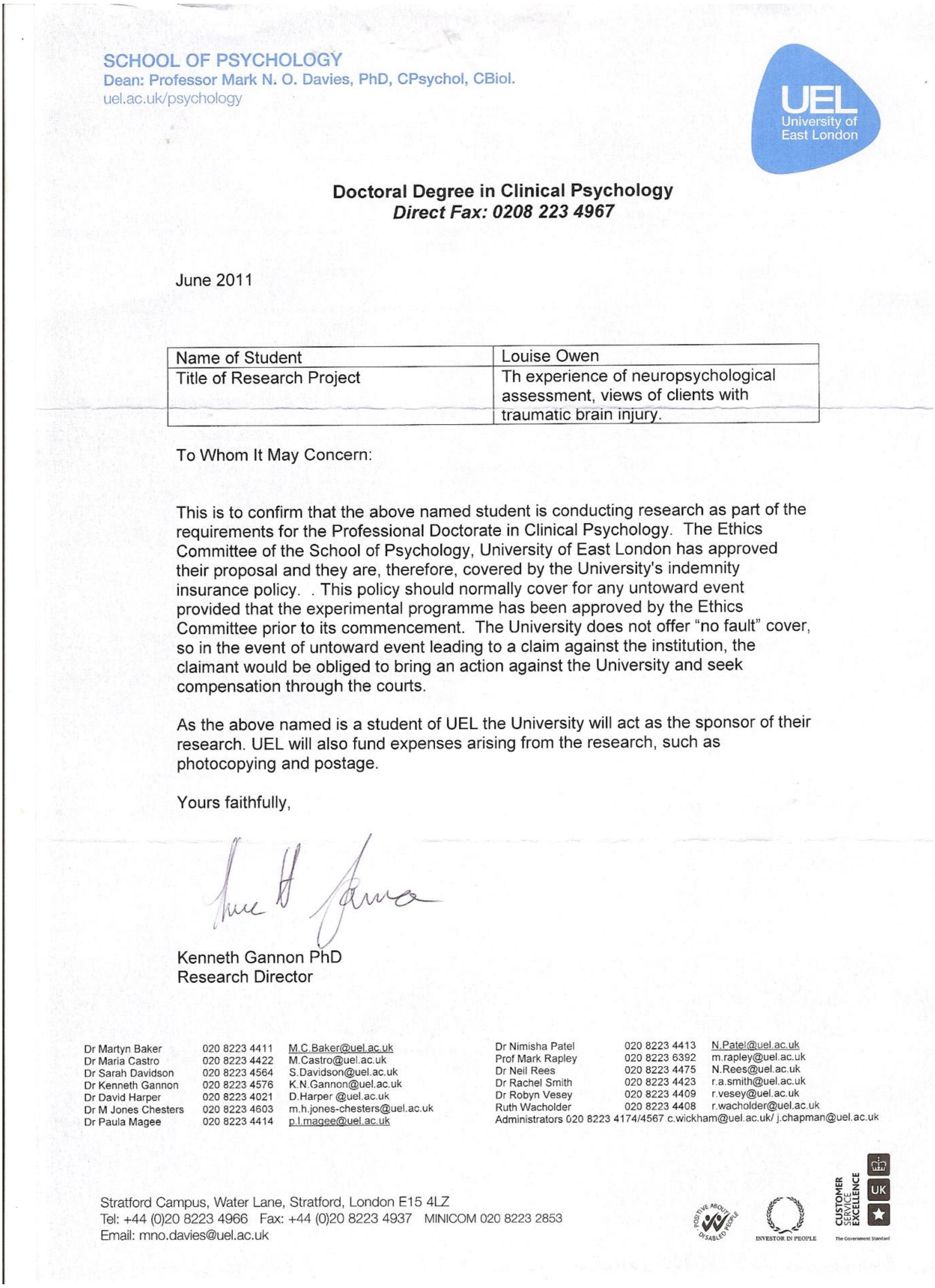
I appreciate you taking time to read this information sheet, please do not hesitate to email me on the address below should you require any further information.

The Principal Investigator(s): XXXX

Researcher

Miss Louise Owen (please contact Louise if you have any questions)
Trainee Clinical Psychologist
University of East London, Water Lane, London E15 4LZ
Email: **XXXXX**

Appendix 3: Ethics Committee's Confirmation Letter



SCHOOL OF PSYCHOLOGY
Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.
uel.ac.uk/psychology

UEL
University of
East London

Doctoral Degree in Clinical Psychology
Direct Fax: 0208 223 4967

June 2011

Name of Student	Louise Owen
Title of Research Project	Th experience of neuropsychological assessment, views of clients with traumatic brain injury.

To Whom It May Concern:

This is to confirm that the above named student is conducting research as part of the requirements for the Professional Doctorate in Clinical Psychology. The Ethics Committee of the School of Psychology, University of East London has approved their proposal and they are, therefore, covered by the University's indemnity insurance policy. . This policy should normally cover for any untoward event provided that the experimental programme has been approved by the Ethics Committee prior to its commencement. The University does not offer "no fault" cover, so in the event of untoward event leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the above named is a student of UEL the University will act as the sponsor of their research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Kenneth Gannon PhD
Research Director

Dr Martyn Baker	020 8223 4411	M.C.Baker@uel.ac.uk	Dr Nimisha Patel	020 8223 4413	N.Patel@uel.ac.uk
Dr Maria Castro	020 8223 4422	M.Castro@uel.ac.uk	Prof Mark Rapley	020 8223 6392	m.rapley@uel.ac.uk
Dr Sarah Davidson	020 8223 4564	S.Davidson@uel.ac.uk	Dr Neil Rees	020 8223 4475	N.Rees@uel.ac.uk
Dr Kenneth Gannon	020 8223 4576	K.N.Gannon@uel.ac.uk	Dr Rachel Smith	020 8223 4423	r.a.smith@uel.ac.uk
Dr David Harper	020 8223 4021	D.Harper @uel.ac.uk	Dr Robyn Vesey	020 8223 4409	r.vesey@uel.ac.uk
Dr M Jones Chesters	020 8223 4603	m.h.jones-chesters@uel.ac.uk	Ruth Wacholder	020 8223 4408	r.wacholder@uel.ac.uk
Dr Paula Magee	020 8223 4414	p.l.magee@uel.ac.uk			

Administrators 020 8223 4174/4567 c.wickham@uel.ac.uk/ j.chapman@uel.ac.uk

Stratford Campus, Water Lane, Stratford, London E15 4LZ
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Email: mno.davies@uel.ac.uk

POSITIVE ABOUT DISABLED PEOPLE
INVESTOR IN PEOPLE
CUSTOMER SERVICE EXCELLENCE UK
The Government Standard

Appendix 4: Consent Form

“The experience of neuropsychological assessment, views of clients with traumatic brain injury”.

Louise Owen, Trainee Clinical Psychologist

University of East London, Clinical Psychology Department

Water Lane, London, E15 4LZ

Telephone: 0208 223 4174

School of Psychology Research ethics Committee Chair: Dr Mark Finn

This form is for you to fill in to show that you have agreed to take part in this study. Please read each section and circle either yes or no to say whether you agree.

Name of person taking part:______________________________________

- Louise Owen has explained this study and I understand what she is asking me to do. I have had the chance to read the information sheet and had the opportunity to ask any questions about the study.

  YES/NO

- I understand that I do not have to take part and that if I do, I can chose to stop whenever I like.

  YES/NO

- I understand that the things I say may be written down and directly quoted in the final report. I also understand that this may later be published but my real name and any other details that may identify me will not be used.

YES/NO

- I agree to take part in this study by Louise Owen

  YES/NO

- I agree to the discussion being tape-recorded

  YES/NO

Signed by the person taking part_______________________________

Date:______________

***I, Louise Owen, have fully explained to the participant what is involved in this study*.**

Signed by the researcher, Louise Owen________________________________

Date: __________________

Appendix 5: Interview Schedule

Interview Schedule

1. Tell me about the neuropsychological assessment you underwent?

What was the purpose of the assessment?

What were you being assessed for? What had you been told as to why assessed?

Prompts: Why was it arranged? What were the aims? Who booked/arranged it for you.

2. Tell me what you remember of the assessment.

What was your experience of being assessed?

Prompts: How did it feel? Was it a good experience? Are there parts that you particularly remember? Tester qualities? Experience of being in the room?

3. Tell me what the main results of the assessment were.

What were the main findings? What did the tester tell you about the results of the assessment?

Prompts: were you told the results. Were they explained to you?

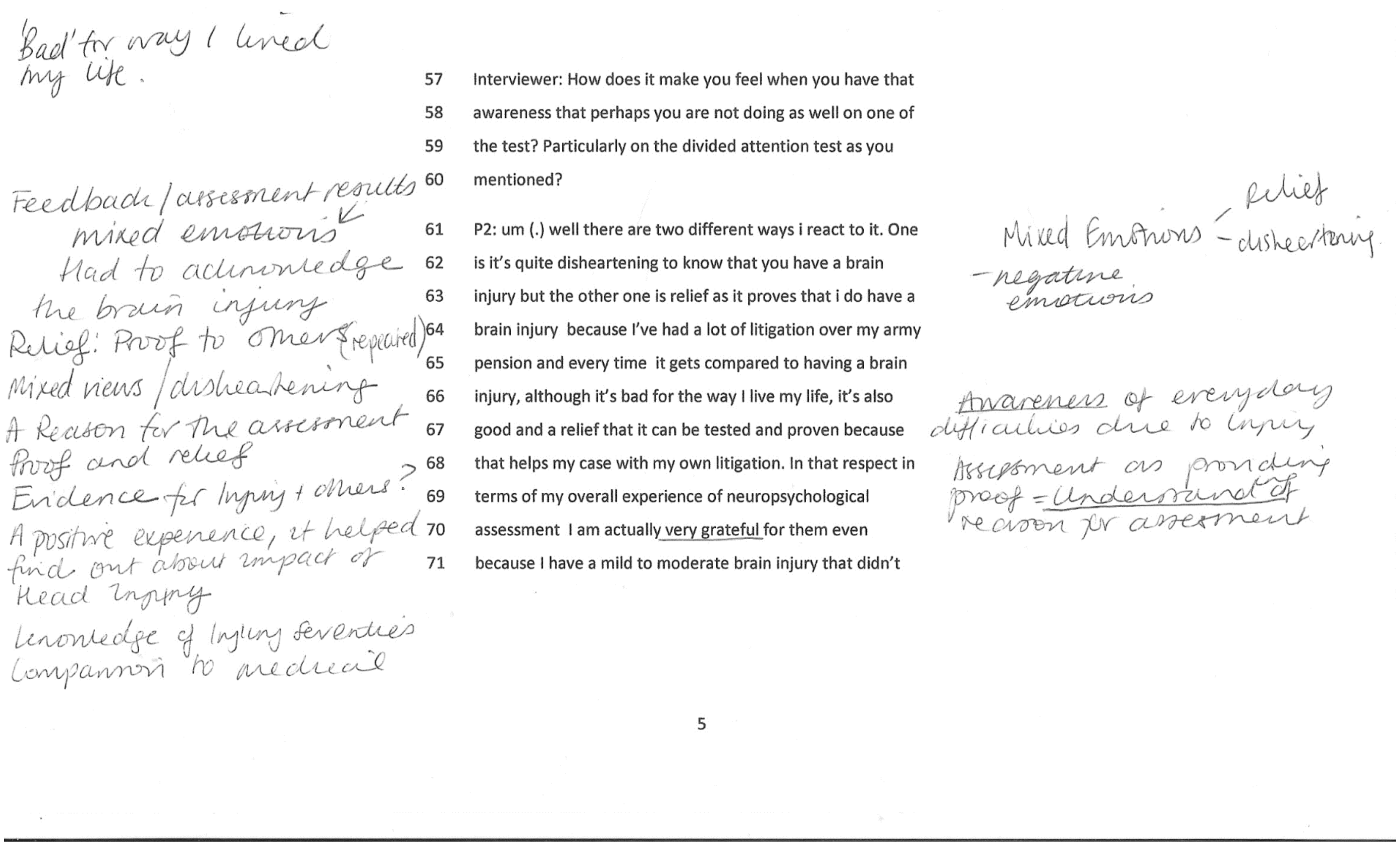
4. What were the outcomes of the assessment?

Was it a useful process?

Has it changed how you view yourself or actions?

Prompts: Were the results meaningful for you/family/carers. What happened as a result. Did any of the assessment make you feel better/worse?

Appendix 6: Worked Example of Transcript



'Bad' for way I lived my life.

Feedback / assessment results
mixed emotions
Had to acknowledge the brain injury
Relief: Proof to others (repeated)
Mixed views / disheartening
A Reason for the assessment
Proof and relief
Evidence for Injury + others?
A positive experience, it helped find out about impact of Head Injury
Knowledge of Injury severities
Comparison to medical

Interviewer: How does it make you feel when you have that awareness that perhaps you are not doing as well on one of the test? Particularly on the divided attention test as you mentioned?

P2: um (.) well there are two different ways i react to it. One is it's quite disheartening to know that you have a brain injury but the other one is relief as it proves that i do have a brain injury because I've had a lot of litigation over my army pension and every time it gets compared to having a brain injury, although it's bad for the way I live my life, it's also good and a relief that it can be tested and proven because that helps my case with my own litigation. In that respect in terms of my overall experience of neuropsychological assessment I am actually very grateful for them even because I have a mild to moderate brain injury that didn't

Mixed Emotions – relief
– disheartening
– negative emotions

Awareness of everyday difficulties due to injury

Assessment as providing proof = Understand of reason for assessment

5

Not detected by medical methods, associated difficulties very real.
Assessment as helpful
Assessment as a means for accessing support.
A diagnostic method.
Reason for assessment

diagnosis
Grateful ; helpful
Repeats how grateful: so obviously very important for them. Ongoing the impact on life.
'really' glad

Why? What's wrong?

Assessment as a means of discovery
Finding out about self

show on MRI scans um, so it showed on ECG scans but the primary diagnostic method for me was neuropsychological assessments, so they have been extremely helpful to me as without them I would had got the support I needed from the military in term of rehabilitation and a pension because it's through the assessments that my brain injury has been diagnosed. So I am actually very grateful for them as my brain injury wasn't picked up on the MRIs so I'm really glad they exist as without them I would not have known what was wrong with me or why.

confusion

Interviewer: I think I can understand you, so are you saying it provides proof for yourself and proof for others?

P2: yes because if there's something wrong with you , you want to know why and the first three months after my brain

Explanation ECG based medical explanation. Neuro Ax. more emphasis in-depth explanation

Support & moving on from head injury
Reason for assessment.

Feelings about assessment
- grateful
- A Relief
emphasis 'really' 'very'
process obviously really helped.

A need for explanation ('what')
Awareness — understanding of injury ('why')

Appendix 7: Audit Trail of Themes

Initial Phase

Super/subordinate Themes	Elements of Themes
Professionalism **Expertise/Knowledge** **Presentation of feedback** **Qualifications of assessor**	**Professionalism** How professional conducted themselves Unprofessional Lack of authority. **Expertise and Knowledge** Appreciate assessor as highly intelligent Recognition of professional boundaries Trust in assessor Mistrust and paranoia Confidentiality of results **Feedback** written in professional language/accessibility of feedback. Client marginalised-feedback to significant other or professionals. **Qualifications** Under qualified, unprofessional, lacked authority-negative experiences. Comparison to experiences from school-teacher/pupil, teacher holding the qualifications.
Relationship with assessor **Style of assessor** **Familiarity/unfamiliarity**	**Relationship with assessor** As Informal as possible A decrease in power differential if informal **Style** Communication style: Reassuring and

	validating Feeling comfortable, listened to and understood by assessor Not just another number to be assessed-a box ticking exercise. Not feeling under any pressure, creation of a relaxed atmosphere. A friendly and hospitable nature. Feeling respected and not treated like a child. A collaborative style **Familiarity/Unfamiliarity** Nervous to meet a new person Calmer if significant other allowed in the room Less anxiety and a sense of comfort if already know assessor.
Understanding of purpose of assessment **To help find out the problem** **To test the brain** **To test different cognitive abilities/domains** **Moving on/Recovery/Making progress**	**Purpose of assessment** To measure current capabilities To measure strengths and weaknesses. To measure ‘level’ person is at To measure memory Measure cognitive ability/cognitive impairment To test areas of the brain To find out the type of brain injury MRI scans could not detect injury so this was method of diagnosis. To help professionals to help me So they know what difficulties are and can offer help and support Assessment allowed progression since

	injury to be seen. Hope for full recovery Realistic expectations/unrealistic expectations
Approaching the assessment **Expectations from assessor/ Expectation of self** **Determination and to try my best** **Mixed emotions** **Positive** **Negative**	**Trying my best** High self expectations Pleasing the assessor, wanting praise from the assessor. **Determination** Competition against self Unrealistic self expectations. Hope and determination to do the best possible, a challenge to the self. **Negative** Dissatisfaction with assessment environment Unhappy with style of person assessing/anxiety as do not know assessor Anxiety about performance., anticipatory anxiety Increased self esteem Worried about performance Angry at self and assessor, embarrassed, frustrated. Time pressures on tests lead to stress and anxiety. Dissatisfied, confusing, nervous **Positive** Feeling comfortable and relaxed Appreciating tester qualities and environment. A challenge enjoyed it. Intriguing as Learnt about self

	Fun Competiveness against self **Mixed** Feelings depended on how difficult or easy perceived test to be. Conflict of interest: Insurance company vs. a need to know.
Insight **An awareness of differences (required more knowledge of injury impact)** **Understanding of differences (no Insight)** **Comparison of pre-injury self to post-injury self** **An awareness of everyday difficulties**	**Awareness of differences** No insight regarding difficulties prior to assessment. A new awareness from the assessment **Understanding of difficulties** Clearer picture of problems A reality check Proof and confirmation-for self and others. Evidence Reassurance-can hold on to old memories (intact cognitive abilities) Grateful, relieved (Now know where difficulties lie) Disheartening but a relief **Comparison pre and post injury** Differences made apparent Discussions of academic abilities pre-injury A new sense of self-a platform from which to now progress. **Everyday difficulties** Relevance of test: old fashioned, tacky-not personally meaningful. Awareness of reasons for difficulties in day-to-day functioning Feedback relevant to personally

	meaningful everyday situations.
Limitations of assessment **Element of fatigue** **Feedback Setbacks** **Assessment environment** **Anxiety experienced during assessment**	**Fatigue** Not measured, suggestion for fatigue measure included in assessment. Fatigue as a consequence of the assessment Fatigue impacting on assessment performance Awareness of personal; limits due to fatigue Fatigue during assessment vs. fatigue in everyday life Mental and physical fatigue **Feedback Setbacks** Belief doing well on tests-feedback shows not the case. Failures and weaknesses bought up again **Assessment Environment** Comparison to school environment Small room External noise A distracting environment Temperature not optimal **Anxiety** Nervous, worried. Anxiety regarding performance. Anxiety regarding feedback.

Middle Phase

Superordinate Themes	**Subordinate Themes**	**Elements of Themes**
Professionalism	**Qualifications of assessor**	Qualifications held by assessor: Under qualified, unprofessional, lacked authority, negative experiences. Comparison to experiences from school- teacher/pupil, teacher holding the qualifications.
	Expertise and Power	Appreciate assessor as highly intelligent Recognition of professional boundaries Trust in assessor Mistrust and paranoia Confidentiality of results Unprofessional, lack of authority. Feedback written in professional language/accessibility of feedback. Client marginalised- feedback to significant other or professional
Ideas about assessment	**Trying to find out the problem**	To measure current capabilities To measure strengths and weaknesses.

	Recovery	To measure 'level' person is at To measure memory Measure cognitive ability/cognitive impairment To find out the type of brain injury MRI scans could not detect injury so this was method of diagnosis. To help professionals to help me So they [professionals] know what the difficulties are and can offer help and support. Assessment helped access support and services. Assessment helped in moving on/looking to the future Assessment allowed progression since injury to be seen. Hope for full recovery Realistic expectations/unrealistic expectations
Approach to assessment	**Trying my best** **Determination**	High self expectations Expectations from assessor regarding performance

	Mixed emotions	Hope and determination to do the best possible, a challenge to the self. Competition against self Unrealistic self expectations Pleasing the assessor, wanting praise from the assessor. Dissatisfaction with assessment environment Unhappy with style of person assessing/anxiety as do not know assessor Anxiety about performance., anticipatory anxiety Increased self esteem Worried about performance Angry at self and assessor, embarrassed, frustrated. Time pressures on tests lead to stress and anxiety. Dissatisfied, confusing, nervous Feeling comfortable and relaxed Appreciating tester qualities and environment**.** A challenge enjoyed it.

		Intriguing as learnt about self Fun Competiveness against self Feelings depended on how difficult or easy perceived test to be. Conflict of interest: Insurance company vs a need to know
Results of assessment	**Understanding of differences**	Clearer picture of problems A reality check Proof and confirmation-for self and others. Reassurance-can hold on to old memories (intact cognitive abilities) Grateful, relieved (Now know where difficulties lie)
	Awareness of differences	No insight regarding difficulties prior to assessment. A new awareness of difficulties from head injury
	Everyday difficulties	Relevance of test: old fashioned, tacky-not personally meaningful. Awareness of reasons for difficulties in day-to-day functioning

	Comparing present self with previous self	Feedback relevant to personally meaningful everyday situations Differences made apparent Discussions of academic abilities pre-injury A new sense of self-a platform from which to now progress.
Limitation of assessment	**Fatigue**	Fatigue not measured in assessment. Fatigue as a consequence of the assessment Fatigue impacting on assessment performance
	Feedback Setbacks	Belief doing well on tests- feedback shows not the case. Failures and weaknesses bought up again
	Impact of environment	Comparison to school environment Small room External noise A distracting environment Temperature not optimal

Final Stage

Superordinate Themes	Subordinate Themes
Professionalism	Expertise and Power Qualifications of assessor
Relationship with Assessor	Familiarity/Unfamiliarity Style of assessor
Ideas about Assessment	Trying to find out the problem Recovery
Approach to Assessment	Trying my best Determination Mixed emotions
Results of Assessment	Understanding of differences Awareness of differences Everyday difficulties Comparing present self with previous self
Limitations of Assessment	Fatigue Negative reinforcement Impact of the environment