# Exploring Acquired Brain Injury (ABI) clients' experiences of receiving Cognitive Behavioural Therapy (CBT) delivered by trainees: A qualitative study

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### **Declaration**

I would like to declare that all of the information in this dissertation is either my own
original work or has been gathered from accepted sources and referenced accordingly.
Signed:

#### **Reflective Preface**

My enthusiasm for working with clients with acquired brain injury (ABI) began when I was an undergraduate psychology student. I became fascinated through making links between the knowledge I was acquiring from various strands of psychology, especially neuropsychology, cognitive psychology and biopsychology. This led me to volunteering at a charity organisation which provided neuropsychological rehabilitation services to people with ABI in a social healthcare context. I worked predominantly with older adults with ABI who suffered from stroke, and helped them on a one-to-one basis to achieve their rehabilitation goals. These were mainly behavioural goals for restoring their everyday life functioning. Preeminent in that experience was their strong sense of despair, hopelessness, helplessness, social isolation and meaningless existence. The traditional focus of neuropsychological rehabilitation was on cognitive functioning assessment and treatment of cognitive deficit resulting from ABI, such as memory, concentration, problem solving, information processing, and linguistic ability. Consequently, psychological treatment was not widely available to ABI clients. None of my clients had the option of receiving psychological interventions for addressing their emotional difficulties as part of their Since then, I have committed my professional career to providing rehabilitation. psychological interventions to this client group in the context of neuropsychological rehabilitation.

After finishing my undergraduate training in the discipline of psychology, I joined a Professional Doctorate Course in Counselling Psychology at the London Metropolitan University. I continued my therapeutic work with ABI clients in the field of neuropsychological rehabilitation. Counselling psychology includes multiple theories and concepts, which can contribute to healthcare professionals' understanding of the clients' conditions and the idiosyncratic nature of ABI. Similar to many other professional domains, a strong emphasis on evidence-based practice (EBP) has emerged in the field of neuropsychological rehabilitation. Healthcare professionals are required to make a clinical judgment based on the current best evidence for providing appropriate care for their service users, together with using their professional skills to evaluate both personal experience and external evidence in a systemic and objective manner (Sackett, Richardson, Rosenberg & Haynes, 1997). The rationale for EBP relies heavily on healthcare professionals' analytical and critical ability to evaluate the previous and/or existing practices; otherwise, clinical practice can become robotic and habitual.

There is a strong association between quantitative research and the EBP movement, where the evidence derived from 'double-blinded' randomised controlled trials (RCTs) has a greater value than other research designs. This notion extends to the evaluation of the effectiveness of psychological treatment in the field of neuropsychological rehabilitation. However, utilising RCTs in rehabilitation research might be problematic for several reasons. Firstly, randomly allocating ABI clients to different treatment conditions is a challenge due to the complexities of their clinical presentations. Secondly, outcome measures in rehabilitation research predominately employ standardised questionnaires, which do not tell us how the clients improve, or in what ways the clients have found treatment helpful or unhelpful. Most importantly, these test scores cannot evaluate adequately the effectiveness of psychological treatment in neuropsychological rehabilitation. For example, the commonly used questionnaires, Hospital Anxiety and Depression Scales (HADS) and Beck Depression Inventory (BDI) contain physical symptoms such as fatigue, which may inflate scores due to the consequence of brain injury rather than the consequence of depression and/or anxiety.

This qualitative study aims to explore and illuminate some of the complex and challenging issues that many healthcare professionals face when working with ABI clients in the U.K. Although CBT is the most influential psychological model in addressing the emotional consequences of ABI injury, I have often heard comments such as, 'How can CBT work better for this client group?' and 'What do clients find helpful or unhelpful in the course of CBT?' My research idea developed from my increasing uncertainty about the effectiveness of the current best evidence-based practice relating to CBT interventions for ABI clients. This emerged from discussions with healthcare professionals working with ABI clients, from my own clinical experience and observations gained from the past eight years, and from clients' feedback to neuropsychological rehabilitation services.

My hope was this study could provide an in-depth understanding for developing adapted CBT interventions that better meet ABI clients' needs, by learning from ABI clients' personal experiences of receiving CBT. Thus, I hoped findings from this qualitative study would contribute to the evidence-based practice in the field of neuropsychological rehabilitation.

In keeping with the philosophy of counselling psychology, I have adopted both a dialectical and a relational stance towards my clinical practice and research. Through a

dialectical stance I actively engage with different opinions and viewpoints. In adopting a relational stance I aim to reconstruct meanings, have respect for and be open to the other's subjective experiences, and seek an understanding of human difficulties in a relational manner.

This qualitative research places its emphasis on the meaning and interpretation of ABI clients' experiences of receiving CBT. It recognises the complexity of ABI clients' differences and focuses on understanding how to better work with this client group, rather than seeking the 'cure' and demanding objective and universal truths. I adopt phenomenological philosophy for this research, and comprehend ABI clients' lived experiences using Interpretative Phenomenological Analysis (IPA). As an IPA researcher, I needed determination, persistence and curiosity to engage and respond fully to the participants' life worlds. This experience has been challenging but rewarding for me, it has given me a sense of liberation and connection to the research. Most importantly, it provides a valuable learning opportunity for me to engage with complexity, and deal with the uncertainty and unpredictability that often arise during the research process.

#### **Abstract**

A recent systematic review suggests the effectiveness of Cognitive Behavioural Therapy (CBT) with brain injury client groups has been inconclusive and limited (Cattelani, Zettin & Zoccolotti, 2010). Although CBT has beneficial results in many specific psychiatric disorders, the rates of positive outcomes for managing psychological difficulties in the acquired brain injury (ABI) client group are still not satisfactory. Mixed or negative results have been reported in the existing literature (Cattelani, Zettin & Zoccolotti, 2010). Indeed, recent literature has highlighted a need to further develop existing CBT approaches for clients with ABI (Wilson, 2011), to assist practitioners in overcoming potential challenges caused by the complexities faced in this field. This qualitative study explores ABI clients' experiences of CBT to provide better understanding of what may produce a greater therapeutic alliance and positive outcome. Six participants with ABI were interviewed in a semi-structured format about their experiences of CBT. Interpretative Phenomenological Analysis (IPA) was employed to develop an in-depth and coherent understanding of participants' experiences. Three super-ordinate themes were identified namely, 'Professional relationship'; 'Understanding my struggles'; and 'Acceptance'. Each super-ordinate theme was associated with three sub-themes. Findings of the present study highlight the essential elements for the effectiveness of CBT. These elements are the quality of the therapeutic relationship, the client's willingness and readiness to engage in therapy, the adaptations needed in therapy to address the client's limitations, and the need for a balanced focus between the behavioural and cognitive components employed in Furthermore, findings imply that process-based adaption is as important as technique-based adaption when delivering CBT to ABI clients, suggesting that the quality of therapeutic relationship and the process issues are both relevant to the therapeutic outcome.

#### 1. Introduction

#### 1.1 Overview and Background

Acquired Brain Injury (ABI) covers all situations where brain injury occurred since birth. Common neurological conditions include stroke, brain tumour, brain haemorrhage, encephalitis and other brain diseases (Headway, 2011). A subtype of ABI is Traumatic Brain Injury (TBI) which is caused by head trauma, resulting from events such as road traffic accidents, assaults, falls, accidents at work or at home (Headway, 2011). The consequences of ABI can have a significant impact on persons' emotional, physical, behavioural, and cognitive functioning. Three major frontal-subcortical circuits in the brain are associated with specific emotional and behavioural difficulties during social interactions, namely the dorsolateral, ventromedial and orbitofrontal (Sbordone, 2000). Clients with dorsolateral prefrontal cortex damage show reduced levels of cognitive flexibility, a tendency towards perseveration and reduced verbal fluency, and may appear 'pseudo-depressed' due to a lack of organising and planning skills, and experience difficulty in developing new strategies to cope with situations (Milner & Petrides, 1984). Clients with ventromedial prefrontal cortex damage show lower levels of motivation and initiative, mutism, and decreased social activities (Sbordone, 2000). Finally, clients with orbitofrontal cortex damage appear to be easily distracted and unable to suppress automatic responses, particularly in the case of bilateral cortex damage, personality changes can occur with prominent characteristics of lacking insight and displays of antisocial behaviours (Damasio, 1996).

According to recent data provided by Headway, a leading head injury U.K. charity organisation, it is estimated one million people attend hospital A & E following a head injury each year (Headway, 2011). Around 500,000 people aged from 16-74 are living with disabilities as a result of TBI across the U.K. Over 130,000 people have a stroke each year in England and Wales, and there is an estimated 450,000 people living with severe disabilities as a result of stroke (Headway, 2011). Stroke care costs the National Health Service £2.8 billion per year, with informal care costs (provided by families) estimated to cost an additional £2.4 billion per year (Source: National Audit Office, 2005). Additionally, there is an estimated 500,000 people living in the UK today with various brain diseases, and an estimated 13,000 people are diagnosed with a brain tumour each year (Headway, 2011). The effects of brain injury can vary tremendously depending on

the type, location and the severity of injury, every client's presentation is unique. Their experiences of brain injury effects can range from mild to severe. The effects of brain injury may include different dimensions such as physical impairments, cognitive deficits, and changes in emotional reaction and behaviour. These effects can have a significant impact on everyday life functioning.

#### 1.2 Psychological Distress Following Acquired Brain Injury (ABI)

Psychological difficulties such as depression, anxiety and anger are the common emotional responses after brain injury (Seel & Kreutzer, 2003; Mateer, Sira & O'Connell, 2005; Ponsford, 2005; Tiersky, et al., 2005). However, such emotional distress can mistakenly be attributed to neurological factors and therefore sometimes may remain unrecognised (Ghaffar & Feinstein, 2008; Iverson, 2006; Clayton & Lewis, 1981). This is often due to these difficulties being expressed atypically by the ABI population and the considerable overlap of psychological and neurological symptoms (Williams, Evans & Fleminger, 2003; Khan-borne & Brown, 2003; Lincoln & Flannaghan 2003). The challenge of understanding the aetiological factors in relation to emotional difficulties, in the context of ABI, is complicated by many other psychosocial factors. These include pre-morbid personality, pre-injury history of the survivor, coping strategies, the forms of support available, life adjustment ability, the emotional trauma of the event, the nature and severity of the ABI, and the presence of additional post-injury stressors such as divorce, physical pain and sleeping disturbances (Williams, Evans & Fleminer, 2003). Additionally, ABI individuals may not be able to voice their anxiety and depressive symptoms adequately, nor be aware of these psychological symptoms and their origins. Another concern is that limited communication ability in some ABI groups may result in the development of aggression, agitation and anger (Williams, Evans & Fleminger, 2003). Furthermore, there are many other psychological factors that may contribute to the development of mood disorders after ABI. These factors include identity changes, the life adjustment process, loss of independence, the struggle to make sense of cognitive, physical and psychological changes, and acceptance of the traumatic event suffered (Cantor et al., 2005; Nochi, 2000; Ben-Yishay, 2000).

In a quantitative pilot study of 21 TBI individuals, Cantor et al. (2005) found a discrepancy between the images of past (pre-injury) self, the images of present (post-injury) self and the images of future (completion of recovery process) self, was associated with anxiety and

depression. Untreated psychological difficulties can increase ABI clients' physical disabilities and cognitive deficits, interfere with their rehabilitation progress and impact on the recovery of cognitive and psychosocial function (Parikh, Robinson, Lipsey, Starkstein, Fedoroff, & Price, 1990; Pohjasvaara, Vataja, Leppavuori, Kaste & Erkinjuntti, 2001). The National Clinical Guideline (2003) *Rehabilitation Following Acquired Brain Injury* suggests that the treatment options for emotional difficulties for this client group range from anti-depressants drugs, to providing access to individual and/or group psychological interventions in which the therapy approach is adapted to take into account individual neuropsychological deficits.

#### 1.3 Historic Aspect of Neuropsychological Rehabilitation

Theories and models employed in neuropsychological rehabilitation have predominately stemmed from Behavioural Psychology (Wilson, Rous & Sopena, 2008). Theories and models are invaluable as they play an important role in informing assessment, treatment and the measurement of the efficacy of neuropsychological rehabilitation. These include the behaviour therapy approach, the holistic milieu approach and the models of cognitive functioning. These approaches focus on different levels of functioning, e.g. concentration, motivation, memory, and attention span. However, other aspects of the client's difficulties such as emotional distress, appear to be overlooked. Despite the organic causes, there are many other psychosocial factors (e.g. pre-morbid personality, social support system, coping skills, family changes and financial impact after injury, identity and role changes) that interact to determine the probability of distress in clients with ABI. Therefore, it may seem reasonable to expect that behavioural and psychological interventions would be a major component of neuropsychological rehabilitation programs.

#### 1.3.1 Behaviour Therapy Approach

Behavioural Therapy (BT) has been employed in neuropsychological rehabilitation for more than 40 years. This approach provides influential contributions to manage, understand, and to alleviate disruptive behaviours (Wilson, 1999; Wilson, Herbert & Shiel, 2003). BT derived from the principles of learning theory, has proven to be effective in modifying ABI clients' unhelpful behaviours by replacing them with more adaptive ones. This therapeutic approach aims to reinforce desirable responses while discouraging maladaptive behaviours. Case studies in the field of ABI neurorehabilitation suggest BT has been somewhat effective in treating behavioural disturbances (Schlund & Pace, 1999),

and in social skills training (Brotherton, Thomas, Wisotzek, & Milan, 1988). However, to date there is still a lack of evidence to support BT's effectiveness for the treatment of depression and anxiety in the ABI population. Such findings suggest that a pure behavioural approach may not always work for ABI clients, as it merely focuses on the behavioural aspect of their difficulties. In theory, moods will improve by increasing social events and activity levels (Khan-Bourne & Brown, 2003). However, the loss or restriction of opportunities for pleasant events or activities, due to disabilities as a result of ABI, make a behavioural approach challenging when treating or managing depression and anxiety in these client groups.

#### 1.3.2 Holistic Milieu Approach

Traditionally, a holistic milieu approach (Malec & Basford, 1996) is commonly employed in neurorehabilitation programs, which uses elements of behavioural intervention to develop skills that enhance cooperation and motivation, and focuses on changing the lifestyles of clients and their significant others. These interventions often integrate aspect of Family Therapy, e.g. inviting the client's and their family member's perspectives, which can help with communication, and enhance family member's understanding of the nature and extent of their loved one's ABI. This holistic approach aims at facilitating a life adjustment process for the clients and their families, with an ultimate goal of helping ABI clients to regain a level of community functioning and productivity, e.g. returning to work. This approach places an emphasis on helping them to develop a positive working alliance with family members, through encouraging active participations.

Group psychological treatment is often employed within a holistic approach. This provides a therapeutic venue for the development of awareness after ABI (Klonoff, 2010). It is often facilitated by clinical neuropsychologists with aims of facilitating an understanding of the consequences of ABI, and providing an interpersonal forum for learning and sharing experiences with other people (Wilson, Gracey, Evans & Bateman, 2009). Group psychological treatment can provide mutual support and psycho-education for ABI clients, and is often delivered in a well-structured manner (Christensen, 2000; Daniels-Zide & Ben-Yishay, 2000; Klonoff, Lamb, Henderson, Reichert & Tully, 2000). This approach offers guidance and peer support to ABI clients to help them share their experiences and challenges that relate to emotional, behavioural and cognitive difficulties (Klonoff et al., 2000).

#### 1.3.3 Models of cognitive functioning

Models of cognitive functioning, including memory, attention, language and perception, are useful for informing neuropsychological rehabilitation, which aims to ameliorate cognitive, psychological and behavioural deficits caused by ABI. The current practice of neuropsychological rehabilitation in the UK has predominantly employed these models, with rehabilitation programs mainly designed and delivered by clinical psychologists and neuropsychologists. Neuropsychological, functional, and behavioural assessments are widely used to identify the areas that need to be rehabilitated, and place a heavy emphasis on identifying cognitive deficits and functioning, and in predicting behaviours (Wilson, Rous & Sopena, 2008). However, this model may not be sufficient to address other areas of functioning that need to be rehabilitated, for example, social functioning, emotional disturbances such as depression and anxiety, and the practical everyday needs faced by These areas are an essential part of neuropsychological individuals with ABI. rehabilitation, but do not feature in the models of cognitive functioning. As Wilson (2002) argues, one group of models such as cognitive neuropsychology is insufficient to determine what needs to be rehabilitated, given that neuropsychological rehabilitation requires a broad theoretical base that incorporates different frameworks and models from a multi-disciplinary group. Indeed, Prigatano (1999) suggests that rehabilitation is likely to fail if emotional issues are not addressed sufficiently. This implies a need to include psychological intervention within rehabilitation services.

# 1.4 Psychopharmacological and Psychological Approaches for the Management of Emotional Difficulties after Brain Injury

#### 1.4.1 Psychopharmacological Approaches

Psychopharmacological treatment is often combined with psychological treatment for ABI clients, especially for various moods disorders including depression, anxiety and emotional dysregulation (Fann, Jones, Dikmen, Temkin, Esselman & Bombardier, 2009). Psychotropic medications can help ABI clients' to attain the psychological stability needed to tolerate and benefit from psychological interventions. These medications may include selective serotonin reuptake inhibitors (SSRIs), mood stabilizers, antidepressants, and antipsychotics, which have been commonly utilised to eliminate psychological symptoms such as aggression, anger and agitation after ABI (Ghaffar & Feinstein, 2008; Silver, Arciniegas & Yudofsky, 2005). However, these drugs can have various side effects, i.e.

insomnia, sexual dysfunction and apathy (Ghaffy & Feinstein, 2008). Another consideration when prescribing antidepressant or antipsychotic drugs, is possible complications caused by the different drug interactions, and ABI client's susceptibility to these potential side effects. Electroconvulsive therapy is another form of treatment for clients who have not responded well to pharmacotherapy (Greenberg & Kellner, 2005). It uses an electric induction in treating clinical depression for therapeutic gain, however, there are no absolute contraindications to the procedure and this form of treatment may put ABI clients at risk for an intracerebral bleed or an increase of intracranial pressure, therefore demand caution and close monitoring.

#### 1.4.2 Psychological Approaches

A wide range of therapeutic frameworks are employed in helping ABI clients to deal with psychological difficulties including, Psychodynamic Psychotherapy, Humanistic approach, Family Therapy, CBT, and Mindfulness, 'the third wave' of CBT approach.

Psychodynamic Psychotherapy helps the client to gain insight towards his difficulties, using transference and counter-transference interpretations to draw the link between their present relationships and their past circumstances (Hobson & Kapur, 2005; Prigatano, 1999). The concepts of Psychodynamic Psychotherapy are particularly useful to understand the defence mechanism, the potential ruptures, and predicting the direction and assessing the quality of therapeutic relationships. Furthermore, drawing on the unconscious communications during sessions with the client facilitates a means to monitor the therapeutic process. An understanding of client's attachment issues, and early experiences helps to provide guidance for the therapist in gaining an understanding of clients' relational issues with others, especially in preparing for the ending of therapy. More recently, there has been an increased interest in using this insight-oriented approach to address the process of mourning as part of the ABI client's adjustment process (Kaplan-Solms & Solms, 2000). Despite its benefit to assist clients' understanding of difficulties, its potential limitations are that it focuses less on coping strategies in managing their emotional distress. Also, this approach requires a higher level of cognitive functioning which may limit its accessibility and applicability to this client group.

A humanistic approach has been applied to clients with ABI. The core principles of this approach are congruence, empathy and unconditional positive regard which play an important role in facilitating client's engagement during therapy. This approach aims at

increasing client's self-worth and working towards self-actualization. It assists clients to find new direction and address some of the existential issues including loss of independence and isolation, making sense of what happened to them and exploring new meaning and purpose in life (Patterson & Staton, 2009). Furthermore, the clients with ABI and their family members constitute a complex system such as changes in roles, relationship patterns, and communications styles. Seemingly, family plays an important role in the rehabilitation settings, therefore, Systemic and Family Therapy can be particular helpful in addressing the family system to accommodate ABI clients' functional, personal and social changes. These approaches aim to meet the needs of ABI clients, as well as those of their family members, to achieve a healthy level of social functioning and ensure meaningful relationships within the family unit (Palmer & Glass, 2003).

CBT is one of the most popular approaches for ABI clients, which proposes that emotions and behaviour are influenced by cognitive processes. It adopts an educational and directive approach to assist clients in understanding the relationship between thought, emotion, physical sensation and behaviour. CBT helps to identify unhelpful beliefs and thoughts, and assists clients to find ways to replace unhelpful thinking pattern with a more adaptive and balanced views (Beck, 2005). CBT emphasises coping strategies and skills enhancement. Recent literature has indicated a strong interest in employing the 'third wave' of CBT in the neuropsychological rehabilitation context (Aniskiewicz, 2007). The 'third wave' approach of CBT includes Mindfulness Based Cognitive Therapy (Teasdale & Barnard, 1993; Crane, 2009), Metacognitive Therapy (Mateer, Sira & O'Connell, 2005) and Compassion Focused Therapy (Gilbert, 2000; Ashworth, Gracey, & Gilbert, 2011). The main goal of the 'third wave' CBT approach focuses on building a different relationship with difficulties, which works towards living a life to the best of clients' abilities in the present time.

#### 1.5 Cognitive Behavioural Therapy (CBT) for Individuals with ABI

Reflecting on my clinical experience to date in the field of neuropsychological rehabilitation, I belief that CBT provides a good fit for achieving the major aim of rehabilitation, which involves improving ABI clients' levels of functioning. This process includes identifying goals and facilitating changes (such as improved mood, increased pleasurable activities, independent travel on public transport, and greater sense of self-efficacy). As Giles and Manchester (2006) assert, the main goal of CBT is to help ABI clients recognise illness perpetuating behaviour and illness-related cognitions; to change

dysfunctional thought patterns; to increase the use of effective coping strategies; to reduce and manage levels of stress; to teach skills for preventing a relapse into emotional distress; and to help clients to cope with feelings of loss relating to decreased functioning. These aims are most often facilitated through the learning of new adaptive coping strategies. Both the reported popularity of CBT in this field for managing emotional difficulties (Wilson, Rous & Sopena, 2008) and my own clinical experience with this client group, have served to suggest to me that appropriately tailored CBT can work well for ABI clients across a range of different levels of cognitive functioning. Indeed, with a CBT focus on the 'here and now' rather than past events, it can impose less of a cognitive demand during therapy. In my own clinical practice, I found CBT's emphasis on assessment and formulation, very helpful. It provides an open invitation for me and my client to actively explore their pre-injury and post-injury experiences, values, beliefs about self and others, coping strategies, social contexts, rules for living and critical life events, etc. Through the process of exploration and formulation, the clients can gain better understanding about their issues, and with their guidance, this can then guide me towards an appropriate treatment plan that meets their emotional needs. Moreover, the 'third wave' of CBT is particular relevant to this client group due to its emphasis on mindfulness and acceptance.

#### 1.5.1 Development and Adaptation of CBT

CBT has developed an evidence-based for clinical practice in treating various mental health issues such as depression and anxiety disorders. Its application has broadened to other areas within the healthcare setting, including learning disabilities and health problems (e.g. chronic pain, cancer), aiming at symptoms reduction and pleasurable Recent findings suggest that CBT may produce a positive activities restoration. therapeutic outcome when interventions are adjusted and adapted to consider individual needs and limitations. For example, a UK case series study using 19 stroke clients, conducted by Lincoln, Flannaghan, Sutcliff and Rother (1997) demonstrated that the cognitive aspects of CBT, e.g. cognitive restructuring and thought records, were more difficult to apply than the behavioural aspects of CBT due to clients' cognitive deficit. Furthermore, Harvey, Watkins, Mansell and Shafran (2004) stated that the emotional processes, such as worry and rumination, were linked to the disruption of memory, attention and executive systems. Thus, there is growing evidence that supports the integration of attention training skills (from Metacognitive therapy) with CBT for enhancing therapeutic outcome with ABI clients (Mateer et al., 2005). Additionally, new ideas led by cognitive neuroscience suggest that compassion mind training would be helpful for changing feelings and expression of anger (Gilbert, 2000; Ashworth, Gracey & Gilbert, 2011).

However, King (2002) conducted a case study of Post Traumatic Stress Disorder (PTSD) where brain injury and dysexecutive impairment were presented. The standardised CBT approach of exposure and cognitive restructuring were employed. A detrimental effect of re-experiencing the trauma had led to a perseverated emotional response, which was referred to as a prolong period of distress caused by the traumatic event. King proposed that the exposure element of CBT could have triggered this traumatic perseveration. This suggests caution is required in the application of therapeutic models for complex ABI cases. Despite progress in this field to date, it remains unclear how to better work with this client group, how CBT can be delivered to facilitate stronger therapeutic alliance, and how interventions can be adapted to lessen the cognitive demand in therapy when dealing with cognitive and memory deficits in the context of ABI. Indeed, Wilson (2011) stated that one of the most important areas for improving the delivery of psychological treatment in the field of neuropsychological rehabilitation is the further development of CBT.

#### 1.5.2 Existing Evidence of the Effectiveness of CBT

Existing qualitative research into the effectiveness of adapting CBT for ABI clients in the UK has predominately adopted a single case study methodology. This methodology is particularly valuable in researching and evaluating an innovative treatment effect in a particular client group. It provides an in-depth description and seeks to explain an individual case presentation in a real life context. However, the major limitation of such methodology is the potential lack of generalizability. Also, its findings do not address 'how' and 'why' certain interventions are effective for clients, especially when treatment components are adapted from different therapeutic orientations.

According to the recent systematic review conducted by Cattelani, Zettin and Zoccolotti (2010), 'Rehabilitation treatments for adults with behavioural and psychosocial disorders following acquired brain injury', there are five pieces of qualitative research conducted in the UK addressing the effectiveness of the treatment outcome based on adapted CBT interventions with ABI clients, using single or series case studies. These findings are far from conclusive, indicating either equivocal or mixed results in providing a sufficient level of evidence for the effectiveness of adapted CBT interventions for ABI clients. For example, Dewar and Gracey (2007) conducted a case study to explore the possible effectiveness of CBT interventions for the issues of adjustment and identity change after

ABI. A female client recovering from herpes simplex viral encephalitis (HSVE) was employed, and an individualised, tailored approach of CBT interventions was delivered. The aim was to reduce anxiety, increase confidence and develop a positive sense-of-self. The findings from this study are somewhat unclear. The client's qualitative feedback reported a more integrated pre- and post- encephalitis identity, increased confidence in her functional ability, and a positive adjustment towards self-acceptance by the end of treatment. However, the client's depressive and anxiety symptoms measured by Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI) remained elevated. There are several plausible explanations for this incongruent result relating to the treatment protocol used in Dewar and Gracey's study. The multiple components of CBT make it difficult to determine which, or if any of those components are effective. Treatment process issues such as the characteristics of therapist and client, the intensity of treatment and the timing of delivery, may have an impact on the outcome responses. 'How' and 'Why' interventions are chosen could also have an influential effect on the therapeutic outcome. Further concerns such as the relevance and the choice of the measure used, BDI and BAI include physical and cognitive symptoms which can overlap the symptoms caused by HSVE, as this may affect the validity and reliability of those measures.

Another example, Gracey, Oldham & Kritzinger (2007) provided evidence for effective CBT interventions in treating anxiety disorder in the case of ABI and seizure disorder. The theoretical framework used to adapt CBT was based on Clark's cognitive model (1986), integrated with Silver, Surawy, and Sanders (2004) model of behavioural experiments in the context of CBT with physical illness, which highlighted the role of illness-related cognitions. Twelve weekly sessions of an individualised approach of CBT were delivered to the client with subarachnoid haemorrhage and cavernoma. This is a form of ABI condition and its consequences include emotional, cognitive and physical impairments, with an increased likelihood of seizure disorders and restricted social participation as a result of these problems (Lishman, 1998). The client attained all of the behavioural goals (for example, going to the supermarket), reduced anxiety level about having a seizure in public, and eliminated unhelpful coping behaviours (for example, social avoidance) by the end of treatment. These findings suggested that adapted CBT approach may be helpful in understanding and treating anxiety disorders where symptom presentation is complicated by neurological problems. Although this case study demonstrated improvement in the client's social participation, and reduced anxiety and depressive symptoms by the end of treatment, an increase in the client's anxiety and depressive symptoms measured by Hospital Anxiety And Depression Scale (HADS) was

reported six months after the end of treatment. This suggests that the existing approach of addressing behavioural goals with target illness-related cognition has no lasting effect.

Furthermore, it is unclear why various adapted CBT approach have no lasting effect whilst other qualitative studies have demonstrated mixed outcomes. Single case studies certainly account for some confounding variables, such as the client case presentations. However, they may not consider variables such as therapist and client factors, e.g. personality, experience, attitude, and personal values. Importantly, treatment process issues including when and what interventions facilitate changes require further examination, which supports the suggestion that an in-depth exploratory investigation into how this client group experiences therapy would be helpful in understanding how a CBT approach can be adapted. CBT has been criticised for not paying enough attention to the importance of therapeutic relationship. However, more advanced CBT has developed a new way of thinking to address processes and issues concerning the therapeutic relationship. For example, Gilbert and Leahy (2007) focus on gaining better understanding of working with the therapeutic relationship in CBT (e.g. validation and resistance issues) and recognising the role of process which can play a significant role in helping or hindering the effectiveness of therapy. This may explain why various adapted CBT approaches have no lasting effect, as these approaches may focus primarily on the technique adaptation, but neglect the importance of the process issues.

Furthermore, according to the recent systematic review, by Cattelani, Zettin and Zoccolotti, (2010), into rehabilitation treatment for adults with behavioural and psychosocial disorders following ABI, there is only one quantitative study in the UK evaluating the efficacy of CBT with ABI clients. This was a randomised controlled trial study of CBT efficacy for post-stroke depression conducted by Lincoln and Flannaghan (2003). Participants were recruited at one, three and six months after experiencing a stroke, and had pre-treatment Beck Depression Inventory (BDI) scores above cut-off for depressive symptoms. The findings did not demonstrate efficacy of CBT, the results indicated that ten sessions of standardised CBT did not show any differences in depressive symptoms when compared with a placebo treatment, ten sessions of attention control interviews with no therapeutic intervention, and standard care with no treatment. Lincoln and Flannaghan were disappointed and offered a plausible explanation for these results. The use of inexperience therapists in the study, who might have lacked sufficient understanding of the complex symptoms presented, could have resulted in CBT being delivered poorly. The findings suggest standardised CBT does not fit all of the clients,

especially in the field of ABI where case presentations are varied and complex. It would be more helpful to adopt a tailored approach to therapy for meeting individual client's needs. Also, therapy focus may need to shift from the symptom reduction approach, to a more wellbeing approach. This may produce a long lasting effect when therapy focuses on changing the clients' relationship with their distress, drawing upon the mindfulness approach that focuses on the clients' experiences at the present moment.

Lincoln and Flannaghan's (2003) RCT study reported no significant differences between groups in participants' depressive symptoms. Although they provided a general description of the standardised intervention protocol, and used a standardised measure such as BDI, for the purpose of study replication. There continues to be lacking of significant information about treatment process issues, for example the intensity and duration of interventions, how these interventions were delivered, and the characteristics of the practitioners who provided the interventions (level of training, discipline and experience). One of the main problems using RCTs is how to determine the specific and non-specific factors that are more likely to influence the effectiveness of complex interventions employed, in particular with more complex cases, such as ABI clients. Alternative methodologies such as qualitative studies may be useful for exploring different aspects of complex interventions, and thus extend the current practice of such therapeutic paradigms. Indeed, such exploratory research within the context of neuropsychological rehabilitation may have direct value and relevancy for clinical decision-making.

#### 1.6 Challenges Applying Psychological Approaches for ABI Clients

Judd and Wilson (2005) state that, despite the clinical evidence indicating the efficacy of psychological interventions with ABI clients, the provision of psychological services in the context of neuropsychological rehabilitation remains scarce. The reasons for not applying psychological treatment due to the presence of brain pathology are still expressed discreetly in the context of rehabilitation. This might be tentatively explained as the assumption made by many health professionals that if psychological symptoms are caused by the organic brain pathology (rather than by psychological mechanisms) then the treatment approach must primarily address the brain pathology, and psychological approach for treatment may be somewhat irrelevant and ineffectual (Bennett-Levy et al, 2004). Indeed, robust empirical evidence indicates that the frontal lobes play a critical role in social cognition, social behaviours and skills, and social interactions (Alvarez & Emory, 2006; Grafman, 2007). However, the situation is not as clear-cut and it is more

complex than this. Psychological processes (e.g. catastrophic reaction caused by loss and grief) remain highly important, especially in the complex cases where psychological and neurological symptoms occur, and deserve to be addressed in their own right.

#### 1.6.1 Specific demands on therapists

McGrath and King (2004) state that providing therapy to ABI clients is often seen as a specialist field, which entails sophisticated knowledge in neuropsychology, and is dominated by psychometric assessment. Additionally, there are several challenges for therapists when delivering therapy for individuals with brain injury, due to their neuropsychological impairments, for example, the clients' lack of insight, memory impairment, inflexible thinking, disinhibited behaviour and emotional ability to cope with post-injury changes (Judd & Wilson, 2005). These challenges need to be addressed with thoughtful consideration and creativity. Inevitably, this can impose specific demands on therapists, for example, how does the therapist connect with the less cognitively able client? What can the therapist do to keep the client's motivation and engagement in therapy? Or how does the therapist know which intervention is appropriate to use, when to use it and for who? These issues require more attention on understanding the complexity of each client case and seeking relevant therapeutic models that can work flexibly and effectively in this context. Many therapeutic approaches such as Psychodynamic Psychotherapy, CBT, Humanistic and Existential Psychotherapy are equally beneficial for individuals with brain injury. As each approach can offer different ways of understanding the client's difficulties and shedding light on different therapeutic focuses. Indeed, pluralistic approach in therapy is more likely to enhance positive therapeutic outcome (Constantino et. al, 2008). It can enhance therapists' professional skills to understand each complex case more effectively, by adopting different conceptualisations from various theoretical orientations. Also it provides therapists with a selection of tools which in turn building on their ability to respond to the clients' needs more rapidly and flexibly, offers an alternative way of working with them.

#### 1.7 Current Neuropsychological Rehabilitation Research and Practice

Seemingly, to date, there has been no evidence to suggest that counselling psychologists engage in any research within the context of neuropsychological rehabilitation. Plausibly, this is due to the 'newcomer' status of counselling psychology, which recently established its divisional status with BPS in 1994 (Woolfe, 2006). Additionally, the predominant

psychopharmacological and clinical approaches may have influenced counselling psychologists' decisions about entering the field. Indeed, it appears the current neuropsychological rehabilitation research and practices are being delivered by either neuropsychologists or clinical psychologists.

Although brain injury rehabilitation research has predominately adopted the quantitative research method (RCTs), there are six qualitative studies in the UK, exploring ABI or TBI clients' experiences of brain injury (Howes, Benton & Edwards, 2005; Yeates, Henwood, Gracey & Evans, 2007; O'Callaghan, Powell & Oyebode, 2006; Roundhill, Williams & Hughes, 2007; Shotton, Simpson & Smith, 2007; Murray & Harrison, 2004). As a minority and new group member of counselling psychologists in the field of ABI, it is obvious that there has been a great deal to learn from colleagues who are commonly working with diagnosis and medical models, as these models provide invaluable information for identifying areas for rehabilitation. However, counselling psychologists can contribute an alternative perspective that focuses on the importance of a client-centred approach, individuality and reflective practice, which may provide a different way to conceptualise ABI clients' difficulties.

Howes, Benton and Edwards (2005) conducted an IPA study on women's experience of brain injury. They interviewed six women with acquired traumatic brain injury (TBI). Their findings highlighted the significant impact of changes after brain injury on these women's perceptions of themselves such as physical, cognitive, and social aspects. The researchers focused on exploring participants' new existence in the world that they did not recognise after their injury; and their struggles in making sense of the changes that led to various difficulties, i.e. emotional reactions to the process of adaptation and acceptance. Although Howes, Benton and Edwards's study mentioned that healthcare professionals' support was seen to be helpful for facilitating adaptation and acceptance, it did not provide any information about what kind of interventions might facilitate the helpful process of adaptation and adjustment.

Another IPA study, conducted by O'Callaghan, Powell and Oyebode (2006), explored ten participants' experiences of gaining awareness of deficit following a traumatic brain injury (TBI). The study findings proposed that the acknowledgment of deficits was acquired through personal discovery and the reactions of others from outside of the rehabilitation context. Although rehabilitation provided explanations and facilitated a supportive environment to normalise their disabilities, TBI clients' experiences of difficulties might

have different meanings in the real life environment. The study provided evidence that the existence of denial and avoidance were perceived as active processes to deal with overwhelming feelings, rather than unconscious mechanisms. Therefore, it is important for therapists to support brain injured clients to get through such confusing periods of denial, and explore what strategies they have employed to facilitate avoidance, e.g. evidence suggests that there has been an increased risk of alcohol use in the TBI client group (Taylor, Kreutzer, Demm, Meade, 2003).

A qualitative study conducted by Yeates, Henwood, Gracey and Evans (2007), researching the awareness of disability outside the rehabilitation context, examined the issues of awareness in the complex and diverse family context. This exploration was carried out by interviewing six participants, three individuals with ABI who had been defined as lacking awareness for social difficulties, and their families, using a qualitative discourse analysis. The study findings highlighted that the role of social interactions in the context of families might be crucial in facilitating adjustment and awareness of disabilities after ABI. They suggested further family therapy intervention using 'third person approach' might be useful for facilitating family adjustment and awareness. This proposed approach may be better facilitated by counselling psychologists as they are more likely to adopt a relational approach in facilitating changes, by taking psychological, social and cultural aspects into account when understanding emotional difficulties and respecting the client's subjective perspective.

Furthermore, three qualitative studies have been conducted by clinical psychologists in the UK, primarily focusing on the meanings of being a stroke survivor, the experience of loss after ABI, and clients' experiences of appraisal and coping with the process of psychosocical adjustment (Roundhill, Williams & Hughes, 2007; Shotton, Simpson & Smith, 2007; Murray & Harrison, 2004). These studies were helpful in identifying the future potential therapeutic focus for improving the delivery of therapy. Findings from these studies provided alternative evidence to support the need for psychological treatment as an important strand of the neuropsychological rehabilitation service. Although there are differences between the clinical psychology perspective and the counselling psychology perspective, they share the same goal for improving ABI client's lives. Clinical psychology traditionally focuses on categorisation and diagnosis whereas counselling psychology places its emphasis on wellbeing and empowerment through the use of therapeutic relationship. However, working together, while recognising each perspective's

strength, practitioners can gain a rounder picture for understanding ABI client's complex needs in their rehabilitation process.

#### 1.8 The Position of Psychologists

Recent study findings underline the need for including psychological intervention in neuropsychological rehabilitation, and highlight that more therapeutic models may be required to further improve service provision (Wilson, 2002). This gap may perhaps be addressed by counselling psychologists as this profession has a philosophy which places an importance on the therapeutic relationship and the individual's subjective experiences, values and beliefs<sup>1</sup>.

The philosophy and key principle of counselling psychology are centred around its engagement with people in a relational way, which attends to each individual's unique experiences, and appreciates the diversity of differences based on various social contexts and socio-cultural factors. One of the core principles of counselling psychology is to engage with dialectical viewpoints and worldviews, thus supporting the transformative change for individuals and for the wider society. In this way, I adopt an open mind to actively explore how the clients experience their distress, rather than assuming a position of 'expert' knowledge. This approach redistributes the power within the therapeutic relationship, and works towards a shared understanding about the clients' concerns. This therapeutic position shifts from the psychology 'within' the client, to a focus on what happens 'between' people, i.e. the therapist and the client. Also, I have an appreciation of integrating various therapeutic approaches for understanding and addressing individuals' difficulties in a specific context, with a conscious consideration of individual differences, contexts and circumstances. This can avoid technicalising and pathologising the client's experiences.

Due to this idiosyncratic professional position, the counselling psychology perspective contributes to an alternative viewpoint in conducting research, and challenges research that

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<sup>&</sup>lt;sup>1</sup> For example, in my own clinical practice, I adopt a therapeutic position that seeks understanding of people from their viewpoints and experiences, exploring ways in which they perceive and attribute meaning to their 'subjective realities'. Instead of attempting to categorise clients' experiences and their distress, I consciously attend to their narratives, through the use of active listening and my sense of curiosity which helps me to understand and explain their behaviours and experiences in a biographical and social context. Working with the client and following their guidance can lead me to establish a context-specific formulation that evaluates their emotional difficulties with respect to their lifestyle, current life circumstances and relationships. Thus, moving beyond the models of categorisation and limited conceptualisations to explore the client's difficulties in personal and meaningful ways.

takes a reductionist standpoint which could possibly overlook the complexity of multidimensional contexts. Furthermore, this research study adopts the counselling psychology perspective, contributing in ways that pursue newer knowledge with an inquisitive mind, by exploring the diverse experiences of ABI clients with a sense of openness and curiosity, without any pre-assumptions that restrict the research questions. This research contributes to an alternative perspective that moves away from the medical model of the professional-client relationship, and the traditional use of the diagnostic approach in the context of neuropsychological rehabilitation. Instead, it focuses on exploring ABI clients' experiences with an emphasis on collaboration, and its phenomenological and humanistic value-base which views participants as free agents with an ability to make decisions for change. These underpinning values from the counselling psychology perspective serve to place an importance on facilitating wellbeing rather than on categorising psychological difficulties as pathology. Given the complexity of these client groups' clinical presentations, perhaps it is more helpful to focus on enhancing our understanding of the complexity of each client case in the context of brain injury, and explore ways to better work with their individual complexities and uncertainties, rather than creating new generalised categories within this client group.

Therefore, it is necessary to include psychological models and concepts in the field of neuropsychological rehabilitation, with an aim to better understand brain injury clients' needs in relation to their psychosocial functioning and emotional wellbeing. This is an exciting opportunity for counselling psychologists to join and contribute to the research and practice within this specific field. It is important to remember that it is not all about one particular model or practice, but rather having concerns about how practitioners draw on the relevant theories, models and approaches and helpfully apply them to this complex client group. Taking on one unified approach only limits us in meeting the complexity of needs for our clients in this field. Learning the importance of being flexible and adaptable is the way forward for improving our practice. Counselling psychologists play a crucial role in the attempt to bridge the differences from different theoretical approaches, integrating expertise of knowledge and practice from different professional strands. This can be an eye-opening and exciting experience for practitioners, further enhancing and improving our practice in the field of neuropsychological rehabilitation.

#### 1.9 Rationale of the Current Study

A recent article presented by Coetzer reviews several psychotherapeutic approaches for managing emotional difficulties after acquired brain injury. The author suggests that CBT can be useful for helping ABI clients with their cognitive appraisal and interpretation of events and situations, which may be unfamiliar to their pre-injury personal experiences and identity (Coetzer, 2009). Furthermore, it is important to acknowledge that CBT can be helpful in reducing psychological symptoms caused by depression and anxiety. Additionally, it can help the clients to gain better insight into how their pre-injury social roles, the issues of acceptance, and the adjustment process can trigger and maintain their depressive and anxiety symptoms. It is fair to recognise that CBT is not merely aiming at symptom reduction, but also places an importance on raising clients' awareness and helping them to build different relationships and understandings about their difficulties.

CBT has an intuitive appeal in the management of emotional difficulties after ABI due to its directive and educational approach. This is well suited for the ABI client group in accommodating their limitations. Its goal-oriented focus is consistent with the goal of rehabilitation which emphasises acquiring problem-solving skills and strategies to compensate weaknesses, to maximise residue functionality. Additionally, CBT focuses on thought processes and responses that may contribute to emotional difficulties; it provides the therapist with a wide range of tools to work in an informative and structural manner; it can be delivered flexibly with the potential for accommodating individual differences in terms of circumstances and limitations. However, research on the effectiveness of CBT with ABI clients has been scarce and predominately adopts single case study methodology. These single case studies did not provide enough guidance on how and when to use these skills and intervention. Furthermore, the definition of those skills and interventions can be problematic due to the different terminologies used, and confounding variables of therapist factors, client factors, and exclusion of particular techniques, making findings less generalizable. Coetzer (2009) further asserts that many professionals working in brain injury rehabilitation settings have insufficient guidance and a minimum working knowledge of psychotherapeutic approaches. Furthermore, Judd and Wilson (2005) propose that the assumption of 'lack of intelligence' labels the ABI client as 'an emotional cripple' and therefore, incapable of engaging with the therapeutic process. This label can be attributed to the public's lack of understanding and misconceptions about people with ABI (Linden & Boylan, 2010; Chapman & Hudson, 2010; McClure, 2011). Similar to people with learning disabilities, there are current debates concerning the level of functioning required for psychological therapy as a treatment option for their emotional difficulties (Jones, 2013). Social attitudes towards people with ABI and learning disabilities have had an impact on whether these groups have been considered for psychological treatments. These social influences may have affected practitioners' levels of interest in providing psychological therapy to these client groups. Certainly, these client groups' limitations may have presented practitioners with various challenges to engage and form a sound therapeutic alliance. The specialist nature of working therapeutically with ABI clients' complex needs raises further questions about practitioners' competence, which may have affected the number of practitioners who choose a career in this context. As a consequence, the number of practitioners who are skilled, interested, and motivated to offer CBT to these vulnerable client groups remain limited (Brown & Marshall, 2006).

The focus of this study is to explore the therapeutic process with ABI clients through their experiences of CBT, with an intention to identify how to better work with them and what facilitates or hinders therapeutic process and engagement during therapy.

#### 1.10 Research Questions and Aims for the Study

In summary, having reviewed the existing research, seemingly there are challenges in providing effective CBT for ABI clients, which may not have been fully addressed in the field of neurorehabilitation. Further qualitative investigation could develop our understanding of how ABI clients experience CBT and might help develop our ability to maximise the effectiveness of CBT for this group. Indeed, the current evidence base for the effectiveness of CBT in brain injury still remains unclear and research in this particular area is somewhat limited. The conflicting findings between single case studies and quantitative studies concerning the efficacy of CBT may be explained by the differing types of CBT approaches. Notably, some positive therapeutic outcomes were achieved in single case studies that employed CBT approaches more tailored towards individual client's needs, whereas no benefits were found in the use of standardised CBT approaches, which were employed in the quantitative studies. Seemingly, little is known about what adaptations to CBT approaches work best for this client group, or how therapy might be delivered in a more effective way. This prompts questions such as: 'How do ABI clients experience CBT?' and 'What have they found helpful/unhelpful in the course of receiving CBT?' In an attempt to answer such questions, it is necessary to gain a better understanding of the brain injury clients' first hand experiences of CBT. This could then direct practitioners towards adapting CBT approaches that better meets the clients' needs.

The major aim of this study is to further develop understanding of how CBT can work effectively with Acquired Brain Injury (ABI) clients, through exploring their subjective experiences of receiving CBT in the context of neurorehabilitation within the healthcare setting. The present study intends to provide an in-depth account of ABI clients' experiences of therapy for those who work with them, such as neuropsychologists, clinical psychologists, counselling psychologists, language and speech therapists, physiotherapists and occupational therapists. As research in this particular area is limited, it is hoped that the study's findings may improve practitioners' understanding of what may be helpful and/or unhelpful for ABI clients during therapy. Furthermore, it is hoped that the findings may contribute to the process of adapting CBT approaches that could better meet the needs of a brain injured population (especially in treating depression and anxiety where more complex symptoms associated with ABI are presented). It is also hoped that the findings from this qualitative research would contribute to the existing evidence-based practice, providing new insight to further improve our clinical practice in the field of neuropsychological rehabilitation.

The research question of this study:

• How do ABI clients experience CBT?

The aims of this study:

- Explore ABI clients' experiences of CBT
- Explore the impact CBT has on ABI clients' post-injury lives
- Provide better understanding of how to better work with ABI clients
- Provide alternative evidence for CBT practice with ABI clients

#### 2. Methodology

#### 2.1 Research Design

This study employed a qualitative methodology to explore brain injury individuals' experiences of receiving cognitive behavioural therapy. Six semi-structured interviews were used to collect data. Interpretative Phenomenological Analysis (IPA) was adopted

for the purpose of data analysis. The rationale for adopting this research design will be discussed in the following sections.

#### 2.2 Rationale for Adopting a Qualitative Approach

Qualitative research methodology, which is concerned with the naturalistic description of a particular phenomenon, has become more popular in the field of psychology and social science (Langdridge, 2007). This methodology enables researchers to view participants' subjective meanings and the complexity of processes from outside the quantitative framework. Qualitative research focuses on the subjective experiences of a given phenomenon, which is in tune with the philosophy of counselling psychology with respect to exploring and valuing subjective meanings, beliefs and values, and seeking empathic engagement with the reality of the client (BPS, 2005, p.1).

Qualitative research places an emphasis on the insider perspective on reality, involving analysis of individuals' subjective accounts rather than examining an objective reality outside of lived experience. The inductive principle refers to a specific way that theory is evolved from the meanings derived from individuals' subjective accounts. This contrasts with the deductive principle adopted by quantitative research, which involves theory-driven, hypothesis testing for reaching an objective reality. Quantitative research adopts the positivist paradigm, with an epistemological focus on the objective and universal truth, which can be gained through quantification and the use of statistics. Although the positivist paradigm seems to be appropriate for conducting research in the field of the natural sciences such as biology, physics and chemistry, this can seem inappropriate for the study of human nature and psychology, due to the complexity and diversity of human experiences within different contexts which cannot be reduced to a simplistic form.

Employing a qualitative approach to answer the main research question for the present study appeared to be appropriate given the complex nature of brain injury. Qualitative approaches allow researchers to gain in-depth understandings about phenomena within particular contexts. Given the exploratory nature of this research topic, a qualitative approach is well suited and allows for unanticipated findings to emerge (Bazeley, 2013).

#### 2.3 Ontological Position

Ontology is concerned with the way reality can be viewed. Eriksson and Kovalainen (2008) assert that ontology is concerned with the existence of and relationship between people, society, and the world. This research adopts the view that there is no fixed reality or objective truth. Social reality can only be socially and personally constructed from people's actions, experiences and perceptions. The researcher believes that social reality should be interpreted through the meanings that participants give to their life world. The world is very complex with no simple explanations, it cannot be observed with an objective and detached manner, due to the role of socio-cultural, political, and theoretical baggage we obtained from our previous experiences. Through interactions between people, new meanings can be reconstructed and/or deconstructed for gaining better understanding of particular phenomena. The current research question aims to explore ABI clients' experiences of CBT. Given the complex nature of the context of ABI, it might helpfully be understood from ABI clients' insider perspectives. achieved through the meaning making process and interpretation between the researcher and the participant.

#### 2.4 Epistemological Standpoint

Epistemology refers to how knowledge can be discovered, acquired and demonstrated. In this study, the researcher adopts a constructivist epistemological standpoint, believing that reality is constructed intersubjectively through the meanings and understandings developed within social interactions. The researcher takes a relativist stance which considers reality as being multiple and socially constructed, such that there is no single reality out there. Thus, it is impossible to separate the researcher's knowledge from what she has already known, and remain in an objective and detached position. Both the researcher and participant are actively involved in the processes of meaning making of their experiences, and both are the constructors of knowledge. Out of these multiple constructions, they can then construct something call knowledge (Schawndt, 1998). Constructivism views subjectivity as the only way to reveal the unknown through our own individual belief systems, which reflects the researcher's viewpoint about subjectivity being the key to unlock the constructions held by different individuals. Given the complexity of ABI clients' experiences of CBT, the researcher has been drawn towards a contextual constructionist position, acknowledging the importance of context. Indeed, it can be argued that knowledge is domain specific, changes and evolves in the light of new

experience, and is influenced by the perspective taken from the perceiver (Lyons & Coyle, 2007).

#### 2.5 Rationale for the selection of IPA

The present study attempts to gain better understanding of an under-researched area, and IPA therefore is a highly relevant method for the research question about exploring clients' experiences of receiving CBT following brain injury, especially given the uniqueness of brain injury case presentations. IPA focuses on the unique, idiosyncratic account of a person's experiences and perceptions of them. It adopts an interpretative stance with a focus on understanding a person's lived experiences and how to make sense of them based on the person's embodied and situated relationship to the world. This relational aspect of IPA is particularly relevant to the counselling psychology research. The philosophy of IPA echoes the philosophy of counselling psychology, as both of them place their emphasis on the relationships to one's world, taking into account subjective meanings, experiences and worldviews, as well as the person's relationships to others and environments. Furthermore, IPA's idiographic approach allows more general claims to be made, yet remains committed to exploring subjective personal meanings and perspectives on their relationships to the particular phenomenon (Smith et al., 2009).

#### 2.5.1 Interpretative Phenomenological Analysis (IPA) Overview

Smith et al. (2009) describe IPA as 'an approach to qualitative, experiential and psychological research which has been informed by concepts and debates from three key areas of philosophy of knowledge: phenomenology, hermeneutics and idiography' (p.11). IPA draws on these perspectives to inform its epistemological framework and research methodology. IPA is also influenced by symbolic interactionism (Denzin, 1995) which is concerned with how meanings are attributed by individuals within both their social and personal worlds. Researchers enter the research process with a general question that they wish to explore without any predetermined research hypothesis. IPA research intends to be idiographic with a small sample size (five or six participants for student projects) due to the time constraint and the time-consuming nature of the analytical process (Langdridge, 2007). IPA researchers usually employ fairly homogeneous samples therefore purposive sampling technique is often used to gather detailed information about the particular client group's experience on a specific topic (Smith et al., 2009).

#### 2.5.2 Data Collection Process

IPA studies predominately employ semi-structured interviews to collect data, providing flexibility for the researcher to penetrate new areas, and offers potential for rich data to emerge. Open-ended questions are used to enable participants to articulate issues or concerns that are important to them, rather than answering questions derived from the researcher's preconceived ideas. Participants are asked to describe or reflect on different aspects of their experiences. Interviews are normally audio-recorded and transcribed verbatim (Smith & Osborn, 2008).

#### 2.5.3 Stages of Analysis

The analytical process of IPA is an iterative and inductive cycle that engages with a set of common processes such as moving from the particular to the shared, and from the descriptive to the interpretative. This process focuses on meaning making in particular contexts with a commitment to understand the participant's viewpoint (Smith et al., 2009).

My analysis is based on guidance provided by Smith et al. (2009). Firstly, I read and reread the transcript, engaging with the original data actively by listening to the audiorecording. Then, I noted down meaningful exploratory comments in the right-hand margin and summarised remarks about any associations and interpretations based on knowledge of the psychological literature (refer to appendix 1). Then I repeated the process again to maximize the likelihood of capturing meaningful data. Secondly, I noted down initial themes in the left-hand margin by examining semantic meanings derived from the transcript. I attended to the language used and the context of participants' concerns when generating the initial themes (refer to appendix 2). I then identified concepts and themes that could help to make sense of the patterns of meaning in the participant's account. These initial themes were not fixed, and they were likely to change during later stages. Thirdly, I attempted to identify any associations or links between initial themes; reorganised them in a more systematic manner by categorising them based on their similarities and differences; and interpreted them using concepts evident within the psychological literature. Then I clustered relevant themes together, breaking down themes that were different into other categories as sub-themes, and discarded themes that were irrelevant to my research question. I repeated the analytical process of developing emerging themes by revisiting the transcripts, and rethinking and restructuring initial themes. Fourthly, I searched for connections across emergent themes by mapping the related themes into a table, in a coherent order (refer to appendix 3). Emergent themes that I identified were appropriately generated with reference to the original data derived from the transcripts. At this stage, I discarded the irrelevant emerging themes as they did not fit well into my super-ordinate themes and sub themes.

After I analysed a single case, I then moved to the next case and repeated the entire analytical process. I consciously reminded myself that it was important to keep IPA's idiographic commitment by treating the next case as being individual, bracketing the themes that had emerged from the previous case with the intention of allowing new themes to emerge in each case. Finally, I looked for patterns across all six cases by attending to the similarities and differences between transcripts, identifying themes that were potent for one case but also represented and shared with other cases. It was important to demonstrate connections for the group as a whole, therefore, I restructured and rename themes in order to achieve a more recognisable account on a theoretical level. As a result, I generated a master table of themes for the group, illustrating super-ordinate themes and their associated sub-themes (refer to appendix 4).

#### 2.6 Reflexivity

Reflectivity is a way the researcher makes sense of the entire research process, and increases rigor of the findings. The major aim of reflectivity is to improve the quality of research (Guillemin & Gillam, 2004), and it is necessary throughout the entire research process to promote transparency and validity (Eriksson & Kovalainen, 2008). Furthermore, reflexivity is particularly crucial to IPA due to its emphasis on the idiographic underpinning and the interpretative process that aims to identify emerging themes derived from participants' subjective accounts. One of the main methodological concerns in IPA study is whether the researcher can become personally involved in the research process and still retain a scientific measure of objectivity. As McLeod (2003) stated, this dual importance upon reflective skill and scientific enquiry skill is congruent with the philosophy of counselling psychology. Thus, a reflective stance will be adopted by the researcher throughout this research study. Reflexivity will be demonstrated throughout the study with the use of the first person to stay close to the researcher's personal experience.

#### 2.7 Credibility

Validity measures incorporated in this study include keeping a portfolio that illustrated the step-by-step research process, which allows the researcher to trace back and check the coherence of analysis and chain of findings presented (Yardley, 2008). This portfolio contained the researcher's diary, initial notes after each interview (refer to appendix 5), drafts from annotated transcripts for identifying emerging themes, first draft reports, and the final report. Another measure involved inviting the participants to attend subsequent meetings a week after their interviews to ensure the credibility and validity of the data analysis. This provided opportunities for the researcher to clarify any ambiguities from the raw data obtained, to further elucidate the participants' interpretations of their experiences in particular contexts, and to discuss any concerns regarding the initial emergent themes (refer to appendix 2). This allowed the researcher to check whether the developed initial emergent themes (the researcher's interpretation of data) had adequately reflected the participants' experiences of receiving CBT. Data were collected and transcribed the next day. The process of analysis for each participant took place within a week after feedback was provided from the subsequent meeting to discuss and clarify the initial emergent themes. The entire process of data collection and analysis took place between August and November in 2012.

#### 3. Research Procedure

#### 3.1 Participants

Six participants with acquired brain injury were interviewed, five females and one male, with ages ranging from 35 to 60. The number of years post-injury for the participants range from 2 to 6 (refer to appendix 6). Information for participants' brain injury related disabilities at the time of referral was provided by their key workers based on their internal quarterly care review. Each participant's care review reported their physical weaknesses; time and reason of injury; cognitive assessment results ranging from mild, moderate and severe level, based on Addenbrooke's Cognitive Examination – Revised version (ACE-R) (Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006). ACE-R examined participants' level of cognitive functioning including attention, concentration, memory, recall, language ability, and visual spatial ability. Results measuring participants' level of anxiety and depression were also reported using Hospital Anxiety and Depression Scales (HADS)

(Zigmond & Snaith, 1983), indicating participants' level of anxiety and depression as either mild, moderate or severe. These assessments were conducted by a qualified occupational therapist who worked at the organisation.

CBT was provided by advanced trainees currently undertaking a professional doctorate in counselling psychology, and in either year two or three of their training. They were supervised by internal and external supervisors who are Health and Care Professions Council (HCPC) registered Counselling Psychologists, to ensure the quality and standard of the therapy provided.

A summary of participants' characteristics are shown below.

<u>Participant</u>	Ethnicity/ Gender	Age	Marital status	Years Post- Injury	Employment status	Brain injury related disabilities at time of referral
SM	White British Female	54	Divorced	4	Part-time work as cafe manager; Volunteer at charity organisations	Left-sided weakness; mild concentration difficulties; fatigue; severe back pain; migraine.  Depression and anxiety.
DD	African British Female	42	Single	5	Part-time undergraduate student	Reduced strength in lower body and limbs; difficulties in walking; concentration and motivation issues; fatigue; easily distracted; anxiety and depression.
PPJ	White British Female	52	Married	2	Volunteer at charity organisation	Depression; panic attach, minor cognitive difficulties; forgetfulness; fatigue; occasional headache.
AD	White Canadian Female	35	Married	6	Unemployed; Caring for her new born baby	Depression; minor memory and cognitive difficulties.
JR	White British Female	60	Married	5	Volunteer at charity organisation	Right-sided weakness; walking with stick; fatigue; anxiety; minor cognitive and memory difficulties.
PC	White British Male	53	Married	3	Volunteer at charity organisations	Reduced strength in one arm; walking with stick; forgetfulness; depression and anxiety; minor word finding/ speech difficulties.

Table 1. Summary of participants' characteristics

Participants who were willing to share their experiences of receiving CBT and met the following criteria were invited to participate in a face-to-face interview for this study.

### **Inclusion Criteria:**

- 1) Minimum age of 18-years-old.
- 2) ABI caused by stroke.
- 3) Have attended Headway's in-house counselling service (adopted CBT as the choice of treatment for anxiety and depression) within the past 12 months.

#### **Exclusion Criteria:**

- 1) Neurological assessment result indicated less than a high level of cognitive functioning, to ensure their capacity to provide informed consent.
- 2) Neurological assessment result indicated speech disabilities.

# 3.2 Sample Size

This study used a sample of six participants. Smith et al. (2009) suggest that a sample size of up to six is sufficient to obtain rich data that captures the participants' lived experience. A sample size of six is manageable for the researcher to engage in an in-depth analysis with each sample, and compare similarities and differences between cases. If the sample size is larger, it is inevitably difficult to analyse each case in-depth due to the vast amount of data gathered (Smith et al., 2009).

### 3.3 Materials

A recruitment poster was used to advertise the study (refer to appendix 7). An information sheet provided details such as the aim and purpose of the study, and why the participant was approached and invited to take part (refer to appendix 8). An informed consent form was used to ask and gain participants' consent to participate (refer to appendix 9). A debriefing sheet provided potentially useful information about organisations that may be required by the participant after the interview (refer to appendix 10). A distress protocol outlined step-by-step procedures for dealing with participants' potential distress (refer to appendix 11). An interview schedule was developed with a list of open-ended questions to allow participants to freely articulate any aspects that were important to their experiences (refer to appendix 12). These questions were selected based on three stages of the therapy process namely: 1) participant's reasons for seeking CBT, 2) the process of therapy and 3) the outcome of therapy. These stages aimed to encompass participants' experiences from the beginning to the ending of their therapy. Finally, an audio-recorder was used to record the interview, and the researcher's thoughts, emotions and impressions after each interview.

#### 3.4 Recruitment Procedure

The participants were recruited from Headway. Headway is a charity organisation which provides rehabilitation services for individuals with brain injury across the UK. The

research proposal was presented to a service manager at the organisation, and an approval for collaboration was granted (refer to appendix 13). Purposive sampling was used to recruit participants. A recruitment poster was placed on Headway's noticeboard. Potential participants showed their interest in participating in the study by contacting their key worker at Headway. The key worker then notified and arranged an initial meeting for the potential participant to meet with the researcher on a one to one basis, without the presence of the key worker. The aim of the initial meeting was to provide an opportunity for the researcher to explain the nature and purpose of this study to potential participants. An information sheet was provided to ensure potential participants were fully informed about the study, and they were given sufficient time (at least one week) to decide whether or not to take part. The information sheet emphasised that participation was absolutely voluntary and that participants had up to seven days from the date of their interviews to withdraw from the study without giving any reason or explanation for doing so. Potential participants were reassured that their service at Headway would not be affected if they decided to withdraw. At the end of the initial meeting, potential participants were given the opportunity to ask any questions or raise any concerns about the study. To help reduce any pressure on potential participants to take part, they were advised to contact their key workers with their decision about whether or not to participate in the study, and it was emphasised again that their decision would have no consequences on the services they receive at Headway.

## 3.5 Interview Procedure

Once participants agreed to take part, they were invited to attend a face-to-face interview. The interviews took place in a meeting room at Headway's premises. The interview was arranged by the participant's key worker, and other healthcare professionals were aware of where and when interviews were held. This ensured the researcher's and participants' personal safety. Before interviewing, a signed informed consent was required to ensure participants' full understanding of what participating in the study involved. This informed them of their right to confidentiality, anonymity, and withdrawal. Semi-structured interview schedules were used to encourage participants to articulate their experiences of

CBT. Each interview was audio-recorded. The duration time ranged from 34 to 50 minutes. After interviews, debrief sheets were given to participants, and opportunities were provided for them to voice any concerns relating to the study. All participants were

invited to attend subsequent meetings providing an opportunity for the researcher to check the transcribed data with participants, and allowing participants to give any feedback.

#### 3.6 Ethical Considerations

This study gained ethical approval from the London Metropolitan University before the researcher proceeded with data collection.

Due to the emotive nature of the topic to be explored there might be risk of potential distress to participants, as their involvement in the research process might bring up a range of feelings (positive and negative). Potential participants were made fully aware of this before they decided whether to take part. Participants were provided with adequate information about sources of support if they felt they had been affected by the study and felt that discussing it further would be beneficial for them. Both the researcher and participants reserved the right to terminate participation at any time if participants become distressed during and/or after their interview. A distress protocol was devised to monitor and manage the possibility that participants might become distressed during their involvement in the research. It was agreed with Headway that the in-house counselling service would be available to participants who experience distress, if necessary. After the interview, a debrief sheet was given to participants which included the researcher's and supervisor's contact details, potential helpful organisation contact details, and an opportunity was provided for them to voice any issues or concerns after their involvement in the research.

# 3.7 Confidentiality

All information obtained from the interview (audio-recordings and transcripts) were kept strictly confidential. However, if any details involved or conveyed any imminent harm to self or others, the relevant statutory sector/body would be informed to ensure their safety. Transcripts were made anonymous and without any identifying information, and securely kept in the possession of the researcher. Audio-recordings and transcripts of the interview will be kept for a period of five years in case of publication and will then be destroyed. It was made clear to each participant that the data was collected as part of a doctoral thesis, and academic staff such as thesis supervisors, academic tutors and lecturers marking the thesis would have access to the information. It was explained that all possible measures would be taken to ensure confidentiality of the participant. No identifying information

would be used in this study. The participants were told that they could withdraw from the study up until a specified date (the date before the data analysis).

#### 3.8 Researcher's reflection

As a qualitative researcher, it is crucial to reflect upon my personal and professional identities and experiences, and to be aware of the differences between me and my participants, as these differences can play an essential role that may influence the entire research process. I am a Hong Kong Chinese woman, who has lived and been educated abroad for many years. My late grandmother had a stroke and suffered from its consequences for many years during my childhood and teenage years. This experience cultivated my devotion towards working within the context of neuropsychological rehabilitation.

Throughout the four years of training towards my professional doctorate in counselling psychology, I have been counselling individuals with mental health issues in various organisations within social and mental healthcare settings, mainly in the context of primary and secondary care. I have also been working with individuals with brain injury within a social healthcare setting, as part of a multi-disciplinary team, in the context of neuropsychological rehabilitation. I believe my professional identity as a counselling psychologist trainee allowed me to relate professionally and competently to the brain injury individuals during the research interview process. I feel it is particularly important to be seen as an 'insider' with respect to the research topic under investigation. My 'insider' status relates to my familiarity with the brain injury rehabilitation context, and my knowledge of brain injury and the shared understanding of language used between service users and health professionals in this context. This allowed me to develop an interactive relationship with participants, enabling me to obtain meaningful and valuable data from their subjective experiences. Outsiders unfamiliar with this context might experience difficulties in understanding and relating to the brain injury individuals, and therefore they might experience potential obstacles in obtaining meaningful data.

Furthermore, I was aware that my 'insider' status as a practitioner in the field of research topic might have an influence on the research process. I acknowledged my dual role as a researcher as well as a practitioner in this field, and to help increase my focus towards research, I temporarily ceased my role as a clinical practitioner before I started my research and throughout the whole process. Additionally, I prepared myself for the researcher's

role by engaging with research activities, such as engaging with the IPA forum and reading guidance for research interview and analysis. However, I believe that my 'insider' status as a clinical practitioner has served me well for engaging with participants, putting them at ease and allowing them to discuss issues freely and openly as we both were in a familiar environment. My clinical experience in the field of my research topic provided me with some insight into the participants' dilemmas or difficulties, having a 'shared language' and 'shared understanding' of what they might mean. This might not be evident to 'outsiders' who had not worked with this client groups. Nevertheless, this could be one of my assumptions that could threaten validity, in that I might have assumed that I understood the participants' world due to my prior experience in this field, and this could in turn lead to premature conclusions and misinterpretations. To help address any unhelpful impact of my 'insider' status, I used a reflexive approach which provided me with an opportunity to check out my understandings and ways of interpreting data.

During the data collection process, I became aware that data being collected was not focusing on how participants felt about different CBT interventions, e.g. behavioural interventions or cognitive reframing techniques. This outcome did not meet my expectations which had been heavily influenced by previously gained knowledge from literature and clinical practice. I quickly became consciously aware of my urge to explore those areas with participants during interviews. However, I acknowledged that these were my assumptions about what was important to the participants. In doing so, I was able to maintain a neutral approach, rather than attempting to fulfil my need of knowing what interventions were helpful for them. This allowed participants to articulate what was important to their experience of CBT. Indeed, in order to collect meaningful data that fully represented participants' experience of therapy, it was crucial to bracket my assumptions derived from my previously gained knowledge, literature and clinical experiences.

Additionally, I was aware of other potential challenges that could occur during the research process. For example, participants often expressed their frustration about how long they had been waiting to access the psychological service. Naturally, I appreciated their frustration, and on occasions felt an urge within me as a clinical practitioner to contain their frustration, for example by providing an explanation about the limited resources available to the service. However, rather than digressing from the role as a researcher, I always managed to remind myself about focusing on the participants' lived experiences of therapy.

# 4. Analysis

The findings of an interpretative phenomenological analysis (IPA) of six brain injury individuals' experiences of receiving cognitive behavioural therapy (CBT) are presented. Emerging themes were initially identified and grounded from the transcribed data, and then organised in a thematic order (Smith et al., 2009).

Analysis began with initial noting of descriptive comments and any identified themes in the margins of each transcript. These comments and themes were used as a foundation for the development of the analysis. Once the initial themes were identified by the researcher, they were openly discussed and clarified with each participant in the subsequent meeting on a one to one basis, without the presence of their key worker. This aimed to ensure the researcher's interpretation appropriately reflected participants' meanings. All participants attended a subsequent meeting. In all cases, the participants were in agreement that the proposed initial themes were broadly representative of their experiences of CBT. At this point, a handwritten document was created which included all of the initial themes from each participant. The process of analysing these initial themes involved searching for connections between them. This was made easier by cutting up the document so each theme was on a separate piece of paper, allowing themes to be moved around and placed into clustering groups based on the possible meanings of each theme. Themes that shared similar meanings would then be grouped together, whereas those themes that were opposed to each other would then be placed separately. After putting themes together in a series of related emergent themes, it became easier to identity patterns between them and thus develop sub-themes. For example, emergent themes were identified from one of the participant's transcript, 'negative aspect of brain injury', 'unaware of the impact of brain injury had on my life', 'lack of knowledge and understanding about cognitive difficulties by others', and 'conscious awareness of the consequences of brain injury'. These themes were grouped together and developed a sub-theme of 'other's understanding and knowledge of the consequences of brain injury'. The process of theme refinement continued by cutting and moving sub-themes around until the super-ordinate themes were revealed based on different aspects of the participant's experience. For example, the first super-ordinate theme, 'professional relationship', elaborated on the way participants related to their therapists and what motivated them to engage with therapy. 'Confidentiality and trust' was an important element in this theme, having a trustworthy therapeutic relationship was seen as a starting point for participants to engage with therapy across

cases. The process of analysis was repeated for each participant, before performing a search for patterns and making connections across cases. This led to a reconfiguring and renaming of the themes which would then be grouped into a master table of themes. At this point, a table was created to illustrate the development of super-ordinate themes and sub-themes that had emerged from the analysis, with helpful annotated page numbers and key words from each participants, demonstrating the source of the themes.

In this study, the super-ordinate themes and sub-themes were identified to reflect and capture participants' experiences of CBT as follows: 'Professional relationship', 'Understanding my struggles', and 'Acceptance' – refer to Table 2. below:

<b>Super-ordinate Themes</b>	Sub-themes and number of participants reporting		
	4.1.1	At the rock bottom point where anything may help. (6) (p.95)	
4.1 Professional relationship (p.94)	4.1.2	Understanding me and my brain injury. (5) (p.97)	
	4.1.3	4.1.3 Confidentiality and trust. (6) (p.100)	
	4.2.1	Adaptation and flexibility to therapy approach. (5) (p.102)	
4.2 Understanding my struggles (p.102)	4.2.2	Learning new skills to cope. (6) (p.105)	
	4.2.3	Looking forward to sessions after knowing what CBT is. (5) (p.107)	
	4.3.1	Who am I after brain injury (5) (p.109)	
4.3 Acceptance (p.109)	4.3.2	Re-gaining a sense of control, self-esteem and confidence. (6) (p.112)	
	4.3.3	Learning to know myself and believe in future (6) (p.114)	

Table 2. Summary of Super-ordinate themes and sub-themes

The following section illustrates each super-ordinate theme and its corresponding subthemes with interpretations that are firmly grounded from the data through the use of verbatim extracts from the transcripts. It is recognised that the researcher's interpretations are one possible way to interpret and analyse the participants' narratives and experiences, and that other researchers may have placed a different focus on different aspects of the same account. Furthermore, themes were identified based on the relevancy to the research questions, therefore they may not represent every aspect of the participants' experiences. Although there were commonalities to all participants' experiences of receiving cognitive behavioural therapy, there were also differences which have been explored where appropriate and relevant. A detailed examination of each participant's account was conducted before moving to more general claims. Finally, to protect anonymity, identification coding was applied to each participant throughout the analysis, and any other identifying information was removed from the transcripts.

# 4.1 Professional relationship

Three sub-themes relate to this super-ordinate theme, namely: 'At the rock bottom point where anything may help'; 'Understanding me and my brain injury'; and 'Confidentiality and trust'. All participants explained the importance of seeking psychological help once they realised 'getting help' would be beneficial in their rehabilitation process. participant described, 'At the point anything that I could do to help me get into a better frame of mind was useful' (PPJ, 2, 33-34). A review article into clinical pathways for managing emotional difficulties after ABI suggested that psychological therapy might be more useful than pharmacology for managing issues such as insight, adjustment and existential issues (Coetzer, 2009). All participants described the importance of having a 'good', 'trustworthy', 'positive' and 'professional' relationship with their therapists. They felt that a good therapeutic relationship provided a safe and secure place for them to explore their difficulties freely and openly without feeling 'judged' and 'misunderstood' due to their disabilities. Importantly, they felt their voices and experiences were 'heard' within a therapeutic context, and this was strongly evident from all participants' narratives. For instance, one participant expressed, 'somebody finally listened of how you was feeling, how you've been feeling' (SM, 2, 40). Furthermore, most participants explained their experiences of working with their therapists collaboratively. They reported that engaging with meaningful therapeutic interventions, which involved active sharing and participation, led to the facilitation of change. This suggested the development and maintenance of the therapeutic relationship and the working alliance between participants and their therapists were intrinsic to participants' experiences of cognitive behavioural therapy. Participants searched for insight and tried to make sense of their experiences assisted by their therapists' input of knowledge and empathic understanding, which underpinned the establishment of a relationship built on trust and collaboration (Judd & Wilson, 2005). One participant clearly articulated, 'Very important that the person you're talking to, you can trust and they're not going to tell the world' (SM, 9, 233-234). Indeed, this seemed to support the recent research findings which indicated that better therapeutic

outcome and higher client satisfaction from therapy were related to stronger therapistclient alliances (Kim, Kim & Boren, 2008).

#### 4.1.1 At the rock bottom point where anything may help

All participants explained that they were in a stage of recovery where they recognised their difficulties associated with their brain injury. Those difficulties had become overwhelming for them, and for those who interact with them. The consequences of their brain injury not only appeared to have implications on the cognitive functioning level, but also affected them on the psychosocial functioning level (such as work failures, financial setbacks, emotional difficulties, social isolation and disruption of family life). Therefore, they decided to seek psychological treatment, and most of the participants had been referred to CBT by their support system. Most participants appeared to have a basic trust in the treatment recommendations of their neuropsychological rehabilitation team. Importantly, participants seemed to acknowledge their difficulties, and adopted a realistic stance by accepting that they would not make a full recovery on their own. They demonstrated a sense of willingness to try out an alternative treatment option, hoping for the benefits of psychological treatment that might possibly lead to positive changes in their life.

#### Participants' accounts:

'I've been depressed for a long time and after having a stroke made it a lot worse, and I just really needed help.' (SM, 1, 7-8)

The overwhelming event of having a stroke seemed to represent a turning point, where a conscious decision was made to seek help and move forward through the rehabilitation process.

'It was because I had no motivation and I just couldn't be bothered to do anything, so I just sort of coasted, so I needed something to put a bit more oomph into me so that I could carry on getting better.' (DD, 1, 6-8)

DD's use of language, 'needed something to put a bit more oomph into me' signified that she was waiting for something to be done for her. She implied that she had experienced difficulty in motivating herself and hoped for something that might be able to give her a

sense of drive, something that could push her further in her recovery process. This seemed to be consistent with CBT's directive and structured approach which provided a kind of framework for her.

'It's believed that I had some brain damage in the front of my brain. It made the depression a lot worse and my anxiety a lot worse. I basically couldn't pull myself out of the depression.' (AD, 1, 13-15)

AD described how the event impacted on her functioning and capabilities, and led to difficult emotional responses. This seemed to motivate her to seek an alternative treatment option for addressing them. Similar to these experiences, two participants explained how the event of having a stroke confronted them with feelings associated with losses, which gradually led to feelings of social isolation:

'You can become a prisoner, I thought well how can I move on from this? Could anything else happen to me, and I got depressed and that's when I seeked help. That was at rock bottom really'. (PC, 2, 30-32)

The consequences of stroke described by PC signified the loss of freedom and independence. This account suggested the confinement of a prisoner in his own home. This domestic contextualisation of temporal and spatial entrapment appeared to have a great impact on PC's sense-of-self. PC recognised that he was not the same person and therefore experienced feelings of insecurity, vulnerability and uncertainty (Howes, Benton, & Edwards, 2005). Furthermore, the negative post-injury self was portrayed by PC as fragile and vulnerable, and the lack of confidence and trust in his physical ability had hindered his social functioning.

'Well I think I have got a place in a mind that was very lonely. I thought I will be the only person that had a stroke. I would go into a room and nobody would talk to me. I almost felt a bit of nothingness. I was a bit sad and... a bit sad really. I'm not really sad, I'm a bubbly person, you know?' (JR, 3, 58-61)

Unlike PC, JR described subsequent emotional responses to the confrontation of losses within the social context, which frequently led to inevitable distress (including sadness, fear, anxiety, grief and emptiness). In the case of JR, the changes in self-representation or image from pre-injury to post-injury seemed to pose a 'threat to self', and such a threat

contributed to her negative sense-of-self, as the comparison was made between her preinjury abilities and post-injury realities. Indeed, Ben-Yishay (2000) described the occurrence of 'catastrophic reaction' during the rehabilitation of brain injury individuals, due to an emotional response to the 'threat' of post-injury changes. Also participants' negative perceptions of their disability and the public misconceptions of brain injured persons further contributed to participants' negative sense-of-self and created a barrier between 'me' and 'others', which separated them from their social world and increased isolation (Linden & Boylan, 2010).

#### 4.1.2 Understanding of me and my brain injury

Five participants' narratives provided evidence for the importance of therapists' characteristics, knowledge and their understanding of brain injury in developing a therapeutic relationship with reference to their experiences of CBT. They felt it was crucial to have someone who acquired structured therapeutic skills (e.g. problem solving and goal setting skills), specialized knowledge (e.g. neuropsychology, cognitive psychology and counselling psychology) and facilitative abilities (e.g. flexibility and creativity) to understand the complex nature of their emotional difficulties. Also the importance of the personal qualities of therapists was highlighted, in particular the need for substantial empathy, patience, kindness and supportiveness. Some participants described the qualities of therapists as follows:

'The fact that my therapist had an understanding of brain injury was important because otherwise I might not follow.' (AD, 7, 181-182)

AD clearly explained the importance of therapist's knowledge in brain injury, otherwise it would have affected her engagement in therapeutic process.

'With the prompting I can be reminded and then it will start to come back.' (PPJ, 12, 324-325)

PPJ expressed her need to have prompts during therapy to help bring back her memory of previous sessions. This adaptation to the therapeutic process seemed to play a significant role in keeping PPJ engaged in therapy.

'So they have the patience to go through it before they move onto the next thing, to make sure that you've understood what you've done and to check that you've got something out of it as well'. (PPJ, 12, 329-332)

PPJ expressed how the therapist's patience, with the use of appropriate prompting, was important to keep her engaged with therapy from one session to another. Having empathic support from her therapist seemed to validated her difficulties caused by her memory deficit. Furthermore, putting strategies into place served to reassure her that there were ways to deal with her issues. Another participant described how the therapist's personality was important to her experience of CBT:

'For me, it wouldn't have worked, because I'd feel that I was the therapist to the therapist if they were a bit weak and fragile. You have to have someone that is confident and open and chatty, and that knows their subjects and get the job done.' (DD, 13, 356-359)

DD explained that the therapist needed to have a strong personal qualities such as openness, friendliness and confidence, as well as professional knowledge and understanding of brain injury, to make therapy helpful for her. Seemingly, a therapist with these qualities and capabilities can enhance the participant's confidence in her own ability to get through difficult times, and can thus inspire a sense of hope for her future. Indeed, Freed (2002) noted a psychotherapist must function as brain injury client's 'auxiliary ego' or 'alter ego' and guide the client in the process of decision making, flexible thinking and viewing the bigger picture. Furthermore, participant SM described her therapist's qualities as follows:

'Somebody finally listened of how you was feeling, how you've been feeling, not just that day but before that day, which nobody's done before'. (SM, 2, 40-41) 'Because my therapist didn't make me feel silly, and it felt you know, by showing me more just helped really.' (SM, 5, 110-111)

Active listening skills and empathic understanding appeared to make a difference in SM's experience of therapy. She used the word 'finally' suggesting that she had waited for that moment for a long time. Finally her voice was heard and someone was willing to listen to what she had to say. Having someone who listened and tolerated her pain and sorrow in the therapeutic context seemed to validate her distress, and this might have a consoling and

healing effect within her rehabilitation process. Similar to these experiences, participant JR compared her therapist referred by her GP and her therapist referred by her rehabilitation key worker at Headway, she further described the differences in her experiences of CBT as follows:

'So my GP referral therapist, we had a different kind of relationship because she was very much a stranger on the outside looking in'. (JR, 11, 287-289)

JR described the GP referral therapist as a stranger who looked at her issues from the outside. This might suggest that JR and the GP referral therapist did not have a shared understanding about her emotional difficulties, which in turn could have hindered the development of therapeutic relationship.

'The GP referral and the therapist, she had no knowledge of my head injury. Apart from what my GP told her. And that wasn't very much, so to speak. And she quite honestly didn't want to know about my brain injury.' (JR, 11, 296-297, 299, 301-302)

The therapist's lack of knowledge about brain injury seemed to affect JR's perception of her. Also the therapist's attitude towards her brain injury appeared to affect the way JR related to her.

'But my other therapist knew about my head injury, we talked about it. I found I could tell as much as I know. I just felt very comfortable.' (JR, 11, 306-307)

JR made a comparison between her two therapists, one from her GP referral and one from Headway. She asserted the importance of a therapist's knowledge and understanding of brain injury for gaining an insider perspective to facilitate a shared understanding of her experiences of difficulties. She felt accepted and not judged within the therapeutic context. The therapist's knowledge and empathic understanding of brain injury seemed to facilitate a safe and secure place for the participant to explore her issues, thus facilitating the development of a sound working alliance.

#### 4.1.3 Confidentiality and trust

The issue of confidentiality and the quality of trust were reported as an essential element in the participants' experiences of CBT. Although this might be viewed as being generic to all clients' experience of therapy, it appeared to be particularly relevant to ABI clients. Seemingly, this stemmed from participant's awareness of the specific nature of neuropsychological rehabilitation context where information is commonly shared with various health professionals and clients' family members. According to this study, all participants emphasized the significant impact that confidentiality and trust had on the relational and emotional aspects of their therapeutic relationships. Some participants appeared to be more aware of the multi-disciplinary health care team context, understanding the need for sharing information within their support systems. However, they felt reassured by their therapists that their words would not be circulated within the rehabilitation team and it would be safe to openly discuss their emotional difficulties. Participants described their potential concerns as follows:

'Because straightaway when I was informed that whatever I said within these four walls was completely personal, disregarding the organisation it was associated with. It was between me and my therapist, full stop, so that encouraged me as well, because I thought that there might be some link as they are all worker, they all colleagues might discuss things behind the scenes.' (DD, 3, 66-70)

'Very important that the person you're talking to, you can trust and they're not going to tell the world that whatever you say, you know that's going to stay with them.' (SM, 9, 233-235)

The quality of trust was essential to all participants and it was this safe and secure base which allowed them to explore their issues and difficulties, without needing to worry if there were any consequences or negative impacts on their engagement with the existing rehabilitation services. Moreover, participants felt that they were able to relate to their therapists differently within the same social health care context. Another participant explained:

'And if you don't trust that person or if you feel that that person isn't supportive then you wouldn't open yourself up to that person.' (AD, 8, 200-201)

'Trust' and being 'Supportive' appeared to be an important aspect of a good therapeutic relationship for AD to open up. Being 'supportive' could be interpreted as the therapist understanding, acknowledging and validating her difficulties.

'I think confidentiality is important because you do open up to these people in your therapy.' (PC, 5, 111-112)

PC also expressed the importance of confidentiality as a crucial determinant for facilitating a safe and secure environment, enabling him to discuss his issues freely.

'You ... build up a certain trust. You know? You have to trust the person to do this with your innermost thought and your anxiety and the way you behave. (JR, 9-10, 255-257)

Unlike PC, JR emphasised trust as playing a significant role in therapy. Her narrative might imply two different dimensions of trust in the therapeutic context. Firstly, being able to trust the therapist to provide a safe place to explore inner thoughts in a non-judgemental manner. Secondly, trusting the therapist's ability to deal with emotional difficulties and help with the process of meaning making.

'You have to have a good relationship with your therapist and trust, because otherwise they're not going to be able to bring out the best in you if you don't feel that you can trust each other. Trust is very important.' (PPJ, 15-16, 422-424)

Similar to JR, PPJ articulated that trust was an essential element for building a good relationship with her therapist, and it seemed that trust was important to facilitate a meaningful therapeutic process. If trust failed to develop, participants would not engage, which might lead to a premature termination or resistance to change (Dryden, 2000).

# 4.2 Understanding my struggles

Three sub-themes are associated with this super-ordinate theme, namely: 'Adaptation and flexibility to therapy approach'; 'Learning new skills to cope'; and 'Looking forward to sessions after knowing what CBT is'. Most of the participants mentioned the importance of having an individualised approach to therapy, describing how they worked with their therapists to identify potential cognitive limitations, personal interests, and individual

needs. One participant explained how her therapist accommodated her needs, 'if there is a piece of writing and then there is a check' (JR, 12, 336). This required collaborative participation, with flexibility and creativity from both therapist and participant. Another participant expressed, 'my therapist is flexible enough to give me more time to discover and discuss.' (PPJ, 13, 338). This suggested it is important for therapists to identify each client's individual needs to facilitate engagement. Based on five participants' accounts, this individualised approach appeared to enhance motivation for completing home tasks, setting meaningful goals, tailoring coping strategies and improving engagement. As Wilson, Gracey, Evans and Bateman (2009) suggest, real-life targets and individualizing programs within a specific framework is the way forward in the field of cognitive rehabilitation.

#### 4.2.1 Adaptation and flexibility to therapy approach

Five participants explained how therapy sessions were usefully adapted to meet their individual needs. Participants further described the importance of adapting therapy sessions to address their individual needs due to their differences in cognitive functioning and abilities, memory deficits, and social and family circumstances. Furthermore, participants' accounts seemed to support the concept of adapting individual psychotherapy. A recent literature review conducted by Whitehouse, Tudway, Look and Kroese (2006), highlighted that CBT could be adapted to accommodate the needs of adults with intellectual disabilities by understanding and responding to individual subjectivity. Similar adaptations to CBT for the brain injury client group are perceived as important by the participants. Indeed, the participants' narratives highlighted the appropriateness of several adaptations to CBT, including a review of the previous session, flexibility with the length of sessions, the nature of home tasks, clear explanations to ensure understanding, and simplifications to tasks.

'It's good to have somebody that they know that they need to go back over it to make sure that I did understand what we did last time. Because each time I come into a session, I try and remember what we've done, and on the whole I can't remember clearly.' (PPJ, 12, 320-324)

PPJ expressed that reviewing the previous session helped her to remember what she did. This seemed to keep her engaged with therapy. This adaptation addressed her memory deficits and reassured her that therapy could be retained with therapist prompts.

Furthermore, PPJ seemed to appreciate her therapist's patience when clarifying her understanding about what she did in her last session, and this might provide a sense of safety and continuity for her.

'I do know that one or two sessions we've had, because it's opened up a lot of things, my therapist is flexible enough to give me more time to discover and discuss those rather than just chopping off short, like when my time's up.' (PPJ, 13, 337-339)

PPJ further explained how her therapist's flexible approach to the length of sessions made her feel valued as a human being and worthy of the therapist's time. Unlike PPJ, DD had different needs for adaptation to her therapy. She explained the reasons for not wanting to complete her paperwork-based home tasks due to her need to keep her treatment private from her family:

'I didn't want somebody else reading and questioning and arguing about what I'd done, and why I'd put things a certain way.' (DD, 8, 210-211)

'Discussion and we would do them within the session rather than have paperwork based homework.' (DD, 8, 213-214)

DD decided with her therapist to complete 'homework' tasks during therapy sessions. DD felt her therapist respected her needs by taking her home circumstances into account. This seemed to have a positive effect on DD's engagement and motivation, as her therapist demonstrated a willingness to work collaboratively with her, instead of attributing her lack of engagement with homework tasks negatively and doubting her suitability for CBT treatment. This illustrated the importance of focusing on how the client experienced and responded to the therapeutic process, rather than making the content of therapy the only consideration.

JR's narrative suggested that there was a collaborative relationship between her and her therapist:

'But she used to she always... if there is a piece of writing and then there is a check. I would read it back, what she had written, so I could get it in my head what was said. Then it made more and more sense.' (JR, 12, 336-339)

The meaningful interactions seemed to facilitate the therapeutic alliance, and thus helped her to make sense of what she was learning in therapy. Importantly, the clarification of her understanding facilitated by her therapist, appeared to be useful in keeping her engagement in the 'here and now' approach.

'Because it's not so full on, all in one go, so you can take longer to go through things, and it's perhaps easier to explain if you take it over longer.' (SM, 10, 275-276)

SM used the phrase, 'not so full on', which might imply that breaking things down into manageable chunks could be helpful, as it reduces cognitive loading. This adaptation seemed to have a reassuring effect for SM, suggesting that it was possible to engage with therapy if things could be delivered differently by the therapist.

'My therapist encouraged me to try to only do a little bit of first... then once I did that to build on it. My therapist encouraged me to take small steps and then from there and not to be hard on myself for only taking small steps.' (AD, 4, 86-90) 'My therapist wrote down things for me and my therapist also gave me photocopies'. (AD, 6, 164)

Furthermore, AD explained how her therapist's encouragement kept her motivation in completing her task in therapy. Indeed, the therapist's attitude and belief in AD's ability to achieve seemed to facilitate her compliance and engagement with home tasks. This suggested that the issue of process played a significant role in therapy.

#### 4.2.2 Learning new skills to cope

All participants described an adjustment process involving adaptations for coping and acquisition of skills to address their cognitive, physical and emotional difficulties. Participants explained the complexity of adjustment in three interrelated domains: adaptation to cognitive and social functioning (activities and situation), psychological effects (self-esteem and self-confidence) and existential aspirations (meanings and self-actualisation). According to participants' narratives, adjustment is an on-going process that requires taking responsibility in adopting an active role. This included finding ways to cope with their difficulties, and re-learning skills to deal with challenging situations during rehabilitation recovery. Participants' accounts included the following:

'It was emotional because I feel as though I was mourning and I continued to mourn the person I was before versus the person I am now.' (AD, 10, 277-280)

AD felt that she was mourning her pre-injury self, which inevitably led to extreme emotions associated with losses. The loss of cognitive capabilities and the imposition of psychological constraints could be perceived as a profound loss of sense-of-self. The losses of pre-injury engagement with activities, skills and coping strategies markedly affected AD's sense of identity. An increased level of awareness of the consequences of her brain injury unavoidably resulted in strong emotional reactions relating to grief and mourning. However, they could also play an important part in her adjustment process for evolving new sense-of-self, identity, values and social roles through self-transformation and reconstruction of meaning (Mathews & Marwit, 2006; Klonoff, 2010).

'Just because I'm in a wheelchair doesn't mean that I can't achieve more things in life than what I already have, so it was just getting past, I was my own worst enemy really and it was just getting past that.' (DD, 9, 233-235)

DD felt her physical disability did not change her as a person after her stroke. However, she recognised she needed to overcome her emotional difficulties to achieve more in life. She tried to come up with alternative meanings of what sitting in a wheelchair would mean and how having a disability would affect her personal and social worlds. As part of DD's adjustment process it seemed that reclaiming self-esteem and self-confidence through the accomplishment of activities and social integration might be helpful for her. Self-esteem has been considered as a mediator of improved psychosocial functioning and facilitates adjustment to brain injury (Vickery, Sherer, Evans, Gontkovsky & Lee, 2008). Moreover, DD used the words, 'I was my own worst enemy', which implied her attribution and controllability to emotional difficulties was internal rather than external. This seemed to be different from other participants, who attributed their emotional difficulties as caused by the external event of their brain injury.

Unlike DD, SM attributed her difficulties as external, and caused by the event of her stroke:

'because since my stroke you get frustrated because you can't always think straightaway. You've got to have the time to think about it.' (SM, 10, 281-282)

'If you're not sure it's difficult to ask, but if you don't ask you won't do it.' (SM, 7, 190)

This implied she considered her issues were uncontrollable. Her sense of external locus of control might relate to whether she would make changes and take responsibility for her difficulties. As Ogden (2005) proposed, attribution about the causes of problems, and the individual's health locus of control (internal or external) are associated with promoting changes.

'Because I want to do it for me... you have to do the tasks. In order to gain something, you have to put your input into it.' (JR, 16-17, 47-453)

JR expressed her strong sense of willpower, her attitude and determination to gain something. She appeared to have an internal locus of control and took responsibility for her emotional difficulties.

T've been working on it for a long time with help through rehabilitation, so it's given me the strategies to be aware that I need to concentrate, I need to remind myself to do things to get the benefit out of it.' (PPJ, 14, 368-370)

PPJ's narrative illustrated her realisation that she needed to adjust her ways of coping with cognitive and emotional difficulties as a result of her brain injury. Similar to other participants, her desires to get better seemed to reflect an internal drive which encouraged her to take the initiative for improving. Indeed, the participants' adjustment processes seemed to be influenced by their health locus of control, determining whether or not participants took responsibility for their difficulties.

'Well it makes me realise we're all vulnerable as human beings. That's what the stroke made me realise.' (PC, 6, 149-150)

PC reported changes in his life philosophy, reframing his experience of stroke as a 'wake-up call' about human vulnerabilities and limitations. This reframing of a negative life event altered how PC viewed his life course. His brain injury had broadened his viewpoint that everybody at some point in their life would need help from others, and this transformation facilitated a greater sense of self-reflection and a search for different meanings and purposes in life. This appeared to enhance his personal development for

existential aspirations (such as engaging with voluntary work, and helping others with life struggles or difficulties), which in turn could be seen as an improvement in the participant's social integration and life satisfaction. As Smith (2008) suggested, an essential part of the transformation process after brain injury is to define and redefine a life philosophy.

#### 4.2.3 Looking forward to sessions after knowing what CBT is

Five participants reported that 'knowing more about CBT' and 'what to expect in CBT', before or during the initial stage of therapy was helpful, as it reduced their anxieties. This was achieved by providing information about CBT's theoretical assumptions, practical guidance regarding interventions, and expectations of equal participation between therapist and client. It was evident that the psycho-education helped participants to understand the CBT model, potentially increasing retention and engagement. Furthermore, participants felt reassured by a discussion about how CBT was structured, and could be adapted to meet their individual needs. Indeed, the structured and concrete techniques involved with written aids, prompts, and repetition of practice, seem to fit well with brain injury clients' needs (Anson & Ponsford, 2006; Mateer, Sira & O'Connell, 2005).

SM and JR explained their experiences before they attended their CBT sessions:

'I hadn't heard about it before, no. It sounded a lot different. I'd tried counselling over many years at different points and it just didn't work, so I was hoping trying something completely different would work, well help.' (SM, 1, 14, 16-18)

After being introduced to CBT by her key worker, SM was willing to try something new and was hopeful CBT would provide a different counselling experience for her, which potentially had a transformation effect. Indeed, Smith (2008) proposed hopefulness played a vital part of the transcendence process after brain injury.

'Well it's because at first I didn't know what this cognitive behaviour therapy was. It wasn't until I went to Headway and they explained the difference to me, all about people and the way they think... I just thought it could benefit me because I was feeling very low.' (JR, 1, 9-13)

JR explained how psycho-education about CBT helped her understanding of emotional difficulties and the proposed treatment. This seemed to encourage JR to believe this approach might have potential benefits for her. Thus, this appeared to help JR with making an informed choice about treatment.

Unlike SM and JR, PC had not heard about CBT, however, he took a proactive approach by talking to other people who had experienced CBT after a stroke:

'No I hadn't [heard of CBT], but obviously you start to speak to people who've been through strokes, and these people who've had strokes and you know it's not uncommon... a few people I knew had help.' (PC, 2, 39-42)

Other people's comments might have suggested to PC that the CBT approach might be beneficial for him. Seemingly, PC's keenness to find out more about CBT and positive comments by others increased his motivation to attend the forthcoming sessions.

PPJ found out about CBT by doing a bit of research:

'I knew a little bit [about CBT]. I did a bit of research as well, to have a look as to what to possibly expect, which didn't put me off at all with that, and then I was looking forward to coming.' (PPJ, 2, 37-39)

She expressed her keenness to engage with this type of therapy after she knew what to expect from CBT. Based on participants' narratives, knowing something about CBT before attending the sessions appeared to be beneficial for encouraging them to engage with CBT. DD explained her experience before attending CBT session:

'It was a little bit daunting because it was going into the unknown' (DD, 2, 37)

DD talked about her anxiety of not knowing what CBT was about, and described her first thoughts about attending CBT as 'daunting'. However, after the first session discussing her concerns with her therapist, she gained some understanding of what CBT was. This helped her manage her fear of the unknown and kept her engaged with therapy.

# 4.3 Acceptance

Three sub-themes relate to this super-ordinate theme namely: 'Who am I after brain injury', 'Re-gaining a sense of control, self-esteem and confidence', and 'Learning to know myself and believe in future'. All of the participants made reference to the changes in their lives since attending CBT treatment after their brain injury. Most participants expressed how CBT facilitated an adjustment process and improved their level of self-awareness, and how they gained better understanding of their emotional difficulties. However, some participants felt that there were negative aspects of transforming self and identity, which in turn affected how they related to their life world. These negative aspects of self and identity separated 'them' from 'others' in the social world, due to the stigma attached to brain injury people and the general lack of understanding of brain injury perceived by the public in the UK (McClure, 2011; Chapman & Hudson, 2010).

### 4.3.1 Who am I after brain injury?

Five participants described how brain injury affected their life experiences, changing the way they viewed themselves physically, emotionally and socially. Transformation of self and identity seemed to be associated with the alternation of self-image from the past to the present, and related to how others in their social world perceived them as an individual before and after their brain injury. Indeed, a general lack of knowledge and understanding in the UK has resulted in negative misconceptions about brain injury (Chapman & Hudson, 2010), such as an under-estimation of the memory deficits, inaccurate expectations about full recovery, and a general negative attitude towards brain injury and rehabilitation due to the invisible nature of the disability. For example, PPJ described how others in society might have perceived her difficulties arising from her 'being lazy' after her brain injury:

'One of the things that I've had real problems with is organising anything since the brain injury, so tasks are difficult, and you sometimes get accused of being lazy when it's not.' (PPJ, 4, 80-82)

PPJ conveyed her experience of negative attitudes towards brain injury people. Due to her invisible disabilities, other people in her social world might under-estimate the impact of her brain injury on her everyday life functioning. This misconception might have negative effects on her self-esteem, and increased her levels of anxiety, depression and frustration. This appeared to be an attribution bias towards her conditions where people might over-

estimated her ability and recovery progress, but under-estimated her limitations due to her invisible difficulties. However, unlike PPJ, DD incurred a visible disability after her stroke:

'I can't move one half of my body, and that for me is major, because then it means that I can't go back to work, because being a [sports] therapist I would need both hands to actually do my work.' (DD, 12, 327-329)

DD was conscious of her physical impairment due to her stroke. She emphasised her professional identity as a sports 'therapist'. Seemingly, losing an ability to work was significant to her as she used the word 'major', conveying an important implication for personal meaning, purpose, and her positioning in her social world. Indeed, this seems to convey a sense of loss concerning her social roles and identity, which might contribute to her negative sense-of-self, lowering her self-esteem and confidence.

PC and JR explained how having stroke changed the way they viewed themselves as a person:

'I thought I will be the only person that had a stroke. I would go into a room and nobody would talk to me. I almost felt a bit of a nothingness'. (JR, 3, 58-60)

JR described how her stroke made her feel socially excluded, as if she was 'the only person that had a stroke'. JR perceived others as negative in a social situations, 'nobody would talk to me', which created a sense of distress that contributed to her negative sense-of-self. Evidently, her stroke had affected her social interactions with others and her confidence to socialise with people. However, these internal interpretations of social events could have been changed or altered by CBT interventions. Moreover, PC explained how his stroke changed the way he perceived himself as a human being:

'Well it makes me realise we're all vulnerable as human beings. That's what the stroke made me realise. Before the stroke I was a strong man emotionally I thought, and physically. Well after the stroke was finished with me I was physically not strong, emotionally weak... so it makes you realise how vulnerable we are as human beings and we all need help'. (PC, 6, 149-158)

According to PC's narrative, he seemed to evaluate his pre-injury characters and capabilities strongly, which contrasted to how things were for him post-injury. He described himself as a 'physically and emotionally strong man', however, his pre-injury sense-of-self was challenged after brain injury. PC's experience of having a stroke seemed to raise his awareness of some of the existential issues with regard to human vulnerability and uncertainty.

Indeed, AD described her grieving process as a mourning for her lost pre-injury self, coupled with feelings of insecurity about her post-injury self:

'I think... well I think because it was a loss, because I was mourning a loss of who I was... who I am... who I was... the temptation is to assume that you have lost everything.' (AD, 11, 285-288)

Losing her pre-injury self might signify that she lost 'everything' in terms of her purpose, meanings and existence in her life world. For her, this raised the question: 'Who am I now?' Accompanying this would be feelings of uncertainty about how she would relate to herself and others from now on. This conveyed a strong sense of loss, sadness and feeling disconnected from her own reality.

## 4.3.2 Re-gaining a sense of control, self-esteem and confidence

All participants reported positive therapeutic outcomes after receiving CBT. They described examples of how CBT helped them with 'conquering that fear', and 'how to handle low days'. Participants' narratives illustrated that CBT had helped to 're-build self-confidence', 're-gain some sense of control', and 'change the way I think about myself'. These positive changes seemed to have a potentially significant impact on their self-esteem and on the formation of their new identity. Participants seemed to go through a process of social withdrawal from their social world after their injury. However, they appeared to reconstruct their new personal and social identities after the course of CBT interventions. Importantly, these interventions helped them to explore new ways of engaging with people, activities, and social events. This seemed to support findings presented by Khan-Bourne and Brown (2003), which proposed that CBT could be a potential treatment for adults with neuropsychological impairments when adaptation was implemented throughout the course of therapy. Indeed, PPJ implied that CBT helped her to find out what her actual capabilities were at this present stage of her recovery:

'It's given me more confidence in myself with going through the therapy, because it's shown me the way forward, and how if you don't push yourself to do something new, you're never going to find out what your capabilities are.' (PPJ, 4, 95-98)

However, this also suggested that PPJ had a level of insightfulness in considering the possibility of engaging with new tasks. Furthermore, this signified the future challenges she might face, as she realised she was the only agent that could facilitate growth and change, which in turn encourages a stronger sense of autonomy and self-reliance. Likewise, DD expressed how she re-gained a sense of freedom and independence by being able to go out on her own:

'I think it's helped emotionally. Not much with the physical, but emotionally it's helped a great deal because I've made decisions and stuck to them and done something, whereas before I wouldn't go out on my own, whereas now as long as I've been there once, it's not so much of an issue, so it's helped along the way.'
(DD, 9, 252-255)

This might suggest that DD had somewhat transformed her sense of suffering into something meaningful. This might reaffirm her sense of an individual existence including freedom, choice, purpose and self-actualization (Yalom, 1980). Additionally, participants reported that CBT had taught them new ways of coping with their difficulties. SM spoke of the positive changes that she had experienced after her course of CBT:

'I feel more comfortable around people and I still get low days but I know how to handle low days, which I couldn't have done before.' (SM, 5, 127-128)

These changes reflected significant differences in how SM dealt with her 'low days'. She felt that she could deal with her emotional difficulties differently, in a more manageable way. This implied that she had regained a sense of control, which might in turn help her towards acceptance of her conditions. Similar to SM, both PC and JR described CBT as helpful:

'So it gives you a different way of looking at things and coping I guess, which helps with depression.' (PC, 3, 76-77)

'I learned that through my day to day life I could manage them, I could learn to cope.' (JR, 4, 108-109)

Cognitive restructuring and facilitating coping strategies were two important facets of CBT. For PC, it seemed to be helpful to gain an insight into how he viewed and dealt with his situations in everyday life. A consequence of this was an increased ability and awareness of his thoughts, which in turn allowed him to challenge these thoughts, and then generate alternative more helpful ones that helped to better deal with his depression. For JR, it appeared to be useful to learn coping strategies where she felt she could be more able to manage and regulate her emotions. Based on participants' narratives, CBT could be helpful in facilitating coping strategies and gaining insight into how depression and anxiety were developed and maintained. In addition, paying attention to the process issues during therapy was important to participants' experience of CBT, as it could help to address participants' cognitive limitations and engagement. Seemingly, the process-based adaptation as well as the technique-based adaptation can affect CBT's treatment effect for the brain injury client groups.

### 4.3.3 Learning to know myself and believe in future

Given that the traumatic event of brain injury often causes irreversible, profound and enduring life changes, the acceptance process is likely to be painful, complex and prolonged. Indeed, brain injury clients' acceptance of their current life circumstances is an important part of the rehabilitation process. Acceptance can be explained as clients' ability and willingness to cope with their new reality, life situation and new identity by employing their residual resiliency and adaptive compensatory strategies flexibly and creatively. A participant explained how CBT had helped her to accept 'who she is now' by engaging with a piece of artwork that involved exploring her pre- and post-injury self. Generally speaking, there is no endpoint to the acceptance process, as it is an evolving maturation process towards new practicalities and ideals. However, phase five of Prigatano's (1999) Patient Experiential Model (PEM) of recovery after brain injury, emphasizes 'acceptance', and that clients manifest the acceptance process through embracing compensatory strategies. It is those helpful compensatory strategies that can assist clients to resolve their problems and improving their everyday life functioning. This 'acceptance' aspect of recovery can be seen in PPJ's narrative about how CBT had helped her to accept her postinjury self:

'... it's given me more confidence in myself. It's reminded me that it's okay to be the way I am now and to stop thinking back to how I was before, sort of benchmarking myself against myself isn't a happy way to be.' (PPJ, 8, 204-207)

Furthermore, she seemed to be empowered by her increased self- confidence. As Man (2001) suggested, empowerment was a crucial tool for brain injury clients as it could optimize their coping capacity and future planning. This would have helped PPJ to move forward in her rehabilitation recovery process. Similarly, SM explained the difference in how she viewed herself before and after CBT treatment:

'Learned to know me. I started to like me, which I didn't like me at all. But doing the sessions has really changed the way I think about me.' (SM, 13, 362-363)

This appeared helpful for SM in getting through her acceptance process, and creating a new sense-of-self. As recent findings suggest, resiliency and coping capacity are the essential elements to the acceptance process for brain injury clients (Anson & Ponsford, 2006; Schutz, 2007; Dawson & Winocur, 2008).

PC explained a level of uncertainty about his acceptance process, although he seemed to embrace a 'come to terms' attitude towards his limitations:

'I thought I had accepted but I was told I hadn't and I don't think, to be honest I never will. Just come to terms with it and realise our limitations in life and accept them really.' (PC, 4, 93-95)

However, there appeared to be an inner contradiction where he did not believe he would ever achieve the full acceptance of his injury. This signified the intense and painful process of recovery he was going through. As Davis, Gemeinhardt, Gan, Anstey and Gargaro (2003) stated that the event of brain injury created a 'transcrisis state', which refers to an unstable state with inadequate resolution of situational crises, due to the chronic and long-term consequences after the injury. In contrast, JR appeared to have developed some sense of inner strength and courage to face her new reality and future after CBT treatment. This seemed to echo the final stage of PEM, where brain injury clients accepted their present reality:

'I don't at the moment feel sad or miserable or want to get rid of myself or fall into a hole somewhere. I can see some future.' (JR, 15, 404-405)

However, unlike JR, AD seemed to be at a different level of her acceptance process. AD appeared to embrace the CBT treatment by taking on board what might be helpful for her, enabling her to develop compensatory strategies:

'I needed to get out and focus on the positive aspects and not think about myself as being a sick person.' (AD, 2, 49-50)

This seemed to signify her willingness to accept her present conditions and take responsibility for her rehabilitation recovery process.

# 5. Discussion

## 5.1 Review of the Current Findings in relation to the Existing Literature

The current findings relate to the challenges UK health practitioners face when forming therapeutic relationships and building working alliances with brain injury clients (Judd & Wilson, 2005). The findings revealed that the readiness to engage with CBT can be perceived as one of the crucial factors for increasing engagement and improving accessibility in the context of neuropsychological rehabilitation. According to participants' experiences of CBT based on the present study, accessing CBT at the right moment has a direct effect on their motivational and engagement level to therapy. Additionally, factors such as the quality of therapeutic relationship and the qualities of therapists have an influential effect on the participants' engagement level.

The first super-ordinate theme identified was based on participants' reasons for seeking professional help, the issues they might have confronted during their decision making process and any concerns they might have anticipated during therapy. This super-ordinate theme, 'Professional relationship', reflected the importance of the therapeutic relationship in CBT from the participants' perspectives. The sub-theme of 'At the rock bottom point where anything may help', reflected the importance of accessing CBT at the right time, which referred to the participants' readiness and willingness to engage with CBT, and the effect on their motivational and engagement level, which in turn influenced the therapeutic

outcome (Miller & Rollnick, 2002; Robinson, 2003; Lincoln & Flannaghan, 2003). All participants reported their recognition of problems associated with the consequences of brain injury, and that these problems had become overwhelming for them, resulting in emotional disturbance. Additionally, participants expressed a sense of hope that CBT could help address their emotional difficulties. Indeed, where practitioners pay more attention to detecting the client's readiness for therapy, this may increase accessibility and promote better engagement. Furthermore, practitioners need to take into consideration a readiness to engage with therapy may modify over the course of clients' rehabilitation recovery process (Klonoff, 2010; Prigatano, 1999).

The qualities of therapists were identified by participants as an important factor that determined their engagement and belief in CBT. The complexity of brain injury has certainly caused barriers and challenges to practitioners when delivery therapy, and notably, there is no specific CBT models to provide guidance when working with emotional difficulties experienced by clients with brain injury (Coetzer, 2009). Therefore, it is crucial for the practitioners to develop an appropriate theoretical perspective that places disability caused by brain injury into a broader social and narrative context. Practitioners may need to consider wider issues such as stigma, isolation, loss of role, change in identity and socioeconomic status when conceptualising ABI clients' difficulties. The lack of training for professionals working therapeutically with this client group has contributed to the limited psychological and psychotherapeutic services provided in this context.

Indeed, five participants from this study, made specific reference to the importance of the therapist's quality for their valued experiences of CBT. This could possibly be associated with the therapist's ability to estimate and understand what kind, and to what extent, neurological and psychological issues participants might confront in their everyday life, thus gaining a shared understanding of their emotional difficulties. The sub-theme of 'Understanding me and my brain injury' supports the need for expanding practitioners' knowledge and training in this field, as participants articulated the importance of the qualities of therapists. Similarly, Judd and Wilson (2005) suggest many therapists may lack understanding of brain injury, and overestimate the differences between clients with brain injury and clients without brain injury. They fail to acknowledge the fact that this group share the same psychosocial and emotional issues as everyone else, yet underestimate the extent of the difficulties clients with brain injury have to deal with in their everyday life.

Judd and Wilson (2005) highlighted that UK practitioners may overcome challenges due to brain injury clients' cognitive and memory deficits by allocating greater time for focusing on the development of therapeutic relationships, rather than merely attending to the content of sessions. A more flexible approach may facilitate a greater bonding between therapist and client, with mutual respect, trust, acceptance and confidence for overcoming challenges (Klonoff, 2010). Recent literature has highlighted it is common for practitioners to experience challenges in relation to engagement issues when working with brain injury clients. This can be explained tentatively by therapists' misunderstanding or misinterpretation of clients' emotional difficulties. As Clarkson (1994) argues, expectations of therapy from both therapist and client are likely to be the strong influences affecting the quality of the working alliance. Additionally, the client's preparation and readiness for therapy and the quality of the therapist are important factors in the establishment of the working alliance.

Hardy, Cahill and Barkham (2009) suggest that active ingredients for developing a good therapeutic relationship between client and therapist are trust in the therapist, openness to the process of therapy and a commitment to work with their therapist. It is important for the therapist to facilitate a warm trusting bond and engage with clients on the emotional level. Similarly, participants' narratives reflected the importance of 'trust' and 'confidentiality' for establishing a good therapeutic relationship. This was reflected in the sub-theme of 'Confidentiality and trust'. All participants reported 'trust' was a very important factor that influenced their experiences of receiving CBT. The primary focus of building trust and ensuring confidentiality allowed participants to open up and reveal their inner feelings, thoughts, meanings and underlying pains. It allowed participants to take the risk of being vulnerable with their therapists, while hoping to gain their therapists' understanding about their distress. It appears to be vital that therapists acknowledge and understand the clients' pains, validate their struggles through attentive listening, and demonstrate a caring and non-judgmental stance (Leahy, 2009). This seems to be particularly important to participants in this study, and it is plausibly explained by the context of brain injury. Indeed, ABI clients are well aware of the misunderstandings within general public whereby their difficulties can be misconceived as them being 'lazy', 'dependent on others' or that they 'can't think for themselves', which in turn can make them feel judged and rejected by others (Chapman & Hudson, 2010; Linden & Boylan, 2010). Therefore, having a therapist who can be trustworthy, understanding and validating their difficulties with a non-judgmental manner appears to be significant to them.

The second super-ordinate theme identified was based on participants' experience of entering CBT sessions with concerns about their cognitive limitations, and how they worked with their therapist in order to manage those concerns, and change their attitudes This super-ordinate theme, 'Understanding my struggles', and beliefs about CBT. reflected how adapted CBT interventions could be helpful in dealing with challenges caused by cognitive and memory deficits. This appeared to be consistent with the recent article presented by Coetzer (2009), who proposes that adapted CBT approach can be useful for managing emotional difficulties for brain injury client groups. Similar to learning disability client groups, some of the CBT interventions may be beyond clients' cognitive capacities (Joyce, Globe & Moody, 2006). However, if adaptation can be applied appropriately, clients with learning disabilities can learn new skills from CBT and generalise their learning to new material (Bruce, Collins, Langdon, Powlitch & Reynolds, This seemed to echo the present findings that helpful adaptations to meet 2010). individual client's needs were important to participants' experiences of CBT. The subtheme of 'Adaptation and flexibility to therapy approach', reflected how CBT interventions could be modified regarding the content and the duration of sessions. This was perceived as being particularly helpful by the participants of the current study for increasing their engagement and motivation. All participants explained that the most beneficial outcome of CBT had been the cognitive changes, which suggested that the cognitive components of CBT might need to be delivered before the behavioural components to produce and maximise the treatment effect in this client group.

CBT's educational approach provides a relatively simplistic but productive structure for clients with brain injury. It helps clients to explore different ways of dealing with emotional and physical difficulties. This can be achieved by learning various problem solving skills and emotional management, especially in terms of cognitive appraisal and interpretation of depressive and anxiety symptoms (Gracey, Oldham & Kritzinger, 2007). This may be unfamiliar to the client's pre-injury experience, however, the use of these coping strategies can help with managing their environment, situation and people. This is supported by the sub-theme of 'Learning new skills to cope', which demonstrated how CBT assisted participants in getting through different stages of their adjustment process. All participants reported that CBT had helped in some way to achieve a level of adjustment towards their rehabilitation process. However, they also recognised that the adjustment process was on-going and lengthy and required consistent effort to implement helpful strategies for dealing with their difficulties.

Although the provision of psycho-education is generic to all clients who receive CBT, it can be particularly relevant to ABI clients' experiences. It can help ABI clients to gain a better understanding of how the consequences of their brain injury may trigger unhelpful thinking and behavioural patterns. Familiarising ABI clients with the CBT model during the early stage of therapy would therefore be particularly helpful for engaging them with their treatment. Indeed, recent evidence suggests that many clients with brain injury appear to benefit from sensitively provided information, in relation to the nature of brain injury and its effects on emotional and physical well-being (Coetzer, 2009). This seems to be supported by the sub-theme of 'Looking forward to sessions after knowing what CBT is', which illustrated that it was vital to explain what CBT is and what its expectations are about, as part of the structure during the early stage of therapy. Five participants reported how psycho-education helped to initiate their keenness and interest in engaging with CBT. Importantly, psycho-education provided some sort of certainty about what they were going to be involved with during therapy. This appeared to have a positive effect on engagement and motivation level since anxiety caused by the unknown factor of therapy was significantly reduced. Moreover, psycho-education about CBT might have helped this client group to grasp and understand the concepts before utilising some of the techniques, so that they would be more able to benefit from such an instructive, directive and educational form of therapy. Therefore, it appears to be reasonable and helpful to place the provision of psycho-education as the primary CBT intervention at the beginning of therapy.

These findings seem to echo the existing literature with regard to various single case studies, suggesting that a tailored, individualised CBT approach can produce a more positive therapeutic outcome when interventions are adjusted and adapted to consider individual needs and limitations (Harvey et al., 2004; Gilbert, 2000; Mateer et al., 2005). Indeed, Judd and Wilson (2005) illustrated that UK practitioners regarded memory deficit as the most significant challenge to form a working alliance, and memory aids were the most effective means of addressing such difficulties. Similarly, the findings from this study echo the same challenge identified by brain injury clients whereby they found memory aids helpful to facilitate better engagement during therapy. This suggests that it may be useful to include memory aids as part of the adaptation in the future development of CBT for brain injury client groups. However, it is important to acknowledge that participants' experiences from the present study do not represent the entire brain injured client groups' experiences, as clinical presentations and levels of cognitive functioning vary tremendously in the context of brain injury. Variations in terms of ABI clients' levels

of cognitive functioning (e.g. attention, concentration, memory, recall, language ability, and visual spatial ability) can exist and change from time to time, depending on the nature of the ABI clients' injury, including the severity, the type of neurological condition, and the location and length of their brain damage (Stuss, Winocur & Robertson, 2010).

Interestingly, the findings in the current study, relating to CBT adaptations identified by participants, were more associated with the process based adaptations, e.g. how to structure and deliver each session such as providing a review of the previous session; being flexible to the length of sessions; pacing of the session; the nature of home tasks; setting clientcentred, realistic and meaningful goals; clear explanations to ensure understanding; and clarification of client's understanding of task and simplifications of tasks. This finding is somewhat different from the findings presented by the existing literature with regard to CBT adaptation. For example, recent case studies mainly focus on the CBT technique based adaptations, aiming at integrating techniques from various models to achieve positive therapeutic gain in the context of neuropsychology rehabilitation. For example, Gracey, Oldham and Kritzinger (2007) adapted CBT interventions based on Clark's cognitive model (1986), and integrated with Silver, Surawy and Sanders' behavioural experiments model (2004). Whereas other researchers and/or practitioners adapted CBT with other therapeutic orientations and frameworks, including the integration of attention training skills from Metacognitive therapy, and the consideration of neuroscience concepts for adapting CBT with the use of compassion mind training (Mateer et al., 2005; Gilbert, 2000).

These existing studies have certainly provided an invaluable contribution towards our understanding of how better to work with brain injury clients. However, it is crucial for therapists who work with brain injury clients to pay more attention to the therapeutic process issues, rather than merely focus on technique and skills training when delivering counselling in this context. Indeed, it is important to go back to the basics where the core principles of counselling emphasise the humanistic values, respect individual experiences and create a validating environment for the client to achieve a sense of growth and empowerment (BPS, 2005). Also it is vital to attend to the core elements of providing counselling or psychotherapy in a more interactive and relational manner, regardless of theoretical modality, framework and orientation. Wilson (2011) suggests it is important to improve the delivery of CBT for brain injury clients, and findings from the current study may provide insight and understanding for this aim. Indeed, the findings from the current study suggest that there is a need to focus on process-based adaptations, rather than merely

emphasising the technique and skills training based adaptations. The present findings tentatively suggest that it would be helpful to think about 'how' to deliver therapy instead of 'what' to deliver, and attend to 'being with' the clients' experience rather than 'doing to' them. Plausibly, a combination of process-based adaptation, together with technique-based adaptation may reduce the cognitive demands for brain injury clients.

Importantly, findings from the present study provide further evidence for the effectiveness of CBT in the context of neuropsychological rehabilitation. They also provide evidence to support the view that brain injury clients are able to benefit from CBT despite their cognitive and neurological limitations. Indeed, it is still commonly acknowledged by practitioners that psychological symptoms such as depression and anxiety are associated with the client's brain damage, and therefore the pharmacological approach to manage those symptoms is the preferable choice of treatment (McGrath & King, 2004). Furthermore, there has been research focusing on the possible assumptions that depressive and anxiety symptoms arise as a result of neurological damage, hypothesising that lesion location, such as dorsolateral prefrontal, ventromedial prefrontal, orbitofrontal or bilateral cortex damage, is associated with the development of depression and antisocial behaviours (Milner & Petrides, 1984; Sbordone, 2000; Damasio, 1996). However, a recent metaanalysis examining lesion location and depression suggested that these findings were inconclusive (Carson et al., 2000). In fact, for practitioners who employ CBT for treating depression in this context, it would be the least relevant issue as CBT employs the 'here and now' approach for its interventions.

For ABI clients, it is more beneficial to focus on the consequence of the event, such as isolation caused by physical inability to engage with social events, or hopelessness about changes in cognitive functioning, which are commonly experienced by individuals with brain injury. CBT cannot reverse the consequences caused by the external event of brain injury, however, CBT can help the client to change their responses to the post-injury experiences, finding ways to deal with its consequences rather than seeking the causes of depression or anxiety. Therefore, it may be more helpful to focus on which type of interventions would best fit with this complex client group, how and when to apply those interventions. It is necessary to pay more attention to therapists' and clients' shared understanding of difficulties after injury, as well as setting the meaningful, client-centred therapeutic goals in a collaborative manner (Bachelor, Laverdiere, Gamache & Bordeleau, 2007). These meaningful therapeutic processes would help to provide more guidance for adapting the CBT approach, facilitating an understanding of when and how to integrate

appropriate interventions and/or concepts from different therapeutic frameworks. For example, emotional and catastrophic reaction to brain injury is commonly associated with this client group, whereby he/she withdraws and avoids social activities or situations. Integrating the concepts of psychodynamic psychotherapy is particularly useful during the course of therapy, for understanding the client's defence mechanisms, identifying potential ruptures, and predicting the direction and assessing the quality of therapeutic processes (Hobson & Kapur, 2005). Once clients have worked through their defences and/or resistance issues, they may feel more ready and safe to build a good therapeutic relationship.

The third super-ordinate theme identified was based on the therapeutic outcome described by participants, after receiving CBT treatment for their emotional difficulties and the treatment effect it had on their recovery journey. This super-ordinate theme, 'Acceptance' reflected how CBT could facilitate constructive changes in all the participants' rehabilitation progress, by helping to address and regulate their emotional difficulties. This suggests that CBT can be relevant and effective when it is adapted to meet the needs of individual brain injury clients, despite the existence of cognitive limitations and organic brain pathology. Over time, physical effects after a stroke may become less salient to the clients' clinical presentations, but the psychological effects may become a longer term issue, particularly regarding emotional management. Therefore, it is necessary and appropriate to include the psychological approach to rehabilitation, as this approach can play an augmentative role in this context. And especially with the focus on relapse prevention and early assessment that helps identifying depressive and anxiety symptoms which are caused by environmental, social, and psychological factors. The sub-theme of 'Who am I after brain injury?', reflected the importance of including psychological approaches within neuropsychological rehabilitation. Five participants reported that their injury affected how they viewed themselves and how others viewed them in their social worlds, which may have affected their self-esteem, contributed to their negative transformation of self, and thus increased the likelihood of developing various emotional difficulties, such as post-injury depressive and anxiety symptoms including agitation, frustration and irritability (Rogers & Read, 2007; Jorge, Robinson, Moser, Tateno, Crespo-Facorro & Arndt, 2004; Fleminger, Oliver, Williams & Evans, 2003).

Additionally, participants felt that they experienced physical, emotional and social changes after their brain injury. These changes were vividly reflected in participants' new identities, thus affected their self-perceptions and interpersonal relationships with others.

This finding provided better understanding of how these post-injury changes, might have impacted on participants' social and personal lives. This may help towards the future development of CBT and with designing appropriate adaptive interventions that focus on dealing with post-injury changes, and establishing helpful strategies for exploring newer sense-of-self and identity. This finding supports and agrees with the recent literature presented by Giles and Manchester (2006), who assert that one of the main goals of CBT is to help ABI clients to cope with feelings of loss related to decreased levels of functioning. Importantly, this finding highlights that there is an emergent need for providing and including psychological treatment as part of ABI clients' neuropsychological rehabilitation program, as this would enhance their capacity to be rehabilitated and enable them to make the most of their residue functioning in everyday life.

Unlike other physical illnesses that may occur in life, stroke often occurs 'out of the blue'. Therefore, the individual and their families suddenly have to adjust and adapt to the changes that stroke causes, including fear of the future due to financial and personal implications, such as loss of employment, and dependency issues. Inevitably, there will be an increased risk of developing depressive and anxiety symptoms after a stroke from a psychological standpoint. Seemingly, CBT's behavioural interventions can be useful in helping the client to overcome behavioural issues, such as going out shopping. However, participants in the present study reported, the cognitive changes (in terms of the ways they appraised their situations and their insights) were important and valued by participants as these increased levels of confidence and control. This suggested that the participants' experiences of CBT involved cognitive interventions that facilitated cognitive changes as a result of their CBT treatment. In contrast, most case studies exploring the effectiveness of CBT using brain injury clients have placed their emphases on behavioural interventions (Gracey, Oldham & Kritzinger, 2007; Dewar and Gracey, 2007). Plausibly, this could have arisen out of a hesitance on the part of practitioners in applying the cognitive interventions, due to their uncertainty about the clients' ability to engage with analysis about their own thoughts and feelings. However, as CBT requires a certain level of cognitive ability, it can be argued that this is exactly why psycho-education is so important during the early stage of therapy, because it provides the very cognitive training needed by the clients for accessing and identifying their thoughts and feelings.

Moreover, cognitive interventions, such as cognitive restructuring using thought records, often help the client with a stroke to make sense of their overestimations of likely dangers. However, it is important that practitioners adapt cognitive interventions such as

simplifying the detail of thought records, to make them more accessible for helping clients to monitor and evaluate their thoughts and feelings. Collaborative empiricism would suggest that practitioners ought to have an open mind in believing and helping clients to achieve, rather than assuming and judging that people are cognitively impaired. Furthermore, cognitive interventions are a potentially important element in CBT as it helps clients to develop a sense of control over their depression and enhance their recovery process after their stroke (Nicholl, Lincoln, Muncaster & Thomas, 2002). This seems to reflect the current findings, under the sub-theme of 'Re-gaining a sense of control, self-esteem and confidence', which reflected all participants' experiences of CBT in terms of achieving a sense of control through the cognitive and behavioural changes.

Different approaches of CBT place their emphases on different factors to create a long lasting effect in psychological functioning, such as the adjustment process, the acceptance process, perceived change in role and identity, sense of loss, coping strategies, and/or changing the relationship between emotional difficulties and oneself. For example, MBCT (Teasdale, et al., 2000) aims at changing the relationship between the client and the perceived difficulties, and focuses on living with the present moment and not being affected by the past or the future. Another approach of the 'third wave' CBT is Acceptance and Commitment therapy (ACT) which focuses on the acceptance of human suffering and the commitment to living a purposeful life (Kangas & McDonald, 2011; These approaches of CBT have significant differences in goals and Cullen, 2008). expectations, therefore, it is important for the practitioners to ascertain who may benefit from the psychological treatment, and which factors and interventions may be integrated into the clients' treatment package, to adequately address and meet the individual's needs. Indeed, Ylvisaker and Feeney (2000) assert that a positive sense-of-self can only be facilitated when people are doing something that provides them with a sense of reality towards their positive aspect of self. This may imply that CBT's 'doing' approach could be relevant in facilitating a positive sense-of-self through engaging with activities, which increase the possibility of getting positive feedback from others. Thus improving the client's functioning and mood, as they gain a sense of accomplishment. This seems to echo my participants' narratives when describing the importance of relearning everyday life skills.

The sub-theme of 'Learning to know myself and believe in future' reflected all participants' accounts of the beneficial effect CBT had on their acceptance processes. Hopefully, this suggests a degree of generalizability supporting the notion that CBT's

structured approach to problem solving and the facilitation of new learning may be particularly suitable for this client group. The findings from this study provide further evidence that CBT could be effective for the brain injury client group, and could serve an important purpose for enhancing the effectiveness of neuropsychological rehabilitation programs. The present study indicates that psychological treatments such as CBT should be integrated as part of the brain injury clients' rehabilitation service to more fully accommodate their needs for recovery.

#### 5.2 Evaluation and Limitations of the present study

The strength of this qualitative study lies in the contribution it makes towards the evidence based practice in the context of neuropsychological rehabilitation. Evidence based practice is referred to information, which is derived from systematic data collection, clinical expertise, client preferences and the informed choice of treatments (APA Presidential Task Force on EBP, 2006). This leads to the notion that 'evidence based practice is the integration of best research evidence with clinical expertise and patient values' (Institute of Medicine, 2001, p.147). However, it is questionable as to what constitutes and classifies as best research evidence. The belief that RCTs are the 'gold standard' for guidance in clinical practice and research is widely held by practitioners and researchers. This bias with regard to research methodology and clinical practice is possibly influenced by the rigid hierarchy of evidence based on NICE (the National Institute for Health and Clinical Excellence) guidelines. The development process of NICE guidelines is robust but somewhat limited, as it is based on evidence where RCT studies are given most weight (BACP, 2007). Furthermore, the funding and publishing of RCTs that relate to mental health has been largely focused on evaluating the effectiveness of pharmacological intervention. As a result, there is limited RCT evidence for the efficacy of psychological therapies (BACP, 2007). These biases result in the discrimination between the quality of evidence and methodology, and the neglect of other methodologies' role and practices in developing effective treatments. Seemingly, this study has some value for making a contribution to the evidence based practice, in determining and developing guidance for helpful practice in the context of neuropsychological rehabilitation.

The present study offers evidence to the existing evidence-based practice of CBT in the rehabilitation context, with the use of a qualitative methodology. This provides a dimensional approach in exploring the effectiveness of CBT with brain injury clients, with

an aim to enrich our understanding of the process-based adaptations and psychotherapeutic interventions. Importantly, the findings of the present study highlight the essential elements for the effectiveness of CBT, including the quality of the therapeutic relationship, the client's willingness and readiness to engage in therapy, the adaptations needed in therapy to address the client's limitations, as well as the need for a balanced focus between the behavioural and cognitive components employed in therapy. This would further enhance the future development and delivery of CBT in the neuropsychological rehabilitation context. This exploratory study has provided further understanding of the therapeutic process by eliciting an in-depth and coherent account of participants' experiences of CBT. This study took a radical approach by giving a voice to the ABI client group and allowing them to express their views and experiences of CBT. As a recent article has pointed out, individuals with brain injury may experience difficulties in accessing services due to their invisible disabilities, and consequently place themselves at the receiving end of discrimination (Harder, 2009). Accessing services is made more difficult if service providers are unaware of such discrimination. Therefore, inviting individuals with brain injury to share their subjective experiences, instead of constraining them to report their experiences merely by administering self-report standardised questionnaires with fixed responses and categories is necessary.

Similar to other qualitative studies, there are limitations in this current study. The brain injury clients' clinical case presentations (such as the type of injury, the severity of injury and cognitive deficits) can vary enormously, which means that findings from the present study need to be treated cautiously. One of the limitations in this study is concerned with the selection process. Participants were self-selected and evidently satisfied with their CBT treatment outcomes, which inevitably will have affected the discourse. The recruitment process from the current study could be improved upon by selecting participants with different experiences of CBT which may generate more critical findings. Furthermore, a more explanatory design might be helpful for considering variables such as the type of intervention employed in terms of different approaches of CBT (e.g. traditional CBT or 'third wave' CBT) as well as the therapist factors. For example, a study based on a Grounded Theory Method approach might usefully provide a means for accounting for more divergent views and/or sampling of characteristics.

Another limitation of the current study is related to the lack of information about or control over the therapist factors, as these variables would have affected the participants' experience of CBT. Such factors might include the therapists' beliefs or attitudes towards

this client group, and their level of training, knowledge of brain injury, and competency of delivering CBT in the context of neuropsychological rehabilitation. Additionally, clients' experiences are likely to be impacted by the length of CBT treatment being delivered, and the types of CBT being employed. This study does not capture the qualities of the therapists who delivered the CBT, nor any measures to assess the therapist's adherence to a particular approach of CBT. Furthermore, it is unclear what types of CBT intervention were being used and how they were employed. Inevitably, all of these factors could have influenced the outcome of CBT's treatment effect.

#### **5.3 Future Research Directions**

In future qualitative studies, it would be interesting to purposively select participants who had dropped out of CBT or had experienced different types of therapeutic modalities, to gain a more critical view. Indeed, future research into further examination of the effectiveness of CBT may consider testing the efficacy of CBT interventions against alternative therapeutic modalities including psychodynamic psychotherapy or the humanistic approach. This type of research would be able to determine whether or not CBT interventions are effective for individuals with brain injury. Comparing CBT with different therapeutic modalities can provide a broader picture in determining the effectiveness of CBT. Also it may be helpful to focus on the therapists' factors, as it can be argued that the qualities of the therapist are as important as the effectiveness of a Nevertheless, BACP (2007) stated that NICE guidelines seemed to specific therapy. promote a specific type of therapy rather than the person providing it, despite existing evidence suggesting that therapeutic relationship and therapeutic alliance are both relevant to the treatment effect (Roth & Fonagy, 1996).

Furthermore, a quantitative approach to future research on the effectiveness of CBT, examining factors that are potentially important in influencing the clients' levels of engagement and therapeutic outcome, would further our understanding of how better to work with this client group. Also, longitudinal research would allow further exploration of CBT's lasting effect on brain injury clients, as they move through their rehabilitation recovery. This type of research can provide information about how and when changes occur. Therefore it would be helpful for practitioners to identify the possible relapse time during the clients' rehabilitation process. This information can be very useful for targeting the prevention of relapse in this context, designing the relevant maintenance guide, perhaps

offering several booster sessions at the appropriate times, enabling clients to further consolidate skills learned and reducing the risk of relapse.

With regard to the appropriate outcome measures for CBT's treatment effect in the context of neurological rehabilitation, the General Health Questionnaire (GHQ-28) developed by Goldberg and Williams (1998) has good content validity to measure mood related experience and behaviour in both clinical and general populations, as this measure does not predominately focus on physical symptoms. Another relevant outcome measure for brain injury client groups is the Brain Injury Community Rehabilitation Outcome 39 (BICRO39), developed by Powell, Beckers and Greenwood (1998). BICRO39 measures aspects of personal and social functioning, it can be used to track changes in performance over time which can be particular helpful in a longitudinal study. Furthermore, this questionnaire has been purposefully made simple with an aim of making it accessible to brain injury clients. Importantly, it has been found to be sensitive to the effects of intervention (Powell, Heslin & Greenwood, 2002).

Moreover, future research directions, based on my clinical experience of working with this client group alongside other professional's knowledge and expertise, suggest that clients with brain injury often experience relationship issues with their partners. The once competence and capable person has suddenly become dependent, at least on a temporary basis; the personality aspect of the person may alter and change, he/she may become a 'stranger'; and the post-injury changes in sexuality may become an issue in the marital relationship. All of these factors may require more attention from practitioners, and benefit from future research that focuses on marital or romantic relationships after brain injury.

### 5.4 Implications for Clinical Practice and Training

In the context of working with brain injury clients, it is apparent that there is a need for building a strong therapeutic relationship between therapist and client, which has emerged as one of the most important aspects of CBT for participants in this study. However, replication in other studies and homogenous groups are required before definitive conclusions can be drawn. Based on this study, a strong therapeutic relationship may represent a key ingredient for producing positive therapeutic outcome. Firstly, one of the essential elements in building a strong therapeutic relationship is the qualities of therapist, e.g. patience, non-judgemental attitude, respect, and knowledge of brain injury (Klonoff,

2010). Therapists should adopt those attitudes and beliefs, as well as a willingness to engage with further professional development to acquire relevant knowledge and training about brain injury, to be compatible with an adaptive approach to CBT for this client group.

Secondly, therapists should make their clients aware of the possibilities of distress when engaging with therapy, discussing this with them in an open and honest manner, and thus work proactively to find ways to problem solve and minimize these potential hindrances to making progress in therapy, e.g. exploring the issue of resistance. This involves the flexible and relational approach to CBT, such as collaboration empiricism, which could have beneficial effects for building rapport with clients, and thus achieving a good working alliance.

Thirdly, the therapist's reflexive therapeutic approach appeared to be favourably preferred by participants, when comparing with their experience of health professionals who work with the medical model (such as neuropsychologists, GPs, and clinical psychologists). This reflective stance fits well with counselling psychology practice, which places its emphasis on humanistic values, and rejects diagnosis that categories the client's experience in a generalised classification. These humanistic values are fundamentally important within pluralistic counselling psychology practice, and are reflected in the attitudes that practitioners bring to their work (Ashley, 2010). The individualised, client-led approach of CBT was often perceived as novel to the participants in this study, who were more familiar with the professional-led neuropsychological rehabilitation program. However, the importance of this client-led approach was highlighted by the current study as an integral part of the effectiveness of CBT, through reducing the power imbalance between the therapist and the client, thus promoting a stronger therapeutic relationship and working alliance. This suggests that practitioners in general could adopt this client-led approach to facilitate greater engagement with clients. Participants' appreciation of the process-based adaptations (such as providing a review of the previous session, clarifying their understanding of concept and simplifying home tasks), suggests that these are important for addressing their cognitive deficits. It is apparent that participants' positive experiences of CBT were attributed to the adaptation skills and coping strategies learned during therapy, not only for the immediate symptom reduction but also for the longer term ability to deal with the consequences of brain injury. Seemingly, this is consistent with the aim of CBT to facilitate autonomous and independent living in the context of neuropsychological rehabilitation.

One of the common hindrances therapists may experience when working with ABI clients is the issue of motivation. For instance, evidence suggests that depressed stroke clients are less likely to participate in rehabilitation programs, engage with less social and leisure activities, and make less progress with adaptation and adjustment due to their lack of motivation (Robinson, 2003; Lincoln & Flannaghan, 2003). Clients with stroke may have enduring physical impairments and psychological challenges which require a degree of This demands high levels of continued motivation for self-care and management. sustaining changes by engaging with the use of adaptation and adjustment during the recovery process. Motivation is a state of readiness and keenness to change. A type of CBT technique is motivational interviewing (MI) which was originally used for clients with addictions. More recently, it has been successfully employed with a wide range of populations characterised by poor motivation for behavioural changes (Miller & Rollnick, 2002). MI is a talk-based therapy which aims to help clients in identifying thoughts or behaviours that may be preventing them from achieving an optimal management of a chronic condition. As Watkins et al. (2003) suggest, MI can be a particularly useful tool for facilitating improvements in clients' mood three months after their stroke. Also MI can be helpful for addressing the issue of resistance to change, clarifying ambivalence, eliciting self-motivating statements and assessing readiness to change (Miller & Rollnick, 2002).

Finally, it is important for the therapist to recognise whether or not the client is ready for therapy, especially as ABI clients' motivation levels can change over time during their recovery journey. Although participants from the present study were positive about CBT, they also described their experiences of CBT as 'rocky', 'scary' and 'daunting' at times. The participants' efforts and determination played a crucial part in their continuously engagement with therapy. It would seem vital to assess the clients' readiness for treatment, and their ability to deal with the possible short-term increase in emotion distress, due to the possible increase of self-awareness about the consequence of brain injury resulting from therapy. Therefore, it may be helpful for the practitioners to focus more on the assessment of when would be the appropriate time to introduce therapeutic or psychological interventions during the client's rehabilitation process.

The current study illustrates the process-based adaptations that can be made within CBT for treating ABI clients, with the aim of improving engagement and enhancing the therapeutic process, which may increase the effectiveness of CBT with brain injury client

groups, by addressing and considering a wide range of diversity needs in different contexts. A summary of these adaptations is presented below in Figure. 1.

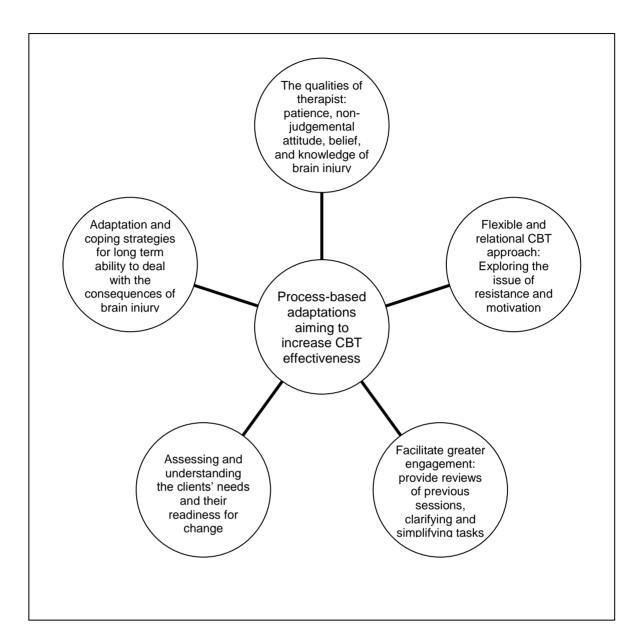


Figure. 1. A summary of process-based adaptations to CBT for ABI clients

#### 5.5 The Role of Counselling Psychologists

Participants in this study valued therapists who demonstrated empathy, respect, and validation towards participants' difficulties, as well as having an understanding of their brain injury. These aspects can be facilitated by counselling psychologists' relational and humanistic approach, which is underpinned by the profession's philosophy and principles (Cooper, 2009). As a counselling psychologist trainee, I place an emphasis on understanding clients' social contexts, ranging from micro (e.g. the family) to macro (e.g.

the socio-political structures). I believe I gain a better understanding of clients' difficulties by demonstrating my interest, engaging with Socratic questioning, and active listening rather than making premature assumptions and judgements. My willingness to embrace individual differences, engage with human experiences, and work collaboratively with clients underpin my therapeutic work. The counselling psychology ethos informs my practice which attends heavily to the therapeutic process through the adoption of a reflective stance. The integration of this position into CBT would further enhance the robustness of its theory development and clinical practice (Fairfax, 2008), which would contribute to the delivery of CBT with ABI clients.

My therapeutic work adopts a relational approach that challenges 'psychopathology', and validates brain injury clients' subjective experiences and sufferings. This approach values meaning making and focuses on their 'wellbeing', rather than following the traditional medical model that places an emphasis on the 'magical cure'. As a counselling psychologist trainee working within a multidisciplinary team, I inevitably encounter challenges relating to the fundamental differences between the social healthcare approaches to conceptualising the clients' difficulties. This may sometimes lead to both myself and/or my clients' experiencing misunderstandings over the issues of treatment. I believe that the role of counselling psychologists involves helping to reduce or prevent these misunderstandings by taking on an educator role, providing evidence-based information and therapeutic approaches to explain different aspects of the clients' rehabilitation goals from 'the pursuit of absolute cure' to 'managing and maintaining well-being'.

I hope that findings from this study will have an impact on influencing the clinical practice and professional training in the context of neuropsychological rehabilitation. Indeed, in the context of brain injury, with the additional burden of low motivation and the issue of loss, practitioners' ability to empathise and validate ABI clients' suffering is essential. As such, it is hoped that this study will encourage discourse about 'what constitutes helpful adaptations' among practitioners who work with ABI client groups. Furthermore, it is also hoped that the findings of this study will encourage discourse within institutions, organisations and healthcare policymakers, and thus increase awareness that specialist skills and training are important and very much needed for practitioners who work with ABI clients.

### 5.6 Accessibility and Applicability of CBT for ABI Clients

'Equality Legislation' (IAPT, 2011), stated within the 'Improving Access to Psychological Therapies' (IAPT) website, outlines the importance of promoting diversity and reducing health inequality across 'protected characteristics', which include age, disability, gender, sexuality, religious and race. Although there is growing literature on the effectiveness of CBT for ABI clients, reduced level of cognitive functioning remains a significant factor that affects the accessibility to CBT for people with neurological disorders, including stroke and head injury (Rossiter & Holmes, 2013). This is possibly the reason why CBT is not widely available to clients with brain injury in the context of neuropsychological rehabilitation. The participants in this study accessed CBT free of charge from a charity organisation instead of through the NHS. This charity provides CBT delivered by volunteer trainee counselling psychologists, who are currently undertaking their Professional Doctorate in Counselling Psychology course. Despite the need for psychological service for ABI client groups being identified, it appears that there is still limited access to psychological service for people with complex and diverse needs, within the provision of the NHS. Seemingly, the NHS may need to expand its service by providing psychological services to clients with cognitive limitations, in order to address the issue of diversity and to further promote health equality. Consequently, specific training and support for health practitioners to work with these vulnerable client groups would be required in order to address the issues.

## 6. Conclusion

The present study supports psychotherapeutic interventions and process-based adaptations to CBT. Conceivably, the findings will enhance practitioners' understandings of how the impact of the therapeutic process issues could affect ABI clients' engagement and therapeutic outcome. This study provides further evidence that CBT is suitable for people with brain injury, and more so when it is adapted to meet individual needs. Importantly, the clinical implications of the findings suggest that having appropriately trained practitioners is important for the clients' experiences of CBT. This implies a need for therapists to acquire specialist professional skills and knowledge of brain injury. This may reduce the barrier to delivering CBT for the ABI client group, and thus improve the

accessibility and applicability of psychological treatment in the field of neuropsychological rehabilitation.

From a therapeutic point of view, the complexity of working with brain injury clients requires an integrative approach that can appropriately respond to the needs of each client. Likewise, counselling psychology takes a critical stance against the 'one size fits all' approach, and adopts a pluralistic stance which enables counselling psychologists to manage different perspectives within multidisciplinary teams. Furthermore, counselling psychologists make a particular contribution to therapeutic work through recognising and incorporating the therapeutic relationship using a relational approach that values subjective experiences. One of their commitments is to pay attention to social context, and to demonstrate high standards of anti-discriminatory practice (Division of Counselling Psychology, 2005). The main tasks for counselling psychologists in the context of this study are twofold: first, to further develop CBT models that account for the variations in the experiences of brain injury clients with a lasting treatment effect. Secondly, to develop the adaptation of CBT with therapeutic interventions that can sensitively address and ameliorate the range of suffering associated with the consequences of brain injury. If the consequence of brain injury cannot be reversed then the significant questions for each individual client become, 'how can I live a valued and meaningful life in the presence of the consequence of my brain injury?', and 'how can I make the most of my residue functioning?'.

There is a significant potential and opportunity for interdisciplinary collaboration and learning between neuropsychology, clinical psychology and counselling psychology, which would surely benefit all the practices. As counselling psychology expands its thinking out of the consulting room by considering the concepts of neuroscience, and as neuropsychology and clinical psychology embrace new philosophies of working with the possibilities and complexities of human experiences, this further enhances our work in the context of neuropsychological rehabilitation.

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# 8. Appendices

# 8.1 Appendix 1 – Sample of Annotated Transcripts for PPJ01

I: Interviewer / R: Respondent

Emergent themes			Original Transcript	Exploratory comments
	19	<u>R</u>	Now I had been offered CBT with Headway. I get a bit muddled about how	
	20		the timeline went, but he was very pleased when I said that Headway had	
Invisibility of cognitive	21		Referred me anyway, but it turned out that somewhere along the line I'd said	Treatment resistance or
difficulties	22		that I was feeling fine, so my referral had sort of been dropped, or not dropped	Simply down to memory
	23		but put back because there wasn't any point, because I'd said I didn't want to.	Deficit?
Consideration	24	I:	Okay Hm Right	
of treatment options	25	R:	e back to see the staff at Headway, they said that I'd said	Memory issues?
Decision making process of	26		that I didn't want to go or didn't feel I needed to go anymore, and I didn't	Can't remember the incident
Seeking psychological	27		recollect that at all. I had no remembrance of saying that. So I said was it	Referral
intervention	28		possible that I could be re-referred, because my GP said it would be much	Where can offer CBT service
	29		f Headway could do it than for him to refer me with that, and he was	Quicker, long waiting list at
	30		very happy that it would be used in conjunction with medication with that, so	GP practice, maybe?
	31		he was very supportive on that.	
	32	ï	Okay, so how do you feel about being referred to CBT?	
Wanting to get better	33	꼾	At that point anything that I could do to help me get into a better frame of	Desperate to get help
	34		mind was useful. I didn't want to be reliant just on medication. That was the	What's her believe about
	35		thinking behind it.	Medication?
	36	I:	Right and at that point did you know anything about CBT?	
Psycho-education to inform	37	꼾	I knew a little bit. I did a bit of research as well, to have a look as to what to	Making effort of researching
expectation	38		possibly expect, which didn't put me off at all with that, and then I was	What is the expectation of

## I: Interviewer / R: Respondent

	39		Looking forward to coming.	Therapy? What the therapist
	40	I:	Okay right So reflecting to your experience, can you tell me what it was	may do and what I may need
	41		like for you to have CBT as somebody with brain injury? Now I'm interested	to do.
	42		in your experience and would you tell me more about your experience of	
	43		having CBT?	
Strategies to address	44	R:	Well one of the problems that I have is short term memory, so I was concerned	Speculating the problem she
memory deficit	45		and apprehensive before coming that I wouldn't remember what we'd	May experience during therapy
H/work, hangout & reminder	46		discussed. In fact that hasn't been too much of a problem because I've been	Because of her memory issue
Adjustment, adaptation	47		given homework to do, and it's been written down for me so I didn't have to	Homework sounds like a good
Acquisition of skills and	48		remember, although I have used my strategies which I've been given to help	Thing for her, strategies being
strategies	49		me remember by setting alarms on my diary to remind me to do the	Put into place right away.
	20		homework, because otherwise I would forget.	
	51	I:	So you've mentioned about homework tasks. How do you feel about homework?	She seemed to think of
Homework as continuity	52	<b>R</b> :	Well homework's not been anything too difficult. It sounds terrible, it sounds	Homework as a facilitator,
Between sessions	53		like going back to school but it's not at all. It's just a follow on from whatever	Promoting positive outcome of
	54		we've been discussing, and the homework's been enjoyable and it's helped me	Therapy rather than a
	55		get more from the therapy.	hindrance
	99	I:	How does it help you?	
Consistency in practice and	57	R:	Well one of the things was to bring a stone in, which I now use on a regular	Sounds like mindfulness
Application of therapeutic	58		basis when I'm feeling anxious. I can either physically get the stone out and I	Approach, meditation and
techniques	59		can hold it or look at it, or I can imagine it, and it helps to bring me to a quieter	Breathing exercise are quite
	9		place and calm me down. Ive been given breathing exercises as well to help	Difficult to do in a regular
	61		with anxiety, and I use those as much as I need to, and they do help as well.	Basic? She seemed to manage

#### 8.2 Appendix 2 – Initial Emergent Themes for PPJ01

Self-awareness and unawareness of Psychological symptoms after brain injury

Informed choice of treatment options

Invisibility of cognitive difficulties

Consideration of treatment options

Decision making process of seeking psychological intervention

Wanting to get better

Psycho-education to inform expectation

Strategies to address memory deficit

Homework, hangout and reminder

Adjustment, adaptation

Acquisition of skills and strategies

Homework as continuity between sessions

Consistency in practice and application of therapeutic techniques

Conscious awareness of the consequences of brain injury

Adaptation to memory aids

Negative aspect of brain injury

Negative perception by others

Lack of knowledge and understanding about cognitive difficulties by others

Cognitive restructuring

Negative thinking pattern

Re-gained a sense of control and confidence

An increased sense of acceptance

Acknowledged her limitations

Acceptance of new, post-injury self

Managing expectation of self

Setting realistic goal

Client's engagement level, responsibility for treatment

Client's stage of recovery

Client's level of cognitive functioning and readiness for change

Unaware of the impact of brain Injury had on my life

Awareness/ unawareness of neurological symptoms, such as cognitive deficits after brain

injury

Equal collaboration and participation

Client's motivation and engagement levels

Possible increase of emotional distress during therapy

Connection of emotion and thought

Readiness for therapy

Acknowledging the problems for psychological or neurological issues

Reliant on significant others

Individual differences

Standardised procedure would not work

An increase of self-confidence

An increase of acceptance

Accepting new sense of self

Transformation of self after brain injury

Individualised intervention

Personal interest for creating meaningful task

Encouragement as important

Goal orientated approach

Client-led goals

Structured nature of CBT

Outcome measure

The importance of engagement and motivation

Realisation of the impact about brain injury

Lengthy and slow process in realisation of problems

Normalisation, shared understanding of the consequences of brain injury

Empathic understanding of experience

Adaptation to address memory, distraction, noise issues

Therapist's understanding of brain injury and its impact on recovery

Therapist's characteristic and knowledge of brain injury

Therapeutic alliance

Flexibility and adapting individual therapeutic needs

Tailored approach as a way forward for clients with brain injury

Acquired coping skills and Learned strategies

Adjustment in life

The use of memory aids to promote therapeutic process

Equal participation during therapy

Application of strategies

Perspective taking

Cognitive reframing

Meaningful and relevant task working alliance promote therapeutic alliance

Therapeutic relationship

Trust worthy relationship

Emotionally, cognitively and physically drained after therapy

Concentration span Length of session

Adaptation to therapy

Clarification of client's understanding without any assumptions

Monitoring client's responses during therapy

Invisibility of cognitive difficulties

Misconception of brain injury client ability

Overestimate cognitive ability to understand

Underestimate the problems brain injury clients face

Re-gained a sense of control

Re-gained a sense of new self, control and confidence

CBT as a useful form of therapy

Raise therapists' awareness of individualised CBT as important

## **8.3** Appendix 3 – Table of Clustered Themes for PPJ01

Suj	per-ordinate The	eme 1: Professional relationship
Sub-theme	Page/Line Number	Themes
At the rock	2, 27-28	Consideration of treatment options
bottom point where anything may help	2, 33-35	Wanting to get better
	5, 116-119	Managing expectation of self
	5, 124-127	Client's engagement level, responsibility for treatment
	5, 127-128	
	5, 133-134	Client's stage of recovery
	6, 156-158	Client's level of cognitive functioning
		Client's motivation and engagement levels
	7, 185-187	Acknowledging the problems for psychological or neurological issues
Understanding	9, 232-234	Encouragement as important
me and my brain injury	11, 287-292	Normalisation, shared understanding of the consequences of brain injury
	11, 294-295	Empathic understanding of experience
	12, 315-318	Therapist's understanding of brain injury and its impact on recovery
	12, 327-332	Therapist's characteristic and knowledge of brain injury
	12, 334-336	Therapeutic alliance
	15-16, 422-424	Therapeutic relationship
	19, 532-534	Raise therapists' awareness of individualised CBT as important
Confidentiality	16, 428, 430-435	Trust worthy relationship
and trust	18, 504-506	Trust
	15, 422-423	Trust your therapist

Supe	er-ordinate Then	ne 2: Understanding my struggles
Sub-theme	Page/Line Number	Themes
Adaptation and	3, 64-70	Adaptation to memory aids
flexibility to therapy	5, 114-116	Setting realistic goal
approach	8, 199	Individual differences
	8, 197-198	Standardised procedure would not work
	9, 222-225	Individualised intervention
	9, 242-244	Client-led goals
	12-13, 336-340	Flexibility and adapting individual therapeutic needs
	13, 349-356	Tailored approach as a way forward for clients with brain injury
	15, 418-421	Meaningful and relevant task working alliance promote therapeutic alliance
	16, 436-440	Emotionally, cognitively and physically drained after therapy
	18, 483-490	Adaptation to therapy
Learning new skills to cope	2-3, 46-50	Adjustment, adaptation, Acquisition of skills and strategies
	11, 297-301	Adaptation to address memory, distraction, noise issues
	14, 368-370	Acquired coping skills and Learned strategies
	14, 369-371	Adjustment in life
	14, 376-381	The use of memory aids to promote therapeutic process
	15, 396-399	Application of strategies
Looking	2, 37-39	Psycho-education to inform expectation
forward to sessions after knowing what CBT is	6, 153-155	Equal collaboration and participation
	9, 236-238	Goal orientated approach
	9, 247-249	Outcome measure
	14, 384-387	Equal participation during therapy
	19, 521-522	CBT as a useful form of therapy

	Super-ordina	ate Theme 3: Acceptance
Sub-theme	Page/Line Number	Themes
Who am I after brain injury	4, 80-84	Lack of knowledge and understanding about cognitive difficulties by others
	8, 211-214	Transformation of self after brain injury
	10, 277-278	Realisation of the impact about brain injury
	11, 281-283	Lengthy and slow process in realisation of problems
	18, 498-502	1
	·	Invisibility of cognitive difficulties
Re-gaining a sense of control, self-esteem and confidence	4, 95-100 18-19, 510-511	Re-gained a sense of control and confidence
Learning to know myself	4, 102-103	An increased sense of acceptance
and believe in future	4, 105-106	Acceptance of new, post-injury self
	8, 204-207 19, 513-519	An increase of acceptance and new sense of self

# **8.4 Appendix 4 - Master Table of Themes Across Cases**

# Table of Super-ordinate Themes and Sub-themes for all participants

<b>Super-ordinate</b>	Sub-themes	Key words	Page
Themes			Line
Professional	At the rock bottom point where		
relationship	anything may help.		
	PPJ: At that point anything that I	Desperate for	2, 33-34
	could do to help me get into a better	getting better	
	frame of mind was useful. I didn't		
	want to be reliant just on		
	medication.		
	DD: It was because I had no	Needed something	1, 6-8
	motivation and I just couldn't be	else	
	bothered to do anything, so I just		
	sort of coasted, so I needed		
	something to put a bit more oomph		
	into me so that I could carry on		
	getting better.		
	SM: I've been depressed for a long	Getting worse, need	1, 7-8
	time and after having a stroke made	help	
	it a lot worse, and I just really		
	needed help.		
	PC: You can become a prisoner, I	Despair, loss of	2, 30-32
	thought well how can I move on	freedom,unbearable	
	from this? Could anything else	pain, need to	
	happen to me, and I got depressed	change	
	and that's when I seeked help. That		
	was at rock bottom really.		
	JR: Well I think I have got a place in	Loneliness,	3, 58-61
	a mind that was very lonely. I	isolation, alienation	
	thought I will be the only person	Depressive	
	that had a stroke. I would go into a	Splitting sense-of-	
	room and nobody would talk to me.	self	
	I almost felt a bit of nothingness. I		
	was a bit sad and a bit sad really.		

person, you know?	
AD: It's believed that I had some Get worse, 1,	, 13-15
brain damage in the front of my helplessness	
brain. It made the depression a lot	
worse and my anxiety a lot worse. I	
basically couldn't pull myself out of	
the depression.	
Understanding me and my brain	
injury.	
PPJ: With the prompting I can be Prompt, reminder. 12	2, 324-
reminded and then it will start to 32	25
come back.	
PPJ: So they have the patience to go Therapist's patience 12	2, 329-
through it before they move onto the to take thing slowly 33	32
next thing, to make sure that you've Clarification, check	
understood what you've done and to understanding	
check that you've got something out	
of it as well.	
DD: For me, it wouldn't have	3, 365-
worked, because I'd feel that I was Strong, directive, 35	59
the therapist to the therapist if they straight down to	
were a bit weak and fragile. You business	
have to have someone that is	
confident and open and chatty, and	
that knows their subjects and get the	
job done.	
SM: Somebody finally listened of	
how you was feeling, how you've Active listening	
been feeling, not just that day but	
before that day, which nobody's	
done before.	
SM: Because my therapist didn't Non-judgemental 2,	, 40-41
make me feel silly, and it felt you manner, repeated	
know, by showing me more just practice	

helped really.		
JR: So my GP referral therapist, we	Insider, outsider	5, 110-
had a different kind of relationship		111
because she was very much a		
stranger on the outside looking in.		
JR: The GP referral and the	Strangers, familiar	11, 287-
therapist, she had no knowledge of	Ignorance of brain	289
my head injury And that wasn't	injury consequence	11, 296-
very much, so to speak. And she		299, 301-
quite honestly didn't want to know		302
about my brain injury.		
JR: But my other therapist knew	Knowledge,	11, 306-
about my head injury, we talked	engagement	307
about it. I found I could tell as much		
as I know. I just felt very		
comfortable.		
AD: The fact that my therapist had	Essential to have	7, 181-
an understanding of brain injury	brain injury	182
was important because otherwise I	knowledge	
might not follow.		
Confidentiality and trust		
PPJ: You have to have a good	Relationship and	15-16,
relationship with your therapist and	trust	422-424
trust, because otherwise they're not		
going to be able to bring out the best		
in you if you don't feel that you can		
trust each other. Trust is very		
important.		
DD: Because straightaway when I	Confidentiality	3, 66-70
was informed that whatever I said	Encouragement to	
within these four walls was	engage	
completely personal, disregarding	Concerns for group	
the organization it was associated	discussion of	
with. It was between me and my	personal issues	
l	L	l

	therapist, full stop, so that		
	encouraged me as well, because I		
	thought that there might be some		
	link as they are all worker, they all		
	colleagues might discuss things		
	behind the scenes.		
	SM: Very important that the person	Confidentiality	9, 233-
	you're talking to, you can trust and	Trust	235
	they're not going to tell the world		
	that whatever you say, you know		
	that's going to stay with them.		
	PC: I think confidentiality is	Persona	5, 111-
	important because you do open up	engagement	112
	to these people in your therapy.		
	JR: You have to have you build up	Intimate therapeutic	9-10,
	a certain trust. You know? You have	relationship	255-257
	to trust the person to do this with		
	your innermost thought and your		
	anxiety and the way you behave.		
	AD: And if you don't trust that	Emotional	8, 200-
	person or if you feel that that person	engagement	201
	isn't supportive then you wouldn't		
	open yourself up to that person.		
Understanding	Adaptation and flexibility to		
my struggles	therapy approach.		
	PPJ: It's good to have somebody	Memory limitation	12, 320-
	that they know that they need to go	to follow therapy	324
	back over it to make sure that I did	content	
	understand what we did last time.		
	Because each time I come into a		
	session, I try and remember what		
	we've done, and on the whole I can't		
	remember clearly.		

PPJ: I do know that one or two	Flexibility about	13, 337-
sessions we've had, because it's	time of session	339
opened up a lot of things, my	Be more human	
therapist is flexible enough to give		
me more time to discover and		
discuss those rather than just		
chopping off short, like when my		
time's up.		
DD: I didn't want somebody else	Very intrusive and	8, 210-
reading and questioning and	controlling	211
arguing about what I'd done, and		
why I'd put things a certain way.		
DD: Discussion and we would do	Negotiation with	8, 213-
them within the session rather than	therapist	214
have paperwork based homework.		
SM: Because it's not so full on, all	Not so full on,	10, 275-
in one go, so you can take longer to	taking more time to	276
go through things, and it's perhaps	adapt conditions	
easier to explain if you take it over		
longer.		
JR: But she used to she always if	Information	12, 336-
there is a piece of writing and then	processing	339
there is a check. I would read it		
back, what she had written, so I		
could get it in my head what was		
said. Then it made more and more		
sense.		
AD: My therapist encouraged me to	Encouragement to	4, 86-90
try to only do a little bit of first	use strategies	
then once I did that to build on it.	Break it down to	
My therapist encouraged me to take	smaller step	
small steps and then from there and		
not to be hard on myself for only		
taking small steps.		
AD: My therapist wrote down things	Adaptation to	6, 164

for me and my therapist also gave	therapy	
me photocopies.		
Learning new skills to cope.		
PPJ: I've been working on it for a	Change ways of	14, 368-
long time with help through	doing things	370
rehabilitation, so it's given me the		
strategies to be aware that I need to		
concentrate, I need to remind myself		
to do things to get the benefit out of		
it.		
DD: Just because I'm in a	Meaning of being	9, 233-
wheelchair doesn't mean that I can't	disable	235
achieve more things in life than	My own enemy	
what I already have, so it was just		
getting past, I was my own worst		
enemy really and it was just getting		
past that.		
SM: Because since my stroke you	Cognitive	10, 281-
get frustrated because you can't	impairment	282
always think straightaway. You've		
got to have the time to think about		
it.'		
SM: 'If you're not sure it's difficult	Seek clarification	7, 190
to ask, but if you don't ask you		
won't do it.		
PC: Well it makes me realise we're	Realization of one's	6, 149-
all vulnerable as human beings.	limit	150
That's what the stroke made me		
realise.		
JR: Because I want to do it for me	Choice to make	16-17,
you have to do the tasks. In order to	decision	447- 453
gain something, you have to put		
your input into it.		
AD: It was emotional because I feel	Emotional	10, 277-

as though I was mourning and I	difficulties involved	280
continued to mourn the person I was		
before versus the person I am now.		
Looking forward to sessions after		
knowing what CBT is.		
PPJ: I knew a little bit. I did a bit of	Research into CBT	2, 37-39
research as well, to have a look as	Expectation	
to what to possibly expect, which		
didn't put me off at all with that, and		
then I was looking forward to		
coming.		
DD: It was a little bit daunting	Unknown of what	2, 37
because it was going into the	happen in therapy	2, 42
unknown		
DD: After the first session you kind		
of look forward to the next one.		
SM: I hadn't heard about it before,	Previous	1, 14, 16-
no. It sounded a lot different. I'd	counselling don't	18
tried counselling over many years at	work, try something different	
different points and it just didn't		
work, so I was hoping trying		
something completely different		
would work, well help.		
PC: No I hadn't, but obviously you	W. 1 6 .1	2 20 42
start to speak to people who've been	Word of mouth	2, 39-42
through strokes, and these people		
who've had strokes and you know		
it's not uncommon a few people I		
knew had help.		
JR: Well it's because at first I didn't		
know what this cognitive behaviour	Introduced by	1 0 12
therapy was. It wasn't until I went to	organization, sound	1, 9-13
Headway and they explained the	interesting and try it out	
difference to me, all about people		
		115

	and the way they think I just		
	thought it could benefit me because I		
	was feeling very low.		
	AD: Yes, I heard about it before I		1 21 22
	had read self-help books before.	Previous knowledge of CBT	1, 21-23
Acceptance	Who am I after brain injury.		
	PPJ: One of the things that I've had	Executive	4, 80-82
	real problems with is organizing	functioning	
	anything since the brain injury, so	Accusation	
	tasks are difficult, and you		
	sometimes get accused of being lazy		
	when it's not.		
	DD: I can't move one half of my	Physical disabilities	12, 327-
	body, and that for me is major,	Career change	329
	because then it means that I can't go	Identity change	
	back to work, because being a		
	therapist I would need both hands to		
	actually do my work.		
	PC: Well it makes me realise we're	Realization	6, 149-
	all vulnerable as human beings.	Pre-injury self	154
	That's what the stroke made me	Post-injury self	
	realise. Before the stroke I was a	Vulnerability	
	strong man emotionally I thought,	Need help what	
	and physically. Well after the stroke	kind	
	was finished with me I was		
	physically not strong, emotionally		
	weak so it makes you realise how		
	vulnerable we are as human beings		
	and we all need help.		
	JR: I thought I will be the only	Socially excluded	3, 58-60
	person that had a stroke. I would go	Empty existence	
	into a room and nobody would talk		
	to me. I almost felt a bit of		
	nothingness.		

	T	44.00
AD: I think well I think because it	Who am I	11, 285-
was a loss, because I was mourning	Existential issue	288
a loss of who I was who I am	Negative	
who I was the temptation is to	assumption	
assume that you have lost		
everything.		
Re-gaining a sense of control, self-		
esteem and confidence.		
PPJ: It's given me more confidence	Re-gained	4, 95-98
in myself with going through the	confidence and a	
therapy, because it's shown me the	sense of positivity	
way forward, and how if you don't	about the future	
push yourself to do something new,		
you're never going to find out what		
your capabilities are.		
DD: I think it's helped emotionally.	Made a conscious	9, 252-
Not much with the physical, but	decision to	255
emotionally it's helped a great deal	overcome social	
because I've made decisions and	anxiety	
stuck to them and done something,		
whereas before I wouldn't go out on		
my own, whereas now as long as		
I've been there once, it's not so		
much of an issue, so it's helped		
along the way.		
SM: I feel more comfortable around	Gained some	5, 127-
people and I still get low days but I	coping strategies to	128
know how to handle low days, which	deal with low days	
I couldn't have done before.		
PC: So it gives you a different way	Different	3, 76-77
of looking at things and coping I	perspectives	
guess, which helps with depression.		
JR: I learned that through my day to	More balance views	4, 108-
day life I could manage them, I		109
	1	

could learn to cope.		
AD: CBT reminded me that I didn't	Lose	11, 290
necessarily lose everything.		
Learning to know myself and		
believe in future.		
PPJ: it's given me more confidence	Self confidence	8, 204-
in myself. It's reminded me that it's	Acceptance the	207
okay to be the way I am now and to	present self	
stop thinking back to how I was	1	
before, sort of benchmarking myself		
against myself isn't a happy way to		
be.		
DD: I've got up and done things	Drawing upon pre-	10, 260-
before and I'm the same person, so	injury self's	263
what's the difference now? Just	strength to conquer	203
because I can't get up and jump in	post-injury	
my car and drive to where I want o	challenge	
	chanenge	
go, I have to be escorted there in my		
chair, but I had to get over it and I		
did, and I'm thankful that I did.	E1	12 262
SM: Learned to know me. I started		13, 362-
to like me, which I didn't like me at	Acceptance of self	363
all. But doing the sessions has		
really changed the way I think about		
me.		
PC: I thought I had accepted but I	Reluctant to accept	4, 93-95
was told I hadn't and I don't think,	Come to terms and	
to be honest I never will. Just come	deal with	
to terms with it and realise our	limitations	
limitations in life and accept them		
really.		
JR: I don't at the moment feel sad or	Reduced depressive	15, 404-
miserable or want to get rid of	mood and see	405
myself or fall into a hole	future	
		I

somewhere. I can see some future.		
AD: I needed to get out and focus on	Sick role	2, 49-50
the positive aspects and not think	Positive aspects	
about myself as being a sick person.		

# 8.5 Appendix 5 – An Example of Reflective Diary

Initial reflections after each interview:

## **Interview with PPJ01**

Very positive experience about CBT, PPJ seemed to learn and gain a lot from it. Her main concern about having CBT was her memory deficits, and managed to find ways to compensate her weaknesses by working together with her therapist, using strategies to help her engagement. I felt I had to remind her of what we said during the interview, and prompted her with the issue we discussed. By giving her a mini summary, seemed to help her to expand on her points when articulating her experiences of CBT. I felt she tried very hard to think about the answer during our interview, I thought it might have been tiring for her in thinking and talking in general after her brain injury. Overall I felt that the interview went well. However, at some points during the interview, there had been some background noise, I wondered if that had an effect on her, making it more difficult to think or need more concentration to answer my questions.

### **Interview with DD02**

What struck me the most was the relaxed approach DD adopted during the interview, her friendly but straight to the point attitude had mixed effect on me and the interview. It kind of helped me to engage with her, however there had been times that I felt stuck and not sure what to say or ask. My anxiety might hinder the quality of this interview, as I would have slowed down and took my time in thinking about my next question. Generally, her experiences of CBT seemed to be positive, helped her to conquer her social anxiety. In the last part of interview, she mentioned about the importance of therapist's personality as an important issue to clients' engagements, I wondered if it reflected on my part, trying to show her that I was a competent researcher and knew what I was doing. There had been some nervous laughter between us when talking about therapist and client's personality and how it impacted on her experiences of having CBT. Interesting thought...

#### **Interview with SM03**

This interview shed light on the issue about pre and post injury mental health history, CBT seemed to help her dealing with her chronic depression. Again it seemed to be a positive experience for her, however she appeared to highlight that CBT did not cure her depression, but to help her dealing with it in a more helpful way. Did not seem like standardised CBT, sounded like 'mindfulness approach' she was referring to based on her

narrative. During the interview process, I felt we engaged well with each other, and I learned from previous interviews, I prepared to ask more of therapeutic questions, slowed down and took my time in thinking, putting my counselling hat on by elaborating on the meanings. What and how questions were used more during the interview, as I felt that I relied less rigidly on the research questions but being more in the moment with the participant. At point, SM seemed to have difficulties explaining how she felt and what it meant.. wondered if that's something to do with her cognitive limitation. I just reassured her and it seemed okay to go back to the previous questions.

## **Interview with PC04**

This interview centred around the issue of stigma attached to therapy and what it meant for him to have a stroke. The rehab team's home visit seemed to be very clinical, only focused of box ticking exercises and asking questions about memory, cognitive processes, concentration, category by category, which in turn might make him feel even worse during the early stage of recovery. And this particular experience might affect his view on health professionals too. This interview certainly provoked a great sense of helplessness for me, imprisonment caused by disability and the uncertainty nature of having seizure made the whole experience of having stroke scary. He seemed to be able to articulate his experiences of CBT as somewhat helpful and needed, however, some difficulties in answering questions about how CBT actually helped in term of dealing with the issue of acceptance. Consequence of brain injury changed his social context, self perception and life view.

#### **Interview with JR05**

Towards the end of the interview, I felt her tiredness after talking and thinking for almost 45 minutes. This reflected on what brain injury clients had to live with in their everyday life. I felt grateful that she kept trying to articulate and share her experience of CBT with me. She vividly compared her experiences of CBT delivered by different health contexts, it seemed that it affected the therapeutic outcome profoundly, as she wouldn't open up to strangers, or outsiders (therapist referred by GP). I felt the interview went well, and she engaged well with me too, might be she viewed me as an insider because of my placement at the organisation as a trainee. Although there were times that I re-phased the questions, trying to get more in-depth understanding of her experiences. I felt I had to work hard with her by helping her out to get the words out, it might reflect on how she worked collaboratively with her therapists. It's been a rewarding experience for me to gain her perspective of what it was liked for her to experience CBT. Very interesting.. after the

interview I actually felt physically tired myself. Again seemed to be a positive experience for her.

### **Interview with AD06**

Very good point about how to improve CBT by focusing on more the positive aspect of human experiences, rather than just placing the emphasis on the negative aspect of distorted thoughts. Identifying client's thought as distorted seemed somewhat too clinical, and sounded very judgemental too. I found it difficult to engage with this interview at point and I felt that I reassured her when she felt she lost her train of thoughts or did not understand the question. It felt like hard work for both of us to get the word out due to her brain injury, it must have been tough for her to do this interview, or perhaps the CBT treatment too. However, she seemed to describe her experience of CBT as helpful. Although it's been a difficult interview for me, with few distractions like phone call and her baby's present, (not sure if the interview would have been better without these distractions) I felt that it still added something to my data.

# **8.6** Appendix 6 – Demographics

How old are you?

How would you describe your nationality/ethnicity?

What is your marital status?

What is your current employment status?

When did you have a stroke?

# 8.7 Appendix 7 – Participant Recruitment

Research study of ABI clients' experiences of Cognitive Behavioral Therapy - **Seeking Participants** 

You could help make a difference to the Rehabilitation Service available for brain injury clients.

- O Would you be interested in participating in a research study of ABI clients' experiences of receiving CBT?
- O Have you attended Headway's in-house counselling service for CBT in the last 12 months?
- O Are you 18 years old or above?
- O Was your ABI caused by stroke?
- O Are you proficient in the use of English language?
- O Did your neurological assessment indicate a high level of cognitive functioning?

My name is Theresa Cheng and I am a trainee Counselling Psychologist with an interest in the provision of psychological therapy to clients with acquired brain injury. The aim of my research is to gain a better understanding of how ABI clients' experience CBT to see if this can help professionals develop and improve services currently provided for this important and under-research group.

If you are interested in speaking with me about your experiences of receiving CBT and the answer to all the above questions is "yes", I would be very interested in hearing from you.

Please contact me on: or via email:





the brain injury association

# 8.8 Appendix 8 – Information Sheet

# **Information Sheet**

Investigating Acquired Brain Injury clients' experiences of Cognitive Behavioural Therapy

Researcher: Theresa S. Y. Cheng

This study is being supervised by Dr. Mark Donati London Metropolitan University

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### Why have I been approached to participate in this study?

You have been approached to take part in this study because you have attended a course of Cognitive Behavioral Therapy (CBT) with the in-house counselling service at Headway. Before you make your decision, it is important for you to understand the nature and purpose of the study. Please read through the following information carefully, you may wish to discuss any concerns or queries with others, or you may request further information about the study from the researcher, Theresa Cheng. Take your time to decide whether or not you wish to take part.

### What is the reason for carrying out this research?

This research is being conducted by Theresa Cheng, a Trainee Counselling Psychologist, as part of a Professional Doctorate in Counselling Psychology at London Metropolitan University. The provision of psychological therapy for people with acquired brain injury is a developing area of treatment for this important group. However, to date not much research has been carried out in this area, with few studies that have asked ABI clients about their experiences of receiving common treatments such as Cognitive Behavioral Therapy. My hope is to provide a better understanding of ABI clients' experiences of using CBT, to improve our knowledge of what has been useful and identify if there have been any concerns for clients during the course of therapy. Findings could be used to inform future practice by adapting CBT to better meet the needs of ABI clients.

## What would participating in this study involve?

Participation in this study will involve taking part in an interview, which will last approximately an hour. The interview will be held at Headway Bedford in a meeting room and will be carried out by the researcher, Theresa Cheng. If you decide to take part, you will be given this information sheet for your records, and also you will be asked to sign a consent form before the interview. During the interview, the researcher will ask you some open-ended questions about your experiences of receiving the course of CBT, the interview will be audio recorded for the purpose of analysis.

### Do I have to participate in this study?

Participation is absolutely voluntary, and if you decide to participate it is your right to withdraw from the study, you will have up to seven days from the date of your interview to withdraw without giving any reason for doing do so. If you find any of the questions difficult or upsetting to discuss during the interview, you do not have to answer them, or give a reason for not answering. You will not be disadvantaged in any way if you decide to withdraw or chose not to answer particular questions.

### What will happen to the data from my interview?

All information obtained during the course of the interview (CD and transcript) will be kept strictly confidential, and will remain in the possession of the researcher. In order to protect your privacy, transcripts will not contain any identifying information. The data will be available to the research supervisor and academic staff for assessment purposes only. Audio recordings of the interview will be erased immediately after the research study has been assessed. Transcripts of the interview will be kept for a period of five years in case of publication, the research results may be published in peer reviewed journals and/or conference presentations, but only group patterns or themes in the interviews will be described and your identity will not be revealed.

#### What do I need to be aware of?

It is possible that participating in this study will bring up a range of feelings (positive and negative) for you, and you may feel uncomfortable when answering some of the questions during the interview. The researcher is aware of this possibility and will understand if you do not want to answer any particular question or wish to end the interview at any time. If you become distressed after the interview and would like additional support, the in-house counselling service at Headway will be available to you, if you wish.

Thank you for your time and assistance,

Theresa S. Y. Cheng, Trainee Counselling Psychologist -

# 8.9 Appendix 9 - Informed Consent

Researcher Signature

# **Informed Consent Form**

Investigating Acquired Brain Injury clients' experiences of Cognitive Behavioural Therapy

Researcher: Theresa S. Y. Cheng This study is being supervised by Dr. Mark Donati London Metropolitan University ..... To be completed by participant(s): I have read and understand the information sheet for this study. I understand that my interview with the researcher will be audio recorded. No identifying information will be associated with the audio recording or the transcript. Other individuals who will have access to the data will be thesis and academic tutors marking the study. I understand that the audio recording will be transcribed by the researcher, transcripts will be reproduced in whole as a written product, data obtained will be analyzed, and in part for the use of written content for the study. No identifying information will be used in presentations or in written products resulting from the study. I further understand that the researcher will keep the audio recording of my interview in a secure location and that it will be treated in a strictly confidential manner. I understand that the exception to maintaining confidentiality is where the researcher believes that anyone is in imminent risk of harm has been disclosed. In such a case the relevant statutory sector/body will be informed. I understand that audio recordings of my interview will be erased immediately after the study has been assessed and completed. Transcripts of the interview will be kept for a period of five years in case of publication and will then be destroyed. I understand that I can withdraw my consent to be audio recorded at any time during the interview and up to ..../.... (7 days after the schedule date of interview), and either the researcher (under ethical practice) and/or I will reserve the right to terminate the interview at any time if I become distressed, without any adverse consequences resulting for me. Under these conditions, I give my permission for my interview to be audio recorded. Participant Signature Date

Date

# 8.10 Appendix 10 - Debrief Sheet

# **Debrief Sheet**

Researcher: Theresa S. Y. Cheng
This study is being supervised by Dr. Mark Donati
London Metropolitan University

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Thank you for your participation!

If you have any concerns or queries regarding this research study, or if you wish to obtain a summary of the study findings, please do not hesitate to contact Theresa Cheng at London Metropolitan University via email:

If you have any concern or complaint about the study and the way you have been treated as a participant, you can contact the researcher supervisor Dr. Mark Donati at London Metropolitan University via email:

If participation has raised any concerns or issues that you wish to discuss further, you may want to consider some of the following options:

- contacting your key worker
- accessing the in-house counselling service at Headway
- using any number of the agencies listed below to obtain advice and support:
  - The Samaritans (24 hours telephone support service)
     0845 790 9090
  - Stroke Association0207 566 0300
  - o Brain Injury Rehabilitation Trust (BIRT)

01924 896100

Email: director@birt.co.uk

# 8.11 Appendix 11 – Distress Protocol

#### **Distress Protocol**

This protocol has been developed to deal with potential distress participants may experience during their involvement in the research process. During or after the interview, unpleasant feelings may be provoked in participants when sharing their experiences of attending CBT therapy. A three-step protocol is there to be followed by the researcher to monitor participants' emotions by using the specified signs of distress, and taking the specified action for the observed stage of distress. In the event of extreme distress, Headway protocols will be actioned by on-site health professionals. However, extreme distress protocol has been planned for to cover any unforeseen set of circumstances where Headway's professional services are not available at the time.

### Mild distress:

### Signs to look out for:

- 1) Tearfulness
- 2) Voice becomes unclear/difficult speaking
- 3) Participant becomes disengaging

#### Action to take:

- 1) Ask participant if they are happy to continue
- 2) Take a break
- 3) Remind them they can stop at any time they wish if they become too distressed

#### **Severe distress:**

#### Signs to look out for:

- 1) Uncontrolled crying, inability to talk coherently
- 2) Panic e.g. hyperventilation, shaking, heart palpitation and becoming tensed up
- 3) Intrusive thoughts of unpleasant events e.g. flashbacks

### Action to take:

1) The researcher will intervene to terminate the interview

- 2) The debrief will begin immediately
- 3) Controlled Breathing Technique will be suggested to participants
- 4) The researcher will acknowledge and validate participants' distress, and remind them that Headway's in-house counselling service is an available option for them.

### **Extreme distress:**

#### Signs to look out for:

- 1) Severe agitation and possible verbal or physical aggression
- 2) In very extreme cases possible emotional and nervous breakdown where the participant becomes devastated and disconnect with reality

#### Action to take:

- 1) Maintain safety of participant and researcher
- 2) If the researcher has concerns for the participant's or others' safety, she will inform the participant that she has a duty to care to inform relevant sectors, e.g. their GP, risk assessment team.
- 3) If the participant becomes unresponsive to immediate help, thus he/she displays violent physical and/or verbal behaviour, then the Police will be called and asked to use their powers under the Mental Health Act to restrain, and take him/her to a place of safety for pending psychiatric assessment. (This option would only be used in an extreme emergency and when Headway professionals are unavailable

# 8.12 Appendix 12 – Interview Schedule

# **Interview Schedule**

Investigating Acquired Brain Injury clients' experiences of Cognitive Behavioural Therapy

Researcher: Theresa S. Y. Cheng

This study is being supervised by Dr. Mark Donati London Metropolitan University

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The interview schedule for this study consists of the following open-ended questions:

 Can you tell me a little bit about your reasons for seeking psychological therapy?

Possible prompt: how did you feel about the prospect of having CBT?

• Reflecting to your experience, can you tell me what it was liked for you to have CBT as somebody with brain injury, I am interested in your experience, and would you tell me more about your experience of having CBT?

Possible prompts: therapeutic relationship, homework assignment, therapeutic goals, level of motivation and engagement?

 How do you think having acquired brain injury may affect your experience of having CBT?

Possible prompts: how did you overcome that? how did your therapist help to make it easier for you? and in what ways?

# 8.13 Appendix 13 - Collaborating Organisation Approval

### LONDON METROPOLITAN UNIVERSITY Department of Psychology - Counselling Psychology RESEARCH PROPOSAL

#### COLLABORATING ORGANISATION APPROVAL

(To be complet	ed when	the student's	research	involves	the	collabo	ration of
		another or	ganisation	n)			

Student Number Student Name Theresa S. Y. Cheng

Student Contact Tel. No.

Headway Bedford Collaborating Organisation (name)

> Bedford Health Village, (address)

Kimbolton Road. Bedford MK40 2NT

Contact/Lialson Person in Collaborating Organisation.

Samantha Booth Tel. No.

I, the undersigned, have given permission to the above named student to carry out fieldwork for their research. I have been fully briefed as to the nature of the project and the requirements for obtaining a suitable sample, administration of questionnaires, conducting Interviews, or other appropriate means of data collection, and agree this can be undertaken in this organisation during the period specified and approved.

All ethical implications that might affect the organisation's reputation and commercial integrity, the well-being of it's employees, and significant third parties have been discussed and where necessary appropriate action taken. (Note, if this action includes the Imposition of some form of restriction or limit on access to the final dissertation, please specify the extent of this restriction e.g. permanent or for a specified period.)

The student has been/will be briefed on company Health & Safety procedures as affects their planned data gathering activities.

Signed: Spal

Position in Organisation: Service Manager.

ZOIL

Should the collaborating organisation wish to discuss any aspect of the student's activities please contact Dr Andreas Vossler (020 7320 1059), Dissertation Planning & Support module organizer, for queries regarding Year 1 (M level) projects.