Abstract

Traumatic brain injury (TBI) is becoming more prevalent in an age of increased motorization and violence. The majority of patients are young adults previously in paid employment. Life expectancy is usually unaffected once past the acute stage of recovery. The reported statistics for successful return to work (RTW) vary from 15% to 77%. However no literature was sourced which examines or discusses the most central component of successful return to work rehabilitation for these individuals – what the individuals themselves have found to be of assistance from their experience of return to work rehabilitation in attempting to return to work.

This study explored the lived experience of return to work rehabilitation from the perspective of individuals who had sustained TBI and who had actively engaged in a return to work programme as part of their rehabilitation. A phenomenological approach, with an interpretative focus was utilized to explore and obtain an enhanced understanding from data gained in semi-structured interviews conducted with ten participants. The interviews were audio-recorded. The position of the researcher was situated within the research, and a reflexive component was interwoven throughout the process. Interpretative Phenomenological Analysis (IPA) was undertaken to elicit themes to enhance my understanding.

Findings formed five main themes; personal cost of lifestyle losses, impact of TBI on perceptions of RTW, factors impacting on engagement in RTW rehabilitation, participants’ perceptions of assistive elements of RTW rehabilitation, impact of RTW rehabilitation on participant. Each master theme comprised a group of sub themes, discussed within the thesis. The meaning of work pre-morbidly for individuals who sustain TBI characterizes their social and familial roles and responsibilities. Upon attempting to RTW following rehabilitation the definition of work often changes in conjunction with the individual’s world views and perceptions of self. Whilst RTW rehabilitation may be an important goal for the
individual and his/her family, because he/she accesses rehabilitation through a community based service, other, external, factors often impact on their ability to fully engage in a RTW rehabilitation programme. Little acknowledgement of this is made by clinicians, and more flexibility and further, additional one to one interventions during times of difficulty would be assistive in optimizing the chances of success for individuals.

Whilst all participants in this study were able to verbalize positive experiences of the outcomes of RTW rehabilitation, none had returned to their previous employment resuming their previous roles.

Thus the core message of this thesis is that the role of the occupational therapist in RTW rehabilitation needs to incorporate many elements including group rehabilitation, one to one rehabilitation and clinical liaison with work places. This can be potentially achieved through adopting Mosey’s (1986) Acquisitional Frame of Reference as a working practice model. In addition, facilitated long-term peer and clinical support is required to ensure individuals maintain success in their attempts to RTW. Clinicians involved in this area of work need to work within an interdisciplinary team approach, recognise and assist with a defined grief reaction that presents in individuals when they attempt to RTW, and be flexible and accommodating in the delivery of RTW rehabilitation to patients.
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Acknowledgements

I wish to extend my thanks to a large number of people whose efforts together culminated in this research.

Professor Ann Moore & Dr Graham Stew at the University of Brighton for showing unwavering kindness, guidance, hard work and support during the many ups and down of the research process. Dr Rudi Coetzer, Consultant Neuropsychologist at the North Wales Brain Injury Service (NWBIS) for creating the opportunity and providing the framework for conducting this study. I also thank you Rudi for your invaluable assistance, time and confidence. Dr Jon Wright at the University of Brighton for his helpful comments and suggestions as academic advisor.

Heartfelt thanks also go to the individuals who sustained TBI and who agreed to take part in this study. They were so generous and forthcoming in giving of their time and their expertise, and allowed me to explore their experiences with them.

I received significant initial assistance and guidance from Dr Liam Clarke, University of Brighton during the first two years of my Doctoral study when identifying my research question. Thank you to my colleagues at NWBIS for your support and cooperation at all stages of this study. Particular thanks to Nest Houghton for her invaluable assistance with the administrative elements of collating and organising the paperwork required to undertake the interviews. Alice Coates deserves special mention for her hard work with the demographic data collection involving the participants of the study. Special thanks, also, to the personnel at the Medical Library, Ysbyty Glan Clwyd for their helpfulness, patience and prompt responses to all requests.
Thanks to Carol McCudden for proof reading, for her understanding and help with my frequent trips to University and especially for her perceptive reflections on my unique writing style.

Last but not least, my three sons Dafydd, Gareth & Tomos for their unwavering support, unselfish understanding, and willingness to take on domestic tasks to relieve me to continue working on the research. Their support enabled me to continue and finish the job. I am indebted to you.

This research would not have been possible without the financial support given by the North Wales Brain Injury Service to enable me to enrol on the Doctoral programme at the University of Brighton.

Dedication

This work is dedicated with love and thanks to my father, John Arthur Hooson and my youngest brother, Richard Thomas Hooson, both of whom would have been so proud and supportive. Their complementary life philosophies live on in my completion of this work. I took time, reflected, and arrived at my way of giving voice to the untold stories. I heard what was not said. This then guided my questions to elicit the stories that needed to be told. I thank you, and miss you both.

“I didn’t care about ‘getting on’. I wanted to live life to the full – to launch out on my own. In the quiet of my room I felt insecure and vulnerable. Although I would not admit it to his face, I knew my father was right. I needed more knowledge”.

Terry Waite “Taken on Trust”,

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Author's Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

Dated
Definitions

For the purpose of clarifying meanings within this study, the following definitions are applied throughout the thesis:

“Traumatic Brain Injury” (TBI) is defined as an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness. This results in an impairment of cognitive abilities and/or physical, behavioural and/or emotional functioning. It is a challenging disability that makes return to pre-injury employment very difficult to predict (Fraser, Machamer, Temkin, Dikmen & Doctor 2006).

“Return to Work” (RTW) is defined as the resumption of gainful employment in any capacity including on a part time basis, paid or unpaid. This was defined individually for each participant in later chapters.

“Rehabilitation” is the combined and co-ordinated use of medical, social, educational and vocational measures for training or re-training the individual to the highest possible level of functional ability (WHO 1986).

“RTW Rehabilitation” is defined as a rehabilitation approach designed to serve survivors of TBI, with the main goal of achieving a vocational outcome (i.e. return to work, employment, re-training, job retention or voluntary work) (Fadyl & McPherson 2009).

“Community based rehabilitation” is defined as rehabilitation provided to individuals in their own homes, or locally based hospitals on an outpatient appointment basis. It was offered to the individual once the in-patient rehabilitation had ceased. It may have occurred some months or many years post injury.

“Acquired Brain Injury” is defined as any non-progressive insult to the brain as a direct result of an organic causation, be that infection e.g. encephalitis, disturbance in the blood supply to the brain e.g. cerebro vascular accident, or tumour.
“Occupation” is defined as ‘groups of activities and tasks of everyday life, named, organised, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care). Enjoying life (leisure), and contributing to the social and economic fabric of their communities (Productivity)’ (CAOT 1997, p.34).

“Well-being” is an internal construct which may be independent of external conditions (Hartweg 1990, Orem 1985). For example it is possible to be ill or not healthy and still have a sense of well-being. Well-being is a perceived state of harmony in all aspects of one’s life. It is a state characterised by experiences of contentment, pleasure, by spiritual experiences, and a sense of happiness (Orem 1985).

“CAT Scan” is a sophisticated form of traditional x ray technology. The CAT Scan takes x rays of the brain at different angles and then uses a computer to compile these images into a 3 dimensional image.

“MRI (Magnetic Resonance Imaging) Scan” is a strong magnet and also sends radio waves through the body. The magnetic tissues in the body then send a faint radio signal back. The receiver collects all these signals and the computer builds a picture of what is inside. This produces no radiation and has no cancer risk.
Chapter 1 Introduction to Thesis

Brain injuries have devastating effects for individuals and their families. As in other countries, brain injuries are common in the United Kingdom (UK). It is estimated that approximately 100-150 per 100,000 of the general population are disabled as a result of a traumatic brain injury (British Society of Rehabilitation Medicine, 1998). Traumatic brain injury (TBI) results in a characteristic presentation of a combination of physical, cognitive and behavioural consequences (Lezak et al. 2004). A considerable percentage of individuals who sustain TBI are unable to fully appreciate their difficulties, and thus are unable to comprehend the effect of their multiple disabilities on their daily functioning, including their area of work (Sherer et al. 1998). The success of return to work of individuals who have TBI has received significant interest in the brain injury and neuro rehabilitation literature. This seems to be related primarily to the pre-injury indicators and injury predictors on recovery from the presenting problems. Failure to return to work (RTW) following TBI can lower motivation towards, and engagement in, the rehabilitation, and also often has devastating consequences on the individual’s perception of self worth and societal roles. Indeed, failure to RTW has been shown to impact negatively on development of social and leisure contacts (Kersel et al. 2001), enabling an independent lifestyle (Lezak et al. 2004), and emotional distress (McCrimmon & Oddy 2006).

Various methods in research have been used to measure the success of RTW rehabilitation following TBI. Yoder et al. (2000) suggested that accuracy in predicting RTW following TBI has improved with the increased use of multivariate models of prediction. These include pre-injury predictors (employment status, familial support, level of education), injury indicators (length of time in coma, additional injuries sustained, location of injury within brain) and others (ability to return to previous employment, level of physical disability, communication ability post injury). Conversely, Saeki & Hachisuka (2004) and Wozniak et al. (1999) argue that there is no relation between the site of the lesion and RTW. A further study by Wozniak & Kittner (2002) argued that it is the severity of the injury,
measured by ability to perform activities of daily living that was the most robust predictor of successful RTW. Koch et al. (2005) undertook a qualitative study exploring the factors associated with successful RTW following brain injury and concluded that it was largely dependent upon a combination of internal resources such as patience or sense of humour, external resources such as emotional support from caregivers and willingness of employers to make reasonable adjustments to the workplace to accommodate any presenting disabilities. Saeki (2000) agreed that successful RTW following brain injury is dependent upon many factors.

Considerably fewer studies exist regarding the exploration of the individual’s subjective experience of engaging in RTW rehabilitation, and making effective use of this information in planning interventions. Virtually no studies have examined this in a manner that values the importance and/or expertise of the individual patients. In the studies that do exist, the focus is on establishing the individual’s perception of their quality of life following sustaining TBI, not on their experience of a specific rehabilitation programme. Given the high frequency of individuals sustaining moderate to severe TBI each year among working-age individuals, even a relatively small percentage of failure to RTW would represent significant social and economic costs to the individual and the national economy. As such it is essential that clinicians explore the value of RTW rehabilitation from the perspective of patients who engage in the therapy.

These individuals often present with complex presentations that makes RTW extremely difficult. For the non-specialist reader who may not have a clear idea of the effects of TBI on the individual, I provide here a fictitious ‘patient’ vignette to illustrate the complexity of human suffering, frustration, and struggle that these patients deal with as part of their changed presentation following TBI:
Jake had an accident at work. He was the owner of a successful building contracting firm. He tripped and fell 6 metres from scaffolding. He suffered a skull fracture, and he was unconscious for two days, and confused and disoriented for a further four or five days. As well as a head injury, he suffered injuries to his spine and right shoulder. He became quite forgetful and, for instance, he would mislay his keys or wallet, and sometimes forget arrangements to meet people. His speech was a little slurred, and he had difficulty choosing the right word, particularly when tired. He suffered from dizziness and his balance was quite poor. He then returned home to his family. He continued to suffer from severe headaches.

A few weeks later, Jake made the decision to return to work. Soon difficulties began to surface. When staff were a few minutes late arriving at work, he talked down to them. On the telephone he was abrupt with customers who were slow to make decisions. With his staff he was extremely impatient if deadlines were not met. He felt bitter about the fall, which was a total accident, and found himself dwelling on it. His headaches were difficult to manage, and he could no longer do the physical aspects of his job due to a combination of the orthopaedic and head injuries he had sustained.

At home Jake was even more demanding. He insisted that meals were ready on time. He could not tolerate the noise of his children playing, or the mess they left afterwards. After a few drinks he was particularly quick-tempered, and also when he was tired at the end of the day. His wife felt that she had constantly to check what she said, in case she upset him, and she said that living with him was like walking on eggshells.
No two patients present with the same presentation, although there are often similarities. However, having such complex presentations result in difficulty in ensuring success for individuals attempting to RTW. Bearing this in mind my ‘disturbance’ regarding this issue in my place of work arose from wanting to explore if individuals with TBI who have been through the RTW rehabilitation process could inform the content of future RTW rehabilitation packages. I was also baffled that there are no uniform guidelines regarding the content of RTW rehabilitation packages for this patient group provided by brain injury rehabilitation experts, such as the British Society of Rehabilitation in Medicine, despite their providing working practice guidelines on other aspects of brain injury rehabilitation provision such as progress through acute care. Whilst the voluntary organisation Headway has produced a booklet regarding RTW following brain injury, this does not constitute clinical working guidelines, rather it offers advice regarding where individuals may access assistance in this regard. As such, the specialist brain injury rehabilitation centres throughout the United Kingdom provide RTW packages with different content based on individual clinical experience and expertise. I wondered if by asking the individuals concerned whether I, as a specialist occupational therapist, could obtain a better understanding of their experience which would in turn guide my clinical practice and possibly assist in improving the statistical success rate of RTW for this patient group. The research question for the present study was:

**What is the lived experience of return to work rehabilitation for individuals following traumatic brain injury?**

The specific aims of this study were:

1. To explore how participants make sense of their personal and social worlds and whether it is possible for clinicians to assist them in this process following TBI.
2. To increase my understanding of what, if anything, is actually assistive in RTW rehabilitation when individuals have multiple impairments and disabilities as a result of TBI.
3. To better define the occupational therapist’s unique role in RTW rehabilitation for individuals with TBI.

This research was undertaken in North Wales and located within the North Wales Brain Injury Service (NWBIS) where the researcher was employed as a clinical specialist occupational therapist. The NWBIS is a community based neuro rehabilitation service in North Wales. The remit of NWBIS is to assess individuals with acquired brain injury and to develop comprehensive management plans. A flow chart of the multi disciplinary pathway for the Service is shown in Appendix 1. Appropriate patients for referral are those with an established diagnosis of an acquired brain injury who have, or are expected to develop, chronic disability needing a long-term, multi disciplinary, community-based rehabilitation programme. Most of the patients meeting these criteria will have one of the following neurological disorders:

- Traumatic brain injury (TBI)
- Hypoxic brain injury
- Brain infection due to meningitis or encephalitis
- Stroke due to aneurismal or subarachnoid haemorrhage
- Intracerebral haemorrhage
- Young people with ischaemic stroke (Rehabilitation services for older stroke victims is provided by care of the elderly consultant led teams. These, however, do not have neuropsychological support and the NWBIS may be consulted for neuropsychological assessment of these patients in selected cases).
The NWBIS is not currently configured to provide care for patients with:

- Recent mild head injury and post-concussion syndrome of less than 6 months in duration
- Progressive degenerative or other dementing illness
- Congenital or developmental neurological or psychiatric disorders
- Brain disorders attributable to toxic effects of alcohol or drugs
- Neuropsychiatric complications of primary epilepsy
- The Service does not function as a ‘memory clinic’ for the diagnosis of patients with memory or other cognitive complaints of unknown aetiology.

Referrals to the NWBIS are accepted from medical practitioners and screened on a weekly basis by clinicians under the guidance of a consultant neurologist. When information in the referral letter does not document the presence of a chronic acquired brain injury, or detail the severity of the injury necessitating long-term, multi disciplinary rehabilitation, the referring doctor is contacted and asked to provide further information and the neurologist obtains relevant medical records and brain scans. For cases of traumatic brain injury (TBI) the records are reviewed to determine the chronicity of the disability as well as the severity of the precipitating injury, and are based on the following criteria:

- History of the injury
- Glasgow Coma Scale(<13)
- Duration of retrograde and post-traumatic amnesia
- Computed Tomography (CT) or Magnetic Resonance Imaging (MRI) evidence of intracranial pathology

The aim of the NWBIS is to provide an assessment, consultation and rehabilitation service for residents of North Wales who have sustained a moderate to severe traumatic brain injury. This includes liaising with all other service providers, including the voluntary sector. Following an initial assessment of a client and his/her family/carer’s needs, the Service will support other general service providers with the rehabilitation process. This is achieved by a
consultation process with the general service providers. An essential aspect of fulfilling that aim is to contribute to the teaching and training of other service providers and students within North Wales. Furthermore, to optimise the consultation element of the NWBIS aim, clinicians will, with the full, informed consent of participants, engage in research relevant to acquired brain injury.

Occupational Therapy is an allied health profession concerned with the individual and the roles, occupations, activities and interactions within the individual’s personal environment. The philosophy of occupational therapy of approaching individuals holistically (Meyer 1977) to optimise their functional ability means that it is a profession that enables and empowers the individual to be a competent and confident performer in his or her daily life within the constraints of their disability and enhances his or her well being. Occupational therapy uses activities creatively and therapeutically to achieve goals which are meaningful to the individual and to minimise the effects of dysfunction (Yerxa & Baum 1986). In order to be a successful mode of rehabilitation, occupational therapy requires the individual to engage actively in the process of therapy and to be a partner with the therapist in designing and directing this process (Persson et al. 1999). Within NWBIS the overall aim of occupational therapy is to identify patients’ needs and provide appropriate therapeutic interventions in conjunction with other Service members which allow the patient to function at his/her optimum level in the community.

Occupational therapy is involved in many aspects of assessment and rehabilitation within NWBIS as patients present with complex and long-standing disabilities that require accommodating and managing within the rehabilitation programme. The combined presentation of physical, cognitive and psycho-social disabilities require occupational therapy involvement to assist with the assessment and rehabilitation of all aspects of daily living, determining the level of support necessary for independent living in the community. This includes the home, occupational and social environments. Therapeutic activities such as
outdoor pursuits, cooking, crafts, walking, music appreciation are utilised to develop and/or maintain patients' functional skills. By ensuring success for patients in the active completion of such activities through using skills of task analysis, and individual functional ability, the dignity and self-esteem of individual patients is further enhanced through productive activity (Csikszentmihalyi 1993). Occupational therapy also plays an active role in supporting patients during periods of difficult emotional states through involvement in activities such as relaxation, anxiety management, anger control, and problem solving. Thus patients are further provided with the life skills required to enable them to confidently live and participate in their local community. With the focus of occupational therapy being to improve productivity, RTW rehabilitation is a major part of the occupational therapy service delivery.

This present study was designed to explore and enhance my understanding, as an occupational therapist, of the individual's experience of RTW rehabilitation following TBI. Specifically, I examined the individuals' reflections of his/her experience through undertaking semi-structured interviews. For the purposes of this study RTW rehabilitation was conceptualised as an intervention provided by any professional, or group of professionals, within the North Wales Brain Injury Service (NWBIS) addressing this issue either in a group basis or on an individual basis. This could involve clinic-based rehabilitation aiming to develop the 'soft skills' needed for employment such as turn taking in conversation, active listening or providing constructive feedback. It could consist of specific RTW placement allocations such as in volunteering projects and overseeing these placements. It could also comprise employment-based rehabilitation such as attending work premises to undertake a risk assessment, liaison with occupational health personnel or involvement in graduated return to work packages.
In contrast to previous studies my study explored all aspects of patient narratives including also negative subjective reflections held by research participants. This was considered necessary to obtain relevant information that would guide future interventions in this area of rehabilitation provision. Whilst it may have been possible to explore intervention provision purely from the viewpoint of clinicians providing the intervention, I rejected this option, as it would not address the issue of enhancing my understanding of what patients find assistive in RTW rehabilitation. I considered that finding how patients experienced RTW rehabilitation would be supportive for exploring which, if any, themes are essential to consider in the planning of future rehabilitation.

To date, no studies in this field have utilised semi-structured interviews to explore a small group of participants' perceptions of the meaning of work to them both prior to and following TBI, and relating this to their experience of RTW rehabilitation. I propose that the perceptions are unique and individual to each person, although there may be common themes. As such, individual patients' perceptions are important in planning for future rehabilitation. As my study is the only study addressing this issue in this manner, caution must be applied, as in all small subject sample studies, in generalising the findings to a larger population. Indeed the philosophical framework of the study dictated that the overall aim of the study was not to obtain findings that were generalisable to the whole population. Rather, the aim was to elicit findings that would enhance my understanding of the research participants' experience of return to work rehabilitation. This, in turn, will guide my future practice and set the foundation to undertake further research in this area.

All participants were registered with the Service and had engaged in RTW rehabilitation programmes provided by professionals in the Service within the last three years. A programme description of NWBIS can be found in Coetzer et al. (2003), (Appendix 2). Potential participants were initially identified by clinicians within the Service, and then approached via letter to consent in the study. The
Awareness Questionnaire (AQ) was utilised to identify that they fell within the inclusion criteria for the study. This is discussed in greater depth in chapter 2.

The aim of the study was to use qualitative methodology that reflected my ontological position as a professional to investigate the variety of patients’ experiences when they engage in a specific rehabilitation intervention to achieve an important life goal in their recovery. Ultimately, this study was designed to improve the needs led RTW rehabilitation provision within the Service in which I work, and to encourage other clinicians working in brain injury rehabilitation to consider their practices also, in light of the findings of this research. The intention is for the reader who is new to, or familiar with, the clinical area of work and involved in providing RTW rehabilitation to be informed about the information that has been elicited from the participants, and my interpretation of this information.
An overview of the plan of investigation for this study is presented below:

10 participants invited & agreed to participate in project by clinicians in North Wales Brain Injury Service. Eligible if:
- Between 18 & 65 years of age
- Have sustained TBI
- Were in employment prior to TBI
- Have engaged in RTW rehabilitation
- Have attempted to RTW (successful or otherwise)

Participants & significant other complete Awareness Questionnaire (n=10) & consent to participate in study.

Decision taken by researcher on suitability for study based on AQ rating compared with clinician rating and significant other rating.

If suitable
inform GP &
invite to interview

If unsuitable,
inform participant & advise re support if required.

Participants consent verified when they attend semi-structured interview for up to 1 ½ hours.

Transcription of scripts and emergent themes generated.

Invite up to 10 participants to return to explore themes in greater detail. Counselling sessions (x2) with psychologist offered if clinically indicated.

Transcription of scripts

Data Analysis using Interpretative Phenomenological Analysis

Write up findings and disseminate research.
The thesis provides a detailed literature search into the progress to date in this area of rehabilitation. It explores the role of occupational therapy in RTW rehabilitation with individuals who have TBI, and evaluates the effectiveness of community based occupational therapy interventions in general. The interpretative phenomenological methodology adopted to undertake the study provides a framework for my constructivist ontological and interpretivist epistemological positions. Through using interpretative phenomenological analysis the data generated from ten participants in semi-structured interviews give voice to both the individual and more generalised aspects of the narratives. The findings are grouped into five main themes of (1) personal cost of lifestyle losses, (2) impact of TBI on perceptions of RTW and occupational activity, (3) factors impacting on the rehabilitation period, (4) participants’ perceptions of assistive elements of RTW rehabilitation and (5) the impact of RTW rehabilitation on the occupational performance of participants. Each master theme comprises a group of sub themes, discussed within the thesis. The findings of this study are discussed in terms of their contribution to the literature and their implications for policy development and clinical practice. The possible methodological and theoretical limitations of the findings are considered and the impact of the findings on potential avenues for future research are explored.
Chapter 2  Background to the Study

2.1 Overview
The introductory chapter provided an overview of the environment where this study was undertaken. It provided information on my clinical role, and described my rationale for arriving at the ‘disturbance’ that I wanted to research within my workplace. This chapter provides an overview of the literature that highlighted the need for further research identifying whether individuals who had sustained traumatic brain injury (TBI) derived any real therapeutic benefit from attending return to work (RTW) rehabilitation as part of their preparation to resume previous life roles.

Within this chapter the incidence and prevalence of TBI in adults is presented demonstrating the extent of the current problem within our society. The research literature documenting the changes in individual presentations following sustaining TBI is examined and the importance of return to work for individuals following traumatic brain injury is considered. The variation in reported success in this area of specialist rehabilitation is scrutinised providing the rationale for the gap in knowledge leading to this research. The review also considers the profession of occupational therapy and explores the literature concerned with identifying the effectiveness, or not, of community based Occupational Therapy rehabilitation within neurological and other clinical areas. Emerging literature relating to the lived experiences of individuals who have undergone rehabilitation is also considered.

The literature reviewed, suggested that the issue of unemployment further to sustaining TBI is becoming a global social and economic problem in today’s Western world (Kissinger 2007, Wehman et al. 2005), and even more so in the developing world according to some papers (Nantulya & Reich 2002). There was some evidence to suggest that success in RTW could be predicted according to pre TBI variables (age, marital status, education) and/or injury indicators (length of time in coma, location of injury, post traumatic amnesia). However what helps
the individual in terms of rehabilitation provision in RTW has not been explored from the patients’ perspective in the literature to date.

2.2 Data Sources
A literature search was conducted based on the Boolean model by defining topic variables and criteria to be included according to the relevance of the topic of interest (see table 2.1). Research papers published within the 24 year period 1985 – current were initially identified using the electronic databases of the *Ovid Journals* database of journals (*MEDLINE, PsychINFO, CINAHL, AMED, Health & Psychosocial Instruments*). A manual search of the bibliographies of the relevant articles was also undertaken to identify articles missed in database searches. The search was limited to articles available in the English language, and articles relating to adults between 16-65 years of age. No limit was placed on study design. Papers for final inclusion were selected on the basis of relevance to the topic area. This was determined initially through scanning of the abstracts for relevant titles and keywords. Further to reading of identified abstracts, full articles that were potentially relevant to the study were obtained. Qualitative articles exploring ‘lived experience’ of phenomena, even outside the remit of TBI were also included. Meta-analytical and review papers were consulted when available.

**Table 2.1 Search Keywords**

<table>
<thead>
<tr>
<th>Population</th>
<th>Keyword (Intervention)</th>
<th>Keyword (Evaluation)</th>
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<tbody>
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<td>Return to work</td>
<td>Personal perspective</td>
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<td>Head Injury</td>
<td>Employment</td>
<td>Lived experience</td>
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<td>Brain Trauma</td>
<td>Work re-entry</td>
<td>Evaluation of intervention</td>
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<tr>
<td>Head Trauma</td>
<td>Vocational programmes</td>
<td>Evaluation of rehabilitation</td>
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<td>Traumatic Brain Injury</td>
<td>Occupation</td>
<td>Clinical effectiveness</td>
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<td>Quality of Life</td>
<td>Outcome</td>
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<td>Participation</td>
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<td>TBI</td>
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<td>Brain Damage</td>
<td>Return to work rehabilitation</td>
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<td></td>
<td>Occupational Therapy rehabilitation</td>
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The Incidence & Prevalence of Traumatic Brain Injury (TBI)

The prevalence of survivors of traumatic brain injury (TBI) in the UK is estimated to be 100-150 per 100,000 population (BRSM 1998, Bryden 1989), with an annual incidence rate of two TBI survivors with a severe disability per 100,000 (Bryden 1989, Miller 1993, DOH SSI 1996, Lyle et al. 1990) and four with a moderate disability per 100,000 (Warnock et al. 1992). An estimated 2% of the American population currently live with disabilities resulting from brain injury (Thurnman et al. 1999), with an incidence rate 30-35 per 100,000 new disabled survivors each year (Kraus 1993, Thurnman et al. 1999). A household survey in Canada estimated a prevalence rate of 54 per 100,000 having a TBI related disability (Moscato et al. 1994). A recent study from Scotland reported an annual incidence of 140 disabled people following TBI per 100,000 of the population.

Unlike many other disease processes with later onset, survivors of TBI often lose the capacity for competitive employment and other meaningful roles, resulting in decades of unrealised productive activity (Wagner et al. 2002). Furthermore the employment picture for persons with moderate to severe TBI is even more sobering. It is estimated that approximately 100,000 persons per year sustain a TBI, perhaps 63% of whom are in the working age category of 15-55 years (Greenspan et al. 1996, Hirsh et al. 1996). Thus TBI disproportionally affects people of working age (Yasuda et al. 2001). Advances in trauma medicine, neuroradiology and improved neurosurgical techniques have resulted in a significant decline in mortality following TBI in the last decade (Sherer et al. 1999, Aras et al. 2004). However the residual presenting problems for the survivors are long-term, complex, and often under estimated by the lay person.

Much research (Sorenson & Kraus 1991, Abrams et al. 1993, Gordon et al. 1993) has suggested that the profile of an individual who suffers from TBI was generally a male in his early 20’s, with a normal life expectancy. Shames et al. (2007) also suggest that TBI is three times more common in men; adolescents and young
adults being at the highest risk. A review by Elovic & Antoinette (1996) and a further review by Greenwald et al. (2003) suggested that motor vehicle accidents followed by falls are the most common causes of TBI, with interpersonal violence being the third most common cause. In a systematic review of the epidemiology of TBI Gordon et al. (2006) concluded that individuals who were injured through violence were more likely to be men, single, unemployed and from a minority background.

2.4 Presentation following TBI

For the individual who sustains TBI there are a variety of complex and, largely, unseen sequelae that he/she has to adapt to and manage. These include cognitive, behavioural and physical impairments. Individuals who sustain TBI do so without prior notice, without planning; it occurs instantaneously. The circumstances of the TBI are usually shocking, agonising and scarring. The recovery is slow and unpredictable involving a degree of spontaneous recovery which is unknown. Recovery is reportedly assisted by engagement in rehabilitation; the effectiveness of which is largely based on anecdotal evidence and to date, has limited researched evidence to demonstrate its effectiveness. This is discussed in greater detail below. Thus there are only the National Service Framework guidelines, which are advisory as opposed to prescriptive, that are available to, and accepted by, clinicians to guide them in their rehabilitation content. The situation is further compounded by the fact that recovery from TBI is individual, thus it is not possible to obtain or provide a concrete and accurate prognosis at any stage in their recovery.

Individuals’ previous abilities and skills are removed completely and/or significantly reduced for an unknown period of time. This impacts on their functional ability at home, at work and in their social environments. Not only does this result in them isolating themselves from previous relationships and roles, but it also evokes fear in people who now know them as a different, and often unpredictable person with whom they do not feel comfortable in interacting. This
persistent presentation has a detrimental effect on the individual’s role within his/her home, often results in the individual being unable to resume previous work lifestyles and results in a significant reduction or loss of engagement in previous leisure pursuits and social activities, leading to isolation.

Two of the most devastating consequences of TBI are difficulty in adequately performing social and work roles held before the injury and that the ability to return to work is frequently disrupted after TBI (Brown et al. 2000, Dikmen et al. 1995). This is largely due to a combination of disruption to both physical and social presentations occurring as a direct result of sustaining TBI. Some of these include the following.

The presentation of hemiplegia (paralysis of one side of the body) or ataxia (shaky movements and unsteady gait that result from the brain’s failure to regulate the body’s posture and the strength and direction of limb movements) are two possible immediately visible changes to an individual’s physical presentation following TBI. However other, more subtle physical problems also impact on work productivity, and may not be immediately apparent. Most individuals suffer from excessive and persistent fatigue for a number of years after sustaining their injury (O’Brien 2007). La Chappelle & Finlayson (1998) concluded that patients frequently reported fatigue as their most serious or troubling symptom. Not only did this impact negatively on the individual’s physical performance, but appeared to both the individual in question, and to their families, work colleagues, etc. to be wholly out of proportion to their productive activity level. Hershenson & Power (2003) indicated that individuals with TBI are often seen as inefficient at work, thus necessitating their termination, transfer or placement in a new assignment. Significant fatigue also impacted on emotional and mental ability and as such had serious implications on the individual’s ability to function on a daily basis. Moreover much research has been undertaken demonstrating that fighting the fatigue rarely acts as a productive strategy in combating this complaint (Haboubi et al. 2001, Van Der Naalt et al. 1999).
Despite this, during rehabilitation sessions, individuals who have sustained TBI often tell me that if only I would get them their job back, their fatigue problems would diminish and their pre-morbid lives would be resumed.

The far-reaching social consequences of sustaining acquired brain injury are not limited to the individual. They also impact on their family and friends, and in all domains of participation (de Jong et al. 2002). Several studies have found that impairments in cognition, emotions and behaviour often created barriers to successful psychosocial functioning (Baddock 1998, Johnson & Newton 1987, Paterson & Stewart 2002). Problems ranged from lack of initiation (starting things), reduced ability to inhibit responses, inability to cope with a group situation and/or poor speech production. This leaves the onus on the other person/persons to control the behaviour of the individual with TBI when socialising. This is not a responsibility that most people are willing, or able, to maintain long-term.

The overall presentation combined with the long-term impact on the individual and others results in distress for the individual, often diagnosed as a clinical depression requiring medical intervention. Many individuals with TBI reported high rates of anxiety and depression, with very low subjective opinions of quality of life (Wehman et al. 2005). This presentation was further compounded by the individual being unable to recognise why they are unable to resume previous roles and skills. They thus repeatedly try to regain those roles and skills, and experience repeated failure in their endeavours. Dawson et al. (2007) suggested that based on previous studies, individuals who sustain TBI and who do not engage in specialist rehabilitation may use one of two models to try to resume pre-injury roles and skills. The first is based on a model offered by Moore & Stambrooke (1995):
Figure 2.1 Moore & Stambrooke’s Model of Skill Re-Learning

The second model is the International Classification of Functioning (ICF) (Stucki et al. 2002) which proposes three levels of disablement which are:

- Impairment
- Activity limitations
- Participation restrictions

Participation restrictions include difficulties in filling roles such as worker or student. The causal relationships between impairments, activities and participation are influenced by environmental and personal factors.
In the field of rehabilitation, impairments and disabilities need to be understood within the contextual environment of the individual concerned, not solely within the pathology of the disease. This means taking into account available support, physical resources, financial resources, emotional wellbeing, cultural factors and how all of these are impacted upon by the changes in functional ability present as a result of having sustained brain injury. As such, although the impairment may seem minimal e.g. loss of peripheral vision, the impact is far reaching for the average middle-aged adult in employment, with a family and financial obligations. They may: lose their job; be unable to drive; be considered unsafe to look after their children independently; be unable to follow a film shown at the local cinema and need assistance to safely cross busy roads. Sadly, for the adult who suffers from TBI, such a presentation is rarely, if ever, seen in isolation. Often there are also changes in cognition levels, behavioural approaches and responses to given situations, emotional presentation, and personality changes in general.

While a TBI is not always inherently fatal, brain trauma has been associated with increased mortality rates particularly at the acute hospitalisation stage of recovery (Selassi et al.2005). However, a significant number of adults of working age survive long-term following a TBI and may continue to live the expected
lifespan. Their difficulty in adopting alternative coping and/or learning skills to their pre-injury subconscious ones lead to frustration and repeated experiences of failure, often for the rest of their lifetime. This is usually very different to repeated positive life experiences pre-injury, and frequently incomprehensible to the individual in question. Moreover their cognitive problems often include reduced problem solving skills, thus they cannot divert to a more constructive resumption of roles without specialist rehabilitation with clinicians who have the required expertise to assist in this regard. As such rehabilitation is an integral component of the medical treatment of individuals with TBI. Indeed, experiments with brain injured animals have repeatedly shown the efficacy of provision of enriched environments and opportunities for physical activity (Will et al. 2004).

2.5 Rehabilitation Following TBI

Whilst recovering from the acute stages of TBI the theoretical basis for rehabilitation is based partly on the benefits of managing and preventing secondary complications of TBI and any related trauma, such as orthopaedic injuries or internal bleeding, and partly on the direct augmentation of neurologic recovery. With the annual increase in the number of survivors there is a need for increasing numbers of specialist regional community-based rehabilitation Services to continue to develop the rehabilitation once individuals return home. Within community settings the goal of rehabilitation changes to focus on reducing the impact of the impairment and/or disabilities on the life of the individual who has sustained TBI. Achieving such a change is most often a long-term venture. Success or failure in the community rehabilitation phase is measured in terms of reduction of the burden on the immediate family, improved social reintegration and/or vocational functionality. Whilst some of these improvements may be achieved by the individuals themselves, regardless of rehabilitation provision, the majority of individuals who sustain TBI require help from a specialist rehabilitation service (Greenwood 1992).
Lannoo et al. (2004) examined the prevalence of long-term disabilities and the resulting needs for ongoing care of individuals who have sustained ABI. The study found that approximately 66% of the individuals experienced long-term cognitive, emotional/behavioural, social and/or vocational problems. Almost 50% experienced mobility problems, and almost 32% reported relational problems, communication problems and dependency problems in activities of daily living. 7% of patients had psychiatric problems, 10% were incontinent. Only 2 out of 186 patients reported experiencing no problems due to their injury. Once back home the focus of rehabilitation aims gradually shifts towards integration and use of local resources to address some of these long-term problems.

Provision of specialist community-based rehabilitation is required from specialist Services, with suitably qualified and experienced staff who understand the nature of the presenting disabilities and have the expertise to address them with the patient and their family. Jelles, Coen, Bennekom et al. (1995:464) stated that:

“Generally, patients in rehabilitation medicine have multiple and complex impairments, disabilities, and handicaps that make intervention of a multidisciplinary team necessary. Professionals ideally work together in an effective and efficient manner. Those collaborating professionals of different disciplines are identified as a team”.

Effective team working within community settings is essential to ensure that individuals who have an ABI can most fully take part in life. According to Kouzes & Posner (1987:15), a team is:

“A group of equally important people collaborating, developing cooperative goals, and building trusting relationships to achieve shared goals”.

Wade (1992) asserts that a productive team demonstrates the ability to be task specific and goal orientated. The International Classification of Impairment, Disability & Handicap (ICIDH) (van Bennekom et al. 1995:169) definition of rehabilitation states that:
“Rehabilitation is a problem-solving and educational process aimed at reducing the disability and handicap experienced by someone as a result of a disease, always within the limitations imposed by both available resources and by the underlying disease.”

Conventional community rehabilitation provision in western countries for individuals who have TBI entails an interdisciplinary approach encompassing an holistic model of assessment and rehabilitation with cross-discipline goal setting and frequent team communications (Vanderploeg et al. 2008). Rehabilitation provision typically comprises three facets focusing on minimising the impact of physical disabilities arising as a result of TBI such as mobilisation, dressing, feeding, personal grooming or avoiding contractures. In addition, attention is paid to addressing cognitive problems such a memory, planning sequencing or difficulty with information processing. The psycho-social wellbeing of the individual is catered for concurrently through addressing issues such as potential depression, guilt, fear and/or social isolation. Adopting this model of community rehabilitation has been found to be of some benefit in addressing presenting problems following TBI (Hall & Cope 1995, Prigatano et al. 1994, Ruff & Niemann 1990), and moreover, is reported to improve functional outcomes across a wide range of diagnoses with multiple demographic, clinical and socio-cultural variables associated with primary functional outcome (Ng et al. 2000).

Thus community rehabilitation is a long-term endeavour that is ever changing, and dependent upon the changing circumstances and improvement made by the individual concerned. Formal therapy will not continue ad infinitum. However the clinical input gradually changes from that of active clinician to becoming an advisor and trouble shooter, thereby progressively encouraging autonomy in the individual with TBI. This may justifiably continue for a number of years as many individuals are young adults with many life changing years ahead of them. For many individuals who have TBI, securing and maintaining employment is perhaps the most important outcome characteristic of successful community-
based treatment and rehabilitation programmes. Indeed, successful re-entry into employment is usually seen as necessary for complete rehabilitation (Rosenthal 1987).

2.6 The Importance of Work Following TBI
The importance of work to the psychological adjustment and health of persons with a TBI has been well established in the literature (Bell & Sandel 1998, Crisp 1992, Lubusko et al. 1994, Kreutzer et al. 2003). Employment has been associated with higher perceived quality of life (Steadman-Pare et al. 2001), whereas failure to return to work has been associated with poorer psychosocial adjustment and physical ailments (Bell & Sandell 1998). Van Velzen et al. (2009) consider that employment is one of the most important areas of participation for people of working age: people who are employed report a better sense of wellbeing, a better quality of life, less health service usage and a better health status than non-employed people. Indeed it has been argued that loss of employment has personal consequences for the individual impacting upon self-identity, autonomy and emotional well being (Bogan et al. 1997, Prigatano 1989, Seel et al. 2003).

Poor employment outcomes following TBI do not only impact on the individual who has sustained the injury and their family, but also represents a global health issue resulting in significant financial, personal, emotional and social burden not only for those concerned, but also for society in general. Financial considerations include the need to take into account the significant number of individuals who survive TBI, the relatively young age at which persons incur TBI (highest incidence at 16-24 years), and the chronic vocational and financial difficulties that individuals with TBI experience. The long-term financial costs of TBI in terms of lost income and increased government assistance are not well known. However the findings of Johnstone et al. (2003) showed that one year following injury only 50% of their sample group were in employment and 40% of their sample group were in receipt of state benefits. No members of the sample group were in
receipt of state benefits prior to sustaining their injury. The average earned monthly income declined by 51%, with a corresponding loss in lost income taxes. In USA the lifetime costs of individuals who have TBI, including losses attributed to medical care and lost productivity, ranges close to $60 billion annually (Finkelstien et al. 2006). Moreover, little is known about the cost of the value of the time and foregone earnings of family members who care without recompense for persons with TBI.

Poor productivity outcomes not only represent a substantial economic burden but also a loss of personal meaning for those unable to resume these roles (Oppermann 2004). These findings were based on a multiple case-study design comprising two randomly selected participants. However the focus of the research was on the meaning individuals ascribe to work. The interview schedule utilised in this study illustrated the thoroughness of Oppermann’s findings as questions were repeated in different ways. This provided confirmation of the responses given by participants. These outcomes are not short-lived and are without a real prospect of improvement in the future. Rather they are the final outcome of rehabilitation for most individuals who have sustained TBI. Wagner et al. (2002) aimed to identify which factors are associated with successful return to productive activity one year post TBI. The study involved 105 participants and found that the survivors of TBI often lose the capacity for competitive employment and other meaningful roles. The conclusions were based on two short-answer outcome measure scales that are widely utilised in rehabilitation settings. However, at such a short time span post TBI hospitalisation (one year) the conclusions regarding the prospects of competitive employment may be considered premature. Kersel et al. (2001) undertook a study looking at the psychosocial functioning of a group of 65 adults with severe TBI. They found that long-term unemployment prospect further decreases the opportunity to develop social contacts and leisure activities, thereby leading to increased isolation and higher levels of depression. A strength of this study is that it explored the effects of being unemployed following TBI not merely through functional engagement in
social and leisure pursuits. It rather assessed the impact of non-productivity on emotional, behavioural and social performances.

McCrimmon & Oddy (2006) suggested that RTW is often one of the main goals identified by individuals who have experienced TBI and provides a sense of purpose, identity, independence and social inclusion, and reduces their emotional distress. Moreover Wehman et al. (2004) suggested that work provides the motivation to leave the house in the morning, and that the opportunity to make new friends and reconnect with previous colleagues is facilitated by work. They further suggested that the opportunity to enhance self-esteem and perceived status is an outcome of steady employment, and that the likelihood of reducing physical disability, substance abuse, and other secondary disabilities historically associated with TBI is improved with productive work. Expanding economic self-sufficiency and access to enriched benefits is directly related to regular employment.

Andrews & Turner-Stokes (2005) reported that as long as fifty years ago successful rehabilitation in mental health was seen in terms of the individual returning to employment. Cope et al. (2005) proposed that the recent gradual change in focus in the rehabilitation of individuals who have sustained TBI to acknowledge the importance of RTW was attributable to changes in societal values. The movement towards empowerment of people with disability commenced initially with survivors of spinal cord injury and mental health advocates. Societal recognition of the truth of the view that all individuals, irrespective of disability, have a right to optimal social access, opportunity, integration and participation has led to acceptance of the need for individuals who have sustained TBI to be able to RTW. Whilst I agree with this perception, I consider it necessary for both patients and clinicians to accept that, based on the complex presentation following TBI, it is highly unlikely that individuals will be able to return to their previous employment at their previous levels in the early
stages of RTW rehabilitation. RTW rehabilitation goals need to be realistic to be successful.

Johansson & Tham (2006) undertook a phenomenological study to explore the meaning of work for individuals who had sustained ABI with 10 individuals. Their findings demonstrated that for all those individuals work was assigned a new meaning in their life because the work tasks no longer gave them the same pleasure as before their injury. However they could all identify that they derived certain benefits from working, for example work brought structure to everyday life in general. Lezak et al. (2004) also argues that employment is important in structuring life, providing stability and enabling an independent lifestyle. Johansson & Tham (2006) also found that work brought structure into leisure time which seemed to be significant for the participants’ experience of satisfaction with their everyday life. Finally the participants described how work protected them from developing feelings of self-pity and falling into bad habits. After a day at work they felt a greater sense of satisfaction and were in a good mood. However all participants acknowledged that they felt they were no longer attractive in the employment market, which influenced their sense of identity. Their worker role had changed; their opportunities for personal development and the possibility of getting appreciation through work had altered. Participants also described a feeling that their personal value as individuals was not the same as it had been before. As a clinician working in this field for over twelve years now I can identify with the conclusions of these studies based on the information provided to me clinically by patients. These findings will be re-visited in light of the findings of my study in the discussion chapter of this thesis.

Johansson & Tham (2006) also identified in their study that the immediate goal of rehabilitation was to get ‘back to normal’ way of life. Being ‘normal’ again or ‘getting back to normal’ was repeatedly mentioned by the respondents as being the most fundamental issue. Work was considered as evidence of being back to ‘normal’ again. This theme was also repeated in Levack, McPherson &
McNaughton’s study (2004) exploring the values of people who had TBI. However there was a qualifying factor elicited in this latter study that working at the pre-injury level was their measure of ‘normal’. One aspect of ‘normality’ in Johanssen & Tham’s study was to regain the familiar feeling of mastering one’s own body and being able to use the old repertoire of skills. During the endeavour to reach that goal, work had been experienced as a motivating factor.

Most individuals, in my experience as a specialist clinician in this area of work, consider that if only they could get back to work, many, if not all, of their problems would be resolved. Wagner et al. (2002) contended that RTW and education are critical measures of independence and community integration after TBI and also individual quality of life (QOL). Webb et al. (1995) evaluated a cohort of individuals 2 years after hospitalisation with TBI and found that employment was the strongest contributor to improved QOL. O’Neill, Hibbard & Brown (1998) also found a strong relation between employment and perceived QOL after TBI. However returning to work is not a straightforward process for individuals who have TBI.

Notwithstanding this, it is well documented that not all patients who engage in RTW rehabilitation are successful in returning to work (Franulic et al. 2004, Johnstone et al. 2003, Ownsworth & Flemming 2005, Wedekind & Lippert Gruner 2005). This is despite returning to work remaining a primary outcome of interest for adults following TBI (Dawson et al. 2007). Within brain injury rehabilitation there is evidence to suggest that RTW issues are amongst the most difficult to overcome for these patients (Johnson 1998, Fraser 1999). Certainly research has suggested that RTW after brain injury has been limited to as little as 1/3 of the population with brain injury, as many as 10 years post injury (Kreutzer et al. 1991, Wehman et al. 1995, Kolakowsky-Hayner & Kreutzer 2004). A more recent systematic review by van Velzen et al. (2009) found that only 30%-65% of individuals with ABI return to work, with a mean of less than 40% returning to work within 2 years post injury. Core data held in NWBIS (2000-2008) comprising...
both patients who have engaged in RTW rehabilitation and those who have not engaged in RTW rehabilitation \((n=143)\) shows that 27% of them were successful in their attempts to RTW in either part time or full time capacity.

2.7 Possible Basis for the Discrepancy in Reported Success for Individuals who Attempt to Return to Work Following TBI.

Post TBI injury employment rates vary from 10% to 70%, compared to pre-injury employment rates ranging from 61% -75 % depending on the study (Sander, Kreutzer, Rosenthal et al. 1996, Yasuda et al. 2001). This is a significant reported discrepancy in the success rate of post TBI employment. Shames et al. (2007) argue that the wide range of RTW outcomes rates can be attributed to several factors, including:

(i) Varied case mixes and classifications of severity of TBI

There are distinctions between types and severity of brain injury, the rehabilitation services and other forms of support after injury, and the time intervals between injury and study reports (Yasuda et al. 2001, Sander et al. 1996). These factors are often not distinguishable in the research, thus making it difficult to draw definitive conclusions from the findings. The severity of TBI may be classified by the Glasgow Coma Scale (GCS); that is individual active response to stimulus post injury which may be recorded at time of injury, time of admission to hospital or day after hospitalisation. Often the time of the recording of the GCS is not specified in the research, and thus may not be comparable classifications within each study. Other studies classify injury severity by length of time in coma; which may or may not be drug induced. It is my experience as a clinician that there are pragmatic considerations in this factor. It is often difficult for clinicians to ascertain when a distinction about injury severity is made, as the time of GCS classification is not always stated in the patient's notes. This can make it difficult, if not impossible, for a researching clinician to be able to define injury severity when undertaking research on this group of patients.
(ii) Different definitions and thresholds for RTW

Various definitions have been used to define work and returning to work, incorporating non-standardized measures or descriptive measures. Some studies have also made use of recognized standardized measures whilst others have incorporated voluntary and/or training opportunities. A number of studies do not specify the measurements used. There is also significant discrepancy in the reported time scale post injury success rate. Many studies offer percentages of success rates post injury, but the time post injury varies and there are few studies concerned with long-term RTW outcomes. Furthermore Shames, Treger et al. (2007) suggest that RTW outcomes are confounded by the threshold for determining success. It is unclear in many studies whether the individuals have returned to their previous job; whether modifications were required or whether it was on a full time or part time basis? It is also often unclear whether the individuals have returned to a different but equivalent job, or a lower skilled job.

Differing studies have shown that RTW has been defined in many ways. Klonoff et al. (1998) use a 10 point outcome rating scale that differentiates between the previous level of work and full time work after modifications or placement when evaluating the effectiveness of a vocational intervention. This is disregarded in many outcome studies. To avoid confusion regarding terminology in this study I defined RTW in the context of the study at the beginning of the thesis.

(iii) Different compensation systems in different countries that promote or discourage RTW

There appears to be a geographical variation in success; that is success rates for RTW following TBI appear to be higher in studies undertaken in USA & Canada than in Belgium. The reasons for this are unclear, although the literature shows that there are significantly greater options for supported work placements in the USA & Canada than there would appear to be in Europe. From my experience in the United Kingdom there is often a distinct differentiation between the effort individuals put into RTW rehabilitation programmes if they have an ongoing financial compensation claim which could eventually ensure financial security
upon closure of their case, and the effort put into this aspect of rehabilitation when the patient is historically the financial provider to the household and there is no alternative available.

(iv) Inconsistent vocational rehabilitation and support services:

Attempts to RTW may be undertaken by individuals independently as it is not part of a rehabilitation programme; it may be undertaken purely with previous employers as part of a graduated RTW programme or it may be an integral part of a rehabilitation programme involving clinicians and employers. The level of clinical support for RTW is often dependent on the services available in different geographical locations, and whether there is/are a lead clinician(s) to take the lead in this aspect of rehabilitation. Indeed this is the case within NWBIS. Even though there is a dedicated RTW rehabilitation programme provided for patients, some decide to undergo the process independently with previous employers. Some also decide to undergo the process independently with personnel from the employment agencies. As a community based service for patients, this is wholly acceptable as an informed decision taken by patients.

Olver (1996) examined the long-term outcome of TBI following discharge from a comprehensive rehabilitation programme and found that, of the 103 participants reviewed at 5 years, 32% that were working at 2 years were not employed at 5 years. Other longitudinal studies have conversely demonstrated increased rates of successful return to work years after injury (Franulic et al. 2004). I would also argue that close review of the literature highlights significant discrepancies in the methodology of past research into the success in RTW for individuals with TBI. Yasuda et al. (2001) conducted a literature review and found that post-injury employment rates ranged from 10-70% compared to pre-injury employment rates ranging from 61-75%. Sander et al. 1996) reviewed studies reporting post-injury employment rates ranging from 22 – 66% and pre-injury rates ranging from 61-75%. Cifu et al. (1997) also reported studies demonstrating rates of return to work to vary from 10 – 70%. Johnstone et al. (1999) stated that of those
individuals that returned to work after injury, 75% would lose employment for various reasons within the first 90 days either due to resignation or termination. This would suggest that some RTW rehabilitation programmes fail to address important issues with individuals, and their prospective employers, when preparing them to resume gainful employment.

Despite RTW being one of the primary goals of clinical rehabilitation for individuals with TBI in my clinical experience, the success rate of RTW and the value of rehabilitation in RTW post TBI is poorly understood by clinicians. This could be attributable to the dearth of studies into the effectiveness of RTW rehabilitation in this field of work, combined with differing RTW rehabilitation approaches being employed in different units within the United Kingdom. However being employed has been associated with a better quality of life in individuals who have sustained TBI (O’Neil et al. 1998, Steadman-Pare et al. 2001). Levack et al. (2004) undertook a phenomenological study and found that most participants noted that employment provided them with feelings of productivity, a sense of having done something worthwhile, and being meaningfully occupied. Longitudinal studies have also demonstrated the importance of employment following ABI in terms of maintaining feelings of wellbeing and health, as well as community integration (Powell et al. 2002, Sloan et al. 2004, Tate et al. 2004, Vestling et al. 2003,). Kissinger (2008) suggested that despite the challenges associated with TBI and the rehabilitation process, individuals who have sustained TBI often remain viable employment candidates. As such it becomes important to identify tangible assistive strategies associated with RTW rehabilitation for this patient group and establish whether rehabilitation provision would benefit from being reviewed or changed completely.
2.8 The Identifiable Gap in Research Knowledge

2.8.1 Literature supporting the need to explore RTW as a current unmet need for individuals with TBI

Brown & Vandergoot (1998) found that, compared to a group of individuals with spinal cord injuries and those with no disability, individuals with TBI have the most challenges regarding the level of unmet important needs. Work and parenting ranked the highest in unmet needs. Oppermann’s (2004) research into the meanings individuals who have sustained acquired brain injury (ABI) ascribe to return to work concluded that current health care systems do not always support attempts to address the long-term needs of brain injury survivors. Petrella et al. (2005) suggested the factors that contribute to productivity outcomes in individuals who have sustained ABI should include study of the experiences of individuals with ABI in their course to resume productive activities. They asserted that this area was largely unexplored. This assertion is supported by Levack et al. (2004) who suggested that there is a gap in the literature where the values and perspectives of people with TBI are potentially misrepresented.

2.8.2 Lack of research into what aspects of rehabilitation are assistive to individuals

There is no consensus in the literature as to what aspects of RTW rehabilitation are truly assistive. Indeed the study undertaken by Minnes et al. (2001) demonstrated that 61% of their sample did not have their rehabilitation needs even identified, never mind supported, in the area of productivity which included employment and education. The focus of the majority of studies identified is rather on pre-injury predictors and/or post-injury indicators as determinants of success in RTW. The reported success rates in previous research are based on employment outcomes at the end of a rehabilitation period. Scant attention has been devoted to exploring the effectiveness of clinical rehabilitation in relation to the outcome. Gordon et al. (2006) reviewed the research requirements in the field of TBI rehabilitation and concluded that rigorous research was needed to measure the effectiveness of rehabilitation interventions and the characteristics
of individuals who may benefit from any single intervention, and from one intervention compared to another. They also concluded that innovative models of service delivery needed development in order to make any real progress in improving the success rate of RTW for individuals who have sustained TBI. I was unable to find any previous research in the field of RTW for individuals with TBI exploring the experience of rehabilitation from the perspective of the individuals engaging in it.

The lack of qualitative investigations into patients’ perceptions of what they have found helpful means that as a specialist clinician in this field, I am less able to understand how a patient’s engagement in rehabilitation will specifically improve their potential to successfully return to work. My practice knowledge and experience suggest to me that through the rehabilitation period patients are challenged about their changed abilities in a supportive environment which then better prepares them for returning to gainful employment. However, these are my hypotheses only and may not be an accurate reflection of how RTW rehabilitation is experienced by patients. The findings of this research provide an insight into how RTW rehabilitation is experienced by patients and is discussed later in the discussion chapter of this thesis. Moreover the dearth of practical and applicable findings for clinical practice means I have been less able to learn from the experience of individuals in order to design effective evidence-based rehabilitation programmes as required to practice in today’s health care systems. And yet, Franulic et al. (2004) concluded that an individual’s return to work is crucial and can possibly be considered one of the best indicators of successful rehabilitation.

Brown et al. (2006) explored how people constructed their experiences of brain injury and the challenges they faced afterwards in rebuilding their lives by conducting in depth interviews with 24 individuals with brain injury. Their findings included the need for professionals to accept and understand that factors outside of rehabilitation such as home support and family involvement need to be
considered when undertaking RTW rehabilitation as these factors impact on individual perceptions of success. It begs the question about the therapeutic value of simply occupying someone in a ‘supported job’ regardless of the individual’s wishes and beliefs as to what constitutes meaningful employment.

2.8.3 Findings of quantitative studies examining RTW

Much previous research in this area has embraced quantitative approaches (Machamer et al. 2005, Malec & Degiorgio 2002, Sherer et al. 1999, Wedekind & Lippert Gruner 2005). Such approaches have framed the problem of lack of success for individuals attempting to RTW following TBI as either a gap in the process of community rehabilitation for individuals with brain injury or theorising how the long-term impact of the physical, cognitive and behavioural presentation of individuals who have sustained TBI inhibits their potential to RTW. My view is that approaching this problem in such a strictly statistical manner merely reports the numbers of individuals with TBI who are successful in their attempts to resume employment. No consideration is given to how the individuals feel or in determining the value of rehabilitation. Intrinsic variables, such as their sense of self efficacy, internal locus of control, attitude towards the productive activity and extrinsic variables such as social and family support, perceived social attitudes and rehabilitation services, which can influence the process of returning to productive employment, require further study. Some of these variables have indeed been captured in this study, particularly familial support and locus of control. They are discussed further in the findings and discussion chapters of this thesis.

2.8.4 The gap in current practice knowledge

This study frames the problem of lack of success to return to any form of gainful employment, be that paid or unpaid, full time or part time, in terms of two factors. Firstly it frames the problem as a gap in professional comprehension of the rehabilitation requirements for success. Secondly it frames the problem as a gap in clinical and/or researcher acknowledgement of the value of patients'
experience. This study addresses both these factors by making it explicit that what is being explored is the participants’ constructions of their experience of engaging in RTW rehabilitation and asking their opinion on what they consider should be included in future RTW rehabilitation programmes. It is clear from gaps in the available literature that research is required in order to obtain an understanding of the individual’s subjective experience of returning to productive activities. I wish to gain a greater understanding of “what works” or “what helps make it work” from the individuals’ perspective as opposed to “successful numbers of statistical importance” from the researcher’s perspective. The focus of my research therefore is to look at how I, as a clinical specialist occupational therapist, can know more about the experience of engaging in specific rehabilitation, and with the enhanced understanding that comes from that knowledge be more able to successfully support individuals to achieve their goals. This involves subjecting the clinical practices of myself, and respected colleagues in this area of rehabilitation to critical scrutiny and debate – considered by Ballinger & Payne (2000) to be a sign of maturity in a profession and academic discipline.

2.9 The Role of Occupational Therapy

Doing, being and having things are the fundamental components of human life according to Jen-Paul Sartre (1943/1956). Occupational therapy is a profession that began with the aim of occupying, engaging, or employing someone in something that would assist in the treatment of a disease or disorder (Reed & Sanderson 1999). The philosophy of occupational therapy adopts a holistic approach to assessment and rehabilitation; that is approaching individuals as total beings as opposed to focussing on one aspect of their presentation. For example an occupational therapist would look at an individual with TBI’s overall daily activity and rest levels and consider those within the context of the socio economic stressors that were unique to that individual when trying to assist in reducing the frequency and severity of headaches. Occupational therapists thus
gear rehabilitation activities to engage, employ or occupy the individual as a person, by directing their mind and attention in occupation.

Early occupational therapy practice reflected popular educational reforms aiming to educate children more comprehensively by encouraging them to learn by ‘doing’ instead of learning by ‘rote’ (Dewey 1915). As such the handicrafts used in early occupational therapy provided patients with an opportunity to develop skills such as concentration, perseverance, hand-eye control, and problem solving; they also contributed to a more holistic acceptance of occupation which included art and valued creativity. H A Pattison wrote the first formal definition of occupational therapy in 1922:19

“Any activity, mental or physical, definitely prescribed and guided for the distinct purpose of contributing to, and hastening recovery from, disease or injury”.

The profession grew dramatically following the world wars when injured soldiers returned home and there was a need to assist those who could, to return to their previous occupation(s) or re-train those who could not return to their previous occupations grew. In both cases rehabilitation started by providing occupations at the bedside and on the ward, it progressed to off-ward activities (which often included workshops) and finally vocational training. Return to work was the goal, and activities were seen as the means to that end (Friedland & Davids-Brumer 2007).

In today’s society the scope of occupational therapy has evolved to include all aspects of daily living roles encompassing self-care, home management, child care, education, independent living, community living, play, leisure and work. Engaging in activity within occupational therapy programmes of rehabilitation is seen to result in positive effects on the patient’s wellness, health, life satisfaction and need fulfilment (Rebeiro & Polgar 1999). This application of activity is considered within each individual’s own environment/s and the impact of the environment on each individual’s ability to be productive. As such, occupational
therapists need to be able to adapt each individual’s environment to optimise his/her ability to engage in activity. This may involve modifying the individual’s actions and/or behaviours, or alternatively modifying the environment itself, for example with the use of assistive technology and/or consulting with family about attitudes or expectations (Reed & Sanderson 1999).

The role of occupational therapy, however, is not merely limited to recovery from illness or disease. There is growing pressure within current health care provision to ensure that the public take on responsibility for their own health and to adopt measures to minimise the risk to themselves of becoming unwell. As such, occupational therapy is concerned with activity and occupation in the preventative elements of illness and the role of occupation in proactively ensuring optimal health and wellness. This incentive has been driven by the current health care trends aiming to prevent injury and disability, with a knock-on effect of decreasing the need for costly (in terms of emotional, physical and financial cost) restorative care. This aspect of occupational therapy was initiated in the 1960’s by Reilly (1962:1) who declared:

“That man, through the use of his hands, as they are energised by mind and will, can influence the state of his own health”.

The states of health and wellness are unique to each individual and fluctuate dependent on changing daily events. Occupational therapists believe in the concept that all individuals are integrated organisms with the mind, body, spirit, emotions and environment having an interrelated impact on health (Reitz 1992). The College of Occupational Therapists (1994:1) stated that:

“The Occupational Therapist assesses the physical, psychological and social functions of the individuals, identifies areas of dysfunction and involves the individual in a structured programme of activity to overcome disability. The activities selected will relate to the consumer’s personal, social, cultural and economic needs and will reflect the environmental factors, which govern his life”.

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As such, community-based rehabilitation programmes emphasise the importance of promoting wellness by improving function and quality of life, as defined by the individuals with TBI, when they are residing once more in their community. Work is considered to be an important contributor to quality of life for individuals. Occupational therapy bases the application of activity in rehabilitation on the task analysis, or the concept of graded activity, a theory that promotes a step by step increase in activity to minimise fatigue and optimise functioning (Hoving et al. 2009). Thus the role of occupational therapy in addressing return to work issues within community-based rehabilitation for multiple aetiologies has been long standing.

Because the onset of TBI most commonly occurs in adolescence and young adulthood, many people living with the long-term sequelae of TBI have difficulty in completing or re-starting further or alternative training and/or attempting to RTW. Consequently members of this population have gaps in the skills required to succeed in the student or worker role. They may also have a history of failed attempts in this regard, as discussed earlier in the coping models often adopted by individuals with TBI. A history of failed experiences further reinforces reduced confidence and self-esteem. Occupational therapy involvement in RTW rehabilitation programmes is highly congruent with two of the profession’s most recognised and used frames of reference. For example Mosey’s (1970, 1986) Acquisitional Frame of Reference (AFR) and Keilhofner’s (2002, 2004) Model of Human Occupation (MOHO).

2.9.1 The Acquisitional Frame Of Reference

Mosey’s Acquisitional Frame of Reference (AFR) (1986) is based on learning theory, and incorporates biomechanical and rehabilitation approaches. It was developed primarily for use in the field of mental health. However as the presentation of problems in individuals following TBI is complex and includes disruption to cognition, emotion and psychosocial functioning, I propose that the
AFR can also be applied to rehabilitation in the field of brain injury. The AFR concerns skills and abilities that are independent of each other and can be addressed in isolation. Mosey suggests that people learn how to behave and perform actions through being in a situation and learning from their experience. Thus if, for example, an individual with TBI is intolerant of noise and works in a busy office environment, they may respond by becoming verbally aggressive with colleagues. This will result in them becoming ostracised from their work colleagues. The individual’s ever-increasing experience of social isolation within the workplace results in the individual learning that outbursts of verbal aggression are not tolerated in the workplace. Thus, significantly, behaviour is not considered to be the result only of the internal state of the person. However, an individual’s internal state may change based on changes in his/her behaviours. As such, individuals with TBI can acquire knowledge about how to monitor and adapt their behaviours so that they conform to socially acceptable norms. These behaviours are individual (verbal aggression) although they may present in multiple environments (meetings at work, attending the pub quiz, interacting with their children). Changes in maladaptive behaviours thus result in more positive experiences for the individual. This then results in a more positive internal state.

Importantly Mosey believes that the acquisition of skills and/or behaviours occurs when the individual is in direct interaction with other people within an environment that is designed for learning a particular skill. As such, discussing how others may not consider verbal aggression acceptable when the individual with TBI attends a clinical appointment at the clinic will not result in a change in behaviour (or the acquisition of skills to manage that particular presentation more constructively). Rather, the individual needs to be placed in a social and/or group situation where they experience other people’s reactions to their behaviours, and are able to acquire more acceptable behaviours based on those modelled to them by others.
The generalised goal within the AFR is for the therapist to:

“assist the individual to acquire an adequate repertoire of behaviour relative to
his or her current life situation or expected environment”. (Mosey, 1986:445).

In accordance with the AFR, the assumption is that individuals can be facilitated to RTW through initial attendance at group based RTW rehabilitation programmes in a semi-structured educationally-based clinical setting with individuals with similar presentations. The group setting can provide an awareness of the behaviours and skills needed for successful interactions and performance in work situations. This can then be transferred to work placement and work situations. A potential limitation of adopting the AFR when working with individuals with TBI may be that having reduced self-awareness would hinder or delay an individual’s attempts to modify his/her behaviour in light of feedback provided by other group members. However this could be compensated for by making feedback explicit to ensure that individuals are aware of the need to modify his/her behaviours.

2.9.2 The Model of Human Occupation (MOHO)

The MOHO seeks to explain how occupation is motivated, patterned and performed, and provides a broad integrative view of occupation. Within MOHO individuals are conceptualised as being made up of three inter-related components: volition (their motivation for occupation), habituation (how occupation is organised into routines), and performance capacity (the physical and mental abilities that underlie skilled occupational performance). In addition, therapists applying MOHO in their interactions with patients need to have an understanding of the physical and social environments in which occupation takes place. MOHO is intended for use with any person experiencing problems in their occupational life, including brain injury. MOHO has been successfully applied in assessment and treatment of individuals in rehabilitation and work programmes.
Law (1998) argued that MOHO is a model that is consistent with patient-centred practice. That is, it views the patient as a unique individual whose individual personality, needs, desires and life philosophy determine the nature of the therapeutic goals. In addition, patient centred therapy believes that it is the individual’s actions, thoughts and feelings that provide the central mechanism for change. The MOHO believes that the process leading to change in an individual’s ability/ies or circumstances can only be achieved through a combination of: becoming aware of novel thoughts, feelings and/or actions; repetition of the circumstances where the novel experiences occurred, thereby allowing internalisation of these experiences and continued interaction between the new experiences and their lifestyle to maintain the re-shaping of themselves.

The role of the therapist in this process is a supportive and facilitatory one. The occupational therapist validates the individual’s perspective by identifying factors that could facilitate enhanced occupational performance. In addition the occupational therapist offers feedback on the individual’s performance, providing advice with regards to goal setting and compensation strategies to overcome presenting problems. Where necessary the occupational therapist negotiates any change to the agreed actions the individual will undertake as part of rehabilitation and structure the demands made of individuals to ensure success. If required, the occupational therapist will explore new ways of achieving success in an activity and encouraging individuals with emotional support and reassurance.

With regard to the MOHO frame of reference, by participating in RTW rehabilitation individuals with TBI are supported by occupational therapists to re-define an occupational identity as an adult, to develop strategies to ensure compensation for any lack of social skills and/or occupational performance in a work setting and occupational adaptation to the demands of being an adult attempting to RTW with a TBI. Through structured activities, educational opportunities, feedback on progress and opportunities to access work based
situations (volunteering, college attendance, work placements) individuals with TBI can attempt to master the habits and routines needed to enable them to be occupationally productive.

As a specialist occupational therapist working with individuals who have TBI it is important to have a frame of reference to justify the approach utilised in the delivery of RTW rehabilitation. This is difficult to accomplish when it is not known what aspect of the rehabilitation provision is truly assistive to the patient. In addition, each patient is unique and presents with different complex presentations. However the philosophy of occupational therapy is to embrace the uniqueness of individuals, and ensure that rehabilitation is activity based and meaningful to each individual. The MOHO is helpful to justify the need to take RTW rehabilitation at the individual’s pace and the need to often repeat aspects of the rehabilitation programme so that individuals can internalise strategies to overcome presenting problems in the workplace. The strength of the AFR is in its tangible structure that can be adapted to work in a different rehabilitation setting to that for which it was designed (mental health). This is discussed further in the discussion chapter of this thesis.

The unique contribution of the occupational therapist in RTW rehabilitation has been evaluated in literature within clinical areas not necessarily related to TBI. Gutman et al. (2009) developed an occupational therapy programme to address further education for young adults with psychiatric problems. They evaluated the unique contribution of occupational therapy into the success of the programme and concluded there were three main aspects. Firstly the strength of occupational therapists in designing compensatory strategies and accommodations that can enhance functional performance in education and work settings. Secondly, occupational therapists use activity analysis and synthesis to break down cognitive and psychosocial skills into smaller components that can be progressively increased as patients become more skilled in those areas. Lastly,
occupational therapists help individuals to newly assume or resume desired occupational roles through enhanced performance in the activities, habits and routines that support desired roles.

Likewise Chan (2008) explored how occupational therapists are involved in RTW rehabilitation with young individuals who sustain CVA in Singapore. Whilst it is difficult to extract information within the paper regarding the specific input of occupational therapy into the success of RTW programmes (55% of participants in study), Chan concludes that the occupational therapist role is vital within the multi disciplinary team to assist with preparation for job trials and job placements in particular. She attributes the necessity of occupational therapy for successful outcomes to the holistic approach to rehabilitation adopted within occupational therapy enabling them to understand and work with the multiple contributing factors that impact on the ability of young individuals with CVA to RTW. She suggests that occupational therapists need to further develop their roles within RTW rehabilitation to include proactively ensuring a fully supportive employment climate at the workplace when individuals with CVA attempt to RTW.

In Occupational Therapy theory it is argued that occupation is the way in which people show others who they are (Keilhofner 2002, Schkade & McClung 2001, Wilcock 1993). It has been argued for some time that sustained engagement in activity or occupation contributes to enhanced occupational performance, enhanced occupational competence and health benefits (Law 1991, Wilcock 1993). Findings about the effect of occupation on health show that the removal of occupation leads to increased stress, physiological changes and decreased health (Harris et al. 1992, Jongbloed 1994, Lokk et al. 1993). However care must be taken to ensure that there is an ‘optimal fit' between the demands of the occupation and the skills of the person in order to maintain the initial and sustained engagement in occupation (Yerxa 1990). If there is a lack of fit between the demands of the occupation and the ability of the individual it leads to
a perceived decrease in the quality of life of the individual (Hachey & Mercier 1993). They argue that when the occupational demands are too low it results in boredom and apathy in the individual. When the demands are too high, it results in heightened anxiety states and a sense of being overwhelmed. It is my experience that this balance is difficult to achieve and/or maintain when working with individuals with TBI. This is because any disruption occurring within an individual’s life, be that problems at home, with recreational activity, or socially, impacts on their functioning in other aspects of their life, including their ability to apply strategies to overcome their problems within the workplace. As such, the demands of activities with this patient group needs to change to ensure that they optimally fit the occupational abilities of the patients.

The ability to engage in work roles requires individuals to make decisions, self-correct and use judgement (Burgess et al. 2006). These executive functions underlie and support the performance in daily life activities, which allow individuals to engage meaningfully with families and friends and remain productive members of their communities and society (Katz & Hartman-Maeir 2005). Involvement in meaningful occupations, whether paid or unpaid, has been recognised as a major determinant for health for many years, being related not just to economic factors but also to social status and time use (Wilcock 2006, Wilkinson 2005). Thus, occupational therapists need to access a wide range of occupations, considering all to have a potential impact on health and wellbeing (Townsend & Wilcock 2004). The College of Occupational Therapists (2006) reasserted the importance of occupation to health and wellbeing and identified the unique contribution of occupational therapy in this process.

2.10 Effectiveness of Occupational Therapy

Chard (2006: 527) defined the goal of community rehabilitation as:

“to maximise functional ability and quality of life through multi dimensional rehabilitation that occurs while the individual is living at home versus acute or transitory care setting".
As far back as 1995 Barnes asserted that regional brain injury rehabilitation services should be located within local communities. Recovery from TBI is prolonged and, as discussed earlier, in the initial stages in particular uncertain. With locally based specialist provision it is possible to engage the family and any significant others in the rehabilitation process at the earliest possible opportunity. Individuals return home, often to the care of their families, and access community-based rehabilitation packages. Mayer (2004:287) acknowledges that:

“With the survival of 80,000 people with severe brain injuries annually, the prevalence of individuals with severe disability grows annually as well. As family caregivers age, they face similar problems experienced by aging parents of adult children with developmental difficulties”.

With the annual increase in the number of survivors there is a corresponding need for increasing numbers of specialist regional community-based rehabilitation Services. Lannoo et al. (2004) examined the prevalence of long-term disabilities and the resulting needs for ongoing care of individuals who have sustained ABI. The study found that approximately 66% of the individuals experienced long-term cognitive, emotional/behavioural, social and/or vocational problems. Almost 50% experienced mobility problems, and almost 32% reported relational problems, communication problems and dependency problems in activities of daily living. Seven percent of patients had psychiatric problems, 10% were incontinent. Only 2 out of 186 patients reported experiencing no problems due to their injury. Once back home the focus of rehabilitation aims gradually shifts towards integration and use of local resources to address some of these long-term problems. Indeed Widen-Holmqvist & von Koch et al. (2000) found that there was a positive effect of home rehabilitation on social activity, activities of daily living, motor capacity, manual dexterity and walking. However the sample size in this study was small.

Current NHS provision does not fully cater for the ever increasing number of individuals with ABI returning to the community presenting with a complex array
of disabilities. Specialist community-based brain injury rehabilitation teams are often under resourced to cope with individuals with long-term neurological conditions facing many complex challenges in attempting to live as they would wish. These problems can cause increased dependency on families and often result in unnecessary hospital admissions.

When undertaking assessment and exploring rehabilitation options with individuals who have sustained TBI it is important to remember that these individuals may have been severely compromised by their injury and their physical, emotional and social selves are very different to what they used to know. Wade and de Jong (2000:1385) advocated rehabilitation approaches that were:

“Pragmatic, functional, or task oriented in contrast with a theory-based, impairment orientated approach”.

It is my experience that with this patient group, the nature of their problems effectively means that intervention is most effective when it is pragmatic and task orientated. Many have impaired ability to think in abstract, and need to focus on realistic concrete goals to experience improved functional ability. Thus although it is important to respect the dignity and values of the individual patient, it is necessary to be more directive in intervention than would be considered ideal in the field of psychiatry for example. It is often the provision of direction and development of structure that then enables the individual to achieve a degree of success in adjusting to the difficulties that have beset them.

Among growing demands on health care resources and escalating health care costs, the capacity to demonstrate outcome and link it to intervention has become an essential part of health delivery. This is seen as a way to enhance the quality of health services provided to patients, and to address spiralling health care costs. Cope, Mayer & Cervelli (2005) proposed that a comprehensive system of care is now conceptualised as including therapy, training and
supported living within the natural environment for extended periods of treatment or including the entire lifetime of the injured person.

Powell et al. (2002) undertook a randomised controlled trial of adults who had sustained TBI comparing the effectiveness of community outreach team rehabilitation provision with provision of written information detailing alternative sources. They concluded that the community occupational therapy teams focused much more on individuals' levels of activity and participation, and thus patients made significantly greater gains in these areas. This was coupled with the finding that as community based occupational therapists channelled more energy into facilitating independence within the patients' home environment, the patients scored significantly higher on the Functional Independence Measure (FIM) and the Functional Assessment Measure (FAM) (Wright 2000) indexes than those following the written information only. Whilst there is some criticism of using the FIM and FAM as measures of independence they are indisputably an often chosen outcome measure of choice by occupational therapists wanting to examine the effectiveness of their interventions with community-based patients.

The strength of the above study is its confirmation that occupational therapy rehabilitation with individuals with brain injury can be effective and yield results many years after sustaining injury. A potential limitation is that individuals with both ABI and TBI are included. There could be a variation in success dependent upon the cause of brain injury. This needs to be explored further. As a specialist clinician in this field of work it is my experience that to provide individuals with written information is rarely followed up unless actively directed by the clinicians. This is because their clinical presentation often includes lack of motivation and/or initiation.

Shawn & Richardson (2007) explored whether individuals who sustained TBI & ABI perceived that they reached self-identified goals related to tasks of daily life when engaging in Occupational Therapy rehabilitation programmes. This study was conducted in a clinic providing an out patient treatment facility. This study
was particularly valid to this present study as it recognized from the outset the potential problems with this sample group having reduced self awareness/insight. This difficulty was overcome through a screening involving self reported scores on a standardised outcome measure. Not only did the results demonstrate a significant improvement in performance for both client groups, but also demonstrated a change in satisfaction with their performance for both client groups. A strength of this study is that it utilised a standardised outcome measure (Canadian Occupational Performance Measure) (Atwal et al. 2003) which is administered by an occupational therapist and involves a semi-structured interview in addition to a structured scoring method. Therefore the reliability of the results is confirmed by comparing the data obtained from both scores. RTW is strongly associated with life satisfaction and social integration, indicating that vocational assistance and training is also a necessary component of a comprehensive system of care (Wehman & Kreutzer 1991, O’Neil et al. 1998).

Birch & Adams (2008) explored the perceptions held by carers on the effectiveness of community occupational therapy provision. Although the diagnostic group was not identified in the article, the overall impression was that occupational therapy can be effective in the community setting. All six participants stated that once they were aware that their significant others were engaging in occupational therapy they acknowledged the quality of the service provided. Whilst the Birch & Adams (2008) study lacks the academic rigour applied to many research articles, the message contained therein is of no less value.

Abrams et al. (1993) reviewed a single RTW programme with 142 individuals who had sustained TBI. They explored the economical benefits to society of successful reintegration into the workplace. They used three different self-administrative questionnaires as their methods. They came to three main conclusions; namely that there is no single best model of vocational intervention...
for individuals with TBI, supported employment is not necessarily the best
treatment approach, and that it is necessary to identify the most appropriate and
cost-beneficial services for placing and retaining persons with TBI in competitive
employment.

Barnes & Radermacher (2001) concluded that most studies have shown that
community rehabilitation in whatever form is at least as effective as the traditional
alternative of hospital care. However they also point out that it is clear there are
many gaps in knowledge and much further work needs to be done. The evidence
of efficacy and cost effectiveness of specialist rehabilitation is sparse and
generally poor, despite there being a fairly large amount of literature on the topic.
Their conclusion, as is mine, is that there is no doubt that there is an urgent need
for more vigorous and thorough evaluation of various community based services’
RTW rehabilitation schemes, including thorough researching of the experiences
of patients of RTW rehabilitation.

2.11 The Lived Experience of Differing Rehabilitation Approaches
It is important for clinicians to investigate issues of best practice and efficacy of
interventions pertaining to RTW following TBI in a manner that acknowledges the
importance of the patient’s perspective in informing future clinical practice
(Darragh et al. 2001). The lived experience of engaging in rehabilitation is
acknowledged as a vital informant to guide future practice within the National
Health Service (NHS), for example patients are now included in Local Health
Boards. Furthermore there are ‘comments’ slips found in every hospital
department to inform future practice. This is in accordance with the belief that
feedback from patients in receipt of healthcare is generally considered to be vital
for quality assessment and quality assurance. Moreover recent UK government
initiatives (DOH 2007; NICE 2007) indicate that the perspectives of service-
users/patients should play an important part in the formal evaluation of the NHS.
Occupational Therapists have long been concerned with patients’ perceptions and concerns about the rehabilitation they invite the patient to engage in. Gitlin et al. (1998) undertook a qualitative study exploring the concerns held by survivors of cerebro vascular accident (CVA) about occupational therapists introducing assistive technology into their homes. Their findings informed the occupational therapists that there was a significantly increased chance of the systems being utilised to their full potential if the patient’s feelings of loss and helplessness are validated at the time the concept is introduced. Schwartzberg (1994) conducted an ethnographic study examining the experiences of participants in a peer-developed support group for persons with head injury. Whilst the value may be questioned by some colleagues, the narratives of the patients validated the positive impact of the group in terms of reduced readmission to hospital, and reduced dependency on medication. Both the above studies suggest that the important factor for consideration when examining the value of rehabilitation provision is to recognise the voice of the patient. The participants in the first study were not wholly positive about the input of the occupational therapists. However the constructive themes generated ensured that good practice was recognised and encouraged as routine practice for the future, thereby improving the quality of service provision.

The current challenge to occupational therapists is to provide efficient and effective services that meet the needs of all the stakeholders while operating within various constraints, such as limited funding, resources and time. Delivering a “needs led service” requires occupational therapists, by definition, to ascertain from the patients themselves how they experienced aspects of their engagement in rehabilitation. Persons with brain injury, their families and friends and service providers all experience the needs, services and outcomes of the rehabilitation experience differently. An appropriate starting point for research into services for individuals with TBI and their effectiveness remains in the expressed experiences of the individual (Darragh et al. 2001).
There has been an increase in the reported lived experience of participants in research in recent years. The methods used to elicit the information are varied, although I identified a greater number of studies in the literature utilising qualitative, as opposed to quantitative, methodologies. I offer a summary of identified studies in Appendix 3 that guided the formulation of the methodology and methods adopted to answer the research question in this study. This will be discussed in greater depth in Chapter 3. Below follows an overview of studies that have utilised different methods to elicit lived experiences within the field of brain injury.

Interestingly Swaine et al. (2003) had undertaken research to develop a tool to assess patient’s perception of the quality of head injury rehabilitation services. I wanted to explore whether this tool, developed in Canada, might be utilised to inform my research. Swaine et al. (2003) identified as recently as six years ago the absence of a standardised method to measure patients’ perception of the quality of the rehabilitation they had engaged in further to sustaining their head injury. However the tool is still in its native French language and a standardised English translation has not been completed yet. Moreover, the tool is designed specifically for patients with severe TBI prior to their discharge from an in-patient rehabilitation facility. The tool is not validated outside of the inpatient facility. Thus, although this tool may be useful for the future, it could not be included in this present research as it was based in the community setting. Also, from my epistemological position using a ‘standardised tool’ to elicit information would be contradictory to my phenomenological enquiry aiming to obtain account of personalised experiences.

Horneman et al. (2005) looked at the impact of TBI on young children and their perception of their functional and social abilities 10 years post injury. They did this by using a standardised Quality of Life questionnaire comprising fifteen measurable dimensions. Whilst this study does not allow for the intimate exploration of feelings verbalised by the participants, it does manage to identify in
some depth a number of generalised themes that can inform future clinical interventions with children who sustain TBI. It was not clarified in the study the reason for using a more quantitative method to elicit the information from this sample group. However, the sample group was large ($n = 109$). Furthermore, as the study also comprised individuals who might have sustained their injury very young in childhood, they may still have been adolescents at the time of the study. As such, this method may have been chosen as the most reliable to elicit this preliminary information.

The previous (Horneman et al. 2005), and other, studies suggested that it is entirely possible to obtain information from individuals who have sustained TBI about their lived experiences through administration of a quantitative investigative tool. These findings seem to be reflected in the study by Powell, Temkin et al. (2007). They conducted structured interviews in addition to administering the Functional Status Examination (FSE) (Dikmen et al. 2001) to explore participants’ perspectives on participation in home management tasks following TBI. The administration of the tool took 15-20 minutes. Much of the information gathered was quantitative and numerical. However the researchers introduced a qualitative focus through asking the participants to score whether they were ‘bothered’ by the changes in their current performance compared to their pre-injury performance. Unfortunately the word ‘bothered’ is not defined, apart from being categorised into ‘not bothered’, mildly bothered’ and significantly bothered’. Interestingly the authors accepted that a clearer picture of the changes in the overall functioning of the participants has to be determined by administration of other standardised questionnaires. It is the combination of the responses to the tools administered that informed the overall conclusions drawn. The authors conceded that:

“More detailed information about each person’s situation is needed in order to understand the role of these factors more completely”.(p.139).
However, they did not suggest how the more detailed information may be elicited from participants. This may suggest that more comprehensive qualitative methods need to be utilised to obtain the richness of the data sought by the researchers.

Earlier studies have adopted qualitative methods to elicit data on the lived experiences of individuals who have sustained TBI. Chamberlain (2006) explored the experience of surviving TBI. She used the narrative from unstructured interviews to generate the themes she elicited from the participants. When reading the narratives illustrating the themes, it is inconceivable that such rich data would have been elicited from purely quantitative methodology. The data generated informed future rehabilitation provision for this patient group and was consistent with the findings of other previous quantitative studies.

Guidetti et al. (2007) undertook a study to explore the lived experience of individuals following sustaining acquired brain injury or a spinal cord injury attempting to recapture their self care skills. They adopted a phenomenological approach and interviewed the participants for an hour. Although this study included two distinct diagnostic groups, the phenomenon being explored was generalised to both groups. The themes generated following analysis of the data were fuller than described in the quantitative study of Horneman et al. (2005) which used a standardised Quality of Life questionnaire, described earlier. Closer examination of the reported findings suggested that Guidetti et al.’s study (2007) were of greater value in informing clinical practice. The study was able to suggest reasons for the progress (or not) of individuals through the rehabilitation process from the perspective of the individual attempting to come to terms with their new disability. The study was also able to identify further specialist clinical intervention necessary to improve the success rate of individuals in this regard.

A further study adopting in depth interviews was conducted by Newton et al. (2007). They explored the experience of group therapy for individuals
experiencing auditory hallucinations (hearing voices). They used in depth semi-structured interviews to elicit data that impacted directly on future clinical practice which would not have been possible using a quantitative methodology. For example, the profound impact of how the individual was perceived by close family and friends indicated that the friends and family also need to be included in a separate support group to fully understand the perspective of the patients in the group and assist seamlessly in their continued rehabilitation. This support for close family members would also assist them in supporting the patients when in community settings, and potentially reducing the need for professional intervention when the patients began to hear voices. Such findings not only impact on maintaining the dignity and wellbeing of the patient, but also inform the development of future staffing and the philosophy of the Service provided. Whilst the study was well designed and innovative in it’s clinical field in positioning individuals with schizophrenia as ‘experts’ in the research process, the development of themes would have been enhanced with a greater inclusion of quotations from the semi-structured interviews which would have grounded the themes in the data more fully.

Darragh et al. (2001) used in-depth interviews to obtain an understanding through the participants’ own words of what qualities rehabilitation providers are perceived to either help or hinder the recovery and rehabilitation process for persons with brain injury. This study acknowledged the prejudice often found against accepting the information provided by an individual who has sustained brain injury because it is considered that the information is flawed in some way due to aspects of their presentation, such as cognitive impairment. However, the authors stated that

“We can unquestionably learn a great deal from this information”,(p. 198).

Not only was this study able to identify qualities necessary to work with individuals who have sustained brain injury, but it also highlighted areas for further research. My research aims to add to the body of knowledge about what individuals with TBI perceive to be helpful in their RTW rehabilitation process, to
include practitioner qualities may have been assistive to their attempts to RTW. The aim of my study, as was that of Darragh et al. (2001), was not to generalise findings but to reveal the meaning structure of the participants’ life-world experiences related to RTW rehabilitation (in the case of my study) to obtain a deeper understanding. This will inform my future RTW rehabilitation provision as an occupational therapist.

Haggstrom & Lund (2008) undertook a study exploring how adults with ABI experience participation in daily life. Although their research did not utilise any narrative from the transcribed scripts, they were able to illustrate that ‘participation’ in activity can only be subjectively experienced. It was not possible to obtain a full picture of the experience from an observation by others of the person concerned engaging in the performance of an activity. They emphasised the importance of professionals considering each individual’s unique experience and not focusing only on the observation of performance in designing individually tailored rehabilitation programmes intended to enhance the patients’ quality of life.

Perhaps the most informative study relating to lived experiences for my research was that of Oppermann (2004) who aimed to describe the meaning individuals ascribed to RTW after TBI. The study was conducted with two participants as a multiple-case study. The participants engaged in a semi-structured interview by telephone in the first instance. The information provided was verified with another telephone interview. Each participant received a copy of the generalised themes generated and were invited to finally comment on them. The study elicited three themes that reflected those generated from the study of Guidetti et al. (2007). The themes were the experience of finding work after injury, the experience of maintaining work after injury, and independence related to work. Oppermann’s (2004) study was one of the first that I reviewed that utilised semi-structured interviews with individuals with brain injury for the purposes of research, which focused on a non quantitative aspect of RTW post injury. In addition, she was
exploring the meaning of work for them. Her findings informed my choice of potential questions; particularly in the early stages of the interviewing. Her study also demonstrated the need for occupational therapists working in this specialist area of work to explore further what aspects of RTW rehabilitation, if any, individuals themselves found assistive.

2.12 Summary

It is generally agreed that qualitative studies provide information of a kind which is often lost in quantitative studies (Chadwick et al. 2000, Jones et al. 2001, Martin 2000). Importantly qualitative studies utilising semi-structured interviews to collate data add substantially to our understanding of how and why changes may have occurred or need to occur during rehabilitation. By comparison, quantitative studies can only provide us with details of the actual changes; they say nothing about the meaning of such numerical changes for our patients.

As Holloway (2001) has pointed out, we cannot afford to be complacent about the kinds of data that we base our evidence for the effectiveness of interventions upon. To base our practice upon quantitative data which demonstrate good outcome measures for an intervention is only part of the task. Qualitative data can help us tailor effective techniques to the needs of our service users – but it can do more than this. Patients have a unique knowledge about what works or does not work for them. The understanding gained from interviewing participants in rehabilitation can contribute to a more complete conceptual understanding of treatment, to inform both theory and practice. Indeed, Rossi & Freeman (1993) argue that participants of a service may be the only valid source of information about what was actually received.

This study is a qualitative investigation of the lived experience of individuals who have sustained TBI and who have engaged in rehabilitation to assist them in their attempts to RTW. It aims to utilise participants’ accounts to explore their experiences of rehabilitation pertaining to RTW to enhance my understanding of
the experience, ultimately informing my future RTW rehabilitation provision. The following chapter provides a detailed overview of the chosen methodology and explores this in light of my ontological and epistemological positions. Details of the data collection and data analysis methods used in the study will be provided. The impact of my role as a researching clinician within the workplace will also be examined.
Chapter 3 Methodology, Methods & Data Analysis

3.1 Overview

In the previous chapter the connection between ‘lived experience’ and clinical practice was considered. The reasons for occupational therapists, in particular, being interested in the lived experience of individuals were explored and a review of the methodologies used in studies to elicit lived experiences was undertaken. This review suggested that my study would need to adopt a qualitative approach to enable me to obtain a comprehensive and enhanced understanding of the lived experience of individuals who have sustained traumatic brain injury (TBI) and who have attempted to return to work (RTW) through engaging in specialist rehabilitation.

This chapter aims to explain why my study needed to investigate the lived experiences of individuals in order to address the research question. My ontological and epistemological positions are clarified and their role in the choice of phenomenological methodology are explained. Ethical and methodological issues that impacted on the selection of participants are discussed. The methods section of the chapter describes how I elicited accounts of the individuals’ lived experiences, and my rationale for choosing Interpretative Phenomenological Analysis (IPA) to analyse the data is discussed. Reflections on my position as a researcher are interwoven throughout the chapter and given particular consideration towards the end of the chapter.

3.2 Defining my Ontological, Epistemological, Methodological & Method Positions

The frames we give our research problems shape what we can look for and what we can see – as well as what we do not look for or see. At the beginning of any good piece of written work, the author will ‘set the scene’ for the reader so that they are able to immerse themselves in the text in an informed, or contextualised, manner from the start. This is also true of research. Porter (1996:414) describes qualitative research as being founded on four levels of understanding:
In considering these questions, it is apparent that the answers will not be the same for all qualitative research as the rationale for collecting the data determines the choice of methodology available to undertake the research. Thus the different levels of understanding need to be clarified by the researcher before proceeding with the research as they cannot be assumed. Using Porter's framework, the levels of understanding that I needed to establish prior to undertaking the research were as follows:

<table>
<thead>
<tr>
<th>Porter's Questions</th>
<th>How Porter's Questions Have Been Addressed in This Study</th>
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<tbody>
<tr>
<td><strong>Ontologically:</strong></td>
<td>The participants’ <strong>perceptions of their experience</strong> of actively engaging in RTW rehabilitation, unique to each participant.</td>
</tr>
<tr>
<td>What did I, as the researcher, consider constituted ‘reality’ for the individual who had sustained TBI &amp; engaged in RTW rehabilitation?</td>
<td></td>
</tr>
<tr>
<td><strong>Epistemologically:</strong></td>
<td>The participants’ <strong>constructions of their experience</strong>; be that positive or negative, plus my interpretation of their experiences.</td>
</tr>
<tr>
<td>What did I, as the researcher, consider to be knowledge in this study?</td>
<td></td>
</tr>
<tr>
<td><strong>Methodologically:</strong></td>
<td>Reality was the <strong>individual's interpretations</strong> of the lived experience of engaging in RTW rehabilitation.</td>
</tr>
<tr>
<td>How did I understand ‘reality’ for the purpose of this study?</td>
<td></td>
</tr>
<tr>
<td><strong>Methods:</strong></td>
<td>By using <strong>semi-structured interviews</strong>.</td>
</tr>
<tr>
<td>How did I collect evidence about the perceptions held by the participants?</td>
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</table>
My research aimed to explore individualised information on the usefulness, or otherwise, of a specific phenomenon (RTW rehabilitation) for a group of people with a diagnosis of TBI. In order to do this comprehensively I needed to ensure that my ontological and epistemological positions informed my chosen methodological approach. The methods used for data collection needed to be analysed within a framework that further complemented my methodological approach. These are discussed further within this chapter.

From an ontological perspective I had to explore ‘what is reality?’ to me, as the researcher. Without declaring this personal knowledge to the reader I would be assuming that ‘reality’ holds the same meaning for everyone. This is not my understanding. Muncey (2006) also stated that we don’t just learn from formal events or historical events but from subjective feelings and thoughts which we experience in the events of our everyday lives. The framework of my inquiry supports the ontological perspective of the belief in the existence of not just one reality, but of multiple realities that are constructed and can be altered by the knower. That is, there is a ‘real’ world out there, but it is subjectively perceived. This is known as constructivism. My research aimed to explore individualised information on the usefulness, or otherwise, of a specific phenomenon (RTW rehabilitation) for a group of people with a shared organic diagnosis. My primary aim as both researcher and clinician in this study was to better understand each individual’s experience and knowledge. As such, I believe that the experience was lived through and constructed in a unique manner for each participant, based on their previous experiences, knowledge, and their cultural and spiritual background. Moreover their constructions of their experience would be shaped by other current issues in their lives at the time of engaging in the rehabilitation, such as familial support and/or other rehabilitation they were engaging in. Thus my ontological position is that of a constructivist; that is I believe that our perceptions of the world are mediated through a series of distorting lenses and can only be known subjectively (Powers & Knapp 1990).
From this ontological position I propose that knowledge is also individual and is obtained through a process of interpretation. This leads on to my epistemological position, which is interpretivist. Carter & Little (2007:1316) define epistemology as ‘the justification of knowledge’. I believe that all individuals construct or interpret reality based on their past experiences and current predicament. Within this epistemological framework I consider that reality and/or knowledge is constructed on an individual basis based on life experiences. Moreover, the same reality (event, belief or experience) could occur for two people at the same time but this reality is interpreted and lived differently by each, and thus has a different meaning to both people. Furthermore any other individual observing the reality, having the reality recounted to them, or even actively engaged from a different perspective in the reality will have a different construct on that experience.

There is much debate within the phenomenological approach about the requirement of researchers to be able to ‘bracket’ their presuppositions and assumptions when undertaking research to avoid ‘contamination’. Researchers should be able to state from the outset what their presuppositions are, and then bracket them for the purpose of undertaking the study. When undertaking interpretative phenomenological research in the spirit of Heidegger (1962/1965) it is not possible for such bracketing to occur. Dowling (2004) stated that as researchers we cannot dissociate ourselves from the experience of collecting data. I do not consider it possible to bracket one’s own knowledge; rather there is a relationship, be that conscious or unconscious, between each individual’s experience and the understanding of that experience by another individual.

The methodology of a given study gives us a theoretical analysis defining a research problem and how research should proceed (Harding 1987). Allen et al. (1986) argue that for a study to successfully address or generate its research questions, it must be firmly grounded within a methodological approach. Indeed Giorgi (2000) argues further the considerable impact that the chosen
methodology has on sample size, sampling method, data collection and analysis techniques. Without explicitly stating the methodology adopted for a study the researcher makes it necessary for the readers to try to make sense of the researcher’s intentions. This can lead to the written account being, at best confusing and at worst, indecipherable to the reader.

Willig (2008) proposes that qualitative researchers tend to be concerned with meaning; that is they are interested in how people make sense of the world and how they experience events. Thus in stating explicitly that I adopted a qualitative approach for this study I informed the reader that my study was concerned with social processes as opposed to quantifying responses. In stating my choice of methodology, I further provide the reader with the framework informing them of the rationale for the sequential steps involved in undertaking and completing the study.

With regard to my research therefore my ontological and epistemological position determined that my methodology needed to recognise the value of the individual experience of RTW rehabilitation. Indeed much research has concluded that the experiences of those living with the consequences of brain injury can give important information to rehabilitation professionals to enable them to understand their patients better and to plan interventions appropriately (Kielhofner 2002, Mattingley & Flemming 1994, Nochi 1998). One area in which there is still lack of knowledge is the experience of RTW rehabilitation for those with TBI. There needs to be explicit acknowledgement from the start that there would be differences in the way that RTW rehabilitation was experienced by different individuals, and that each experience was as valid as the next. The aim of this study was to describe and understand from a phenomenological and occupational therapy perspective whether there was any actual value to RTW rehabilitation for individuals who had sustained TBI. My choice of method also needed to reflect these ideals.
The methods are the tools utilised to elicit the data when conducting the research. In my research I wished to gain a detailed picture of the participant’s perceptions or beliefs, that is their ‘reality’, about the phenomenon of RTW rehabilitation. My aim in obtaining this information was to enhance my understanding of the experience of RTW rehabilitation as lived through by individuals who have sustained TBI. My enhanced understanding would, I hoped, impact on my own and others’ clinical practice in this specialised area of rehabilitation provision. As the data needed to be rich and descriptive, the chosen method of semi-structured interviews needed to facilitate this.

3.3 The Importance of Exploring Lived Experience to Address the Research Question

As discussed in the previous chapter, difficulties in successful RTW are often attributed to the complex presentation of problems in the individual who has sustained TBI, as the physical, emotional and psychological problems occur concurrently. Medication is a common treatment for individuals who have TBI in particular to treat the presentation of aggression, depression and/or headaches. Physiotherapy is also used extensively to treat the visible symptoms of TBI such as ataxia, hemiplegia or vestibular disturbance. However, psychological, emotional and environmental factors also contribute to a lack of success in RTW attempts. Pre-existing psychological wellbeing, poor coping, school and work history have all been identified as predictors of unsuccessful attempts to RTW in individuals with TBI (Yasuda et al. 2001, Ownsworth & McKenna 2004, Machamer et al. 2005). Therefore it is important that drug and physiotherapy management form only part of the treatment package, and occupational therapy rehabilitation and psychological support are also provided (Arciniegas et al. 2001, Fleminger et al. 2003).

In their review of RTW outcomes for persons with TBI Wehman et al. (2005) conclude that there are larger numbers of people who are unemployed (than employed) following TBI. They recommend that more studies be undertaken to
explore the impact (or not) of certain types of rehabilitation on the individuals who are attempting to RTW. At this stage, no guidance is offered regarding how this may be achieved. However historically, from a clinical perspective, when the effectiveness of an intervention is evaluated, it is undertaken by clinicians and based on their interpretation of feedback provided by patients. Patients are regularly required to complete questionnaires stating their satisfaction with an aspect of health care provision but are rarely asked in-depth questions regarding their experience of an intervention or the personal context from which they are making their judgements. As such, the majority of feedback is positively biased and quantitatively summarised. The ‘fuller picture’ is not considered and changes that could potentially affect practice positively are rarely identified.

Reid et al. (2005) suggest that understanding the lived experience of an individual offers clinicians the opportunity to learn from the insights of the experts – the research participants themselves. What, if anything, is truly assistive in rehabilitation when you are suffering from anger management problems? What is it like to experience chronic fatigue? What is an individual’s experience of societal attitudes when diagnosed with epilepsy and how does this impact on their choices of lifestyle?

In the case of my study, what, if anything, is actually assistive in RTW rehabilitation when you have multiple impairments and disabilities as a result of having sustained TBI? Is there truly a role for occupational therapy and psychological rehabilitation when providing RTW rehabilitation for an individual who has sustained TBI? Exploring the lived experience of individuals should assist in informing clinicians of how participants are making sense of their personal and social worlds and identifying if, and how, clinicians may assist them in this process.
3.4 Eliciting Return to Work Rehabilitation Experiences: Methodological Issues

As discussed in the previous chapter, there is a scarcity of literature relating to return to work rehabilitation experiences. However a small number of studies have been identified that attempt to evaluate some other aspects of rehabilitation provision for individuals with TBI. In terms of RTW rehabilitation, attempts to measure successful outcomes have employed both specified and unspecified scales that have, from the outset, imposed a restrictive framework upon any response an individual can make.

Attempts have, rightly, been made to broaden the area of interest and establish the importance of rehabilitation as comprehensively as possible. These have led to the increased use of qualitative multi-item instruments for quantifying the different aspects of changes in presentation for the individual during rehabilitation. For example Dou et al. (2004) examined the need for cognitive rehabilitation services in the community for persons with brain injuries from the perspective of both patients and clinicians. They utilised self-administered scales to elicit the information from patients, although some interviews were conducted with clinicians. The categories of questions did not allow for comparison of individual experiences of changes in presentation or individual needs in terms of rehabilitation. Although there were four open-ended questions contained in the last part of the questionnaire, the information elicited from this part of the research is sparsely discussed.

More recently, the utilisation of mixed methods has been introduced to elicit information regarding the impact of certain interventions for individuals who engage with clinicians following TBI. For example Forman et al. (2006) evaluated the impact of an adjustment group on patients following TBI using a single case study design. It is interesting that the participants were asked to provide information on the impact using two self administered questionnaires; Hospital Anxiety & Depression scale (HADS) (Zigmund & Snaith 1983) & the Mental
Adjustment to Brain Injury scale (MABI) (Burton & Volpe 1993) which are both quantitatively based instruments. They were also asked to answer questions about the impact of the group through a paper-based activity. The only interview was with the group facilitator. It could be argued that the methods utilised in this study would have been more useful in terms of addressing the aims of the researcher had they been reversed; that is interviewing the participants, and providing a paper-based method for the group facilitator. This would have allowed for a deeper understanding of the impact of the group on the participants, probably eliciting accounts to provide a fuller picture.

Paterson & Stewart (2002) explored the perceptions held by individuals with ABI of their social world. They utilised focus groups with trigger questions to elicit information about each individual's experience. The narratives provide rich descriptive accounts of group perceptions although it is difficult to obtain a perspective of individual perceptions. The possible reasons for this are not discussed, and leads me, as a clinician, to wonder whether this may be due to the nature of the presentation of ABI making it difficult for individuals to focus and concentrate within a fully interactive and possibly challenging group situation.

Methods aimed at eliciting experiences from individuals should ideally allow the individual to identify his/her individual experience, without being coerced by reference to any potentially leading and/or misleading labels. This has led most recently to an increased utilisation of semi-structured interviews, focus groups and unstructured interviews. The low number of participants has been criticised as a limitation in some studies. However they are still valuable in terms of offering an enhanced understanding of individual experiences of adapting to their changed presentation.

Reviewing recent studies, from a methodological perspective, I decided that my study would adopt a methodology that aimed to elicit the lived experience of individuals. In view of the investigative nature of my study, and the focus on
subjective experience, a qualitative approach adopting a phenomenological methodology was identified as most appropriate. This offered the advantage of the participants being allowed to voice their thoughts and tell their stories in their own way, without premature imposition of predetermined categories.

3.5 Phenomenological Methodology
Interest in phenomenological research has been growing steadily over the last decade as researchers have sought to capture the richness of the individual experience to inform their practice, be that in clinical or other fields. However there are many confusing aspects to phenomenology, not least the need to decipher whether it is being utilised as a philosophy or a research methodology to inform studies. Misconceptions and contradictions are apparent in much of the existing literature, with researchers combining the principles of descriptive and interpretative phenomenology.

Phenomenology began as a movement in philosophy that deals with the essences of objects, or phenomena, as they present themselves in human consciousness (Finlay 1999). The word ‘phenomenon’ comes from the Greek ‘phaenesthai’ to flare up, to show itself, or to appear (Moustakas 1994). Within phenomenology the traditions have developed over the years. To my mind, not one particular tradition is either right or wrong; they merely offer different understandings of phenomenological research methodologies, and the researcher can adopt the one that best fits their ontological and epistemological beliefs. The phenomenology advocated by Husserl (Giorgi 2000) was inspired by Franz Brentano (Moran 2000). Husserl adopted the term ‘intentionality’ which is described by Moran (2000) as being the “principle that every mental act is related to some object, and implies that all perceptions have meaning”. Husserl developed ‘descriptive phenomenology’. His aim was to provide an account of things as they appear in order to arrive at an essential understanding of human consciousness and experience (Valle et al. 1989). Husserl’s phenomenology is post positivist in that it attempts to understand the phenomenon as free as
possible from any cultural context. Because the objective is to describe an experience without the hindsight offered in reflection, there can be no interpretation of the description by the individual who has had the experience or the researcher. This phenomenological methodology, in my mind, would offer a description that defines the phenomena in question from a distance, as it is observed. It is not compatible with my research aims of wanting to look back on a lived experience, which implicitly involves reflection and interpretation.

Van Manen’s phenomenology is pedagogic and as such is useful in this study as RTW rehabilitation is about teaching individuals how to optimise their chances of successfully resuming gainful employment. It is worth looking at this in more detail as phenomenology with this as its focus complements my research question. Van Manen suggests that phenomenological research involves

“Reflectively bringing into nearness that which tends to be obscure, that which tends to evade the intelligibility of our natural attitude about everyday life” (1997:30).

This deceptively simplistic description of the purpose of adopting a phenomenological methodology to undertake research appeals to me as it epitomises what I hope to achieve in my interactions with participants. That is, I hope to achieve a better understanding of whether, and how, any aspect of RTW rehabilitation actually assists individuals with TBI in the process of attempting to RTW. It is often difficult to verbalise exactly what are the aspects of certain rehabilitation, or literature that make it particularly worthwhile to each individual.

Indeed, I have struggled whilst undertaking this Doctoral programme to articulate to colleagues, friends and even family what benefits I am getting from undertaking the study. To many, the prospect of undertaking Doctoral study without there being an explicit requirement for study at this level to practice as a clinical expert in a particular field is incomprehensible. However for me the reasons are both personal and professional. What I gain from the experience affects both my personal and professional life. What I am able to contribute
depends on the other demands on my personal and professional life at any given point in the journey. All of this is individual to me, and impossible to replicate in another occupational therapist undertaking the same Doctoral programme. However, should there be a discussion, I am sure that there would be common themes that would assist others to make an informed decision when considering undertaking Doctoral study in the future. Those themes would, in my opinion, be interpreted individually by any number of persons who read them and take on a personal meaning that could not be wholly replicated by another person.

Van Manen (1997:9) also argues that phenomenology within research aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. He continues:

“It differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomising, classifying, or abstracting it”.

As stated earlier, Husserl’s phenomenology is the descriptive study of the lived experience (phenomena) in the attempt to enrich lived experience by mining its meaning. Hermeneutics is the interpretive study of the expressions and objectifications (texts) of the lived experience in the attempt to determine the meaning embodied in them. The aim of interpretative phenomenology is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which the reader is powerfully animated in his or her own experience (Van Manen 1997). This is an important aspect of occupational therapy practice, and indeed is a main feature of being an advanced practitioner. Table 3.2 provides a summary of the differences between descriptive and interpretative phenomenology.
Table 3.2  Descriptive & Interpretative Phenomenology
From: Maggs-Rapport (2001)

<table>
<thead>
<tr>
<th>Descriptive Phenomenology</th>
<th>Interpretative Phenomenology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Going back to the subjects or using ‘judges’ is not a legitimate way of validating data. The expertise of the researcher and, most importantly, the participants determines that imaginative variation and intuition is the basis of the validity</td>
<td>Validity may involve returning to the subjects themselves for confirmation or denial of the authenticity of the data or using external judges to test the validity of findings</td>
</tr>
<tr>
<td>Analysis as an intensely in-depth process means limits on size are necessary for the research to be practical. Small sample, in-depth work is preferable.</td>
<td>Analysis enables samples of varying sizes to be examined</td>
</tr>
<tr>
<td>Whatever shows up is described precisely as it shows itself. The researcher does not go beyond the data.</td>
<td>The interpreter attempts to go beyond the data to account for the data in a complete and non-contradictory manner</td>
</tr>
<tr>
<td>The descriptivist does not try to reduce the data but to describe the account in a non-ambiguous manner.</td>
<td>The interpreter offers an interpretation of the data to make sense of disparate or ambiguous meanings</td>
</tr>
<tr>
<td>Self-interpretation like all other types of interpretation can be bracketed. Only coherent descriptions can be made.</td>
<td>Data can only be interpreted, because humans are self-interpretative</td>
</tr>
<tr>
<td>If the statement opposite were true then the statement itself would be an interpretation and as such its validity would be open to question.</td>
<td>Everything is an interpretation</td>
</tr>
</tbody>
</table>

3.6  Interpretative Phenomenology
To undertake an interpretative phenomenological study of any topic it is not enough to simply recall experiences others may have had with respect to a particular phenomenon. Instead, the researcher must recall the experience in such a way that the essential aspect, the meaning structures of this experience as lived through, are brought back, as it were and in such a way that we recognise this description as a possible experience. This means that we accept
that the recounting is an individual interpretation of that experience. By the same token, in order to fully appreciate what is happening in a setting we need to know what things mean to participants (Charmaz 2004). This means that the researcher needs to have an understanding of their language and be able to convey this in the formulation of themes.

Interpretative phenomenology based on Heideggerian philosophy (Allen et al. 1986, Heidegger 1962, 1975) is a qualitative research methodology used when the research question asks for meanings of a phenomenon with the purpose of understanding the human experience (Crist & Tanner 2003). The research methodology informed by interpretative phenomenology seeks to reveal and convey deep insight and understanding of the concealed meanings of everyday life experiences (Cohen & Omery 1994, Ray 1994). The goal of interpretative phenomenology is to achieve an increased understanding of the multiple interpretations of the meaning of human experience (Crist & Tanner 2003, Lopez & Willis 2004). As such, the research is discursive and reflexive. The interpreter attempts to go beyond the data to account for the data in a complete and non-contradictory manner.

According to Maggs-Rapport (2001) interpretative phenomenology can be used for many purposes within research:

- To explore the meanings in phenomena
- To explore the hidden meaning embedded in the words of research participants.
- To undertake data collection in the workplace or research environment (interviews/texts/dialogue)
- To understand through language without which there would be no meaning.
- To enable the interpreter to go beyond the data in order to draw out an explanation for the data.
In summary, my choice of methodology for the research was that of interpretative phenomenology. The main purpose of undertaking this research was to enhance my understanding of the lived experience of engaging in return to work rehabilitation. This did not comply with Husserl’s initial concept of phenomenology as being purely descriptive and non-interpretative. Moreover it would not have been possible for me to ‘bracket’ my own understandings of the experience as I am involved in the delivery of much of the RTW rehabilitation provision within NWBIS.

As phenomenology developed, Heidegger developed the concept of understanding within phenomenology, and suggested that it is not necessary to set aside one’s own pre-understandings of phenomena under question. He argued that these pre-understandings need to be declared and form part of the eventual themes that are generated. This will inform the reader of the context in which the researcher makes their interpretations of the text. Despite the scarcity of literature informing clinicians of the value, or not, of RTW rehabilitation, I, as a specialist clinician in this area of work, have provided RTW rehabilitation for individuals with TBI for twelve years. Whilst both the content and delivery of the package has differed for different patients it generally includes exploring current abilities and correlating those to occupational demands in both the clinical and occupational/employment settings. However this phenomenon (RTW rehabilitation) needed exploring in greater depth, and in a manner that acknowledged the individual who had experienced it. Thus my choice of interpretative phenomenology as the methodology for this study was influenced initially by the works of Heidegger, and, latterly, van Manen.

3.7 Choice of Method
Within the framework of interpretative phenomenology it was necessary to adopt a method of eliciting data that would further complement the requirement to focus on the patients who had undergone the experience of RTW rehabilitation. To this
end, the most recent literature was searched to explore methods utilised by previous researchers undertaking research with participants who had brain injury. Oppermann (2004) collected her data initially via semi-structured telephone interviews with two participants who had TBI, and with whom she had not previously established a therapeutic rapport. Oppermann was exploring individuals’ experiences of the meaning of the concept of work, which is not tangible and is emotionally laden dependent upon experience. It could be argued that divulging emotive and possibly contentious viewpoints over the telephone with an individual, with whom they had not established a therapeutic relationship, bearing in mind possible cognitive and dysexecutive difficulties may have been restrictive for the participants. Telephone interviews have a tendency to generate superficial data and to be restrictive in getting to the nub of issues as there is no face to face contact. This is evident in the verbatim quotations she produces to justify her analyses, which are, in many instances brief and scant, and open to many alternative interpretations. Possible methodological limitations of the study are not discussed by Oppermann.

The study by Bowen et al. (1999) aimed to evaluate the effectiveness of a specialist community-based neuropsychological rehabilitation service for people with TBI compared with the previous generic locally based services that had been available to them. They used standardised outcome measures in the fields of emotion, social behaviour and cognition to evaluate the effectiveness. The measures provided strictly quantitative data and reported success (or not) in terms of statistical significance. The focus of the discussion was, interestingly, on the skill base of the clinicians in the service, as opposed to the therapeutic value of the service form the patients’ perspective. Moreover, despite the study having a large number of participants \( n = 142 \) it was not possible to generate any generalisable findings. Whilst the study was useful for identifying that there is a need for long-term intervention with adults who have TBI, the data collection methods used did not fully address the aim of the research.
Darragh et al. (2001) utilised semi-structured interviews to elicit themes from a sample of 51 participants to identify practitioner qualities and traits that clients with brain injury see as important. Despite using an interview guide, the interviews were conducted by 4 different researchers. Whilst the researchers were trained in their interviewing, and asked the same questions in the same order, there must have been biases in the narratives because the nature of the interviewing was semi-structured. The authors openly admit in their introduction that people’s experience of the needs, services and outcomes of rehabilitation differ based on the position from which they experience the phenomenon. Thus, it follows that the 4 researchers would have experienced the responses to the questions posed to the sample group differently. The results may have been more rigorous had there been only one researcher actually interviewing, thereby ensuring consistency in approach with a semi-structured method.

Huebner et al. (2003) examined outcomes salient to occupational therapy, including work related activity, in adults who had sustained TBI (n=25). This study used telephone interviews to administer standardised questionnaires to the participants. Using this method can be an effective method for eliciting data suitable for comparisons across a larger participant sample. However, the results are numerical, and in using a number of standardised measurements (4) during one telephone discussion it may have led to a degree of confusion, bearing in mind the presentation of the sample group. In addition, such telephone interviews may be associated with fatigue, inaccuracies in rating systems, and distractibility. All these factors may have impacted on the results. The authors admit that despite feedback on the occupational therapy services being extremely positive, this was not reflected in outcome ratings of the standardised measurements used in the study.

Patton (1990) describes phenomenological inquiry as a focus on “what people experience and how they experience the world”. Patton also noted that persons experiencing a similar phenomenon share an ‘essence’. In this study, adopting
an interpretative phenomenological framework enabled me to examine the shared experiences of individuals who had engaged in RTW rehabilitation further to sustaining TBI, and attempted to return to the employment market. There is a general acceptance that utilising a semi-structured interview format enables participants to offer richer and fuller accounts of their own views and concerns, thereby producing a more in-depth analysis (Willig 2008, Smith 2008). Tyerman & Humphrey (1984) contend that the head injured person’s own perspective has been sadly neglected in the literature. Indeed Russell (2001) suggests that many individuals with TBI report fervent feelings of the experience that outweigh the physical changes in their bodies. Such feelings would be impossible to extrapolate fully in numerical data generated through use of quantitative methods. It must be remembered that the participants in the study presented with varying degrees of executive and dysexecutive functioning which, it could be argued, could have biased their narrative, and thus the interpretation of the findings by the researcher. However Tyerman and Humphrey (1984) argue that even though accurate self appraisal is limited in individuals who have sustained TBI, the subjective impairment is the reality for these patients. A person’s subjective experience also provides important information to the researcher and the therapist. Thus, based on the literature, a semi-structured interview method was adopted for this study.

3.8 Semi-structured Interviews
Semi-structured interviews were chosen for this research because my ontological position suggested that people’s knowledge, views, understandings, interpretations, experiences and interactions are meaningful properties of the individual realities which my research questions were designed to explore. Furthermore my epistemological position suggested that a legitimate way to generate data was to interact with people and gain access to their accounts of their experiences. However some clinicians and researchers may argue that using interviews is limiting in this respect because I was interested in people’s experiences; but in the interview, those experiences would only be recounted.
Thus I could only gain access to those interpretations and understandings which would be revealed in some way during the interview. However, history is generated in the present, even though it occurs in the past, and as such the responses of the participants were essential to inform future clinical practice.

What I wanted to know about was complex and may not have been clearly formulated in the interviewee’s minds in a way in which they could simply articulate in response to a short standardised question. My role as researcher was thus an active one, facilitating question answering. I positioned myself as active and reflexive in the process of data generation, rather than as a neutral data collector, and I proposed to analyse my role within this process by keeping field notes of the interviews and exploring my preconceptions and reactions during the individual interviews. However in this process I explicitly accepted that during some interviews I may have become uncomfortable with the constructions held by participants and was aware that I may have been able to suppress the flow of discussion sub-consciously by changing my posture and re-directing questions. By being aware of this dynamic prior to undertaking the interviews I was able to prepare to minimise the opportunity for this to occur and colour the interview. I saw the interaction between me and the participants as pivotal in eliciting the information required to answer the research questions.

It was possible to undertake semi-structured interviews with the participants ensuring that the research question was addressed within the discussions whilst simultaneously allowing flexibility for other, relevant information to be elicited by having an ‘interview aide de memoire’ with a flexible list of potential topics to cover in the interviews (Appendix 4). The flexible list of topics were summarised on cue cards taken by the researcher into each interview. The questions were generally open-ended and constructed to focus on the participants’ experience of RTW rehabilitation, and to facilitate their verbalisations of their perspectives and/or feelings regarding this. A degree of structure was required as there were a number of aspects in the individuals’ presentation that made it difficult for them to
focus or ‘keep to the topic in hand’. This was managed by referring back to the
list of topics and/or asking questions in a different way to prompt participants
back to the initial question. This was in accordance with Mason (1996) who
suggested that semi-structured interviewing should adopt a thematic, topic-
centred, biographical or narrative approach, for example where the researcher
does not have a structured list of questions, but does usually have a range of
topics, themes or issues which s/he wishes to cover. As such the discussion
during the interviews was led, in the main, by the participants. Not all the topic
areas were necessarily addressed in the same order with the participants, in line
with my epistemological position of the interviews being participant directed.
Mason (1996) also considers that qualitative interviewing is characterised by a
relatively informal style, for example with the appearance of a conversation or
discussion rather than a formal question and answer format. The assumption is
that data are generated via the interaction, because either the interviewee(s), or
the interactions itself, are the data sources.

The interview questions were divided into five broad areas and sought
information regarding the individuals’ experiences of:

- Their employment status prior to sustaining their TBI and what value it held
  for them
- Their current employment status
- RTW rehabilitation
- The changes which they feel may have occurred as a result
- Their suggestions for ensuring quality RTW rehabilitation for individuals in the
  future

Employing a semi-structured interview format allowed sufficient focus upon those
aspects requiring direct examination as implicated by the interpretative
phenomenological methodology, while providing enough open-endedness to
facilitate exploration of other salient themes that arose.
All participants were provided with a consent verification form to complete ten minutes prior to the interviews taking place (Appendix 5). This was to ensure that they were fully informed of what they were agreeing to participate in, and was considered essential in view of their cognitive and emotional presentations. This form provided them with the opportunity to withdraw from the study at this point. The interviews were audio recorded using a Sony Digital Recorder that was placed adjacent to the participant. They were informed at the start of the interviews that they had control of this equipment and may turn it off at any time. Throughout the interview process, vocal intonations, physical expressions, and gestures that might not be audible in the recorded interview were included in the field notes and were later incorporated into the analysis of the transcribed texts.

3.9 The venue
All participants were offered the opportunity to be interviewed in a clinical room within the NWBIS, or if necessary due to transport or familial issues, they could be interviewed in their own homes. Nine participants requested to be interviewed in the clinical setting, and one in her own home. The room chosen in NWBIS was a room used by clinicians for routine appointments and rehabilitation activities on a regular basis. It was familiar to all participants. It was located in a secluded area of the unit, thereby attempting to eliminate possible distractions such as noise from traffic, noise from other clinical appointments and/or interruptions by clinicians. The telephone in the room was disconnected for the time of the interview. The panic alarm was not disconnected. In addition it was ensured that no interviews took place during the times of a regular fire alarm practice.

The room was set out with two comfortable armchairs around a small coffee table. Cold drinks (fruit juice, still and sparkling water) were placed on the table, and glasses for the participants to use. In addition a small selection of biscuits were available. Hot drinks were offered before the interview commenced, and again at the end. Participants were offered regular breaks, particularly when they
presented with signs of fatigue such as yawning, reverting to closed answers to questions, or inability to focus on the questions put to them. To promote freedom of expression of personal feelings and needs participants attended the interview independently as it is recognised that often patients and carers ‘protect each other’ from their individual fears and needs. The only exception considered was if a patient had expressive communication problems that required the input of a specialist Speech & Language Therapist to be present during the interview.

3.10 Selection of Participants
After gaining ethical approval from the North Wales Central Research Ethics Committee potential participants were selected from a database of over 1,500 adult patients registered with the North Wales Brain Injury Service (NWBIS). All these individuals have a non-degenerative acquired brain injury. Further to informal presentations to my colleagues working at NWBIS regarding the research, and their subsequent agreement to assist in the process of recruitment of participants, the clinicians identified potential research participants who fell within the inclusion criteria for the study. The clinicians involved in recruiting the participants formed the multi disciplinary team within NWBIS and included physiotherapists, occupational therapists, social workers, neuropsychologists, speech and language therapists, and neurologists. It was agreed from the start that no potential participants would be identified who, in the opinion of their key clinician, would have no possibility of obtaining a therapeutic score on the Awareness Questionnaire (AQ) (Sherer 2004). This consideration was included to reduce the chances of potential participants being rejected from the study once they had consented to participate.

Ten participants were approached by their key clinician to take part in the study. All ten agreed to participate. In addition, all ten of the identified ‘significant other’ in the participants’ lives agreed to participate. As such, no one was eliminated from the study. Further to administering the AQ, all ten participants fell within the inclusion criteria for the study. This is discussed further later in the chapter.
3.10.1 Sampling

Purposive sampling of participants was essential for this study. Sampling in research is the active process or technique of selecting a suitable sample or representative part of a specified population for the purpose of either determining parameters or characteristics of either the whole population, or further informing the understanding of that specified population (Mugo 2006). In order to avoid sampling errors this study was constrained by inclusion and exclusion criteria in order to, as far was reasonably practicable, ensure that the sample group had experience of some similar life events both before and following sustaining their TBI and would therefore have a lived experience of the RTW rehabilitation post TBI phenomenon.

Miles & Huberman (1994) offer a comprehensive account of sampling which guided my choice to include intensity and criterion sampling for my study. Intensity sampling selects information-rich cases that manifest the phenomenon intensely but not extremely. Thus the participants had to have actively participated in the RTW rehabilitation experience and have the cognitive ability to verbalise their constructed individual experiences. Criterion sampling selects individuals that meet the same criteria, hence the conformation of participants with the inclusion and exclusion criteria. Details of the inclusion and exclusion criteria for participants in my study are given below:

3.10.2 Inclusion criteria

That participants:
- Were over 18 years of age
- Were under 65 years of age
- Had sustained a TBI
- Were in productive employment prior to sustaining their injury
- Had engaged in specialist RTW rehabilitation
- Had attempted to return to work following the rehabilitation
• Had completed the Awareness Questionnaire and their scores were comparable to the scores provided by their key clinician and significant other.

3.10.3 Exclusion criteria
• Brain injury acquired through a non-traumatic cause
• No previous experience of employment prior to sustaining their TBI
• Current drug and/or alcohol related problem
• Current diagnosis of mental health problems requiring active intervention from a Psychiatrist or Neuro-psychiatrist
• Over 65 years of age

3.10.4 The Awareness Questionnaire (AQ) (Appendices 6, 7, 8)
An important part of the criterion sampling for this study was the administration of the self-awareness survey instrument as part of the inclusion criteria. Some researchers have questioned the ability of individuals with TBI to give valid and reliable information (McKinlay & Brooks 1984). Distortion of judgement, self-awareness and insight are common presentations in individuals who have sustained TBI. Current theories on self-awareness in the ABI population suggest that impairments of self-awareness are either organic-neurologically based, psychologically based, or an integration of both (Abreu et al. 2001, Ownsworth et al. 2002). An often voiced criticism of previous studies extrapolating narratives from individuals with ABI is that there have been no measures to ensure quality of the information provided, based purely on the common problems with insight and self-awareness (Brown et al. 2006, Crisp 1992). However others have argued that the unique insight that these individuals have into the changes and their experience of those changes should be explored (Burleigh et al. 1998). Furthermore, some evidence has shown that information provided by individuals with ABI correlates well with information provided by their relatives (Kreutzer et al. 1998).
More recently researchers in the field of ABI have utilised scaled instruments to verify the potential for eliciting ‘true’ accounts from individuals who participate in research looking at their experiences of phenomena (Paterson & Stewart 2002). However the methodology used from then is strictly qualitative in design, utilising methods facilitating rich narrative accounts (Brown et al. 2006). I considered that utilising a self-awareness survey instrument in the recruitment stage of the research process would determine whether the accounts provided by the potential participants in the semi-structured interviews would be born out of a credible and trustworthy basis. A range of methods are available to assess awareness. These include clinician ratings of awareness, ratings based on patient versus significant other’s perceptions, and the difference between patient prediction of and performance on cognitive or functional analysis.

Clinician ratings of awareness utilise open-ended (Giacino & Cicerone 1998), semi-structured (Starkstein et al. 1992) or structured interviews (Flemming et al. 1996). The presence of impaired awareness is ascertained either by clinical decision or by the use of a scoring method. The determination of impaired awareness by clinical decision is underpinned by the assumption that it is a symptom reliably elicited in clinical interview (Clare 2004). This method is relatively unsophisticated and may be applicable for more obvious anosognosia, that is a condition in which a person who suffers disability seems unaware of or denies the existence of his or her disability (Campodonico & McGlynn 1995). In contrast, Flemming et al. (1996) developed the Self-Awareness of Deficits Interview (SADI) as a means of gathering both qualitative and quantitative information on self-awareness. This is a structured interview in which the examiner asks the individual specific questions relating to self-awareness. The scale allows questioning in three areas: self-awareness of deficit, self awareness of functional implication of deficit, and ability to set realistic goals. The interviewer then scores according to a pre-established rating scale to determine the level of self awareness. Whilst this instrument has been widely used and evaluated in the field of brain injury (Flashman & McAllister 2002, Ownsworth et al. 2000), it was
not considered suitable for the purpose of providing a snapshot of levels of self-awareness in potential participants for this research. As I was looking for a tool to use as part of the inclusion/exclusion criteria, I needed an instrument that would be quick to administer, not cause undue distress to the potential participant, and not distract from the focus of the study itself.

Self-awareness is most commonly assessed by comparing patient self-ratings with those of significant others or clinicians (Simmond & Flemming 2003). Two such instruments are the Patient Competency Rating Scale (PCRS) (Prigatano et al. 1986) and the Awareness Questionnaire (AQ) (Sherer et al. 1998). The PCRS was developed as a method of comparing patient’ self ratings of competencies with those of relatives or clinicians. The AQ was developed as an alternative research tool to the PCRS (Sherer et al. 2003) and requires pre and post-injury comparisons to be made. Trosset & Kaszniak (1996) have queried whether the discrepancy scores accurately reflect impaired awareness. Toglia & Kirk (2000) have raised concerns as to whether a significant other will provide an accurate and valid rating, and also suggested that clinician ratings may not be objective if biased by factors such as the likeability of the individual. However Campodonico and McGlynn (1995) contend that the three way approach appears to be the most concrete and contextually based method of assessing impaired awareness. The AQ was thus chosen for this study.

The AQ requires persons with TBI to compare their post-injury abilities to their pre-injury abilities. The AQ consists of 3 forms; one form is completed by the person with TBI, one by a family member/significant other, and one by a clinician familiar with the person with TBI. The self-rated and family/significant others forms have 17 items while the clinician form has 18 items. On each form, the abilities of the person with TBI to perform various tasks after the injury as compared to before the injury are rated on a five point scale ranging from "much worse" to "much better." The scale allows questioning in three areas: Self-
awareness of deficit, self awareness of functional implications of deficit, and ability to set realistic goals. The AQ takes about 10 minutes to administer.

Three indices of self-awareness can be derived from the three forms of the Awareness Questionnaire. Individuals who have impaired self-awareness will rate themselves as less impaired in cognitive, behavioral, and motor functioning than will family members or clinicians. Two indices of the degree of impaired self-awareness can be calculated by subtracting the total for the 17 family/significant other ratings from the total for the 17 patient self-ratings and by subtracting the total for the first 17 clinician ratings from the total for the patient self-ratings. The larger the difference scores, the greater the impairment of self-awareness. Finally, the direct clinician rating of accuracy of self-awareness provides a third measure of impaired self-awareness.

Studies of the AQ have produced good inter-rater reliability of 0.82 (Fleming et al. 1996), 0.85 (Flemming et al. 1998), and test re-test reliability 0.94 (Simmond & Flemming 2003). Preliminary concurrent validity data have also been produced for the AQ (Ownsworth et al. 2000). Further details of the procedural process in administration of the AQ to the potential participant, their significant other, and their key clinician is discussed under recruitment of participants.

3.10.5 Recruitment of Participants

Further to concerns re ethical considerations in undertaking research within my workplace, the North Wales NHS Trust Research & Ethics Committee and I decided that in order to avoid causing stress and possible distress to patients by mailing letters of introduction, clinicians (not including the researcher) within NWBIS would approach the potential participants regarding my research at the end of a routine clinical appointment and provide them with a verbal overview of my research.

In addition, potential participants were provided with:
• An information pack containing an invitation to participate letter (Appendix 9), information sheets about the research (Appendix 10) and consent form (Appendix 11)
• An AQ for them to complete (Appendix 6).
• A stamped envelope addressed to the NWBIS for the participant to return the completed consent form and AQ.

The covering invitation letter asked patients to identify the person they felt assisted them with most of their informal care requirements. This person is referred to within the context of this study as the ‘significant other’. Within the pack provided to the potential participant, there was a pack provided for the identified significant other containing:

• A covering letter providing information regarding the research involving the participant (Appendix 12).
• Information sheets about the research (Appendix 13)
• An AQ for a significant person in the participants’ life to complete about the participant (Appendix 7)
• A stamped envelope addressed to NWBIS for the participant’s significant other to return the completed AQ.

No contact was made by the researcher, either directly or indirectly, with any potential participant until the consent forms and AQ’s from both the potential participant and their significant other were returned. This addressed the concern that participants should not feel coerced to participate, thus causing them unnecessary stress and potential distress.

Upon receipt of the completed forms and questionnaires from both the potential participant and the ‘significant other’, the researcher contacted the key clinician involved with the potential participant by looking in the medical files and establishing the potential participants’ key worker. The clinician completed an AQ on the participant (Appendix 9) and the scores were analysed to establish that the potential participants had obtained a therapeutic score; that is there was little
discrepancy in the scoring provided by all three individuals: participant, significant other and key clinician. Once accepted as fulfilling all the inclusion criteria of the study, a letter was sent to their GP informing them of the individual’s intention to participate in the study (Appendix 14).

3.10.6 Number of Participants

The sample size in a qualitative study is difficult to establish without having a firm methodological framework. When adopting interpretative phenomenology and having semi-structured interviews as the method it is essential the sample should be large enough to capture the many facets of the phenomenon, and limitations to the sample size should be clearly justified (Kuper et al. 2008).

In a review of qualitative research where interviews were utilised as the data collection method Brocki & Weardon (2006) found that participant numbers vary from one (Robson 2002) to thirty (Collins and Nicholson 2002). Smith & Osborn (2003) note that sample size depends on a number of factors and that there is no ‘right’ sample size. Touroni & Coyle (2002) argue that qualitative research seeks to produce in-depth analyses of a small group’s account rather than representative samples. Turner et al. (2002) used twelve participants in their study as they felt that this number of participants provided them with sufficient data to generate the themes. For this study I included ten participants as I considered this would provide me with the richness of the data required to undertake a robust study.

3.11 Data Analysis

3.11.1 Interpretative Phenomenological Analysis:

In considering the most appropriate qualitative data analysis framework for the proposed study it was important for me to keep in mind the rationale for the study, described previously. There were several qualitative data analysis frameworks available, which differ from each other with regards to their theoretical perspective and methods of collecting and analysing the data.
Interpretative Phenomenological Analysis (IPA) is a qualitative framework of data analysis that has been recently developed (Willig 2008, Smith & Eatough 2006). This framework aims at understanding the personal perception of an event or an object and is thus phenomenological. IPA is concerned with cognitions and attempts to gain an understanding of what a person believes or thinks about an object or event; that is how they are making sense of their personal world. It is conceded (Smith 1996) that the person’s thoughts and beliefs are not transparently available through interview data, as access depends upon, and is complicated by, the researchers own conceptions of the topic being explored. However, unlike Grounded Theory approaches IPA does not attempt to eliminate such preconceptions but rather considers their inclusion essential for the interpretative understanding of the person’s perceptions, attitudes and beliefs. For this reason IPA is employed to represent these facets of the data analysis.

3.11.2 Conducting Interpretative Phenomenological Analysis

Smith and Osborn (2008) describe semi-structured interviews as the exemplary method for IPA, and the vast majority of work published using IPA follows suit. Alexander and Clare (2004) describe their interview process as ‘collaborative, emphasising that the participants were the primary experts’ (p.82) and this sort of approach is certainly in keeping with the aims of IPA research.

“The aim of Interpretative Phenomenological Analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants”. (Smith & Osborn 2008:53)

The focus of IPA is very much on the uniqueness of the individual’s experiences, how experiences are made meaningful and these meanings manifest themselves within the context of the person both as an individual and in their many cultural roles, for example as an individual who has sustained TBI, as a parent, partner, employee, friend. Thus, once the data have been collated and transcribed, IPA is utilised as an iterative framework of data analysis, which, through successive
interactions between the analyst and the text allows identification of themes amongst the responses of individuals forming the sample.

According to Smith & Osborn (2008) when employing IPA, a two-stage system of interpretation takes place. The participants are trying to make sense of their world (or in the case of my study; their experience of a specific aspect of rehabilitation). The second stage is that the researcher is trying to make sense of the participants trying to make sense of their world. I would further propose, that in the reading of the analysis, a further interpretation takes place in that the reader is trying to make sense of the researcher’s analysis of the participants’ interpretation of their world.

3.11.3 Possible Limitations of Using IPA For my Study and How They Were Addressed:

IPA studies are, out of necessity, conducted on small sample sizes. Review of the literature reveals that most studies have between four and twelve participants, with many averaging eight participants. It is argued that the small sample sizes involved in studies adopting IPA as their method of data analysis could be considered a weakness of the research as the results are not generalisable to the population at large. This was not a concern for my study as my aim was to develop an enhanced understanding of the phenomenon of RTW rehabilitation as experienced by individuals who had sustained TBI. Thus my research framework was not geared towards eliciting results that would be generalisable to the population at large.

More pertinent in my research was the concern that my interpretations were bounded by the participants’ abilities to articulate their thoughts and experiences adequately (Baillie et al. 2000). I addressed this issue by utilising semi-structured interviews as my data collection method. This strategy was in keeping with my methodological framework and also provided a structure enabling me to facilitate participants to share rich narratives of their experience of the phenomenon. As
such my role as interviewer needed to be skilled to elicit detailed experiences from participants who often found focusing on the question being asked difficult. This is discussed further in my description of participants. My role as a skilled interviewer, therefore, depended upon my ability to adopt each participant’s language during interview and understand their narratives. This included, on occasion, the skill of being bilingual, as some phrases were given in the Welsh language and do not have a literal translation into English.

The successful analysis of each account to elicit ‘true’ themes was dependent upon the researcher’s ability to reflect and analyse. As such, my role was active and making sense of the accounts collated. Each account was read and re-read, and the benefits were that the more familiar I became with each account the more enlightened and complete was the subsequent analysis (Shaw 2001). Many researchers consider it essential to have a method for ‘checking’ that the analysis of each account is truly representational of the narratives elicited. This has been included in many of the published studies (Alexander & Clare 2004, Shaw 2001). Indeed Robson (1993) suggested that researcher triangulation was essential to confirm the dependability of the research. Whilst I did not adopt triangulation for my ‘checking’ I did liaise with another researcher experienced in IPA to ensure that I had followed the IPA process to generate the themes.

I did not include respondent validation in my research, that is, provide the participants with a copy of the transcript and initial themes, and confirm that my interpretations of their accounts accurately reflected what they meant. This was a deliberate choice based on the ontological and, particularly, epistemological position I held in undertaking this study. The accounts provided on a particular day by each participant were, in my opinion, dependent upon perceptions of their experiences that day which may change over time. As such, if the participants were asked to confirm their accounts at a later date, their perceptions may have changed somewhat and they may have disagreed with what they had said at the time of interview. My study stated explicitly that I was interested in the accounts provided at a given time and the interpretations were purely mine. This subject is
currently the topic of debate amongst researchers undertaking IPA data analysis, but given the interpretative nature of the approach, it is not now applied in the majority of IPA research (Flowers 2007). The one safeguard that was included is that I stated that possibly all the participants would be invited for a further interview to re-visit specific themes if there was ambiguity. This would have provided me with the opportunity to ensure that my understandings and interpretations were as robust as possible with the participants. However this was not necessary, and is debated further in the discussion chapter.

3.11.4 How Interpretative Phenomenological Analysis was conducted:
IPA is small sample research based on the detailed case-by-case analysis of individual transcripts. An audit trail of the data collection and analysis of the data is provided in Appendix 15. Transcripts were analysed in accordance with IPA (Smith 1995, Smith et al. 1999, Smith et al. 2002). Smith (2008) advised that transcription of the interview should be undertaken as one uninterrupted task. This was not always possible due to other commitments. The interviewer’s questions were also transcribed. All interviews were fully transcribed by the researcher after listening to the recordings on at least two occasions. Once transcribed, I also read the transcripts three times. This enabled me to immerse myself in the data.

The transcripts were annotated and coded for the presence of important themes. Space was provided on the left and right margins of the page to allow for notations involved in the analysis. During the first two readings the left-hand margin on the transcript allowed me to note what was interesting or significant about what the participant has said. Smith (2008:67) suggested the following possibilities:
- Attempts at summarising or paraphrasing the text, some of which will be associations or connections that come to mind
- Preliminary interpretations
• Comments on the use of language by the participants and/or the sense of the persons themselves coming across
• Similarities and differences, amplifications and contradictions in what a person is saying

The right hand margin was used to document emerging theme titles during the third, and any subsequent, readings of the transcripts. An example of the analysis is seen in Appendix 16.

The initial notes were transformed into concise phrases that aimed to capture the essential quality of what was found in the text. This was where the process became explicitly interpretative. As discussed by Larkin & Griffiths (2004) some of the themes were unique to individual participants, and others drew on concepts developed across the transcripts. A summary document containing all instances of each topic were generated from the first transcript. The process was repeated for each transcript with the interviews analysed in turn. A summary of the topics generated during interviews is seen in Appendix 17.

The themes generated from the first transcript helped to orient the subsequent analysis of texts. By being aware of the themes that had been generated previously it was possible for me to identify what was new and different in subsequent transcripts, and at the same time find responses that further articulated the existing themes. The initial list of themes was drafted in chronological order, based on the sequence they came up in the script.

For the purposes of ensuring that the principles of IPA had been fully adhered to during the process of analysis another researcher experienced in the process of IPA read through each transcript and list of themes, master themes and quotes ensuring the emerging themes were visibly grounded in the data and none had been omitted. Discussion between the researchers resulted in minor changes to the arrangement of themes. The master theme list changed constantly throughout analysis and write up, with the addition and collapsing of themes into
categories until a final list of five themes emerged. An audit trail of the process is presented in Appendix 15.

A table of themes was collated which captured the participants’ experience of the RTW rehabilitation they had engaged in. This is seen in chapter 5. The clusters were divided into named sub-themes. The table listed the sub themes, which went with each superordinate theme, and an identifier was added to each instance to aid the organisation of the analysis and facilitate finding the source in the original text.

All of the above stages followed the basic procedures of inductive research, from the particular, to the general, which is the underpinning of IPA. They were derived from those outlined by Osborn & Smith (1998), Smith et al. (1999), Willig (2008). Moreover in developing an account which focused first on experience (phenomenology) and then upon a wider range of epistemological approaches (interpretation of the individual’s reflections on their subjective experiences) I adhered to the principles of IPA as outlined by Smith & Osborn (2008).

3.12 Establishing Rigour in the Study

It is argued by de Wit & Ploeg (2006) that it is difficult to define a generic set of qualitative criteria to establish rigour for interpretative phenomenological studies because to do so is philosophically inconsistent with the methodology and creates obstacles to full expression. For the purpose of this study, rigour is defined as the ‘trustworthiness’ of research. However my study adopted the following criteria to ensure rigour as suggested by de Wit & Ploeg (2006):

- Balanced integration – that is the intertwining of philosophical concepts in the study methods and findings and a balance between the voices of the study participants and the philosophical explanation.
- Openness – this is related to the systematic, explicit process of accounting for the multiple decisions made throughout the study process. This criterion is an often repeated one spanning ten years of dialogue in the literature and

- Concreteness – relates to the usefulness for practice of the study findings
- Resonance – this encompasses the experiential or felt effect upon the reader of reading the study findings.
- Actualization – this refers to the future realisation of the resonance of the study findings.

3.13 Demonstrating Rigour in the Process of Data Analysis
There were a number of general considerations concerning phenomenological methodology that had implications for the choice of specific methods of qualitative analysis. Recently a much greater interest has been taken in the standards required for reliable and valid exploration of clinical and psychological phenomena. This interest has resulted in the development of guidelines (Elliott et al. 2000) that aim at the generation of qualitative research that allows reliability and validity of findings to be openly assessed. It is, however, recognised that such guidelines must stop short of demanding complete uniformity of method, which could stifle creativity. With regard to rigour in the data analysis process in this study Elliott et al.’s (2000) guidelines were addressed in the following manner:
Table 3.3 Implementation of Elliott et al. (2000) Guidelines on Data Analysis

<table>
<thead>
<tr>
<th>Guideline</th>
<th>How it was addressed in this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owning one’s perspective and stating the researcher’s personal position</td>
<td>I stated my ontological and epistemological position and how they impacted on my methodological choice. I also placed myself as an active and reflexive researcher in interviewing.</td>
</tr>
<tr>
<td>with regard to the object or event to the object or event under</td>
<td></td>
</tr>
<tr>
<td>examination.</td>
<td></td>
</tr>
<tr>
<td>Situating the sample relative to the general population that serves to</td>
<td>The criteria for inclusion in the study were made explicit. The following chapter provides details of the participants’ demographic data and vignettes of their cultural contexts.</td>
</tr>
<tr>
<td>aid the reader in judging the ranges of people and situations to which</td>
<td></td>
</tr>
<tr>
<td>the findings may be relevant.</td>
<td></td>
</tr>
<tr>
<td>The use of examples that allow appraisal of the data and the researchers’</td>
<td>An excerpt of a transcription is provided in Appendix 16. Verbatim quotations are included in the chapter detailing my findings along with my interpretations, and further explanatory information where necessary to clarify interpretations for the reader.</td>
</tr>
<tr>
<td>interpretation.</td>
<td></td>
</tr>
<tr>
<td>Providing credibility checks such as verification of an identified theme</td>
<td>Multiple excerpts of verbatim quotations are included in the findings chapter where relevant. However this is not the case throughout as IPA also embraces individuality.</td>
</tr>
<tr>
<td>amongst the data, through checking that such a theme can be located in</td>
<td></td>
</tr>
<tr>
<td>the data obtained from individuals across the sample.</td>
<td></td>
</tr>
<tr>
<td>Where possible and relevant, employing a process of ‘triangulation’ which</td>
<td>The generation of themes that were grounded in the verbatim quotations in this study was verified by an external researcher experienced in the data analysis method of IPA.</td>
</tr>
<tr>
<td>employs useful sources of data external to the primary data source, which</td>
<td></td>
</tr>
<tr>
<td>may also verify the legitimacy of the identified data.</td>
<td></td>
</tr>
</tbody>
</table>

3.14 The position of the researcher

Brew (2001:3) suggests that:

“Anyone coming into the research arena or wanting to understand more about the nature of research faces a number of puzzles”.

This is caused partly be the fact the traditional empirical research has to give way to new forms of enquiry, requiring self-knowledge on the part of researchers
(Dunne et al. 2005). This is discussed further in the following paragraphs as it related to my research.

Giddens (1984) offered his structuration theory to help researchers locate themselves within their studies. His theory was that as reflexive researchers we simultaneously draw on and construct a social reality. Thus in my study, whilst interviewing the participants, I drew on the experiential narrative material that would provide a deeper and richer understanding of the lived experience of the phenomenon of RTW rehabilitation. In addition, the interviews were considered, by me, to be a vehicle to develop a conversation with participants about the meaning that experience held for them. Simultaneously I was constructing my own understanding of their narratives, based on the content of their narratives, their actions, display of emotion etc.

As such, my role as interviewer needed to be disciplined and focused to ensure that the participants’ responses satisfied those criteria. This involved being directive both verbally and non-verbally; encouraging when the aims of the research were being addressed, and gently re-directing when participants veered off the topic in hand. By adopting semi-structured interviews as my method, I guarded against letting the method rule the question (which would have been the case had I used unstructured interviews). By utilising semi-structured interviews I ensured, rather, that the research question determined the most appropriate method within my methodological framework. Furthermore, as a researcher, I produced accounts, or interpretations, to explain my understanding of the texts which then become part of the reader’s understanding of the experience of RTW rehabilitation. Koch (1995) argued that studying human experiences in this manner is not concerned with generating new knowledge, but rather with interpreting the lived experience that the individual has understood in a certain way.
The research process in this study was a balanced and co-operative relationship between the researcher and the participants. However, I concede that it was not an equal relationship, as the participants were there to provide accounts of their experiences, but, as stated in the last paragraph, the findings were my interpretations of the meanings of their accounts. In order to generate an enhanced understanding of a phenomenon, I considered it essential that the participants involved in constructing their realities were able, with facilitation, to recount these experiences honestly. This meant that as the researcher, I became involved in the interviewing with the mind set of being willing to have my viewpoint changed, and I came to understand the viewpoint of the participants more. In order to understand, I needed to be able to interpret what was being recounted (Thompson 1990).

My role throughout the research process, therefore, was of an active researcher. My interpretations were made on the basis of the existing understandings between the participants and myself of their experiences. My views were an additional factor that contributed to my interpretations. Haggman-Laitila (1999) argued that this research process thus leads to an understanding between the researcher and the participant, which is a fusion of their views.

My position as a clinical researcher in this study with individuals who ‘knew’ me in the capacity of a clinical specialist posed certain concerns when considering how to undertake the research using semi-structured interviews as the method of data collection. My role as ‘researcher’ was queried and scrutinised; not only by me, but also by the University sponsoring the research, my clinical supervisor and the Ethical teams that reviewed my proposed study. This led me to initially consider not undertaking the research in my workplace due to the potential conflict of roles. This is discussed more fully in later in this chapter. However the Doctoral programme encouraged identifying a ‘disturbance’ within the workplace. Moreover it made sense to add to the existing pool of knowledge, or understanding, by undertaking my research in my ‘back yard’. Charmaz
(2004:978) suggests that when considering the relationship between researcher and participant:

“Conventional scrutiny implies potential damage”. However she further states that “Like postmodernists who argue that we assume power over our participants, review committees inflate our effect on them”.

As such the scrutiny from ethical committees regarding my role would have been the same had I undertaken the research at an alternative location.

When undertaking research in the workplace Dowling (2006) suggested it is impossible to divorce the clinician from the researcher identities when undertaking qualitative research. This may have been because it was the clinician in the researcher that prompted the patients to consent to participate in the study in the first instance. As such I needed to question whether it was me as an occupational therapist or me as a researcher that obtained consent from the potential participants in my research. I suspect it was, in most instances, a combination of both. My duty was to ensure that in the documentation provided to participants beforehand that they were fully aware that in the context of the study, I was a researcher, not a clinician. Moreover, in recognising the potential overlap of roles from the perspective of participants, I needed to bear in mind that it may not have been possible to recruit participants solely on the assumption that it was in my role as a researcher. As such I retained an acknowledgement of my occupational therapist role even whilst undertaking the semi-structured interviews with each participant. In acknowledging this duality of roles for the participants, I propose that this also contributed to generating a more collaborative, non-hierarchical relationship between me and the participants during the research process, where the participants played an active role in the construction of my enhanced understanding of their lived experience (Fontana 2004).

In the analysis stage my role as the researcher was to ‘see’ the phenomenon (RTW rehabilitation) as it was experienced by the participants in order to
enhance my understanding of their experience. To this end I made summary notes at the end of each interview and kept self-reflective notes throughout the research process. This provided me with a reflective account of my understanding of the meaning of the RTW rehabilitation experience had for the participants, in line with my interpretative phenomenological inquiry.

Details of issues relating to my role as a researching clinician have been interwoven previously into the bulk of this chapter. This section, in particular, has provided further details of more complicated issues that required acknowledging prior to, and whilst, undertaking the research. In summary, my role throughout was that of facilitator and interpretator, the degree of which was dependent on each individual participant’s account. The results of my research will provide us with the best understandings to date of the lived experience of engaging in RTW rehabilitation for an individual who has sustained TBI.

3.15 Ethical Considerations in my Study
The National Research Ethics Committee, the Research Ethics and Governors Committee of the University of Brighton’s Faculty of Health, the Conwy & Denbighshire R&D Ethics Committee and the North Wales Central Research Ethics Committee approved the proposal for this study. All participants were deemed to have the capacity to choose to take part. The interview procedure was explained carefully to the participants, and their consent was verified again at the start of the interview process. All participants were assured that they were free to withdraw from the research at any time. Follow up contact with the participants by their key clinicians at their next routine clinical appointments following the interviews did not suggest that they had been adversely affected by the research procedure.

Whilst this research did not focus specifically on sensitive topics such as abuse or death, the emotive area of returning to work could have induced feelings of stress, reduced self belief and isolation for the participants; particularly as the
associated ramifications could include problems in relationships, family breakdown and/or financial hardship not previously experienced. This was managed by offering up to 2 sessions of counselling with an experienced neuropsychologist further to the participant engaging in the research to address any emotive issues constructively. A further monitoring strategy was also implemented in that I took responsibility to inform each participant’s key clinician of the interview date and requested that the clinician also confirm with the participant whether they required the sessions with a psychologist at the key clinician’s next appointment with the participant.

Another consideration was the potential vulnerability of participants in the study as they had sustained an insult to the brain which altered many aspects of their functioning. Although this research did not target children or those with mental health problems, adults who have experienced traumatic brain injury may be considered vulnerable. The researcher addressed this by ensuring that all participants involved in study were individuals over 18 years of age when they had experienced traumatic brain injury (TBI). They were all deemed to have ‘capacity’ under the Mental Capacity Act (2007) and thus were able to consent to participate. They were informed that they were free to withdraw at any time. There was no dependency between the participant and the researcher. This was ensured through the initial recruitment of participants being through a clinician known to them, thus eliminating pressure from the researcher. Furthermore each participant approached by a clinician received an information pack. Ethical issues relating to this recruitment stage have been discussed previously in this chapter.

3.16 Summary
This chapter has provided the reader with knowledge about my ontological and epistemological positions which directed my methodological framework for the study. I have explicitly declared that my role as researcher was an active one, facilitating my enhanced understanding of the meaning that RTW rehabilitation held for the participants through developing a dialogue with them. My
interpretations consisted of the constructions made by each individual of their experience coupled with my understandings of their experiences, which I then interpreted. Strategies to ensure rigour in the study have been discussed and the chronological stages involved in data collection and data analysis have been debated.

A short chapter follows detailing both demographic and descriptive information regarding the participants. An account of the development of themes will also be provided to place the findings in context for the reader thus enhancing their understanding of the chapter detailing my findings.
Chapter 4 Participant Profiles

4.1 Overview
The previous chapter provides the framework justifying my methodology, data collection and data analysis method. Details of the selection process of the participants were included, and ethical considerations related to the study were discussed. This chapter provides both demographic data and descriptive data regarding the participants to enable the reader to contextualise the narratives recounted. Particular effort has been made to ensure that no specific individual identifying information on individual participants is presented within this thesis to adhere to the anonymisation of the participants as agreed at ethical approval. Information pertaining to some individual interviews will also be given to explain the requirement for a more directive approach being utilised in questioning, on occasion, than would be considered traditionally within the framework of a phenomenological study.

4.2 Demographic Data
The participants were drawn from a group of over 1,500 patients registered with the North Wales Brain Injury Service (NWBIS). Ten adults who had sustained traumatic brain injury (TBI) completed the interview (described in the previous chapter). These participants were individuals who had been in employment prior to sustaining their TBI, had engaged in specialised return to work (RTW) rehabilitation as part of their overall rehabilitation package, and had identified RTW as a main goal of rehabilitation. The participants are identified by ‘M’ for male and ‘F’ for female and an identification number to follow. Table 4.1 provides demographic details of the participants.
<table>
<thead>
<tr>
<th>Participant Identifier</th>
<th>Age at time of Study</th>
<th>Level of Education pre-TBI</th>
<th>Age at time of injury</th>
<th>Time since Injury at date of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>M 1</td>
<td>33 years</td>
<td>4 University graduate</td>
<td>30 years</td>
<td>38 months</td>
</tr>
<tr>
<td>M 2</td>
<td>62 years</td>
<td>4 Electrician</td>
<td>54 years</td>
<td>106 months</td>
</tr>
<tr>
<td>M 3</td>
<td>55 years</td>
<td>3 A levels when he left school</td>
<td>52 years</td>
<td>40 months</td>
</tr>
<tr>
<td>M 4</td>
<td>31</td>
<td>3 B Tech</td>
<td>28 years</td>
<td>41 months</td>
</tr>
<tr>
<td>F 1</td>
<td>23 years</td>
<td>3 Completing A levels</td>
<td>19 years</td>
<td>58 months</td>
</tr>
<tr>
<td>M 5</td>
<td>37 years</td>
<td>4 University graduate in computing</td>
<td>31 years</td>
<td>60 months</td>
</tr>
<tr>
<td>M 6</td>
<td>59 years</td>
<td>2 GCSE’s upon leaving school</td>
<td>53 years</td>
<td>63 months</td>
</tr>
<tr>
<td>F 2</td>
<td>31 years</td>
<td>4 University graduate in psychology</td>
<td>27 years</td>
<td>51 months</td>
</tr>
<tr>
<td>M 7</td>
<td>47 years</td>
<td>4 Engineer</td>
<td>40 years</td>
<td>82 months</td>
</tr>
<tr>
<td>M 8</td>
<td>53 years</td>
<td>4 Mechanics</td>
<td>44 years</td>
<td>118 months</td>
</tr>
</tbody>
</table>

**Codes for Education:**

1. No qualifications
2. CSE/GCSE/NVQ/"O" level
3. ‘A’ level/B tech
4. Degree/Professional Qualification
5. Post Graduate

The ages of the participants ranged from 23 years to 62 years (M = 43.1 years, SD = 13.75). The participants were aged between 19 years and 54 years (M = 37.8 years, SD = 12.52) at the time they sustained their TBI, and the mean time since their TBI was 5 ½ years (range 38 months -118 months; M = 65.7 months, SD = 27.85). Four of the participants were English (living in North Wales), and six were Welsh. Two were fluent Welsh speakers. They both received their information packs in both the English and Welsh languages and both requested that their interviews be conducted through the medium of English. Both attributed this request to the fact that they were in relationships where their partners were English speaking and thus were more comfortable in speaking in the English language. None of the participants had sustained a previous head injury prior to
the one documented for the purpose of this study. Details of the brain injury sustained are summarised in Table 4.2.

It is important to ascertain the severity and location of the TBI sustained by participants in order to further contextualise the reader when reading the analysis of the narratives provided. The severity of injury and the location were important considerations for me, as the researcher, when undertaking the interviews as it impacted on my interviewing approach. This is discussed further later in this chapter. Malec et al. (2007) developed a classification system for severity of TBI in order to ensure consistency of classification within their Service (Appendix 18). This system was developed because the details regarding severity of injury were not consistently documented at time of admission to hospital, leading to confusion. The system was constructed to conservatively reflect the severity of brain trauma based on the strength of available evidence. When I undertook my study, I came across similar difficulties in classification of severity of injury. Thus all available information is provided to ensure that the reader understands the reason for the coding for severity of injury. It can be seen that in this study, all participants sustained a moderate to severe TBI based on the Mayo severity classification system.

The Mayo moderate – severe classification can be utilised when one or more of the following criteria apply:

1. Death due to this TBI
2. Loss of consciousness of 30 minutes or more
3. Post traumatic anterograde amnesia of 24 hours or more
4. Worst Glasgow Coma Scale full score in first 24 hours <13
5. One or more of the following present:
   - Intracerebral haematoma
   - Epidural haematoma
   - Haemorrhagic contusion
   - Subarachnoid haemorrhage
   - Subdural haematoma
   - Cerebral contusion
   - Penetrating TBI (dura penetrated)
   - Brain Stem Injury
Table 4.2 provides the available evidence in the participants’ notes to reflect the classification.

**Table 4.2 Details of TBI sustained by participants**

<table>
<thead>
<tr>
<th>Participant Identifier</th>
<th>MAYO TBI Severity Classification System</th>
<th>Glasgow Coma Scale (GCS)</th>
<th>Loss of Consciousness (LOC)</th>
<th>Post Traumatic Amnesia (PTA)</th>
<th>Location of Brain Injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>Moderate – Severe (Based on GCS, LOC &amp; PTA)</td>
<td>8</td>
<td>2 weeks</td>
<td>2 months</td>
<td>Acute L/S extra dural haematoma &amp; orbital, mandible and nasal bones fracture</td>
</tr>
<tr>
<td>M2</td>
<td>Moderate- Severe (based on GCS)</td>
<td>11</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Right basal ganglia, extending into temporal pole &amp; inferior frontal lesion</td>
</tr>
<tr>
<td>M3</td>
<td>Moderate- Severe (based on GCS)</td>
<td>8</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Left occipital contusions</td>
</tr>
<tr>
<td>M4</td>
<td>Moderate- Severe (based on LOC &amp; PTA)</td>
<td>Unknown</td>
<td>3 weeks</td>
<td>3 weeks</td>
<td>Left extradural fronto-parietal haematoma</td>
</tr>
<tr>
<td>F1</td>
<td>Moderate- Severe (based on LOC)</td>
<td>Unknown</td>
<td>6 weeks</td>
<td></td>
<td>Haematoma in corpus callosum, scattered small foci of blood at the grey-white matter of the frontal poles bilaterally &amp; in the left basal ganglia consistent with diffuse axonal injury</td>
</tr>
<tr>
<td>M5</td>
<td>Moderate- Severe (based on GCS)</td>
<td>7</td>
<td></td>
<td></td>
<td>Left occipital skull fracture, extradural haematoma</td>
</tr>
<tr>
<td>M6</td>
<td>Moderate- Severe (based on GCS, LOC &amp; PTA)</td>
<td>3</td>
<td>5 days</td>
<td>3+ weeks</td>
<td>Left frontal hygroma, right parietal contusions</td>
</tr>
<tr>
<td>F2</td>
<td>Moderate- Severe (based on GCS &amp; nature of injury)</td>
<td>5</td>
<td></td>
<td></td>
<td>Bilateral contusions, traumatic subarachnoid haemorrhage</td>
</tr>
<tr>
<td>M7</td>
<td>Moderate- Severe (based on PTA)</td>
<td>14</td>
<td>2-3 minutes</td>
<td>Several weeks</td>
<td>Left sided extradural haematoma</td>
</tr>
<tr>
<td>M8</td>
<td>Moderate- Severe (based on GCS)</td>
<td>6</td>
<td></td>
<td></td>
<td>Left fronto parietal haematoma, minimal mass effect, left frontal intracerebral bleed in occipital horns, left frontal intracerebral bleed &amp; low attenuation in right frontal lobe</td>
</tr>
</tbody>
</table>
These codes for determining the severity of injury are internationally recognised and determined by the Glasgow Coma Scale (GCS) at time of injury, the Loss of Consciousness (LOC), the Post Traumatic Amnesia (PTA), or neuro pathological findings.

The GCS (Teasdale & Jennett 1974) is a neurological scale that aims to give a reliable, objective way of recording the conscious state of a person, for initial as well as continuing assessment. A patient is assessed against the criteria of the scale, and the resulting points give a score between 3 (indicating deep unconsciousness) and 15. The scale comprises three tests: eye, verbal and motor responses. The three values separately as well as their sum are considered. Generally brain injury is classified as:

<table>
<thead>
<tr>
<th>Severe</th>
<th>GCS &lt; 8</th>
<th>Moderate</th>
<th>GCS 9-12</th>
<th>Minor</th>
<th>GCS &gt;13</th>
</tr>
</thead>
</table>

These scores are accepted within the Mayo classification system. The GCS scores provided in Table 4.2 were those taken at the time of admission to hospital following TBI. Further scores are taken later at hospital, but these are not included in this table, as it would confuse the issue of severity, as this is a sliding scale, dependent upon medication and nature of injury.

<table>
<thead>
<tr>
<th>Table 4.3 Glasgow Coma Scale:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eyes</strong></td>
</tr>
<tr>
<td>1: Does not open eyes</td>
</tr>
<tr>
<td>2: Opens eyes in response to painful stimuli</td>
</tr>
<tr>
<td>3: Opens eyes in response to voice</td>
</tr>
<tr>
<td>4: Opens eyes spontaneously</td>
</tr>
<tr>
<td>5: N/A</td>
</tr>
<tr>
<td>6: N/A</td>
</tr>
<tr>
<td><strong>Verbal</strong></td>
</tr>
<tr>
<td>Makes no sounds</td>
</tr>
<tr>
<td>Incomprehensible sounds</td>
</tr>
<tr>
<td>Uppers inappropriate words</td>
</tr>
<tr>
<td>Confused, disorientated</td>
</tr>
<tr>
<td>Orientated converses normally</td>
</tr>
<tr>
<td>N/A</td>
</tr>
<tr>
<td><strong>Motor</strong></td>
</tr>
<tr>
<td>Makes no movements</td>
</tr>
<tr>
<td>Extensions to painful stimuli</td>
</tr>
<tr>
<td>Abnormal flexion to painful stimuli</td>
</tr>
<tr>
<td>Flexion/withdrawal to painful stimuli</td>
</tr>
<tr>
<td>Localizes painful stimuli</td>
</tr>
<tr>
<td>Obeys commands</td>
</tr>
</tbody>
</table>

Loss of consciousness (LOC) is commonly defined in TBI as falling within the following categories:

- **Mild TBI**: LOC of up to 30 minutes
- **Moderate TBI**: LOC from 30 minutes to 6 hours
- **Severe TBI**: LOC for 24 hours plus
These scores also fall within the Mayo classification seen above for moderate – severe injury.

Post traumatic amnesia (PTA) (Powell 2005) may last a few minutes, hours, days, weeks or even months. The duration of PTA is a good indicator of the severity of the head injury.

Table 4.4 Post Traumatic Amnesia

<table>
<thead>
<tr>
<th>Time in PTA</th>
<th>Severity of Injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 1 hour</td>
<td>Very mild injury, full recovery, though a few may experience post-concussion symptoms</td>
</tr>
<tr>
<td>1-24 hours</td>
<td>Moderate injury, likely to recover as above</td>
</tr>
<tr>
<td>1-7 days</td>
<td>Severe injury. Recovery period longer, may take weeks or months. May be able to return to the same job but less capable than before.</td>
</tr>
<tr>
<td>1-2 weeks</td>
<td>Very severe injury. Recovery may take many months, and long lasting cognitive problems are likely. Should be able to work &amp; enjoy family life.</td>
</tr>
<tr>
<td>2 - 12 weeks</td>
<td>Very severe injury. Very prolonged recovery, one year or longer. Permanent deficits very likely. Very unlikely to be able to do the same job as before.</td>
</tr>
<tr>
<td>12+ weeks</td>
<td>Very severe injury. Significant disabilities requiring very long-term retraining and management. Unlikely to ever work again, though may manage sheltered workshop type setting.</td>
</tr>
</tbody>
</table>
All participants were employed prior to sustaining their TBI and had attempted to RTW since sustaining their TBI as described in Table 4.5.

Table 4.5
Employment status of participants

<table>
<thead>
<tr>
<th>Participant Identifier</th>
<th>Employment Status Prior to TBI</th>
<th>Current Employment Status</th>
<th>Part Time Definition</th>
<th>Change in Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>F/T Graduate bar manager</td>
<td>P/T Voluntary work &amp; Training</td>
<td>1 day per week</td>
<td>3, 4</td>
</tr>
<tr>
<td>M2</td>
<td>F/T Electrician</td>
<td>P/T Voluntary work</td>
<td>2 days per week</td>
<td>3</td>
</tr>
<tr>
<td>M3</td>
<td>F/T Manager</td>
<td>P/T Reduced duties Manager</td>
<td>3 days per week</td>
<td>2</td>
</tr>
<tr>
<td>M4</td>
<td>F/T gardener</td>
<td>F/T Gardener</td>
<td>N/A</td>
<td>5</td>
</tr>
<tr>
<td>F1</td>
<td>P/T Casual employment &amp; training</td>
<td>Unemployed &amp; training</td>
<td>Training 3 hours per week</td>
<td>1, 6</td>
</tr>
<tr>
<td>M5</td>
<td>F/T Software programmer</td>
<td>F/T Computer work</td>
<td>N/A</td>
<td>5</td>
</tr>
<tr>
<td>M6</td>
<td>F/T Manager &amp; Technician</td>
<td>Unemployed</td>
<td>N/A</td>
<td>1</td>
</tr>
<tr>
<td>F2</td>
<td>F/T Careers Advisor</td>
<td>F/T Parent</td>
<td>N/A</td>
<td>1</td>
</tr>
<tr>
<td>M7</td>
<td>F/T Self Employed</td>
<td>Unemployed</td>
<td>N/A</td>
<td>1</td>
</tr>
<tr>
<td>M8</td>
<td>F/T Engineering Inspector &amp; Quality Assurance Manager</td>
<td>P/T Mechanical Engineer</td>
<td>1 ½ days per week</td>
<td>2</td>
</tr>
</tbody>
</table>

Code for Table:

- **F/T** Full Time
- **P/T** Part Time

Code for Change in Employment Status at time of interview:

- Change from employed to unemployed: 1
- Change from F/T to P/T employment: 2
- Change from F/T employed to voluntary: 3
- Change from F/T employed to training: 4
- Remain in F/T employment: 5
- Change from P/T employed to training: 6

The change in employment status code was developed from one used in NWBIS (Roberts et al. 2004). It can be seen that following RTW rehabilitation only 2 out of the 10 participants have remained in full time employment. However, only one of those 2 participants has retained the same skill level of job as pre injury. The others have all needed to modify their employment objectives.
4.3 Participant Vignettes

Demographic details of the baseline profiles of age, gender, marital status, etc is provided in the preceding tables. In addition individual vignettes of each participant are given to provide the reader with a social and personality context from which they can interpret the information provided. Whilst the information provided about each participant is small, I consider it is sufficient to situate the sample for the reader. To provide more information would, in my opinion, be unethical with regards to the anonymity of the participants in the study.

Participant M 1
This gentleman worked in bars/restaurants/clubs in a bustling city prior to sustaining his TBI when he was the victim of an horrific attack by two youths after complaining about their behaviour on a bus. Since his TBI he has had to return to live with his aging parents in a small village in a different geographical location. He remains very focused on physical appearance and is determined that he will return to gainful employment, but not in his past line of work, due to the temptations with recreational drugs and alcohol inherent with his work.

Participant M 2
This gentleman worked as an electrician and prior to sustaining his TBI further to falling. Since his TBI he has returned to the family home and has had to struggle to regain any role in life. He presented a determined character, used to working in business where targets had to be met and ensuring that others do the work required to ensure success of his company. At the time of the interview he was wheelchair independent and worked part time in a voluntary capacity.

Participant M 3
This gentleman worked in a managerial post in the civil service prior to sustaining his TBI further to a car accident. Since his injury he had suffered from significant fatigue. He had struggled to resume his role as father and husband and continued to have a perfectionist aspect to his personality. He had returned to his previous employment working part time in a restricted post.
Participant M 4
This gentleman worked as a landscape gardener for a large firm prior to sustaining his TBI when he fell off his push bike. No other vehicle was involved. He had to leave his property and return to live with his parents in a different geographical area. His social life essentially revolved around his work colleagues prior to his TBI. Post TBI he had long-term physical, emotional and cognitive difficulties. He became socially avoidant and focused on his therapy, and therapists. At the time of the interview he was employed full time in the same line of work as pre TBI.

Participant F 1
This young lady was part way through completing her A levels when she was the victim of a road traffic accident as a result of a mechanical fault in her car, and sustained a TBI. She worked in a leisure centre and in a local restaurant pre morbidly. Following her TBI she presented with long-term physical, cognitive and emotional problems. She was unable to complete her A levels and her career prospects changed dramatically. She could not consider progressing to university and living independently of her parents as her brother had done. At the time of the interview she was training to be a child care assistant and worked voluntarily in schools.

Participant F 2
This young lady was a university graduate who worked in the Careers Advice section of the employment agency. She was in a long-term relationship when she was the victim of a road traffic accident that left her with physical, cognitive and emotional disabilities. She maintained her long-term relationship and focused on resuming a productive lifestyle by RTW. Her pregnancy changed the focus of her life. At the time of the interview she was a full time mother.
Participant M 5
This gentleman was a university graduate who had been working as a self taught web designer for a period of months prior to sustaining his TBI as a result of being a passenger of a motor vehicle involved in an RTA. The resulting physical disabilities impacted negatively on his social and emotional abilities and behaviours. This was further compounded by his presenting dysexecutive problems and initial poor insight into his resultant disinhibitive behaviours. At the time of the interview he was employed as a web designer by a large firm.

Participant M 6
This gentleman was employed as a production technician with managerial responsibilities at a power station. He had been employed by the company for over fifteen years. He sustained his TBI when he fell downstairs. His visible physical recovery had been excellent, but he continued to suffer from debilitating fatigue. In addition, he was experiencing emotional, social and dysexecutive problems that impacted on his opportunities to move forwards. He was unemployed at the time of the interview.

Participant M 7
This gentleman had worked all his life in engineering. He decided two years pre injury to set up his own business. He suffered a TBI when he was knocked over by a motor vehicle driven by his partner. He suffered significant orthopaedic injuries in addition to his TBI. Five years post TBI he remained unable to consider RTW in a paid capacity due to his physical emotional and cognitive disabilities. He was motivated to engage in rehabilitation but was hampered by a diagnosis of clinical depression. He was unemployed at the time of the interview.

Participant M 8
This gentleman was an engineering supervisor and was a motorcyclist involved in an RTA where he sustained TBI and significant orthopaedic injuries. He
experienced significant problems with dysexecutive functioning (that is initiation and planning of tasks, and remaining focussed on tasks). He also experienced problems with fine finger dexterity and co-ordination of his dominant hand. He worked part time as a self-employed mechanical engineer at the time of the interview.

4.4 Participant Interviews

As stated in the previous chapter, participants were offered the opportunity to read a detailed Participant Information Sheet (Appendix 10) before deciding whether to take part in the study. In addition, all participants accepted for this study obtained a clinically significant score on the Awareness Questionnaire when rated by clinicians and their significant other.

As discussed in the previous chapter a flexible potential list of topics to cover during interview (Appendix 4) was developed which was designed to elicit experiences (e.g. What did your RTW rehabilitation consist of?), understandings (e.g. How did you become aware of the fact you may not be able to return to the same employment?) and evaluations (e.g. What, if anything, did the RTW rehabilitation experience do to assist you in attempting to RTW?). Development of the schedule for the interviews was informed by established conventions for semi-structured interviews (Mischer 1986, Smith 1995). The interviews were conducted in person at a quiet location, with the environment prepared to being conducive to sharing information (comfortable armchairs, hot and cold drinks, biscuits, time given for regular breaks) as discussed in chapter 3. Nine participants were interviewed in the clinic, and one participant was interviewed in her lounge area at home. This approach has been rated in previous studies as being more in keeping with the philosophy of phenomenology than conducting interviews by telephone (Neimeyer & Hogan 2002, Smith 2008). Participants were interviewed separately, and on separate days, and they were informed that their comments would not have any implications for continued rehabilitation with any professional in NWBIS. With participants’ consent the interviews were
digitally recorded using a Sony Digital Recorder. The interviews lasted an average of 43 minutes, with the range being from 18 minutes to 59 minutes.

By beginning with general questions about their current employment status and their work prior to sustaining their TBI, participants became more relaxed, became familiar with me, as the researcher, and were visibly more at ease about telling their story. This was demonstrated by a change into a more relaxed posture and increased eye contact. Allowing participants to tell their entire story has been highlighted as important in qualitative research (Long & Godfrey 2002, Burnell & O’Keefe 2004; Dyregrov 2004). The order in which the topics were discussed was guided by the interview schedule and at the end of the interview participants were given the opportunity to raise any additional topics. One participant became tearful at one point of the interview (M 4), and when this happened I encouraged him to take his time and asked if he wanted to discuss his emotions. Many participants sighed audibly during the interview, and there were many silences. No one requested that the interview end prematurely. All of the interviews were single episode interviews carried out face to face.

The interviews were not straightforward – at least not in comparison to interviewing a stereotypical articulate adult. I often needed to ask questions more than once, in more than one way. I regularly needed to offer a little further prompting, and sometimes a little more listening time while the participants gathered their thoughts. Participant F 1 experienced significant difficulties with her expressive verbal communication which was difficult for the recording equipment to record. In addition, she experienced difficulty in focusing on the questions put to her, and needed the questions to be more closed and directive to comprehend what was being asked. This was not in keeping with the interview schedule which contained open questions asked in the spirit of eliciting narratives. However, it was necessary to facilitate the narrative from this particular participant. This is discussed in more detail in the discussion chapter.
Any unanswered questions were asked at the end of the interview. After the interview, the recorder was switched off and participants were given an opportunity to discuss the experience of the interview. An example of a transcript can be found in Appendix 19. Participants were sent a letter thanking them for their participation and were provided with a list of relevant support contacts should they wish to discuss issues further (Appendix 20).

4.5 Analysis of Transcripts
All interviews were fully transcribed by the researcher after listening to the recordings on at least two occasions prior to commencing transcription. The transcriptions were not shared with the participants. This subject of whether or not to share the transcriptions with the participants is currently the topic of debate amongst IPA researchers. However given the interpretative nature of the approach this sharing is not applied by the majority of IPA researchers (Flowers 2007). Transcripts were then analysed in accordance with Interpretative Phenomenological Analysis (IPA) (Smith 1995, Smith et al. 1999, Smith et al. 2002). A diagrammatic representation of the IPA process is provided overleaf.
IPA is a qualitative approach whereby the participant is deemed an expert on their own experience, and methods of interpretative analysis are used to uncover the central themes from participants’ accounts of particular events; in this case their experience of RTW rehabilitation. These themes may be common across, or unique to participants, and IPA aims to reveal rather than suppress the diversity of participants’ accounts (Jarrett et al. 1999). By allowing the participants to identify what was truly assistive, or not, from their experience of specifically RTW rehabilitation IPA captures how the participants themselves make sense of their experiences. This is different to content analysis which is a means of quantifying qualitative data, reducing it via forced choice frequency ranking. This can give a false impression of what is important, and to a large extent, content analysis disregards meaning, context and experience, and therefore it is not consistent with the key aims of this study. By using IPA, I was able to understand more...
about the participants’ experiences within the context of their life situations, and, as a consequence, also understand more about my clinical intervention. In this respect, IPA generated a richness and depth of qualitative data that allowed me to engage with the topic at a level which would have been extremely difficult to reach with quantitative data or with less idiographic methods.

The transcripts were annotated and coded for the presence of important themes, an example of which can be seen in Appendix 16. The example shows how the initial themes originated in the raw data, and were incorporated into the master themes. Summary documents containing all instances of each topic were generated. The process was repeated for each transcript with the interviews analysed in turn. For the purposes of ensuring that the IPA process had been fully adhered to another researcher experienced in the process of IPA read through each transcript and list of themes, master themes and quotes ensuring the emerging themes were visibly grounded in the data and none had been omitted. This resulted in minor changes to the arrangement of themes. The master theme list changed constantly throughout analysis and write up as each interview analysed informed the formation of the next analysis, with the addition and collapsing of themes into categories until a final list of five themes emerged. These five master themes were:

1. The personal cost of lifestyle losses when unable to resume gainful employment following traumatic brain injury (TBI) (loss of me, missing being part of a gang, amended future occupational dreams, redefining wellbeing)
2. Impact of TBI on my work now (volunteering, re-training, return to previous employment)
3. Factors impacting on the rehabilitation period (change in my physical abilities, rollercoaster emotions, therapeutic relationship)
4. What helped in RTW rehabilitation (in work, personal perspective, faith in clinicians’ knowledge and guidance, involving the family)
5. Impact of RTW rehabilitation on the occupational performance of participants (positive, negative)

These themes are discussed in the next chapter and illustrated with verbatim quotes from the interviews. Verbal consent was obtained from the individual participants at the end of each interview to include verbatim quotes in the body of the thesis. For the purposes of confidentiality all quotes have been anonymised. When providing extracts from the interviews the following transcript conventions are used:

… Short pause
(…) Words omitted to shorten quote
[text] Explanatory information included by author
X Initial of participant providing the quote
I Comment by interviewer

This chapter has provided information regarding the demographic details of the participants along with descriptive data to contextualise the individuals. Details of some issues raised during data gathering have been summarised, and the data analysis and transcription procedures have been described. The following chapter will discuss the themes elicited in greater detail, grounding them in examples from the narratives.
Chapter 5 Findings

5.1 Overview
The aim of this thesis was to use qualitative methodology to illustrate the return to work (RTW) rehabilitation experiences of individuals who have sustained traumatic brain injury (TBI). An interpretative phenomenological methodology was adopted and semi-structured interviews used to allow for the in-depth exploration of a relatively unknown phenomenon, (RTW rehabilitation). The aim was to enhance my understanding as an occupational therapist, and the understanding of others, in this aspect of clinical practice. The aim of this chapter is to illustrate and organise the data, giving a rich description of both the individual and the general data (Finlay 1999).

One problem of phenomenological inquiry is that as practising researchers we potentially know too much about the phenomenon we wish to investigate. As a researcher undertaking research within my workplace, it was important that I clarified my biases or prior knowledge as they presented themselves in the data. In accepting the centrality of my role in this research, influencing the collection, selection and interpretation of data, I acknowledge that my prior experiences and understandings affected how I constructed what I saw. The key to this being acceptable to those who review and consider such research is the concept of reflexivity. Finlay and Ballinger (2006) consider that reflexivity involves deep and critical self-reflection, and consideration of how the researcher’s social background, assumptions, positioning and behaviour affect the research process. That being the case, I shall endeavour to make explicit as appropriate how I personally connected with the data.

5.2 Themes Generated
Following Interpretative Phenomenological Analysis (IPA), a number of themes were identified (See Appendix 17) which were relevant to the research question and were grouped into five master themes:
1. The personal cost of lifestyle losses when unable to resume gainful employment following traumatic brain injury (TBI) (loss of me, missing being part of a gang, amended future occupational dreams, redefining wellbeing)

2. Impact of TBI on my work now (volunteering, re-training, return to previous employment)

3. Factors impacting on the rehabilitation period (change in my physical abilities, emotional ability and stability, therapeutic relationship)

4. Participants’ perceptions of assistive elements of RTW rehabilitation (vocational, personal perspective, faith in clinicians’ knowledge and guidance, familial involvement)

5. Impact of RTW rehabilitation on the occupational performance of participants (positive, negative)

These themes provide the framework for the presentation of my findings and are represented in full in Table 5.1. The titles of the themes are my interpretation of the narrative, and are explicitly grounded in the narratives through provision of numerous quotations to illustrate my interpretation.

Table 5.1 Summary of Themes

<table>
<thead>
<tr>
<th>Master Themes &amp; Sub Themes</th>
<th>Sample of Text</th>
<th>Text References (lines in transcripts)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Personal Costs of Lifestyle Losses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Loss of me</td>
<td>&quot;I've lost the person I was&quot;</td>
<td>M3 589-598</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M6 571-578, 587, 614-625</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M2 1022-1030, 306-308</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M7 592-598, 603-604, 612-623</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F2 251-258</td>
</tr>
<tr>
<td>b) Loss of being part of a gang</td>
<td>&quot;The laughter the camaraderie of it all … supervising lads, telling people what to do … I miss that&quot;</td>
<td>M2 338-340</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M4 121-124</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M6 108-115</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M7 154-171</td>
</tr>
<tr>
<td>c) Amended Future Occupational Dreams</td>
<td>&quot;My promotion prospects within my current employment are probably diminished&quot;</td>
<td>M3 110-117, 123-129, 307-309, 311-312,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>314-317</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F1 244-246, 430,437</td>
</tr>
<tr>
<td>d) Redefining Wellbeing – What makes me feel good</td>
<td>&quot;I get a feeling of wellbeing from doing voluntary work at the moment&quot;</td>
<td>F2 284-290</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M4 33-43, 69-74, 175-180, 182-184</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M1 93-97, 107-111</td>
</tr>
</tbody>
</table>
2. Impact of TBI on my work now

<table>
<thead>
<tr>
<th>Master Themes and Sub Themes</th>
<th>Sample of Text</th>
<th>Text References (lines in transcripts)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Volunteering</td>
<td>&quot;Volunteering is to put something back… I used to enjoy it&quot;</td>
<td>M2 426-436, M6 344-348,733-739, F2 30-34,47-51</td>
</tr>
<tr>
<td>b) Re-training</td>
<td>&quot;I’m ready for any work opportunities that come my way now&quot;</td>
<td>M2 146-184, M1 81-85,514-521, F1 65-66, F2 220,229-246, 261-267</td>
</tr>
<tr>
<td>c) Returning to previous employment</td>
<td>&quot;It was decided [by the clinicians] that I couldn’t work on a full time basis and I couldn’t go back to my previous remit.&quot;</td>
<td>M2 11-17, M3 39-41, 53-56, M4 153-160</td>
</tr>
</tbody>
</table>

3. Factors Impacting on The Rehabilitation Period

<table>
<thead>
<tr>
<th>Master Themes and Sub Themes</th>
<th>Sample of Text</th>
<th>Text References (lines in transcripts)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Change in my physical abilities</td>
<td>&quot;But in the gym I have got motivation 'cos I want to walk better and faster, and I want to look normal&quot;.</td>
<td>M1 63-66, 153-156, 265-269, 275-279, 218-220, F1 340-344, M2 146-148, 294-299, 306-308</td>
</tr>
<tr>
<td>b) Rollercoaster emotions</td>
<td>&quot;It absolutely knocked me sideways. I was so angry… ummm … It wasn’t my fault&quot;.</td>
<td>M2 297-301, M3 65-66, 79-83, M4 58-60, 219-225, F2 74-78, 90-92, M5 123-132, 165-169, 197-200, M7 223-236, 27-50</td>
</tr>
<tr>
<td>c) Therapeutic relationship</td>
<td>&quot; It’s just a case of the team of people around you just cajoling you and helping you make your own decisions. That’s my experience&quot;</td>
<td>M3 778-784, 793, 794-799, M7 396-401, M6 182-185, 193-195, M2 90-96</td>
</tr>
</tbody>
</table>

4. What Helped in RTW rehabilitation

<table>
<thead>
<tr>
<th>Master Themes and Sub Themes</th>
<th>Sample of Text</th>
<th>Text References (lines in transcripts)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) In work</td>
<td>&quot;… My employers also told me that they valued the input that you [the brain injury service] were able to give them&quot;</td>
<td>M1 620-627, M6 70-76, 87-90, M7 248-251, 257-264, 266-270</td>
</tr>
<tr>
<td>b) The Personal Perspective</td>
<td>&quot;The only way I describe it is that lots of people start ummm … aging over a period of time and I believe that; BANG. I became like … like an old man all of a sudden … overnight&quot;</td>
<td>M1 189-192, M2 518-527, M3 983-892, M4 297-308, 520-525, 538, M5 348-354, 359, 366-368, M7 325-329, 333-337</td>
</tr>
<tr>
<td>d) Involving the Family</td>
<td>&quot;I’m glad I came home with the help and support from my family (…) If I’d had no family to go back to … completely different story …&quot;</td>
<td>M1 417-422, 535-537, 544-545, 658-659, 668-669, 712-717, F2 221-226, M6 516-517, 271-278, F1 174-176, 182-183, 325-331, M3 397-401, 433-438</td>
</tr>
<tr>
<td>Master Themes and Sub Themes</td>
<td>Sample of Text</td>
<td>Text References</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 5. Impact of RTW rehabilitation on the occupational performance of participants | **a. Positive**  
“You kept in contact with my former boss, writing letters (…) you may have met him, I can’t recall really (…) So people can’t really look down at you because you’ve had the pat on the back and the piece of paper to say ‘he’s okay’. That helps a lot”  
**b. Negative**  
“I think to be honest it was a little bit early for me with my injury because I was still a bit too out of it to cope with them” | **F1** 95-98  
**M4** 749-751, 752-753, 761-771, 691-696, 711-712  
**F2** 99-104  
**M3** 517-520, 292-294  
**M4** 416-426  
**M5** 671-681, 698-703, 709-713, 720  
**M6** 934-937, 509-515, 517, 521  
**M7** 774-792 |

These themes, combined, addressed the research aim of wishing to obtain an in-depth insight into the experience of engaging in RTW rehabilitation for the participants in the study. Narratives of the meaning of ‘work’ pre TBI provided insight into what participants felt they had lost when not gainfully employed. The descriptions of changes in perceptions of RTW post TBI illustrated how being gainfully occupied post TBI assumed more importance than being engaged in paid employment. The third theme describing the factors that impacted on the ability of individuals to engage in RTW rehabilitation afforded insightful narratives of difficulties that the participants were confronted with that may not always be given due consideration by clinicians. Assistive elements of RTW rehabilitation provided understanding of the meaning that engaging in the rehabilitation held for individuals and provided guidance on the valuable role of occupational therapy in this regard. The final theme illuminated how worthwhile participants found the RTW rehabilitation experience.

Due to my specific research interest, a number of themes not explicitly relating to my research question were rejected or subsumed into other themes as discussed below. Despite being important to the participants, holding significant clinical value, and providing unique insights into the problems faced for individuals planning to RTW, themes were eliminated or subsumed according to the following criteria:
Individual feelings/emotions were subsumed under the theme 3(a) ‘Factors impacting on engagement in RTW – rollercoaster emotions’. Thus the emotional experiences narrated by participants relating to their RTW rehabilitation have been retained, whilst other emotional issues were not included in this present analysis.

Meaning that ‘work’ held for participants now was rejected because it related to participants talking about their current situations generally (and usually in the abstract), and not necessarily about their RTW rehabilitation. However, issues relating to changes in their perceptions of gainful occupation have been included in themes 2 (a), (b), (c).

A cluster of themes regarding participants’ experiences of information provided regarding their prospects of RTW (‘clarity of information provided by employers’, ‘expectations of clinicians’, ‘lack of understanding from statutory services’) were accepted despite focusing on participants’ perceptions of what was said to them, rather than the rehabilitation experience itself. They are included in theme 3(a).

Acceptance of the change in persona following TBI has been subsumed under the personal sub theme of the theme ‘Requirements of RTW rehabilitation’ 4(b).

In order to make explicit the potential impact of researcher partiality and to ensure clarity of researcher interpretation for the reader, a final re-reading of the transcripts was carried out in order to ensure that all interpretations were grounded in the data. This underlies the philosophy of interpretative phenomenology of the researcher not ‘bracketing’ their pre knowledge as discussed in detail in chapter 2. Direct quotes from interviews have been used as illustrative examples in the subsequent section to provide illustrations of the themes and sub themes developed from the analysis. A participant alphabetical and numerical identifier identifies quotations in the text.
**Theme 1: The Personal Cost of Lifestyle Losses.**

As work is a concept without a clear and unanimous definition, and its perceived benefits are individual, the participants were invited to talk about their personal understanding of what ‘work’ had offered, or meant to, them prior to sustaining their TBI. This first theme illustrates the participants’ perceptions and understanding of the concept of work, and what they lost when it was not possible to work. The insights offered within this theme addressed the aim of my research of wanting to obtain an enhanced understanding of the experience of RTW rehabilitation for each participant. In order to do this, it was important to understand what work gave them prior to sustaining their TBI, and subsequent changes to their lifestyle. This ensured that the RTW rehabilitation experience was put in context by the participants, rather than being contextualised by me, as the researcher. All ten participants shared positive perceptions of working prior to sustaining their TBI, and all reflected on other positive impacts that had been generated from the workplace into their home and social lives. With regard to the entire experience of working both pre and post TBI the participants reflected on the opportunities work opened up to them, and to others (for example partners, spouse, children) important to them, during their life. They also spoke of positive outcomes of working including being able to be financially independent and through this, having more autonomy. Experiencing difficulty in their attempts to return to their previous work due to sustaining a TBI, therefore, had far reaching implications.

Five sub themes expressing the personal cost of lifestyle losses associated with being unable to work emerged, namely; loss of me, missing being part of a gang, amended future dreams, and redefining wellbeing – what makes me feel good. These sub themes assisted the researcher in understanding the participants’ constructions of their RTW rehabilitation experience; that is the epistemological aim of this study. They also provided some initial answers to the first aim of the research which was to understand how the participants made sense of their personal and social worlds, and how clinicians can assist them in this process.
1.a. Loss of Me

All ten participants viewed the primary utility of working as a means to develop as a person and establish their identity based largely on their earning ability. This was expressed quite directly in most accounts. In terms of not having the earning ability they held pre TBI, the participants reported on the sense of individual loss that came with that realisation. Participants typically reflected on the idea that work had meant a lot to them, and their earning ability impacted not only on their assessment of their own self worth, but also on the non-working aspects of their lifestyle. This sub theme thus describes the impact on the me of the participants associated with experiencing difficulty in resuming their pre TBI work roles.

Perceptions regarding earning capacity arose in discussions with participants at two possible levels, with different levels being salient to different participants to varying degrees. At the first level, the concept of financial reward for working meant being able to provide for their own basic requirements such as food and clothing for themselves, and affording a home environment in which to live (where participants were not taking sole responsibility for the household finances). At the second level, the more inclusive impact of financial reward for working impacted on other family members, and not being able to continue in that role was difficult to acknowledge and accept. M3 provides us with an example here:

“Obviously there’s the financial stress ummm … you know what I mean. I’ve lost forty percent of my income, forty percent of my pension … we’re digging into our savings to compensate for that now and when they finish it keeps crossing my mind that we … we will have to make some serious decisions about lifestyle, about where we live … ummm … so clearly, there’s quite a substantial knock on effect in terms of your know … your life”.

M 3, Lines 589-598.

M 3 had expressed the stress that he felt in having to eat into his savings, and how that concerned him for the future. Other participants echoed his concerns (seven out of ten), possibly because of the current economical climate dictating that financial security is of utmost importance, but difficult to attain even if in full
time employment. M2 described, with a degree of poignancy heard in the recording, about the difficulty in accepting post TBI that he was not be able to finance his second son’s education in the same way as he had for the first following sustaining TBI, due to his inability to return to his previous employment:

“I think my youngest son felt it more than anything else because whilst I was still working [my eldest son] went to university and obviously we funded him … we gave him … helped him financially. But then [my youngest son] didn’t go to university until after I’d had the TBI which meant that we weren’t in a position to fund him as much as we could have done with [my eldest son]”

M 2, Lines 1022-1030.

All participants appeared to associate the financial aspect of working with security for the future and the loss of that security impacted on their whole persona:

“I mean everything revolved around the job, you know when you were going on holiday, when you were going to go sick, when you were going to be at home… but everything centred around work… and all that’s gone… It’s a big loss to my lifestyle (…) I’ve lost the person that I was”.

Participant M 6, Lines 571-578, 587.

Participants also appeared to associate the loss of being able to provide financial security for the future as a reflection on their ‘usefulness’ to their immediate family and society in general. For example:

“… I mean like everybody complains sometimes having to go to work and what have you, but the confidence and the sense of achievement and the sense of contribution and you know … security, everything is a mess isn’t it? I mean (…) but you just … you just don’t feel as if you’re ummm … useful any more”.

Participant M 7, Lines 592-598, 603-604.

Having to admit that they had received benefits in the past, or indeed were still in receipt of benefits was difficult for all the participants. Only one participant had been in receipt of benefits prior to sustaining his TBI (M 5) and that was short term whilst he recovered from a broken leg when he was 19 years old. None of the others had been in receipt of benefits prior to sustaining their TBI, and none
of the participants had ever envisaged that there would come a time when they would be in receipt of, and indeed relying on, state benefits. One participant (M 6) effectively described how not only had his inability to RTW resulted in him experiencing a loss of feeling useful, but that it went deeper into a feeling of not being a part of society any more and the shaming aspect of having to concede that he needed financial assistance in the form of state benefits:

“… I feel like I’m on the like … on the outside of it again … I’m not part of the … whole thing … the whole work thing. I’m not part of it any more … and that’s a bit of a disappointment because obviously pride comes into it, because I used to be the main earner and that’s all gone away form me now. But ummm … I don’t have that. What I get [state benefits] is what I get and that’s it. I don’t get any extra so … and the fact that I get benefits as well. And that annoys me and all; that I get benefits. I hate having to admit that I get benefits. ‘What me? I’m all right’ “.

Participant M 6, Lines 614-625.

Accepting and understanding the situation of not being able to RTW was important for the participants, some of whom cited difficulty in conveying the impact of the ‘unseen’ difficulties which contributed negatively to their ability to make gains in attempts to RTW compared to the expectations of family members:

“I don’t know ummm … I do see [named psychologist] in psychotherapy, and if they still work, I don’t know. But my confidence is terrible, and my confidence is stopping me from driving. I haven’t driven since the accident … I’ve had lessons and I’ve taken my test once. But it’s a confidence thing. I can’t do it. My mum says there’s no such word as “can’t” … but there is, because I can’t drive”.

Participant F 2, Lines 251-258.

For some of the participants, circumstances had forced them to look at their productiveness now compared to prior to their sustaining TBI, particularly in the aspect of employment. This in itself was very stressful and traumatic, but it also made acceptance of this being the potential sum of their productivity ability for
the future very difficult. Also, despite attempting to remain positive regarding their future potential to RTW, there were times when participants felt despondent and not in control of events:

“Ummm … I’m not saying I was the best at my job ever. But I wasn’t bad at it, and you know, I do … I do miss the pit of my brains against a piece of metal … I do miss that … fixing it and that … pit of my brains up against … not the pit of my brains, but my personality of getting on with people. And at the end of the day and working with a lot of people. Half the job is getting on with people and working as a team in the … and everything. I considered myself to be half decent at that. And now … what have I got now? … Water the plants maybe, and that’s it … job lot”.

Participant M 7, Lines 612-623.

One participant (M 2) succinctly described the impact on him when he realised that his future productivity was limited, externalising the control over him in every aspect:

“Very depressing … I think at one stage I just felt like I was waiting to die … I had died, and was waiting to be buried”.

Participant M 2, Lines 306-308.

1b Loss of Being Part of a Gang

Several participants, especially those working in team situations in work made a link between work and the feeling that this gave them membership of a specific group or gang. The value of membership was important not only in the work situation, but also impacted significantly on socialisation in general. Whilst reflecting on this experience, some participants expressed a feeling of surprise that this should have been the case:

“A sense of wellbeing a sense of belonging a sense of being a member of society if you like. Sounds a bit soft now doesn’t it?”

Participant M 2, Lines 338-340.

All participants worked with colleagues pre TBI and believed that the relationships they developed whilst at work were a major aspect of the reason they enjoyed their work. Most participants (nine out of ten) spoke of having
deadlines to meet and pressure within their work environment, but still described the alliance between themselves and their colleagues as a major aspect of their enjoyment of work:

“I was working with up to eight lads all around my age… the laughter the camaraderie of it all… supervising lads, telling people what to do… I miss that”.

Participant M 4, Lines 121-124.

Following the TBI, participants described the impact of not having the being part of a gang on their social lives. M 6 reported that his work life implicitly was his social life. Thus by experiencing difficulty in returning to his past employment, he was unable to access the greatest aspect of his social life pre TBI:

“... If there was hundred percent of what your day to day life consisted of. Eighty percent of that was at work, and eighty percent, therefore, is social because you're mixing with people at work, and ummm … Like I say, twenty percent was just when I got home. But is was a big chunk out of my life when ummm … it was decided that I should leave”.

Participant M 6, Lines 108-115.

Participants reported that their experience of working with colleagues was a unique one, set apart from any other individual’s experiences, and different in each work place in which they had worked. This was reflected in the affection heard in the recordings when participants were describing their pre TBI work environments. The narratives revealed the individual language that each work place adopts, which is implicitly learned whilst at work. Adopting the language reaffirmed that you were a member of that particular work group, and was much missed when they were unable to access that group post TBI:

“I used to love going to work and mixing with people… and having a bit of a laugh with those people… and when I look back now I think how much I really do miss it now… I miss it loads… really miss it… and probably the most I miss is the fact that… mixing with people and having a laugh and a banter with workshop crack and all that mentality”.

Participant M 7, Lines 154-171.
Amended Future Occupational dreams

Most of the participants (nine out of ten) claimed that they were not able to fully accept their current occupational status. All participants accepted that their pre TBI future career aspirations had changed significantly. Prior to sustaining their TBI all participants were working towards the goal of either remaining where they were on the career ladder (one participant), or aspiring to progress further in their chosen field (nine out of ten). These aspirations were no longer reported as being realistic even for participants who had returned to their pre TBI employment in some form:

“And I suppose, in some respects, even though I’m still able to contribute at work, it was a case of having to come to terms with … my earning power was vastly reduced and my career prospects were vastly reduced because realistically ummm … I can’t progress within my job (…) So my promotion prospects within my current employment are probably diminished, and probably non-existent. And I don’t really have any option but to move elsewhere because, again, I can … certainly in the short term … I can only consider part time work”.


Participant F1 had aspirations to go to university pre TBI but her physical and cognitive disabilities post TBI meant that those aspirations could not be realised. However, she discussed her presentation in the present, despite it being four years since she sustained her injury, indicating that she continued to feel that she could make further progress in her attempts to RTW; even if she could not follow her pre injury aspirations:

“At the moment I can’t write and I can’t write with this one [left hand] because I shake. And I can’t lift with this one [right upper limb] because this side won’t let this lift (…) I want to prove everyone wrong (…) I want to get a job”

Participant F1, Lines 244-246, 430, 437.

A subset of participants (six out of ten) expressed the fear associated with being aware that they were unable to consider returning to their previous employment and career aspirations. For the male participants in the subset (five out of six) the
potential impact on their personal pride was hugely restrictive on what they were prepared to consider doing in the present, or aspiring to in the future. Participants spoke of fear of publicly being unable to undertake previous tasks involved in their workload, thus making public knowledge that their occupational functioning was below what they had previously been doing without conscious thought:

“I’ve cut myself off because I’m so conscious of … of making a fool of myself in these situations [work] (…) I’ve always been as I’ve said a proud person and to think of (…) going out and … making a fool of yourself … out there… in the big wide world … frightens me to death … it just frightens me to death”.


1.d. Redefining Wellbeing

Beliefs about the feeling of wellbeing integral to being employed arose in discussions with all participants. In the context of this study ‘wellbeing’ is defined as a state of being healthy and contented. Whilst some participants used the word ‘wellbeing’ definitively, others (eight out of ten) spoke more abstractly of the term, referring instead to feelings of happiness, sense of purpose, satisfaction, confidence and pride associated with being employed.

The current situation of not being employed impacted very negatively on participant F 2. Her understanding of the experience of wellbeing was only realised when she was no longer employed, and was reflecting on the impact that situation had on her:

“…That was the most important thing…giving you a purpose because I don’t think it does you any good being at home … I think that’s bad for your confidence and your mood and I think it’s a great thing getting out there and working doing something”

Participant F 2, Lines 284-290.

It appeared that the inherent personal value of wellbeing associated with work may have gone unrecognised for what it was or gave this participant. The feeling of ‘wellbeing’ may have been characterised by successful completion of tasks,
praise received from a colleague or management, or even have been achieved internally from ‘knowing’ that her contribution on that day made a difference to someone or a number of people.

The change in definition of wellbeing was recounted by M 4 and the change was viewed as a positive outcome of attempting to RTW. Although wellbeing is not explicitly mentioned in this transcript, it is implicit within the person’s need to redefine his identity more positively than as a ‘patient’:

“Ummm … being a landscaper I still class it as ummm … in the sun I was still getting paid for a suntan … it was a physical job so I was getting paid to go to the gym … to put muscle on, that’s the way I’ve always thought of it … worked hard ummm … just so I could sort of get the toned body I want without having to go to the gym later, I quite enjoyed the job because of that and ummm … learning a bit of a trade to earn money and possibly do it on my own in the future.

M 4 defining wellbeing in work pre TBI, lines 33-43. His pleasure in the physical aspects of the job were apparent, and his potential future prospects were pleasing to him.

“… I was twenty eight … I’d lived on my own for eight years, looking after myself … no for ten years … I felt like a grown up really and all of a sudden I was brought back down to feeling like a little boy mentally and physically”

M 4 describing his experience of initially attempting to RTW, lines 69-74. His inability to undertake tasks previously undertaken without conscious effort was hard to accept.

“… the first steps of being adult again ummm … yeah … being able to … trusted to make decisions and not have them queried really … that’s what I felt going back to work was, [named himself] was allowed to be [named himself] again really and that was the reason I wanted to go back (…) the day I went back to work was the day … the first step of becoming [myself] again”.

Participant M 4, lines 175-180, 182-184.

The redefining of wellbeing is illustrated here in M 4’s awareness that with RTW he reconnected with his ‘old self’, and that was the crux of feeling healthy and
contented for him, not the physical aspects of the job (which he now found difficult to sustain) or his future prospects (which were now significantly changed as he required support to work).

M 1 described how his physical and dysexecutive (problems with skills requiring high levels of cognition such as problem solving, planning, divided attention) problems had caused him to consciously reflect and redefine wellbeing in the context of work. For example he used to be very outgoing and derive much pleasure from that aspect of his character, but since his TBI this has changed:

“I used to be a party animal in work, so the way I look at things now is soberly and with clarity. It’s nice but completely different so … I used to be like Keith Richards … mmm a reformed character now (…) I get a feeling of wellbeing from doing voluntary work at the moment, and that’s only three hours a day, and I’m okay with that … to start with my people skills weren’t as good as they used to be … but I think I’m there now”.

Participant M 1, lines 93-97, 107-111.

1e Grief Reaction

From the sub themes in this master theme of ‘personal costs of lifestyle losses’ it is apparent that the RTW rehabilitation process involves the participants experiencing a distinct and separate grief reaction based purely on their attempts to RTW. The quotations that describe the process are tabulated on the five stages of grief described by Kubler-Ross (1969) seen below:
Table 5.2  Stages of grieving reaction as defined by Kubler-Ross (1969)

<table>
<thead>
<tr>
<th>EKR Stage of Grief</th>
<th>Quotations from Narratives</th>
<th>Location of quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Denial</strong> – Conscious or unconscious refusal to accept facts, information, reality etc. relating to the situations concerned.</td>
<td>“When I was eventually persuaded by the speech therapist in the local community hospital to come and see you it was with some reluctance… and it took quite a few meetings with you and the psychologist before it began to sink in that even though there were no obvious side effects to the brain injury, there were far more subtle ones that I didn’t want to acknowledge”</td>
<td>M3 233 – 240</td>
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<td></td>
<td>“I was in work and the boss would be saying ‘you can do this can’t you?’ and I’d say ‘hey I’m ok. I know about this. I can still do it. Then I’d stand there and do something. The when I couldn’t do it, I’d feel like I was on the like … on the outside of it again. I’m not part of the .. the whole thing … the work thing. I’m not part of it anymore”</td>
<td>M6 611-616</td>
</tr>
<tr>
<td><strong>Anger</strong> – People dealing with emotional upset can be angry with themselves and/or with others, especially those close to them.</td>
<td>“I didn’t want that. I wanted to get them to break out and find me something I could do … some direction for me to go in … They made me so angry”</td>
<td>M2 318-321</td>
</tr>
<tr>
<td></td>
<td>“It absolutely knocked me sideways. I was so angry … umm … it wasn’t my fault”</td>
<td>M3 79-81</td>
</tr>
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<td></td>
<td>“I wanted to shout ‘you walk a yard in my shoes and see how you cope, you know… just walk up and down… bastard”</td>
<td>M5 439-441</td>
</tr>
<tr>
<td><strong>Bargaining</strong> – People facing trauma can bargain or seek to negotiate a compromise with others or whatever God they believe in.</td>
<td>“I think it would have helped me get over the initial shock… of realising that the life I had was finished, and that I had a new life to go on with … but I didn’t want the new life and so I made deals with God to let me improve. But it didn’t”</td>
<td>M2 518 – 525</td>
</tr>
<tr>
<td><strong>Depression</strong> – This is a sort of acceptance with emotional attachment. It is natural to feel sadness, regret, fear, uncertainty etc. It shows that the person has begun to accept the reality.</td>
<td>“I’m quite shy and timid around people so… male or female any age but I’m gutted about that … I’ve had to confront all of that …. It started last year to worry me”</td>
<td>M1 117- 120</td>
</tr>
<tr>
<td></td>
<td>“Very depressing … I think at one stage I just felt like I was waiting to die … I had died and was waiting to be buried”</td>
<td>M2 306-308</td>
</tr>
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<td></td>
<td>“When I’m alone and I look at myself in the mirror, and see the hole in my head; that is when I bring myself down. I really go down within myself”</td>
<td>M4 625 – 628</td>
</tr>
<tr>
<td></td>
<td>“I feel a failure. It’s in the knowledge that … crikey now my wife is the main earner. […] I beat myself up you know … come on don’t say you’re a failure, but it’s still … that’s still a part of my life. Basically I’m a failure”</td>
<td>M6 541-544, 561-563</td>
</tr>
<tr>
<td><strong>Acceptance</strong> – This stage varies according to the individual’s situation. It broadly gives an indication that there is some emotional detachment and objectivity.</td>
<td>“I’m not as bad as I was… last year was awful… but still it comes along in waves … I’ll be alright for a month and then it will catch up with me for a week or two…”</td>
<td>M1 49-51</td>
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<td></td>
<td>“It took me a while to sort of click … and I thought well, well it’s finished … all the hopes. Al the… you know, the ummm… you have dreams of what you would like to do. I know there is a future… it’s a very different future… and it will happen”</td>
<td>M2 08-815</td>
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</tbody>
</table>
Theme 2  Impact of TBI on Participants’ Perceptions of RTW & Occupational Activity

A number of participants’ quotes have been used for illustration of sub themes within this theme. Two participants did not contribute to this theme as their interview recollections focused more on their experience of the rehabilitation they received. They have thus had verbatim quotes placed in further themes of this chapter. This theme of defining RTW was extrapolated quite unexpectedly for me as the researcher upon listening to, and re-reading, of the transcripts when I came to realise that this was an important aspect of the RTW rehabilitation experience for some of the participants because it determined their line of demarcation between rehabilitation and RTW. The sub themes collated within this theme address my epistemological aim of wanting to know how participants constructed their experiences of attempting to become more functional within their employment capacity during rehabilitation. For example, it will be seen that for some participants, volunteering was part of the rehabilitation process, whereas for others, it was their desired RTW outcome at the time of the interview. In addition the sub themes generated here began to address the second aim of the research which was to explore what, if anything, was actually assistive in RTW rehabilitation when an individual had multiple impairments and disabilities as a result of TBI.

2.a. Volunteering

Participants found various creative ways of exerting as much control over the, often devastating, long-term consequences of sustaining a TBI on their attempts to successfully RTW. Most participants (six out of ten) had undertaken voluntary work in some capacity or another during their RTW rehabilitation, albeit reluctantly in some cases (five out of ten participants). Whilst all ten participants had discussed the option of volunteering with clinicians during RTW rehabilitation, at the time it was considered a temporary measure only; not a long-term solution to being gainfully employed. None of the participants had considered working in a charity shop as being an acceptable volunteering option,
and had sought (and subsequently found) volunteering options, which they considered, would be more worthwhile. All six participants reported favourably on the self-affirmation they achieved whilst undertaking volunteering:

“A sense of achievement when I can sit down with a child who is struggling to learn to read and write and then suddenly they turn round and say ‘Oh, I’ve got it’…. So it is really… really nice when they pick up a book and just start reading it … clearly and accurately because it opens up a whole new world to them. And I suppose I can understand their frustration of not being able to do something as well”.

Participant M 2, Lines 426-436.

This extract appears to illustrate the fact that even though the participant is not paid for his work, he still gets positive feedback from witnessing the success of others through his endeavours. The fact that participant M 2 had experience of struggling to achieve (implicitly stated in this extract as referring to his TBI, and explicitly stated earlier in his narrative when discussing the early phase of recovery) indicated he had empathy with others who struggle, and could relate to their frustrations. He appeared to consider this a positive quality in terms of being of value to others. For this participant, return to paid employment was not an option due to the extent of his physical difficulties and rigidity of thought. However, he now considered volunteering a worthwhile alternative to paid employment. This sentiment is reflected in his narrative by use of descriptive phrases relating to his experience of volunteering such as “It’s brilliant” (line 419), “I’ve been trusted…” (line 1225), “volunteering compensates to a certain extent…” (lines 1229-1230).

Participant M 6 also spoke positively of the value of volunteering. To him, the real value was in being able to ‘give something back’ after all the help he received. The language used here denoted sincere pleasure in undertaking the work, despite there being no financial remuneration. This suggested that he possibly attained a feeling of wellbeing, as discussed in the previous theme of the meaning of work, which made his efforts worthwhile. In addition, he suggested that volunteering had assisted him to realise his potential capacities with regard
to employment. It was formative in his deciding that continuing to volunteer was not a realistic occupational aspiration, and certainly returning to paid employment was out of the question:

“[Volunteering with Headway is] just a way with me putting something back if you like into what the brain injury unit’s been doing for me. I just think… It’s to put something back. (...) 
... I used to enjoy it … I really did enjoy it so I met other people of the same ilk and I was really enjoying it at that stage. I was getting involved and all that. But ummm … it was only then I started realising … what effect I had on other people by saying certain things…”.
Participant M 6, Lines 344-348, 733-739.

The reflections offered by participant F 2 offer a different value to volunteering for me. It is to do with having purposeful activity and actively being a ‘doer’ instead of possibly being an ‘observer’ of life after sustaining her TBI. It was apparent that she was able to undertake volunteering in a field of work that she ‘loved’, that is with children. The true value for this participant would appear to be the beginning of regaining ‘normality’ that volunteering gave her. This replaced her previous perception of ‘normality’ being provided through paid employment. Her emotive language in this extract about being unable to work is powerful: “devastated”, “don’t feel part of society”, “can’t work normally”. Her volunteering had to stop when she became pregnant, and she now has ‘purpose’ or ‘normality’ instilled in her life from being in the role of ‘mother’.

“… Getting me out of the house. Making me feel I had a purpose and I could do something because the children … oh I love children and they liked me I think as well … I used to love it”
... Because you are so devastated and you don’t feel part of society and you can’t take part in things and you can’t work normally. So I just found it a good help”.
Participant F 2, lines 30-34, 47-51.
2.b. Re-Training

Participants reported that their experience of engaging in re-training packages were unique, set apart from those of others, particularly those who had not sustained TBI. Their engagement in re-training was not undertaken voluntarily in order to develop their careers or to explore an alternative lifestyle. Rather it was undertaken due to the change in their presentation as a result of sustaining TBI. Although half the participants (five out of ten) stated they had engaged in re-training as part of their RTW rehabilitation, only three participants spoke in detail about their experience of re-training for alternative employment further to sustaining their TBI. Their reflections provided significant information about how their characters had changed as a result of the TBI and also how they perceived alternative options in terms of employment.

For participant M 2 he was no longer a member of the world where having full functional use of both lower limbs was considered ‘the norm’. Furthermore as an individual who utilised a powered wheelchair to mobilise he had disabilities that needed to be accommodated when considering RTW options. As there was no option of returning to his previous employment he decided his chances of finding alternative gainful employment would be increased if he undertook some re-training; but then did not stop completing courses:

"Well when I realised that … there was very … very little I could do from a wheelchair I suppose I then considered my options. Ummm … and basically the college was so close to where I lived; and one day, just on the off chance I popped in to see what courses were available to people with disabilities. So I decided to do a computer course because everything seemed to revolve around computers at that time … so I did something called the ECDL (European Computer Driving Licence). I spent a year in front of the computer pressing buttons and getting frustrated because it wouldn’t do what I wanted it to do. But we persevered and we got through it. And then I pushed from there, I went on to do some other courses because I was able to talk to ummm the troupers care etc … and then I did a desk top publishing course … and I found that quite … I enjoyed that … So then I thought I would like to
start to learn to draw and paint so then I did a foundation art course which I seemed to pass quite well. So I thought, isn't this great being back at school (...) so after that I enrolled onto a B Tech science course which was totally fascinating ... so after two years I have now got a B Tech science qualification. After that I went back to the art course again to do the next level ... which was brilliant. But I think what really helped me was the fact that I could get up in the morning, have a wash, and get dressed, and have breakfast, and then go out with a purpose”.
Participant M 2, Lines 146-184.

It appears that this participant experienced difficulty in reconciling how he could now utilise his new training and certificates into potential future employment. This uncertainty about the direction of potential re-training is, in my experience as a specialist clinician in this field of work, commonly found in individuals who have sustained TBI, and was echoed by others in their narratives:

“I'm ready for any work opportunities that come my way now so just ... not a hundred percent sure on what I want to do…”
Participant M 1, Lines 81-85.

“To do like ... support work ... hopefully when I get there”
Participant F 1 speaking about her options when she completes her NVQ in child care training, Lines 65-66.

In addition to the uncertainty experienced regarding future direction once a course of re-training is completed, the participants further reflected on the negative elements of their eventual work placement on their salary:

“I'm [not as conscientious a worker] as I was ... probably. But I'm not being paid enough. It's not what I wanted to do, that, which is really frustrating. So I just go to work to be there, and that's it”.
Participant M 5, Lines 647-650.

A further difficulty for participants when considering RTW following re-training was their difficulty in fully comprehending the total demands of a job. This was often due to the location and severity of the TBI they sustained (See table of
injury severity in chapter 4:98). For example after completing a part time counselling course for one year (including two four week placements at NHS mental health facilities), participant M 1 appeared to consider that obtaining a post as a support worker with adults who had drug and/or alcohol dependency problems would consist of achievable tasks for him. However he did not appear to have given consideration to incidents when clients may become disruptive, aggressive or uncooperative. I interpreted this as being symptomatic of his TBI presentation of having difficulty in considering the whole picture, without support:

“… Now I want a nice quiet [job] … sit in an office type or… shelf stacking like this away from other people just to get some money … and I want to study and do something to do with drug and drink rehab so I’ll start there. A support worker … That’s what I fancy doing. There’s no running involved there … it’s just driving, meeting your clients, being on time which I’m okay with now”.

Participant M 1, line 504 – 521.

The following extract from participant F 1 is also illustrative of an inability to take in the whole picture with regards to re-training. As stated earlier this participant was in the middle of her training course to become a registered child minder at the time of her interview. She appeared to have both difficulty and a reluctance to accept that she had difficulty in fulfilling the personal requirements for looking after a group of energetic and boisterous children. For information, this participant was significantly physically disabled as a result of her TBI (reduced core postural stability with low muscle tone producing ataxia in both upper limbs. She also presented with erratic movements, combined with reduced active ranges of movement in her left upper limb. She had ataxic movement bilaterally in the lower limbs, and had slow and dysarthric speech, making it often difficult to understand her). In addition, her cognitive problems meant that it was not possible for much of the interview for me, as the interviewer, to adopt a phenomenological and open mode of questioning with her, as she would not have been able to provide valid responses. As such, although the questions posed to the participant by the interviewer may be perceived to be assumptive here, this was necessary to assist the participant to tell her narrative:
I: What work do you want to do in the future?
Participant: “Be a teacher”
I: “…What skills do you have for being a teacher?”
Participant: Patience to a point... well with young children I think I’ve got patience... I’m caring and loving”
I: What do you think might hold you back in your progressions to become a teacher?”
Participant: At the moment I can’t write and I can’t write with this one because I shake and I can’t lift with this one because this side won’t lift”
I: “Do you believe you will be able to get paid work once you’ve done your training?”
Participant: “Yeah … because I ummm … I’m frightened of going in little cars to get there … I’ll do it in my own way…”

2.c. Return to Previous Employment

Returning to previous employment following TBI is well documented as being very difficult to achieve. This is attributed by Drake & Gray (2000) to the fact that between 70%- 84% of individuals who sustain moderate TBI report continuing problems with cognition. The degree of perceived success in this venture reported during my interviews varied and the excerpts provided illustrated the difficulties perceived by some participants in their plans to return to previous employment. Out of the ten participants, six had aspirations to return to their previous employment following TBI. Three had no such aspirations due to their physical disabilities being so debilitating that this was not an option at any level. One participant was not considering this option as she held two part time posts prior to sustaining her TBI. Out of the ten participants, two were successful in their attempts to return to their previous employment at some level. The other eight participants were not able to do this as a result of the long-standing problems associated with their TBI. The language used in the following excerpt is
matter of fact and blunt, with no ambiguity that considering returning to his previous place of employment was not a realistic option to pursue:

I: “How do you feel your employment prospects have changed after your brain injury?”

Participant: “Well they became zero didn’t they really”

Participant M 2, Lines 11-17

Instead of taking the decision themselves, some participants felt it was important to externalise the decision for their not returning to their previous place of work in the same capacity as pre TBI. It appeared that in doing this the participants were accepting of the reduced control they had over their employment potential. It also appeared that the participants were willing to ‘follow orders or advice’ because they believed that the person/s offering the advice understood their individual situation and genuinely cared about them, and hence the participants trusted their advice:

“It was decided [by the clinicians] that I couldn’t work on a full time basis and I couldn’t go back to my previous remit.

(…) Now I do three days a week covering just creative stuff effectively which I can do pretty much at my own pace most of the time”.


The fact that participants had the goal of RTW did, in one instance with this group of individuals, lead to a successful outcome. However he attributed this to his internalisation of self determined goals and his resolve to achieve his goal within a given time frame. The language used illustrated the sense of achievement he felt at attaining his goal.

“My main [goal] was to get back to work in twelve months [from the date of my accident]… That’s what I wanted and I did it to the day which I was completely chuffed about. So I always knew there as a job there waiting for me, I just had to get physically and mentally tough enough, I suppose, to be able to do it again, and so that’s what I kept in my head psychologically”.

Participant M 4, Lines 153-160.
Theme 3  Factors Impacting on the Rehabilitation Period

The generation of the sub themes within this master theme provided insight into the participants' interpretations of their lived experience of engaging in RTW rehabilitation. This provided the researcher with an enhanced understanding of what constituted as 'reality' for the participants, thereby addressing the methodological aim of the study. In addition, the sub themes address the first and third aims of the study. The first theme was to understand how participants made sense of their personal and social worlds and how clinicians could assist them in this process. The third aim was to explore whether there truly is a role for occupational therapy in RTW rehabilitation for an individual with TBI and is tentatively addressed in the third sub theme 'therapeutic relationship'.

3.a.  Change in my physical abilities

This theme focussed on eliciting information about issues, other than apparent clinical issues, that impacted on all the individuals' ability to fully engage in their RTW rehabilitation. This provided valuable insights into some difficulties experienced by participants in fully cooperating with the demands of the RTW rehabilitation experience as they recounted their interpretations of their lived experiences of having engaged in the rehabilitation. Recovering and working after brain injury is, for many, a tremendous challenge. Moreover individuals who have physical problems such as excessive fatigue, found that it sometimes worsened to the point of exhaustion. Many of the participants (nine out of ten) spoke of the physical fatigue they experienced and how it impacted on their potential to engage in RTW rehabilitation and, ultimately, their RTW.

It appeared that associated with the fatigue element of the physical problems there was an element of fear of failure that was described by many of the participants (seven out of ten). This was expressed as fear of being too tired to be able to function productively within the workplace and therefore not being valued by their colleagues. For some, it made them hesitant to consider placing themselves in the work situation, and suggested that they needed significant
clinical support to ensure they had internalised strategies to confidently cope with their fatigue prior attempting to RTW. For example it seemed, for participant M 1, that his concerns regarding his current fatigue levels (3 years, 2 months post injury) were prohibitive to him being able to consider positively engaging in returning to gainful employment:

“It’s just my fatigue levels I’m a little bit concerned about. If I have a nine to five, and I have to get up at seven and get home at seven it might drain me somewhat. I don’t know… (...) But then, what I don’t want to go for it if I’m going to fall asleep at the desk in the afternoons so… suppose there is only one way to find out”
Participant M 1, Lines 63-66, 153-156.

Conversely the same participant did not find the fatigue element of his presentation restrictive in his willingness to engage in rehabilitation to improve his physical presentation. He even experienced ‘burn out’ fatigue, but continued to see that as a motivating factor to engage further in rehabilitation.

“[The physiotherapy programme] was good, but then you know what I’m like… it’s … you get out what you put in , and I put in an awful lot; it’s just that I burnt out a couple of times because of that… but looking back at it now, I’m glad that I did it like that (...) I slept for eighteen hours a day sometimes, didn’t I, when I burnt out but … I just felt that I needed to push myself and if I only gave ninety percent then I wouldn’t be happy”.
Participant M 1, Lines 265-269, 275-279.

The other physical problem expressed in narratives as impacting on participants’ potential to RTW was changes to their mobility (seven out of ten participants), whether that meant that the individuals were wheelchair dependent (one participant), or whether their mobility (balance, movement, coordination, physical stamina) had changed in some way due to the location of their TBI. In my clinical experience it is common for individuals who have sustained TBI to focus on the observable presentation of their TBI, particularly mobility and have a target of wanting to regain their pre-morbid gait. The physical image indicates a desire to
return to ‘being normal’. It emerged during the participants’ narratives that this impacted significantly on their engagement in rehabilitation, as the improvement in this particular aspect of RTW rehabilitation was visible and measurable, and also observable by others. As such, their motivation to engage in this aspect of rehabilitation was often reported as being higher than, for example, their motivation to engage in the aspect that concentrated on learning strategies to manage some of their cognitive problems (which are not necessarily visible to others:

“Because that’s what you see when you get out of bed. Nobody really sees your mentality; but not being able to walk properly… I’ve still got numb toes and numb fingertips (...) I just wanted to be able to walk properly unaided again and that was my main goal rather than… I know there’s obviously issues with my brain, but to me it was… I just wanted to be able to walk across the road to my gran’s house without my mum holding my arm. So to me it was a hundred and ten percent just physio, physio, physio. That’s all I wanted to do”.
Participant M 1, Lines 218-220.

Participant F1 also described how her motivation was higher to engage in the rehabilitation of her physical injuries, even outside of the clinical environment. She accepted that in the non-visible aspects of her rehabilitation, for example improving the rate of verbal information processing, she needed structure imposed on her to practice strategies outside the clinical setting (such as being given homework tasks with a date for completion). This was not due purely to a lack of willingness to engage in cognitive rehabilitation to assist her RTW potential, but could again be attributable in part to the location of her TBI as the centres involved with initiation of activity were disrupted (frontal lobes bilaterally). However she continued with the physical aspect of her RTW rehabilitation out of the clinical setting with no structure imposed on her. This suggested that the ‘visible’ was a motivating factor in engagement in rehabilitation.

“I know I can do it [speech & language therapy and activity based cognitive rehabilitation tasks] on my own but... if you know you’ve got someone telling you ... like homework, you can do it... you will do ... but I haven’t got no
motivation. *But in the gym I have got motivation ‘cos I want to walk better and faster, and I want to look normal. I know you shouldn’t be discriminated against … because of disability … but I want to look normal going in to interviews*.

Participant F 1, Lines 340-344.

For one participant whose mobility problems meant that he was wheelchair dependent the level of his physical restrictions following TBI had an adverse effect on his willingness to engage in rehabilitation as it impacted severely in his mood levels. His language indicated initial despondency, a need to cling on to hope that his situation would get better, and then realisation that he would be permanently in a wheelchair, and the associated feelings of depression that accompanied this:

“Well when I realised that … there was very … little I could do from a wheelchair, I suppose then I considered my options (...) I was holding on to the idea (...) I would get better. A couple of months and I would be back at work. And it slowly began to dawn on me that you can’t do the sort of things that I did before … from a wheelchair … you just can’t do it (...) [It was] very depressing”.

Participant M 2, line 146-148, 294-299, 306-308.

3.b. **Rollercoaster emotions**

All the participants typically describe two aspects of emotion that impacted on their willingness and ability to engage in RTW rehabilitation. Firstly the frustration and anger they felt at being in the situation of needing to actively consider their ability to return to work due to physical and/or executive difficulties. Executive function describes the ability to initiate and perform non-routine activity, including coping with novelty (creative problem solving), decision –making and dealing with risk (Ruff et al. 1993):

“It slowly began to dawn on me that that you can’t do the sort of things I did before … from a wheelchair … you just can’t do it. It was just so frustrating. I wanted to be the person I was… but I couldn’t”.

Participant M 2, Lines 297-301.
“It was devastating… ummm … until (...) It absolutely knocked me sideways. I was so angry… ummm … It wasn’t my fault. Ummm … and it took me some months to come to terms…”

“I didn’t like that at all. Frustration … not being able to look after myself was the main… was the hardest part of it all. Having to go … stop work”
Participant M 4, Lines 58-60.

Secondly, and most relevant for this research, they spoke of the resultant depression, possibly as part of the classic grief reaction (Kubler-Ross 1986), as they became aware that their world view regarding the meaning of work and their productive role in general needed to undergo a dramatic change. This included, in the majority of cases, depression at the realisation that their long-term earning potential was severely hampered. With the exception of one participant they were all employed in positions involving responsibility for colleagues, and earning good wages prior to their TBI. Post interview, the issue of financial income compared to the participants’ position on the Grafton Manor Rating Scale both pre and post injury was explored. This provided the first hard data regarding a possible connection between the two aspects, and explored the financial cost to the individual, as opposed to the Government. This is discussed further as an original contribution to knowledge in chapter 6.

For participant F 2, who had recently started in a job with excellent career prospects, the realisation that even with RTW rehabilitation her earning potential was extremely slim, was particularly hard and resulted in feelings of there being nothing to aspire to:

“… The only work I got paid for was for two mornings I was doing ‘Capture’ which is reading with different age children, and it was only around thirty pounds a week, and that made me feel quite useless(…) Because, before, I thought I’d go quite far in my career with having a degree … I was training to be a careers advisor, and then nothing”.
Participant F 2, Lines 74-78, 90-92.
Participants also described the overwhelming feelings of difficulty in coming to terms with accepting the full consequences of their TBI and realising that they were not ‘normal’ and how this impacted on their willingness to engage in RTW rehabilitation:

“… Months I think really before I really understood the full consequences of it [the TBI] … how much of what I could expect in my life, if I could do something… It was very difficult. The hardest thing was going back home to my computer and like, not knowing what to do well, you know not having a good idea, and all of a sudden, bang, …loads of things come back literally like Blackpool. (,,,) I just couldn’t talk, could hardly walk; I jut felt, I don’t know, just not of this world… Just not part of the human race sort of thing. It’s just … and also people make you feel like that as well because they just laugh and all that (…) [RTW rehabilitation helped me to] understand that I was not the only one that can’t work things out or… you know that you’re here [in the RTW rehabilitation group and] that is the main thing really”

Accepting, having control over and understanding the fact that his RTW potential was changed for ever was particularly difficult for participant M 7, and he could not actively engage in RTW rehabilitation without concurrent medication, which he also had difficulty in accepting:

“I don’t know where I would be, I mean,… the help I’ve had as far as facing up to ummm … taking ummm… anti-depressants or nonsense tablets as I nickname them ummm … has been invaluable … I didn’t want to take them and fought against it for a long while, but in the end I took them and … ummm …. They … they’ve been a life line to a certain degree and made me start seeing things in a different light a bit more… seeing life differently (…) being a bit more realistic (…) not burying my head in the sand and facing up to stuff (…) … I don’t think realistically I can ever go back into ummm … into a physical job that I’ve done before or done all my life”
For participant M 4 the emotional aspect of being in receipt of benefits was a significant factor in encouraging him to engage in RTW rehabilitation as he felt very negative toward people who accept benefits when they do not need to. This was particularly pertinent for him as he was in a motor vehicle accident with no one else involved:

“… I just wanted to live a normal life, I wanted to … I cannot stand people who are on benefits when they don’t need to be … I don’t know, I just despise people taking money when they don’t need to be … I didn’t want to be on benefits because the accident was my own fault”.

Participant M 4, Lines 219-225.

3.c. Therapeutic Relationship

All the participants spoke of the importance of the therapeutic relationship on their ability to engage in RTW rehabilitation. The participants had individual needs in terms of RTW rehabilitation. They had different options to work towards, and differing skills left intact from their TBI. However, the relationship with the RTW key clinician was perceived as being of utmost importance for them. During the period when participants had attempted to RTW in any capacity, it was important that they had rapid access to the key RTW rehabilitation clinician which was often the occupational therapist, so that they could obtain assistance to problems or difficulties as they arose.

“… I think this was shown when the wheels came off at Christmas … ummm … I mean I was very close to being sectionable at that time … I was able to phone here and I was … [the occupational therapist] was there the following morning at eight o’clock in the morning ummm … and I was able to see [named psychologist] (...) The GP told me (...) he said ‘oh it’s good that you’ve been able to see them quickly because if I’d have referred you ummm… it would have taken three months for you to be able to see a psychiatrist… which you know I think puts it in perspective”.

Participants appreciated clinicians who undertook a proactive role in this. Having access to clinicians who took the trouble to encourage the rehabilitation period made a difference to their ability to engage:

“A lot of it is probably down to yourself and overcoming your own ... ummm ... mental barriers, I mean... it's just a case of the team of people around you just cajoling you and helping you make your own decisions. That's my experience”
Participant M 7, Lines 396-401.

Many (eight out of ten) participants described difficulty in continuing aspects of their RTW rehabilitation within their daily lives to optimise their chances of success in their RTW attempts. This was apparent in participant M 6 even when he asked for tasks to do at home:

“I did have a little bit where I asked yourselves to put me on some sort of fit regime and that, but that didn't work (...)
Well it was just me... just couldn't cope with it; just didn't want to know, as much as I wanted to do it”.
Participant M 6, Lines 182-185, 193-195.

Obtaining helpful advice from clinicians was not always easy, particularly for participant M 2 who recalled simply wanting to know what his RTW prospects were in the early stage of his rehabilitation:

“I found it very difficult to get answers out of the staff as to what was happening ... what I could expect to happen ... I kept getting sort of 'well you'll have to wait and see' or 'someone will talk to you about that later' ... and later never really came did it? So I felt quite ummm isolated in a way”.
Participant M 2, Lines 80-86.

**Theme 4 Participants' Perceptions of Assistive Elements of RTW Rehabilitation**
The sub themes generated within this master theme provided insights into the participants’ constructions of their experience of RTW rehabilitation following TBI; that is addressing the epistemological aim of the study. In addition the sub themes addressed all three aims of the research. Information was elicited
regarding what was assistive in RTW rehabilitation following TBI. The impact of the roles of clinicians, including the occupational therapist were discussed. In addition the researcher obtained an enhanced understanding of how the participants made sense of their personal and social worlds and how clinicians could assist them in this process.

All ten participants shared some positive perceptions of their RTW rehabilitation experience, and reflected constructively on aspects of rehabilitation that were not necessarily covered but which they considered would be assistive. With regard to the entire experience of attempting to RTW, the participants reflected on the opportunities that rehabilitation had offered them. They also spoke of positive outcomes, usually attributed to receiving assistance to come to terms with changes to their pre-TBI world views and aspirations including becoming more productive, resuming roles, identifying new roles, regaining independence, and reducing the amount of benefits they received.

4.a. Vocational

All participants commenced their RTW rehabilitation experience in the belief that they would be engaging in some form of RTW experience at the end of the sessions. Of the ten participants in the study only one was not engaged in any kind of vocational activity at the time of the interviews. All participants had to consider changes to their previous work lives, and where it had become apparent that return to their previous employment was not an option, individuals appreciated having the opportunity to learn about other alternatives they could explore:

“[RTW rehabilitation] has shown me there is … other avenues … as that part of my life last year I just thought that is it … It’s over. Done with. Never be repeated. But you’ve [clinicians involved in RTW rehabilitation] shown me that with small steps … baby steps, I can keep moving forward and other doors will open for me … so there is light at the end of the tunnel”.

Participant M 1, Lines 620-627.
As part of their RTW rehabilitation a number of participants (five out of ten) had experienced involvement from the clinical team with their employers. Two participants, in particular, voiced positive reflections on the liaison between the clinical team involved in RTW and their places of work. Of particular value was the workplace assessment and consequent liaison with the occupational health department. Both participants voiced feelings of experiencing attitudes denoting a lack of understanding of the effects of TBI from their employers. This difficulty was resolved by having contact with clinicians from the NWBIS; even when the outcome was not returning to their previous employment:

“Well I suffered my injury and ummm … [the occupational therapist] came out to the workplace to see exactly what it was that was involved and ummm … [she] must have put something together as well as the company doctor. And when the company doctor got all the stuff back, he was actually concerned very much (…) but yeah I asked the company doctor and he said at the end of the day 'I think we better part company'. That was it … basically thank you very much, goodbye”.
Participant M 6, Lines 70-76, 87-90.

One participant recalled in detail the involvement with occupational health, employment managers and clinicians (occupational therapy and psychology) providing RTW rehabilitation. He admitted that without this input he firmly believed that he would have required readmission to hospital with an associated illness such as high blood pressure or depression. Moreover, he also felt that the liaison needed to continue until he felt that no further involvement was required.

“… My employers also told me that they valued the input that you [occupational therapy and psychology] were able to give them because effectively it was unchartered territory for them (…) and they probably would have assumed I had been signed off by a doctor as being fit for work and there was no real reason to do anything other than the standard policy for someone who has been on long-term sick (…) So it’s pretty clear that if I hadn’t had the input of the brain injury unit I would certainly run the chance of getting back into very … very … serious health problems very quickly”.
4.b. The Personal Perspective:

Participants described various aspects of rehabilitation that they had found assistive and most participants (eight out of ten) spoke of the positive impact of accessing the reaffirmation from clinicians that they, as individuals, could control the pace at which they attempted to RTW as part of their rehabilitation:

“Mmm … quite a lot of it … it’s off my own back isn’t it … so [the occupational therapist, speech & language therapist & physiotherapist] *can take me to the door but I have to do it. I’d say it’s helped me … doing it at my own pace*

Participant M 1, Lines 189-192.

Participants’ progress was dictated by their ability to come to terms with the events that had led to them having long-term problems impacting on their ability to RTW. Whatever pace they adopted was acceptable within the remit of RTW rehabilitation. Some felt they would have made greater progress in accepting and realising that their personal attributes were changed in all aspects of their lives (as opposed to simply the family environment) had they been able to access the full gamut of the RTW rehabilitation experience at an earlier stage of their rehabilitation:

“[If I had attended the RTW rehabilitation earlier than I did] … Mmm … *Well I think it would have helped me over the initial shock (…) Of realising that the life I had was finished and that there was a new life to go on with … ummm of what, how and when*”

Participant M 2, Lines 518-527.

Whilst participants described successfully learning about various management strategies to cope with events in work for which they were unprepared, such as taking on a new task, changing shifts or experiencing a further period of ill health, their narratives illustrated that they had often underestimated the effect such events would have on them. This was despite being forewarned within RTW rehabilitation that this was indeed likely to happen and would need to be managed. For example participant M 3 had returned to his previous place of
employment (part time and restricted duties) and had been pleased with his progress. However he voiced how little it took to disrupt his productivity at work. He was now always mindful of the impact that stressful events in work could have on his overall functional performance not only in work, but also at home and socially, and valued the availability of RTW clinicians by phone to discuss such issues within a period of two days of them arising in work:

“I suppose maybe you can get to a point where the bulk of your recovery is complete … but … it only takes a very small thing to knock you off track … to maybe slip back quite a long way. I didn’t realise … I still find it hard to accept. But now I use the phone to ask for help, even if it is … just to verify that all will be well. That is so important”.

Participant M 3, Lines 883-892.

Similarly another participant described the helpfulness of being able to access clinicians when he encountered a problem whilst working:

“Gino just gave me a conservatory floor to do … I went there and sort of half finished it and that was when I had my first seizure, when I was pushing myself to … to … to go back to work. But obviously my body was saying ‘hang on a minute mate, it’s a long way before you’re going to be doing anything like that’. But (…) that was only four and a half years ago … and since then I haven’t done a day’s work since then … because it frightened me so much (…) and the help I had from the psychotherapist ummm … was invaluable in facing up to that…”

Participant M 7, Lines 118-130, 213-216.

The feeling of being a ‘freak’ or ‘not normal’ aspect of attempting to RTW following sustaining TBI was raised by five participants (out of ten). These feelings were considered potentially destructive by each participant, and wholly incomprehensible to individuals who had not experienced sustaining a TBI. Three of the five participants voiced this theme in relation to their becoming aware that they would not be able to return to their previous place of employment; even if they were given different duties. For Participant F 2 it was difficult to accept these feelings, particularly as she was in a work placement:
“… I did feel normal except on days when I was very tired and I used to think ‘What is wrong with me?’ and get really frustrated because there’s other people my age who are just full of life… and it’s difficult… and I think it’s even more difficult the younger you are because it’s more frustrating (…) You don’t feel normal (…) And I think that’s the hardest thing to come to terms with; that you’re not like everybody else”.


However, all five participants recognised that having clinicians who listened to the voicing of these feelings and verified that it was a circumstance they could not necessarily conceive of was helpful. Moreover being provided with strategies to try to manage these feelings was of great value in their RTW rehabilitation:

“Every time friends and family said they could notice a difference, I knew it was working. I knew I was getting back to normal. I knew the rehabilitation …[the occupational therapist] coming to my mother’s (…) and talking about; getting things off my chest. That’s immensely helped me really … ummm… Knew I didn’t want to do it … Knew I didn’t really want to be here, ummm … but I had to be really otherwise I’d be forever coming back her and I’d never be normal”.

Participant M 4, Lines 297-308.

“The only way I describe it is that lots of people start ummm … aging over a period of time and I believe that … on Mother’s Day, two thousand and four; BANG. I became like … like an old man all of a sudden … overnight (…) It’s tough going sometimes … really is tough going because it’s not normal. But you clinicians accept it … and that helps …”

Participant M 7, Lines 325-329, 333-337.

One participant reported coping positively with the recurring self-doubt regarding his potential to work by attending for individual appointments to supplement group appointments. He found it essential to receive re-affirmation of his continued improvement in rehabilitation from a clinician for it to have any internalised value:
“So every time I seen him [the psychologist] … ‘you’ve done well M 4, you’ve done that’ (…) so stuff like that sort of gets your mind going again (…) Hearing that means a lot – you’re doing well (…). It puts a spring in my step really”.
Participant M 4, Lines 520 – 525, 538.

4.c. Faith in clinicians’ knowledge and guidance
Two participants spoke of the need for RTW rehabilitation to consist of realistic goals with objectively measurable outcomes, whereas all of the participants mentioned the need to have targets to aim for within RTW rehabilitation. A recurring topic acknowledgement that the participants themselves found it very difficult to set their own goals which were realistic:

“But I didn’t know what … what goals I could actually aim for. So I had no way of sort of quantifying whether I was improving or not …”
Participant M 2, Lines 94-96.

“… Looking back with hindsight, if I’d have taken my own course, I hate to think where I would be now. Because I certainly would have gone back to work on a full time basis, and would certainly have gone back to work to my old job description (…) So it’s pretty clear that if I hadn’t had goals set by the brain injury unit I would certainly have run the chance of getting back into very … very … serious health problems very quickly”.
Participant M 3, Lines 243-248, 266-270.

[An effective clinician has to be] “Understanding, caring, but not too like … ummm … They have to set targets for me … I don’t like being molly coddled and I can’t set them myself. I don’t know how. And they’ve got to be older than me … not young”.
Participant F1, Lines 359-363.

When describing the beneficial aspect of attending RTW rehabilitation groups M6 voiced how he needed external cues reaffirmed by his family for him to be able to accept that his conceived RTW goals were unattainable and unrealistic based on his presenting problems:
“It’s good to talk and everybody loved that [RTW rehabilitation group] just purely for that alone you know … but umm … actually me sitting through things ummm … yeah you know thinking ‘I can do that, I can do that, I can do that’ but then reality kicks in a bit later on when I’m talking to my wife or daughter or anybody … reality kicks in and you realise that ‘oh no, I can’t cope because of …’ “
Participant M 6, line 420-429.

An aspect of clinical intervention that participants felt they had not fully accepted whilst engaging in RTW rehabilitation during the clinical sessions was how the full extent of their dysexecutive problems, particularly self-regulation and monitoring of their difficulties, presented as problems. This included, for example, their inability to monitor lowered mood levels, inability to monitor fatigue levels or their inability to realise that they were not paying attention:

“I always remember the one chap that showed me a film and how I should react to it, and all the rest of it and ummm … I just told him the honest … the answers honestly, and all that lot … and when he finished he said ‘You know something’ he said, ‘you are severely ummm … depressed … severely clinically depressed’ I said ‘What? Don’t be daft’. He said ‘I can tell from the way you answered specific scenes and that like, you know’. And I said ‘Bloody hell’
Participant M 6, Lines 873-884.

[My brain injury has affected my ability to work] “A bit, yeah, because my mind wanders a little bit … and if I find something more interesting to look at, I will … but it’s quite hard to focus really … but that’s because there are lots of distractions. I don’t realize I’m not focusing”.
Participant M 5, Lines 286-290.

“Oh getting up … so from getting up at eight o’clock and I’m wanting to go to bed by ummm … half past eight at night and that’s regular, so … that just gives me a straight twelve hours a day and that’s it. I know this. It doesn’t change. I mean … as an example, [my partner] and I went out on Saturday night we went for a couple of beers round the corner, to what was my local pub. And
everyone was saying where have you been and stuff like this … and ummm … we were there and we there till … time we must have got home was quarter past eleven. Well the next day was a wipe out … that was it because I had had that extra three or four hours out. The next day was a complete wipe out so … but I couldn’t monitor it. It’s just restricting … ummm … it restricts me what I can do just now just restricts … restricts … “
Participant M 7, Lines 361-378.

For one participant the fact that the clinicians did not know him prior to his sustaining TBI meant that despite being told that his communication problems were now minimal, he could not conceive himself whether this was the case, or if he was now more accepting of his communication skills because of familiarity. His judgement of his own abilities was impaired:

“I don’t know if I’m back to myself or I’ve just got used to … talking like this … people can understand me now though so … ssseven, eight months ago I used to think aaarr… it sounds like I’m slurring my words”
Participant M 1, Lines 290-294.

All participants spoke of having valued the input of a number of professional groups involved in their RTW rehabilitation. The unique role of each profession was not important, it was the involvement of a team approach that was valued. Participant A’s description indicated that an interdisciplinary team approach was of most value:

“All three, occupational therapy, speech & language and physio so… they all tie in hand in hand I think … without one I wouldn’t be the person I am now”.
Participant M 1, Lines 358-361.

One participant also discussed the need for a seamless team approach from not just within the Service, but also in addressing problems when working with other services. This was a particularly important aspect of rehabilitation for this participant when he was transferred from the rehabilitation services offered within his local community hospital to NWBIS to address his RTW issues. Prior to being referred, he was insistent that he would be returning to work immediately and
lacked the insight to comprehend the full extent of his problems, as they were ‘unseen’. Thus the speech and language therapist referred him to NWBIS for more inclusive rehabilitation to address these issues constructively. This level of rehabilitation was outside the expertise of that provided at the local community hospital:

“It did puzzle me for a long time why I had been referred to yourselves and I think what I had boiled down to she [locally based therapist] had recognised subtle symptoms that if they hadn’t been treated would probably have left me on a very self destructive path (…) So I consider myself in that respect to be very … very lucky … that you know, I didn’t slip through the net”.


One of the participants spoke passionately of the breakthrough he felt upon receiving information about the anatomical and functional presentation of his injury, which went some way to explain his presenting symptomatology. His narrative illustrated the importance that we, as clinicians, provide such information in a manner that makes it easily understood by the individual to enable them to understand why they may be experiencing the problems that they do:

“… One of the doctors here pointed out that the brain compensates for the bit that’s not working and re-routes the passages. But if it’s a bit run down and tired it sort of basically says ‘well I can’t help you out today; you’ll have to get on with it yourself … hence the problems with my mobility (…) that helped me realise that even though the symptoms weren’t that obvious that there was actual damage there”.

Participant M 3, Lines 690-700.

As an occupational therapist I have often been challenged by patients for my choice of activity to address a problem that patients present with. The activities are often thought by the patient and/or their families to be demeaning or childish, and not age appropriate. For example when asking a patient to engage in a game of connect 4 in order to encourage planning, concentration and upper limb control. Unless I can explain and justify the rationale for the choice of activity, it
can render the intervention meaningless if the patient cannot see its rehabilitative value. One participant described experiencing something similar when engaging in speech and language therapy as part of his RTW rehabilitation. However he was able to appreciate the value of the tasks given to him when reflecting on them during the interview:

“There was one or two things that I used to think … bloody hell what was the point of me doing that. But now, looking back … a year and a half down the line it all makes sense to me (…) at thirty years old I shouldn’t be blowing through a straw and reading kiddies poems but (…) I know you’ve got your methods behind the madness”.
Participant M 1, Lines 400-410.

A very important aspect of successful RTW rehabilitation discussed by eight (out of ten) participants was the need for continued contact with clinicians involved in RTW rehabilitation even after the formalised RTW programme had ended. Some participants reported valuing the knowledge that this was possible:

“… I know now that if I do want to keep in touch with … speech therapy and physio … I can get in touch … you haven’t wiped you hands clean of me, and I know that if I reach a problem in six months (…) that I could get in touch with you again so… that’s always quite comforting (…) I’m hoping that I never will … have to … phone and ask for any assistance but … if I did need to or my parents did need to, then I know it’s only a phone call away”.
Participant M 1, Lines 739-747, 759-763.

This was not the case for all the participants, however. Once the formalised RTW rehabilitation package was completed, some participants did not feel confident enough to request further individual therapy form the clinicians, despite recognising that they would have found that beneficial:
“Well I think it should only stop when you feel that you don’t need it any more … but now, as it stands it stopped before you feel you’ve had enough because mine stopped quite early on and I didn’t have any for ages and I felt I needed some”.
Participant F 2, Lines 316-321.

“Good rehab … good … I could have had a bit more, but they … they have other people to see … I would like more writing and reading … I think”.
Participant F 1, Lines 124-127.

Six (out of ten) participants revealed they experienced difficulties in internalising strategies suggested during sessions to manage their problems. Two felt it was acceptable to choose to ignore advice and strategies given during the RTW rehabilitation and to not complete homework tasks. They were confident that this would not have a detrimental effect on the rehabilitation options available to them.

“I can’t ummm … knock people like that … that I’ve had around me. I can’t knock them because I’ve probably been a right git at times where I’ve cut myself off when certain things have happened. I’ve not done any of the things I’ve been taught and gone underground … so many times it’s … its … ummm … I now laugh about it. But it’s taken me … sort of, well it’s gone five years … just turned five years since the accident, and I’m only now just coming to terms with the fact of getting in place a system when I’m struggling to ask for help again. Now I’ll pick the phone up”. Participant M 7, Lines 405-418.

“Some of the coping strategies that have been recommended (…) I’m not very good at doing ummm … like writing things down and not pushing myself too hard (…) I need to be reminded”.
Participant M 3, Lines 492-493, 494-495, 499.

For participants who had experienced RTW rehabilitation in a group setting the value of group dynamics was very important in sustaining them in their rehabilitation. The benefits of meeting others and sharing experiences was a prime inducement to continue to engage in rehabilitation:
“We had people that was in the same situation and they seemed to be just getting on with their lives … so I thought there’s no point just feeling sorry for myself so … some on … buck up and just get on with it … then I found that as I continued with it and tried to move forward then it became easy to keep going forward than sliding back (…) So it was a sort of kick up the backside rally”.
Participant M 2, Lines 251-258, 264.

“It gave me a chance to talk to other people who had a TBI and to find out how they were coping … what their strategies were”
Participant M 2, Lines 671-673.

For one participant receiving rehabilitation in a group environment was particularly beneficial as it also enabled him to take steps to reduce his self-imposed social isolation:

“I remember meeting people in the same situation as me which is a good thing because you realise you weren’t the only one because it made you feel like a freak (…) … Being able to communicate with other people in the same situation makes you feel stronger in yourself (…) because when you’re injured you just tend to be on your own at home and that is it. That’s your life”

4.d. Familial Involvement
Some of the interview questions were about possible other aspects of the participants’ lives that had impacted on their attempts to RTW, that were outside of the direct clinical remit. All participants recounted the impact their families had on their rehabilitation without them being directly asked about this. There was a difference of opinion regarding the value of including significant others/partners in the RTW rehabilitation process. Some did not want the involvement of their partners because they were finding it difficult enough to cope with the changes in their abilities, and to have the active involvement of their carer in the rehabilitation would have simply been too much to bear:
“No I don’t think so [receiving rehabilitation in a group situation] … my mother would have preferred that because she would have met other carers. But to me it was embarrassing enough being cared for by my parents. To have them in the rehab, around other people. I don’t think so”.
Participant M 1, Lines 417-422.

Many participants spoke about the emotional and practical assistance they received from family in their attempts to RTW:

“Ummm … I … I don’t know because before I was a mum, I didn’t cope very well because of tiredness … It was getting up early in the morning and [husband] had to help me; which I have to do now. But I get a lot of help … mum comes and my sister helps, and when I’m tired I have a lie down”.
Participant F 2, Lines 221-226

“Well my wife’s had a lot to do with it, where I am today, like, you know”
Participant M 6, Lines 516-517.

“My dad’s an ex driving instructor, so it wasn’t really … he knew exactly what he was doing … to me it was quite tricky (...) the first few months [driving] were quite scary”.
Participant M 1, Lines 535-537, 544-545.

“I’m glad I came home with the help and support from my family (...) If I’d had no family to go back to … completely different story …”
Participant M 1, Lines 658-659, 668-669.

Two participants in particular described the total dedication of their family in assisting in the RTW rehabilitation process in the earlier stages. The level of practical support they required simply to be able to attend RTW sessions was time consuming and repetitive for them, as family members. The role of the unpaid carer was substantial:
“Everything I needed. I’d either, if I could do it myself; they’d not do it for me, but assist me in doing it … little things like confirming appointments with you … I’d forget. My mother would remind me and make sure I’d get on the phone and sort it out with you. And bank issues, eye tests, other doctors’ appointments, hospital appointments. She’d take me there because I couldn’t get the bus myself. So … they ferried me around. I mean, it’s all well you offering me appointments in Colwyn Bay. But getting there. I couldn’t have done that by myself. So I know there is hospital taxi’s and transport, but I don’t know how reliable they are so … yeah, they got me there, took me around, fed me, gave me quite a bit of stability”.
Participant M 1, Lines 712-717.

“My mum and dad would have made me go [to college] which I am glad that I’ve got someone like mum … she’s brilliant (…) She organises things for me, like what I’m doing and when (…) My mother is pushing me and she will be running me to college … every once a week”.
Participant F 1, Lines 174-176, 182-183, 325-331.

Participant M 3 felt it would have been better for him and his wife if she had been encouraged to be more actively involved in his RTW rehabilitation as it would have increased her understanding and thus her management of his problems:

“ … Sometimes I do believe she was far too hard on me … possibly again because she didn’t realise … the same as I didn’t … quite how subtle some of these after effects were and how potentially damaging they were”.
Participant M 3, Lines 397-401.

However he also recognised that the ‘significant other’ in any relationship needs to be willing to actively engage with the Service if they are to derive any benefit in terms of assisting the patient in their attempts to RTW:

“So I think including the partner is probably very relevant in most cases, but the big problem with that is obviously … you can take a horse to water but they won’t necessarily drink. You have to have a partner who is actively prepared to take part”.
Others also felt that their family didn’t have a comprehensive understanding of the problems they presented with. Participant M 6 spoke of the difficulties he experienced in trying to remember if he had taken his warfarin medication and how this inability to remember impacted on their relationship:

“I know it’s important that I take it. But I think I probably missed it. But I can’t double it. That’s the problem with it. You can’t double dose … So you’ve got to be really careful with it, you know. And it really annoys my wife … It really annoys her when I do things like that. You know why … ‘Why aren’t you more certain about things?’; and all that … ‘I don’t know, you tell me’ “.

Participant M 6, Lines 271-278.

### Theme 5 Impact of RTW Rehabilitation on the Occupational Performance of the Participant

When narrating their experiences of the RTW rehabilitation they had engaged in, many participants spoke freely about the impact of the rehabilitation experience on them and their employment options. This cropped up in discussion as a by product of asking about their RTW rehabilitation experience and what they had found assistive, if anything. Thus this theme was generated from the participants’ own interpretation of their individual constructions of their RTW rehabilitation experience. This addressed my methodological aim of wanting to have an enhanced understanding of the participants’ reality. That is, their narratives of the impact of the RTW rehabilitation experience on their lives placed their current employment situation in context. This sub theme also addressed the second and third aims of the study which were to find out what was actually assistive in RTW rehabilitation following TBI, and whether there was a role for occupational therapy in RTW rehabilitation following TBI.

#### 5.a. Positive

All ten participants shared positive interpretations of engaging in RTW rehabilitation and all reflected on some positive aspects of not being able to necessarily return to their previous employment in their previous capacity. Some spoke positively of how they had changed from the time that they engaged in the
RTW rehabilitation, especially when they undertook at least part of this rehabilitation in group sessions. Participant F1 disclosed how her understanding and acceptance of others with disability had improved compared to pre-injury and rehabilitation:

“I didn’t have any sympathy for anyone. And if they were like … deformed in any way, I’d laugh at them [before my RTW rehabilitation]. Well I know now that … well … I met some of the best people at the RTW rehabilitation sessions”.

Participant F1, Lines 95-98.

The participants who had attempted to RTW no longer felt part of a group of individuals who could compete for employment on an equal footing with individuals who had no disability. Eight of the ten participants described how the RTW rehabilitation sessions assisted them in their endeavours, even if they were not successful:

“… I was just pleased that yourself … you kept in contact with my former boss, writing letters (...) you may have met him, I can’t recall really (...) So people can’t really look down at you because you’ve had the pat on the back and the piece of paper to say ‘he’s okay’. That helps a lot … if you don’t have … if you didn’t have that, you would always have an employer, especially a new one, saying ummm … are you sure … are you lying … how good are you … but when you got ummm … a letter and it’s Headlined … it’s the title of the ‘Brain Injury’ from yourself, that certainly does put your foot in the door really. It certainly does help”

Participant M4, Lines 749-751, 752-753, 761-771.

In addition to the benefit found in accepting that their previous life goals needed reviewing and adapting, participants reflected positively on the need to have closure on their previous work and thus life style. Participants reflected with implicit relief that they could now be free from old expectations; they had something different to look forward to associated with their experience of the RTW rehabilitation. This different expectation included a view that their future would be worthwhile:
“[My perception of work has changed] ummm … It has because I’ve accepted that I can’t do long hours because of tiredness, and some days I do think what can I do. But even when I’m tired I know I can still do something worthwhile even if it’s only putting a smile on [husband’s] face”.

Participant F 2, Lines 99-104.

Better monitoring of emotional levels were suggested to be a positive outcome of attending RTW rehabilitation, possibly due to role play exercises and focusing on anger management issues during the rehabilitation. Whilst many reflected on the difficulty experienced in generalising strategies into anxiety inducing situations at their place of work, some reported success in this regard. Participant M 3 recounted how he was more aware of his ‘unseen’ difficulties and was able to self regulate these more appropriately. As such he was now confident in using the avoidance strategy to manage difficult situations in work:

“I’ve realised that since the TBI, I have to avoid that sort of situation [lose my temper and getting wound up] so I avoid confrontation far more than I ever would have done”.

Participant M 3, Lines 517-520.

Through active the rehabilitation period the participants were able to conceive of a productive role in the future, and a means of contributing to society. As all ten participants were employed pre-injury, this was very important in terms of an outcome of RTW rehabilitation, even if it was a different occupational outcome to that which they had hoped for at the time of injury:

“If I didn’t go to work then I wouldn’t have met … I wouldn’t have a house, if I didn’t go to work I wouldn’t have met my girlfriend. If I didn’t go to work I would just sit at home all day, or I’d go out and spend my benefit money which I didn’t really earn and which I don’t really need (…) It just keeps me going… work. It makes my brain tick over”.

Participant M 4, Lines 691-696, 711-712.
A large part of the RTW rehabilitation experience was reported as becoming aware of a need to accept that their old lives were now over, and that new lives, expectations and employment opportunities would have to be discovered. When reflecting back on the experience participant M3 interpreted his RTW rehabilitation experience as having helped him in this regard:

“[RTW rehabilitation was] designed to make me come to terms with what had happened and the effect it was going to have on me and how to adjust”.

Participant M 3, Lines 292-294

5.b. Negative

Although all reported positive outcomes, some struggled to interpret their constructions of their RTW rehabilitation experience as wholly positive. This was associated with needing time to reflect on and interpret the benefits; finding the attitude of employers uncompromising; being unwilling to accept any further perceived treatment as a ‘second hand citizen’ because of their TBI. Participant M 4, who had experienced difficulty in establishing a working role for himself following RTW rehabilitation displaced his perceived failure to secure a post on others’ inability to cope with his truths:

“… When I went back to my original job, had a row with the boss and resigned on the spot (...) I applied for a gardening job, got that straight away and got bored with that… so I quit … I can’t be bothered telling a lie no more (...) if people don’t like my opinion then that’s fair enough”.

Participant M 4, Lines 416-426.

One participant also suggested that there could have been more structure to the practical element of attempting to assist individuals to RTW. As an individual attending sessions at a community based facility, he was not used to work hours, and felt this should be included in the RTW rehabilitation:

“If you could have some sort of structure… training sort of thing… Two hours each session two afternoons a week basically … ummm … that sort of thing … ummm …. Work hours. That would be quite handy because that does … [when you try to RTW] you do realise that obviously I’m totally not used to this … to
A commonly described problem for individuals who have sustained TBI is that of having difficulty with information processing, particularly when it is provided verbally. There were some suggestions made that the introduction of outside agencies into the RTW rehabilitation needed to be undertaken in a more timely manner, and also to be repeated in order for the individuals to make optimal use of the services they provided. For example the introduction of individuals to locally based personnel working in employment centres:

“… I know we have ummm … careers people coming ummm … I think to be honest it was a little bit early for me with my injury because I was still a bit too out of it to cope with them but yeah … that would have been handy a bit later on to be honest (…) Or they could have come back to see us sort of twice first time … It is quite difficult when learning new things you know, meeting people. Just meeting people is a new thing (…) It was quite a lot to take in to be honest”.

Participant M 5, Lines 698-703, 709-713, 720.

“One participant who had not had access to group based rehabilitation suggested that in terms of RTW this would have been assistive in terms of reducing his feeling of isolation:

“If I could of just picked the phone up and speak … spoke to somebody who had been there, worn the t-shirt. Maybe if they were local, arrange to met them … sat down and had a brew with them and picked their brains and that. That would have made me feel a lot more calm than going into it blind (…) If there was a situation set up where there’s a register of people who are willing to do it.}
I wouldn’t think that many people who’ve been where I’ve been wouldn’t be willing to go ‘yeah, I’ll do that’. It’s like pay back time isn’t it?”.
Participant M 7, Lines 509-515, 517-521.

Furthermore the lack of communication between different services involved in the RTW potential of one participant made for difficulties in his progress to attempt to RTW:

“One thing I would say which … let me down quite badly and it wasn’t the brain injury service s a … just an organisation. I just think that the National Health Service is disjointed. And I do think that instead of the brain injury service working on their own and the orthopaedics service working on their own. They don’t work hand in hand, and basically they don’t understand … orthopaedics don’t understand the fact that my problem with my leg was down to … My situation was lost. I was put back a few years where my leg got worse and worse and worse because there was no communication between the two … I do think that … that was a ummm … definite ummm … ummm … shortfall”.
Participant M 7, Lines 774-792.

5.3 Summary of Findings
This chapter has presented the themes derived from listening to and transcribing semi-structured interviews undertaken with ten participants who engaged in RTW rehabilitation further to sustaining their TBI. I have stated at each theme which part of my research aims the information contained therein addresses, and have referred to my philosophical and methodological position to ensure rigour in the study. In addition, through adopting de Wit & Ploeg’s (2006) criteria in presenting my findings I have demonstrated rigour in the findings:

- This chapter has a balanced integration of my philosophical concepts informing my development of themes. There has also been a balance between the quotations in the text and my interpretations of these.
- The thesis has been open about the decisions at every stage in the study. The review of the literature identified the gap in existing knowledge and justified the research question. The methodological framework was
chosen specifically to answer the research question. The data collection tool was evaluated through a review of existing literature and was informed by the chosen methodology. The data analysis was chosen to reflect the methodological framework and allowed me to include individual narratives as well as more generalised themes. This complemented my ontological and epistemological positions by valuing the participants’ constructions of their unique realities. Throughout the analysis it has been made clear how the chosen themes were generated, explanations have been provided for the choice of themes and for not using other, important clinical information, but not relevant for this study.

- The usefulness of this study to my future clinical practice has been referred to tentatively in the themes described. This will be explored in greater detail in the following chapter.

- Issues of resonance can only be determined by the reader of the findings of the study. The impact and/or effect of the findings will be individual to each reader, as each reader will interpret the information contained within this study uniquely.

- The issue of actualisation of this research will be discussed in depth in the concluding chapter of this thesis.

I consider that through using Porter’s framework as described in the previous chapter I have demonstrated methodological rigour in the study. In addition, through adhering to Elliott et al. (2000) guidelines in the process of data analysis the themes presented provide a comprehensive interpretation of the accounts narrated to me during the interviews. Importantly, this thesis reflects the suggestion of Reid et al. (2005) raised initially in chapter 2 of this thesis that understanding the lived experience of the individual offers clinicians the opportunity to learn from the insights of the experts; the research participants themselves.
The following chapter will consider the impact of the above findings on clinical practice. In chapter 3 it was stated that the overall focus of the research was to look at how I, as a clinician, could know more about the experience of engaging in RTW rehabilitation, and with the enhanced understanding that came from this knowledge be more able to successfully support individuals to achieve their RTW goals. The contribution of new knowledge that was elicited from the stories in this research will be explored in depth in the following chapter. Recommendations regarding how to address some of the issues raised in this chapter to improve the services and support currently offered to this group of patients in their attempts to RTW will be described. Furthermore the importance of ensuring that service providers focus not only on developing services that better provide for the RTW rehabilitation of individuals with TBI, but also the needs of their families who are at risk of being misunderstood and unsupported during this complicated and often painful ordeal will be discussed.
Chapter 6 Discussion of Findings

6.1 Overview

This study intended to explore the experiences of engaging in return to work (RTW) rehabilitation of ten individuals who had sustained a traumatic brain injury (TBI). The specific aims of this study were to explore how participants made sense of their personal and social worlds, and determine whether it was possible for clinicians to assist them in this process following TBI. The study also aimed to examine what, if anything, was actually assistive in RTW rehabilitation when an individual had multiple impairments and disabilities as a result of TBI. The final aim of the study was to look into the unique role of occupational therapy in RTW rehabilitation for individuals with TBI. The focus was on informing my future clinical practice in this area of work. Semi-structured interviews were conducted with the individuals (at an unspecified time) following their engagement in the RTW rehabilitation. The data were analysed using Interpretative Phenomenological Analysis (IPA).

Five master themes emerged from this analysis. Theme 1, ‘The personal cost of lifestyle losses’ primarily provided contextual information on the impact of the TBI on individuals’ lives and lifestyles once they attempted to RTW. This theme was grounded firmly in the participants’ descriptions of feelings of loss when they were not gainfully employed. This theme was a groundbreaking aspect of the research in that it revealed that the participants underwent a secondary distinct grief reaction in their journey through RTW rehabilitation. This has not been discussed in previous literature and is discussed in depth later in this and the concluding chapters. Theme 2, ‘The impact of TBI on my work now’ provided an enhanced understanding of how participants constructed their experiences of attempting to become more functional within their occupational abilities during rehabilitation. This theme reflects findings of previous studies and confirms that perceptions of occupational activity change following TBI. It is important to integrate this into early RTW rehabilitation work with participants. Theme 3,
‘Factors impacting on the rehabilitation period’ provided valuable insights into some difficulties experienced by participants in fully cooperating with the demands of the RTW rehabilitation experience as they recounted their interpretations (of their lived experiences) of having engaged in the rehabilitation. Whilst this may be a factor that is considered by clinicians in this field, the powerful narratives in this theme illustrate that this needs to be explicitly recognised within RTW rehabilitation. This theme also will guide my future practice and is discussed further later in the chapter. Theme 4, ‘What helped in RTW rehabilitation’ explored what aspects of rehabilitation participants found assistive in their attempts to RTW. Some constructive criticism of the RTW rehabilitation experience in their narratives provided valuable insight into possible modifications that need to be considered within a future RTW rehabilitation programme. Theme 5, ‘Impact of RTW rehabilitation on the occupational performance of the participant’ emerged from the participants’ own interpretation (of their individual constructions) of their RTW rehabilitation experience.

This chapter will review the methodological aspects of this study, and my position as researcher. The implications of the findings of this study will be discussed and the findings will be applied to the policy-making, clinical and research arenas. Suggestions for further research will be provided towards the end of this chapter.

6.2 Clinical Relevance of the Research Question to the Researcher

My personal experience played an important role in the decision to investigate the topic of RTW following sustaining TBI. Looking back I can identify key incidents that spurred my interest in the topic. My interest in survival following serious trauma began when as a teenager a friend was disembarking off a school bus and her coat was caught in the door and she was dragged for 3 miles before she was noticed. She lived, with scarring and horrific injuries. I could not conceive of surviving such an ordeal. As I grew up, I developed a passion for mountain walking and, as an avid reader of all books, I became familiar with the
works of Joe Simpson, and his experiences of surviving trauma whilst mountaineering. The role of the brain in overcoming such trauma began to fascinate me, and I concentrated more in the field of neurology, leading to my current role within the North Wales Brain Injury Service. Productivity and quality of life have been the focus of occupational therapy activity from its inception, and activity is the medium utilised for assessment and intervention. As such, I developed an interest in RTW for individuals who had sustained TBI, and began to wonder if my intervention in this specialist clinical area was of any assistance to the patients.

These personal developments and experiences left me with a keen desire to understand the effectiveness of RTW rehabilitation more fully and an eagerness to find out how RTW rehabilitation programmes can best support individuals with TBI to be successful in their endeavours to RTW. Maso (2003) suggests that a research question should be a 'true' question, meaning it is a question that the researcher is eager to know the answer to. He adds that there should be no scientific literature that satisfactorily answers the question. I consider that, according to this definition, my research question was a 'true' one.

6.3 Social and Cultural Context of the Research
This research was undertaken within the National Health Service (NHS) during a time when RTW rehabilitation was a major focus of brain injury rehabilitation, and concerns about the reported success rates were voiced in several journals, for example Brain Injury, Head Trauma Rehabilitation. The mode for delivering RTW rehabilitation within the North Wales Brain Injury Service (NWBIS) was to aim for individualised focused work with patients rather than longer term generalised rehabilitation with one aim being for them to RTW.

The meaning of RTW for the purpose of this study has been defined earlier in the thesis. Furthermore table 4.5 provides a summary of the employment status of all the participants in this study at the time that they were interviewed.
6.4 Methodological Discussion

6.4.1 Overview

It is not appropriate to evaluate qualitative research using the same criteria that are used to evaluate quantitative research. For example, quantitative research strives to produce results that can be generalised to a wider population, whereas qualitative research does not aim to be generalisable. Qualitative research acknowledges that any conclusions are applicable only to the group analysed. Brocki & Weardon (2006:95) stated that in qualitative research:

“It is always possible that the next interview might be the one to produce confounding evidence”.

Several authors have suggested appropriate criteria by which to evaluate qualitative research. Holt and Slade (2003) suggested that the extent to which the illustrated themes could be applied to other, similar situations was a good measure of the validity of qualitative research. Smith (1999) proposed that one of the ways in which qualitative research could be evaluated was the extent to which it was illuminating and informative. Porter’s (1996) framework of understanding was applied to my choice of methodological framework and discussed in chapter 3 of this thesis (p. 59). Furthermore Elliott et al. (2000) criteria for demonstrating rigour in the process of data analysis were also addressed in chapter 3 (p. 94). I propose to use the measures of Holt and Slade (2003) and Smith (1999) to reflect on the quality of my research, including the appropriateness of the methodology to answer the research question, towards the end of the methodological discussion that follows.

In this study the experience of engaging in RTW rehabilitation was explored by adopting an interpretative phenomenological framework with ten individuals who had incurred TBI. Through combining the qualitative data collection method of semi-structured interviews with interpretative phenomenological analysis (IPA), it has been possible to learn a lot from the participants. This has verified the opinions of Schwazberg (1994) and Gitin (1998) as discussed previously in chapter 2 that it is imperative to recognise the voice of the patient as being the
expert on a given experience. The combination of semi-structured interviews and IPA enabled me to build upon previous quantitative data generated from patients who have engaged in RTW rehabilitation (Swaine et al. 2003, Powell et al. 2007, Horneman et al. 2005), and also to provide some initial, valuable data of essential elements required for optimal RTW rehabilitation pathways. Previous research methods used for generating data focussed on different aspects of RTW rehabilitation and, as discussed in chapter 3, would have been less than ideal for answering my research question.

6.4.2 Methodological Choice For This Study:
Patton (1990:217) described phenomenological inquiry as a focus on “what people experience and how they experience the world”. Patton also noted that persons experiencing a similar phenomenon shared an ‘essence’. In this study, adopting an interpretative phenomenological framework enabled the researcher to examine the shared experiences of individuals who had engaged in RTW rehabilitation further to sustaining TBI, and attempted to return to the employment market. There is a general acceptance that utilising a semi-structured interview format enables participants to offer richer and fuller accounts of their own views and concerns, thereby producing a more in-depth analysis (Willig 2008, Smith 2008).

Tyerman & Humphrey (1984) contended that the head injured person’s own perspective had been sadly neglected in the literature. Indeed Russell (2001) suggested that many individuals with TBI report fervent feelings of the experience that outweigh the physical changes in their bodies. Such feelings would be impossible to encapsulate fully in numerical data generated through use of quantitative methods. It must be remembered that the participants in this study presented with varying degrees of executive dysfunction which, it could be argued, could have biased their narrative, and thus the interpretation of the findings by the researcher. However Tyerman and Humphrey (1984) argued that even though accurate self-appraisal is limited in individuals who have sustained
TBI, the subjective perception of impairment is the reality for these patients. Therefore a person’s subjective experience also provides important information to the researcher and the therapist.

By using semi-structured interviews and IPA I was able to not only understand more about the participants’ experiences, but it also provided an insight into the clinical intervention provided with respect to RTW rehabilitation. In this respect the richness and depth of the qualitative data has allowed me to engage with the topic at a level which would have been extremely difficult to reach had I used quantitative methodology or more restrictive qualitative methods as discussed in chapter 3. At the same time I acknowledge that a potential flaw with this methodology was the fact that it was not always possible to elicit the information from the participants in a strictly phenomenological inquiry tradition, due to the nature of the difficulties they experienced. This was seen in particular in the interview with participant F1 who, despite having a clinical score on the AQ thereby making her eligible for inclusion in the study, was unable to grasp the nature of the questioning when questions were posed in the open-ended phenomenological tradition.

In the second and third chapters exploring the research frameworks and methods used by previous researchers to obtain accounts of individuals’ lived experiences of specific phenomena, I commented on the dearth of research exploring the effectiveness of rehabilitation as perceived by the individuals who had sustained TBI. I was also struck by the low number of studies which used semi-structured interviews to obtain their data with this patient group. Having undertaken this study I would suggest there may be good grounds for adopting differing theoretical frameworks to obtain data other than the one I chose for this study. The typical participant in this study continued to experience cognitive, emotional and psychological problems. Most also experienced varying degrees of both visible and invisible physical problems. As such, despite obtaining rich data from the participants, it may have been less time consuming to have elicited the data
by structuring the interviews more, or combining data collection methods such as administering a Likert scale effectiveness questionnaire with a structured interview. This would have changed the focus of the generated data, however, and would not have been rigorous enough to explore the phenomena of RTW rehabilitation in depth. However, a mixed methodology may have made it easier for the participants to voice some aspects of their experiences if they had been provided with a more rigid framework. This needs to be considered for further studies.

There is also a criticism often made of qualitative research that it tends to rely on accounts from articulate participants, thus limiting the populations that can be heard (Newton et al. 2007). This is at odds with one of the main aims of qualitative research, and phenomenological research in particular, which is to allow participants to present their own constructions of the phenomena being explored (Elliott et al. 1999). The opportunity for adults who have sustained TBI and who have engaged in RTW rehabilitation to have their voices heard and discuss what they have found beneficial, if anything from that experience, is rare. Until recently very little emphasis has been placed on the content of such rehabilitation with this patient group from any perspective other than the treating clinician. Indeed, no previous study has specifically explored the subjective value of RTW rehabilitation for individuals with TBI in order to enhance the understanding of the treating clinicians. This is unfortunate because in themes 3 & 4 of this study, the participants clearly stated that the opportunity to discuss their perceptions of their difficulties with the treating clinicians was highly valued. Being a clinical researcher may therefore have assisted in eliciting the richness of the data generated in this study. Through having the experience and expertise of working with this patient group for over ten years, and working with other patient groups with challenging presentations during my clinical career, I was able to ensure, through adapting my mode of interviewing, that most participants were able to engage thoughtfully and reflectively in the interviews.
6.4.3 Participant Selection

A problem encountered by Darragh et al. (2001) in their study was that their findings would be disregarded because of the fact that the participants (adults with brain injury) had impairments of awareness as part of their presenting problems, including dysexecutive functioning. Schwartzberg (1994) explored the perceptions of patients with brain injury using a combination of a semi-structured interview, a structured interview and a ranking activity. The participants’ responses showed that having the opportunity to share their feelings was the most important facet of the group. Through their participation in the group they felt that they had been ‘legitimised’ as persons who had suffered brain injury that had changed their lives. Paterson & Stewart (2002) attempted to overcome this criticism of disrupted awareness of the sample population through administering a standardised measurement to obtain an indication of the truth of the narratives that would be provided by potential participants. I utilised a different standardised measure (Awareness Questionnaire (AQ)) (Appendix 6,7,8) requiring triangulation of information provided by the participant, a significant other and the participant’s key clinician. However I would concede that the ability of an individual who has sustained TBI to complete a relatively short standardised measure (no longer than 10 minutes to complete independently) does not necessarily equate with the individual’s ability to comprehend the requirements of a phenomenologically based semi-structured interview.

A further criticism of participant selection in qualitative studies in the field of brain injury is a lack of homogenous participant samples. This could also be considered a criticism of this study as the age range of the participants at the time of the study varied from 23 years to 62 years (See table 4.1). The level of education varied from GCSE/O level to Degree/Professional qualification, and the age of the participants at the time of incurring their injury varied from 19 years to 54 years. Furthermore the time since injury at the date of interview ranged from 38 months to 118 months. The consistent demographic data in this study were as follows:
The participant population consisted of individuals who sustained TBI
- All participants suffered a moderate to severe TBI
- All participants were in employment prior to sustaining their TBI
- All participants had engaged in RTW rehabilitation with the same service
- All participants had attempted to RTW following rehabilitation.

As discussed previously in chapter 2 the progress of recovery following TBI is individual and cannot be generalised for the population. I thus suggest that it would be very difficult to obtain a participant group which had consistency for all the demographic data. Moreover, for this study, the focus was to explore and understand more fully the individual experience of the phenomenon of RTW rehabilitation. To have attempted to undertake this study by insisting on a fully ‘consistent’ sample would have been contrary to my methodological framework, and the focus of my research. By ensuring some consistency in the demographic data, and accepting that there would be variables in other aspects, I consider that the participant group in this study fulfilled the sampling criteria required for a credible phenomenological study and, combined with the quality criteria of the methodology, fulfilled the criteria required for the findings to be considered trustworthy. Moreover the sample in this study was also more likely to reflect the ‘real world’ population seen in clinical practice.

6.4.4 Power Relationship Between the Participants and Researcher

The contribution of the participants in the study was the essential component of the study. The term ‘participant’ is often assumed to mean ‘co-researcher’ in qualitative researching (Barker et al. 2002). In adopting a phenomenological framework for this study, it seemed appropriate that the individuals who were contributors to my research were positioned as participants, thereby adopting a more inclusive language and philosophy, rather than them being ‘subjects’. Karnieli-Miller at al. (2009:279) considered that

“The unique contribution of researchers and participants to a project makes them both inseparable parts of the final creation”.

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However, as the researcher, I encountered a tension between the position of having the participants fully involved. They were not invited to verify their accounts and my subsequent analysis of the narratives. Their contribution to the process was in providing a narrative that illustrated their interpretations and constructions of their experience of RTW rehabilitation on a given day. As such, their role did not develop into that of co-researchers in this study. It could be argued that in future research projects using a phenomenological framework with this patient group, it would be possible to enlist participants more fully as possible co-researchers so that individuals who have sustained TBI assist in conducting the interviews and/or become involved in the analysis (Tew 2008).

In order to ensure informed consent the participants all had a high level of cognitive functioning. Furthermore it must be remembered that the individuals who agreed to take part in the study were most likely to be those who were coping, at least to some degree, with the changes in their lives following TBI, and felt they could potentially cope with an interview lasting for up to 1 ½ hours. Thus the level of functioning and quality of life experienced by these participants may be higher than typically experienced by individuals who have TBI. As such, it would need individuals with the same level of stamina to assist with the interviews. However based on my own stamina, fitness, drive and experience of conducting the interviews, I think this would be difficult to execute successfully based on the considerable clinical skills I drew upon to facilitate their telling of the narrative.

Interviews were conducted 'in an environment conducive to disclosure' as described in the methodology chapter. However, a seemingly warm and caring interview can not only make a participant feel relaxed enough to disclose material, but could also be interpreted as being a manipulation tactic of the researcher to help them obtain the data they want (Brinkman & Kvale 2005). Hewitt (2007:115) suggested that:
“Ideal research relationships are characterised by genuine rapport, honesty, and emotional closeness, while recognising the potential abuses of power”

My aim was to draw on my clinical skills in eliciting information from the participants, whilst being transparent about the reasons for this research being undertaken. Whilst I believe I achieved this by drawing on considerable clinical skills, this was not always easy during the interviewing process due to the complex presentation of the participants involved. As discussed earlier, one participant was unable to engage at any level in phenomenological questioning, thus her transcript would appear, to the uninitiated, as an unfair power relationship between me, as the researcher, and her. However this directive questioning was essential for her to be able to voice her narrative. Another participant was able to provide a valuable narrative, but requested a hug and kiss at the end of the interview as he had ‘helped’ me to undertake the research. This entailed moving from a facilitative researcher role, to reverting to a clinical detachment that may have proved unsettling for the participant, and possibly leading to feelings of vulnerability. However he did not raise this in subsequent clinical appointments, neither did he request any additional support from the psychologist that was available for this purpose. In this latter instance the balance of power shifted from me, to the participant, and then was regained by me. This situation could have ended very differently (as there were no other personnel close by at the end of the interview) had I not been an experienced clinician in this area of work.

These interviews led me to reflect that it would be extremely difficult, if not impossible for such research to be undertaken unless they were undertaken by individuals with significant clinical expertise in this field of work. This clarified the specialist skills required by an experienced clinician in this field of work to be able to effectively assume the role of clinical researcher:

- Thorough knowledge and understanding of the aetiology and multifaceted nature of TBI so that presenting behaviours and actions are understood
contextually and not perceived by the researcher as abusive or threatening.

- Excellent therapeutic skills in quickly establishing a relationship conducive to divulging information without being clinically threatening to the participant.
- Excellent facilitative skills to adapt their therapeutic/questioning methods to elicit narratives from individuals, recognising and responding to the unique cognitive, physical and emotional needs of the individual.
- Adaptability to cope with extraneous distractions and incorporate them with ease into the interviewing process so that narratives are elicited e.g. allowing one participant to be interviewed with her baby present, as was her request.
- Recognising fatigue, vulnerability, distress, and fear as they presented in participants (be that through the narrative or through visible signs e.g. tears, hesitations, fidgeting), and adapting the questioning to ensure that participants were comfortable to express emotive issues, but not abused, or made psychologically exposed in this regard.

One particular limitation of using interview and subsequent analysis of verbatim text was in giving equal voice to participants who had less fluent, or equally, circumlocutory speech. Communication difficulties are common for individuals who have TBI as they can have problems with articulation (dysarthria), or cognitive impairments that can cause word-finding difficulties (circumlocution), or concentration or memory problems (keeping to the topic, turn taking, loss of train of thought). People who felt they had such problems may not have felt able or wanted to take part (Low 2006). Some participants did have mild forms of communication difficulties:
Researcher: “Is there anything else you want to share with me?”
Participant: “I was at the beginning but surprise … surprise, I’ve forgotten it …”

Researcher: “Is there anything you think… ‘Gosh I wish they had offered me that?’”
Participant: “Again these are questions which … sometimes my mind won’t work unless I’m prompted but ummm … one thing I will … one thing I would say which … “

Researcher: “Tell me a bit more about the fatigue”
Participant: “… The longer and longer I sit and the more I have to sort of concentrate on … on sort of keeping up the gist of a conversation and stuff I just become … my mind goes a blank and I lose track of where I’m going with the conversation and stuff”

Sometimes these difficulties (difficulties, I imply here for me as the researcher, not necessarily the participant) impacted on data collection. As people can feel worse or better at different times of day I was as flexible as possible to see participants when they felt at their best, as fatigue can (as is seen above) impact on individuals’ ability to express themselves. Sometimes it was necessary to prompt participants with specific words. Although this had the danger of leading the participants (Low 2006), it appeared to reduce the effort for the participant and help them continue with their narrative. With some participants, my clinical skills ensured that I was aware of when it was necessary to wait and not rush ahead with the interview as the participant required time to think.

Several participants asked “Have you got what you want?” or “Did I do alright for you?” at the end of the interview which indicated to me that they desired to be a ‘good participant’ and tell me what I wanted to hear. Semi-structured interviews allow for follow-up of areas of interest to participants and permit ideas to be followed which were not preconceived by the researcher (Smith 2004). This was seen in the generation of theme 2 for me which I had not conceived of before the
interviews. Nonetheless the topic areas to be discussed (and the phenomena to be explored) were decided by me as I was conducting this research not only to add to the existing literature on RTW following TBI, but also as part of completing my degree. Participants appeared to want to be helpful in this process and indeed I experienced them so, but this may have also impacted on the data gathered.

The data analysis aspect of the research process is one in which the researcher traditionally holds the power (Karnieli-Miller et al. 2009). One way to increase the contribution of the participants is to seek their opinion on the content of the themes, member checking or respondent validation (Elliott et al. 2000). However the use of member checking is not standard practice in IPA as analysis relies upon the double hermeneutic process, the researcher making sense of (or analysing) the participants’ narrative. Participants and researchers will have different perspectives; indeed each participant has a different perspective. For instance, the researcher may be alert to things that ‘leak out’ during the narrative which participants did not intend (Smith & Osborn 2008) for example criticism of a part of the RTW rehabilitation process, or anger at the response of an employer.

In addition themes were extracted that were not always the most prevalent themes in the discourse of the participants (Braun & Clarke 2006, Brocki & Weardon 2006) but which can be, as in this analysis, driven by the particular research question or by the richness of a particular theme. This is what drew me to the concept of IPA; it is not solely about giving the participants a voice, or simply retelling the participants’ accounts, it is also about recognising the value of the individual perspective that could be of assistance to others. Hence the emergent themes which would have reflected issues of importance to participants (perceptions of rehabilitation in general, impact of TBI on familial relationships) were not included in this study as they were not pertinent to this research project. Thus the balance required for IPA between empathic
understanding (that is trying to stand in the participants' shoes) and a critical understanding required for the interpretative process (Smith & Osborn 2008) remained, for me, an ongoing tension.

In order to go some way to balancing respect for the participants with the requirements for analysis, I sent participants a summary of all the themes (Appendix 16). It is hoped that statements were sufficiently general that individuals may not be recognised, thus protecting confidentiality. But at the same time, participants may perhaps feel that they had been heard and could see how they had contributed to the research.

6.4.5 Rigour in the Findings of the Study
Transparency and rigour in this study are enhanced by providing extracts of the participants' speech to support my interpretations (Elliott et al. 2000). Quotations contained in the findings chapter aimed to be balanced in representing the different participants, and indicating that the analysis does not reflect the view of solely one or two individuals. Nonetheless, exemplars may represent 'the most articulate expression' of a particular theme (Flowers et al. 2001; p.668-669). This presented a difficulty in the current context where the ability of participants to articulate responses varied. Participant F1, quoted above, tended to produce short answers and hence in order to illustrate a point, reproduction of interviewer questions needed to be included in the quotations in order that the reader could make sense of the discourse. Another participant (M 3) was more circumlocutory in his answers and also deviated several times from the topic that I wanted to discuss, either due to attention or memory difficulties, or due to his preference to discuss other topics (perhaps both). In this case, conversation which was pertinent to a particular theme was spread over several pages of text which was unfeasible to reproduce and difficult to follow for the reader. Thus the pertinent themes were extrapolated from the narrative. Thus inevitably it is the most concise and articulate speakers whose voices are reproduced most frequently in
the research findings, although these utterances are felt to be representative of what was conveyed by others (Flowers et al. 2001).

6.5 Discussion of Findings

6.5.1 Overview
Sustaining TBI and attempting to RTW as part of the rehabilitation process is a complex experience, appreciably exclusive to each individual (with some common constructions), and somewhat unmapped. This thesis has begun to unravel the intricacies of this particular rehabilitation experience in individuals who have sustained TBI. First, a thorough review of the literature (Chapter 2) identified that few studies in this clinical area of work had explored any rehabilitation phenomena from the perspective of the individuals concerned. RTW success rates, however, differed noticeably between different studies without pinpointing if any aspect of the rehabilitation process could in some way account for this discrepancy in success rate. The literature review presented substantial evidence to warrant the expansion of investigations in the field.

The findings of this study formed five master themes generated from the narratives of the participants. The themes, combined, addressed the aims of the study and the findings have provided an enhanced understanding of the experience of engaging in RTW rehabilitation for the ten individuals concerned. This enhanced understanding has revealed previously unknown knowledge about the process of RTW rehabilitation and provided important pointers to guide the approach and content of RTW rehabilitation programmes. Furthermore it has identified a previously undiscussed secondary grief reaction that occurs during the process that needs addressing constructively by clinicians. Important practice knowledge relating to the need to involve families and survivors in RTW rehabilitation programmes has been revealed, which would be a new development within RTW rehabilitation provision in NWBIS. The revelations relating to the unique contribution of occupational therapy in RTE rehabilitation has enabled me to develop a potential working practice model based on the
Acquisitional Frame of Reference. Further to evaluation of this model in practice, it could be adopted as a model by other occupational therapists working in this field of work. A final reading of the transcripts revealed hard data relating to participants’ financial situations pre and post injury. Previous literature relating to finance and cost of TBI has focused on the cost of care. The narratives in this study provided previously unknown initial hard data about that financial cost to the individuals. The following discussion explores the findings in greater depth and their significance in relation to previous studies are considered. Furthermore the themes are considered with regards to the impact of the findings contained therein on theory, policy making and clinical practice where relevant.

6.5.2 Master Theme 1: Personal Cost of Lifestyle Losses Related to Return to Work

This theme was revealed when trying to understand the participants’ social and cultural contexts pre TBI and led to the revelation of a secondary and distinct grief reaction related solely to their RTW rehabilitation experience. This is not discussed in previous literature and impacts on future delivery of RTW rehabilitation programmes in NWBIS. The losses experienced impacted on all aspects of their daily functioning and lifestyle. All participants spoke of the personal cost of lifestyle losses they experienced following TBI and being unable to return to their previous work in their previous roles. Harrell and O’Hara (1991) stated that brain injury (BI) does not occur in a vacuum, rather it is one event in a long continuum of life events and its significance must be evaluated within the survivor’s social sphere. Following TBI individuals have several losses to contend with; loss of role, loss of control, loss of physical dexterity, loss of sensible thoughts (Salter 1997).

The findings of this study demonstrated that through experiencing difficulty in RTW following rehabilitation, participants further experienced loss of me, loss of being part of a gang, loss of past aspirations, and a loss of their previous perceptions of wellbeing. These findings contradict the study of Brown et al.
(2006) who explored the recovery path following BI and concluded that there was little evidence in the narratives they elicited to support the concept that individuals with BI experience a loss of the ‘sense of self’. The participants in this study, however, all spoke to some degree of experiencing reactions such as anger, depression, anxiety and fear that are all similar to the features of significant loss processes (Bowlby 1981, Stroebe et al. 2001). Moreover Coelho (2002) suggests that recovery from TBI can only occur when the individual regains the ability to test reality, to do psychological work, and to recognise and grieve for loss.

The feelings of loss associated with finance reported in this study provides an alternative insight into the financial outcomes following TBI compared to previous studies. A number of studies have looked in varying depths on the cost to society of the financial consequences of having so many individuals of working age who are unable to resume employment (Johnstone et al. 2003, Fraser et al. 2006). However, whilst scant, the above studies explored the resultant financial loss from unemployment following TBI in terms of the cost for society. This includes the cost for each hospitalisation, the cost of benefits whilst unemployed, loss in taxes not paid on earnings, and the loss of the same for the carers who have to amend or give up entirely their employment in order to care for the individual with TBI.

Finkelstein et al. (2006) concluded that the lifetime cost for the whole TBI population, including losses attributed to medical care and lost productivity, range close to 60 billion $US annually. The participants in this study provided comparisons of their financial status pre and post injury, and the impact that the change in financial status held for them as individuals. This was presented as ‘leakage’ information in the first few interviews, and was explored more directly in later interviews as I became aware of the impact on lifestyle. Johnstone et al. (2003) did raise the issue of needing to be concerned about the personal and societal repercussions of loss of finance experienced when individuals are
unable to RTW. However this was not explored in any depth in their study; merely highlighted as important. This study has provided the first known hard data referred to in Johnstone et a (2003) study, and needs to be explored with a larger population to see if there is a correlation between the amount of financial loss with the Grafton Manor placement rating scale seen below.

Table 6.1 Participants’ Financial loss and Grafton Manor Scale Rating

<table>
<thead>
<tr>
<th>Participant</th>
<th>Earnings pre TBI</th>
<th>Earnings post TBI</th>
<th>Grafton Manor scale Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Pre TBI</td>
</tr>
<tr>
<td>M1</td>
<td>£16,000 per annum</td>
<td>£3,840 per annum state benefits</td>
<td>0</td>
</tr>
<tr>
<td>M2</td>
<td>£18,000 per annum</td>
<td>£960.00 per annum &amp; Direct Payment Scheme to pay for support workers</td>
<td>0</td>
</tr>
<tr>
<td>M3</td>
<td>£27,000 per annum</td>
<td>£15,000 per annum (+40% pension loss)</td>
<td>0</td>
</tr>
<tr>
<td>M4</td>
<td>£14,500 per annum</td>
<td>£12,500 per annum</td>
<td>0</td>
</tr>
<tr>
<td>F1</td>
<td>£16,656 per annum</td>
<td>£6,096 per annum + mobility</td>
<td>1</td>
</tr>
<tr>
<td>F2</td>
<td>£17,500 per annum</td>
<td>£1,440 per annum + Incapacity Benefit</td>
<td>1</td>
</tr>
<tr>
<td>M5</td>
<td>£20,000 per annum</td>
<td>£12,000 per annum</td>
<td>0</td>
</tr>
<tr>
<td>M6</td>
<td>Wages + overtime</td>
<td>Pension + benefits</td>
<td>0</td>
</tr>
<tr>
<td>M7</td>
<td>£17,500 per annum</td>
<td>£4,200 from benefits per annum</td>
<td>0</td>
</tr>
<tr>
<td>M8</td>
<td>£19,500 per annum</td>
<td>£4,500 from benefits per annum</td>
<td>0</td>
</tr>
</tbody>
</table>

Grafton Manor Hierarchy of Placements (Eames P 1999)

<table>
<thead>
<tr>
<th>Rank</th>
<th>Placement Description</th>
<th>Rank</th>
<th>Placement Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Alone/With partner or friend independently</td>
<td>7</td>
<td>Supervised hostel</td>
</tr>
<tr>
<td>1</td>
<td>With parents independently (as before injury)</td>
<td>8</td>
<td>Own home with help or care</td>
</tr>
<tr>
<td>2</td>
<td>With parents independently (only since injury)</td>
<td>9</td>
<td>Parental home with help or care</td>
</tr>
<tr>
<td>3</td>
<td>Own home with minimal supervision</td>
<td>10</td>
<td>Care placement</td>
</tr>
<tr>
<td>4</td>
<td>Parental home with minimal supervision</td>
<td>11</td>
<td>Rehabilitation Unit</td>
</tr>
<tr>
<td>5</td>
<td>Own home with daily supervision</td>
<td>12</td>
<td>Acute Hospital</td>
</tr>
<tr>
<td>6</td>
<td>Parental home with daily supervision</td>
<td>13</td>
<td>Long stay/psychiatric hospital</td>
</tr>
</tbody>
</table>

Not only were the participants concerned about the financial loss they had already experienced, but they could also foresee how this could impact further on them and their families in the future ('families' in the context of this discussion relates to family members, significant others and/or dependants, related or otherwise). This was further related to their future career aspirations and the potential change in long-term financial planning with the opportunities for increases in salary being perceived as negligible. A disheartening aspect of
financial difficulties for all participants was the fact that they were in receipt of benefits. Johnstone et al. (2003) examined the financial and vocational outcomes following TBI on a group of 45 individuals and found that one year post TBI, 40% of the participants were still in receipt of state funded benefits. Seventy percent of the participants in this study were in receipt of state-funded benefits at the time of the interviews, with the time since injury ranging from 38 months to 118 months (mean 74 months).

Unless RTW rehabilitation recognises the holistic approach required in preparation for work, to include the concepts of acceptance and loss, it will fall into the trap of addressing presenting symptoms and deficits, failing to recognise or engage the whole person (Rapp 1998) and thus dehumanising the individual (Deegan 1996). Thus the findings of this study indicate that not only is there a need to address issues of grieving as part of the recovery from TBI process, but there is also a need to recognise that further grieving takes place at the time of attempting to RTW as the impact of the losses on lifestyle become apparent and focussed due to difficulties in resuming previous work roles and responsibilities. RTW rehabilitation needs to embrace grief work that leads individuals through the stages towards recovery, resolution and acceptance of the reality of the loss. The bereavement process needs to focus on accommodation; accepting the pre-existing knowledge, emotions and experiences of the individual, and leading them to a new reality which is different, but just as valid. This will assist in the acceptance of their amended future aspirations and should assist in addressing the co-developing social isolation that presents with this realisation.

6.5.3 Master Theme 2: Impact of Traumatic Brain Injury on Participants’ Perceptions of RTW & Occupational Activity

This theme was interesting as in the narratives the participants linked their changed perceptions of work with an increase in feelings of self-worth and productivity in general. Opperman (2004) explored the meaning of work for individuals who had sustained TBI and also concluded that work increases a
person’s self-worth and personal fulfilment. In conjunction to their TBI all participants had to contend with interrelated physical, psychological and psychosocial factors when they attempted to RTW. In all bar one instance this meant that the participants in this study could not consider returning to their previous place of work in their previous roles. This situation left the participants with the choice of two options, namely to action either of the two models of coping described in chapter 2 (Moore and Stambrooke 1995, International Classification of Functioning in Stucki et al. 2002) and experience repeated failure in their attempts to RTW. The second option was to action a more productive model of accepting their current limitations, and changing their perceptions of what constitutes a successful outcome in RTW attempts. Stroup (2000) concluded that people with TBI who used these less adaptive coping behaviours had a higher externalised locus of control and reported greater mood disturbance. All the participants in this study, however, expressed that they had, eventually, been able to adopt the second choice and thus experience feelings of control and improved self-esteem through their changed perceptions of work. This correlates with the findings of Judge and Bono (2001) who undertook a meta analysis and reported that locus of control was related to both job satisfaction and job performance. By actioning a change in their perceptions of a successful outcome to RTW rehabilitation, the participants had been able to experience these positive emotions once more.

Volunteering is defined by McMordie et al. (1990) as a successful outcome of RTW. Shames et al. (2007) however, define volunteering as purely a term that reflects vocational activity rather than actual RTW. Kolakowsky-Hayner & Kreutzer (2001) suggest that the value of volunteering should not be marginalised for people following TBI. They further suggest that volunteering could be considered a step along the way to returning to education or RTW as it provides an environment where individuals can regain old skills and/or learn new skills which may ultimately transfer to their old, or even new, paid work. This correlates with Petrella et al. (2005) who found that volunteering was a great part
of assisting individuals to realise their actual employment potential. A number of participants in this study reflected positively on the value of volunteering and could even perceive it to be a successful outcome of RTW rehabilitation.

Yasuda et al. (2001) examined the literature relating to, amongst other things, vocational programmes that enhance employment outcome. Their description of the Work Re-entry Programme (Ellerd & Moore 1992) is similar to the values reflected by participants in this study who undertook voluntary work (be that as part of their rehabilitation programme or as their RTW outcome). The major characteristics reported included training to secure the pre-requisite stamina required for work, work competencies, work behaviour, productivity levels according to individual abilities, job development and job analysis. The narratives of the participants in this study indicate that it may be appropriate for RTW rehabilitation programmes to incorporate voluntary work placements more fully into RTW rehabilitation programmes in this country as a pre-requisite for attempting to return to previous employment.

Within the NWBIS this would certainly be different to current practice where voluntary work is agreed on an individual basis with patients, and there is no structure to the length or quality of the voluntary work undertaken. Furthermore, there is no clinical assessment of job skills within this current volunteering framework, and, upon reflection, this could lead clinicians, particularly occupational therapists, to consider how they are able to appreciate the true value of this advocated practice in RTW rehabilitation terms. A further value of incorporating such a system would be in the provision of more relevant guidance for patients when considering re-training options post-TBI. It is supported in the literature that job security and stability can be increased when an individual seeks a job that matches their current skills (Yasuda et al. 2001). Thus the incorporation of formalised voluntary placements within RTW rehabilitation programmes needs to be seriously considered and evaluated in future practice.
6.5.4 Master Theme 3: Factors Impacting on The Rehabilitation Period

Having a greater sense of control over various life domains was perhaps unsurprisingly associated by the participants in this study with greater physical functioning and less disability. Perceiving greater control over symptoms or self efficacy was also related to the participants’ perceived disability. However the true nature and extent of the physical problems and their impact on participants’ ability to engage in RTW rehabilitation may not always be fully accepted, or indeed understood, by clinicians. Feelings of fatigue amongst the participants commonly existed side by side with reported feelings of grief for their loss of occupational ability. This invariably impacted negatively on the emotional ability and stability of participants, and, if not accommodated by clinicians during the RTW rehabilitation, impacted negatively on the therapeutic relationship between clinicians and participants. Physical symptoms, such as fatigue, worsen because of stress and strain (Kowlasky-Hayner & Kreutzer 2001), and the rehabilitation period programmes may be constructed as stressful to the patients. Fatigue is often cited in the literature as a presenting problem following TBI. However as a clinician, I was not aware of the full impact of this problem for patients until I elicited the narratives for this study. Not only does fatigue impact on an individual’s performance during rehabilitation, but it also impacts on their ability to actually engage in RTW rehabilitation. Furthermore, the greater the levels of reported fatigue, the less perceived control over self-efficacy amongst participants. Whilst this may seem self-evident, I was unable to identify any supporting literature regarding this issue related to TBI.

Dawson et al. (2007) concluded that in addition to cognitive status, physical problems, psychosocial and spiritual factors need to be considered as potentially interfering with individuals’ abilities to resume pre-injury roles. The findings of my study support this assertion, and further suggest that physical problems and psychosocial factors interfere with the patient’s ability to engage in RTW rehabilitation. Indeed Orr et al. (2003) highlighted the close relationship between the physical and emotional wellbeing of individuals with TBI in their study when
they found that higher RTW rates were evident amongst those individuals when they had a combination of stable physical and emotional wellbeing.

The results of this study would indicate that when negotiating with individuals to engage in RTW rehabilitation programmes the clinician needs to be aware of the physical, emotional and therapeutic issues that could potentially impact on an individual’s ability to participate in the RTW rehabilitation. An individual with TBI may experience damaging effects as a result of alterations in their sense of self esteem or monetary autonomy, including depression, social withdrawal and/or diminished motivation (Isaki & Turkstra 2000). This not only impacts on their productivity ability, but also on their initiation and motivation to engage in increasing their productivity levels. This needs to be accommodated in RTW rehabilitation packages, and strategies for managing such problems need to be discussed with the patients as part of the introduction to the RTW programme, and reinforced throughout the programme. Clinicians need to be ever mindful that being labelled by a work position, especially when one thinks he/she could do better, can create an ongoing struggle in which the person fights to regain his/her place in society (Rocchio 1998). There is a strong argument from the findings of this study to have a clinician (or assistant) who is a named contact person throughout the RTW rehabilitation programme with whom patients can raise and, hopefully, resolve such issues so that their ability to participate in the RTW rehabilitation programme is optimised.

6.5.5 Master Theme 4: What Helped in RTW Rehabilitation
The vocational element; that is the provision of information about alternatives to previous paid employment, of the RTW rehabilitation was considered as being extremely beneficial by the participants in this study. As discussed earlier the participants had to adapt their RTW options due to the presenting long-term problems they presented with. An important and assistive element of RTW rehabilitation was reported as being the opportunity to learn about other alternatives to previous work and roles that could be considered in the future.
This was experienced by the participants as a positive aspect of the RTW rehabilitation they had engaged in, as it demonstrated that they could still achieve and be productive. As a clinician, it has always been a tension for me to balance providing information regarding alternative RTW avenues for patients because I have concerns that it could be interpreted as the final “nail in the coffin” confirming that they are no longer able to work at pre-injury levels. As such, this enhanced understanding of how it felt to be provided with that information was affirming of my practice in RTW rehabilitation, and lessens the tension somewhat. However it is always necessary to bear in mind that all patients are unique, and that some may perceive the information provision in a less positive light.

Another aspect of vocational input that was described as having significant value to the participants in this study was the input by the clinicians with the individuals’ previous employers. It is evidenced that employers are not immune to misinterpreting the signs and symptoms of TBI and developing a negative bias towards to employee or potential employee (Kissinger 2006). In some instances these biases may result in the employee being fired, transferred or reassigned (Power & Hershenson 2003). However the input of the clinician can be assistive in facilitating a constructive RTW experience. This is another aspect of RTW rehabilitation that can cause clinicians a degree of tension as there is always concern that by involving clinicians the employers will immediately decide that they cannot cope with the individual back in the workplace (this is despite the current anti-discriminatory legislation discussed earlier in the chapter). The findings of this study confirm that clinical involvement is experienced positively by patients and needs to be continued within the RTW rehabilitation programme.

Within this master theme of assistive elements of RTW rehabilitation the sub-theme of ‘Personal Perspective’ was elicited. This sub-theme was illuminating in terms of informing clinicians of the approach they need to adopt during RTW rehabilitation provision. The findings of this study emphasised the individuality of
the recovery pattern of participants, and also the individuality of the pattern of being able to fully absorb the requirements of the RTW rehabilitation programme. Clinical skills which were valued in terms of making them, as patients, feel valued as individuals was the fact that clinicians were prepared to be adaptable, to change the pace of RTW options (dependent upon the abilities of the individuals at the time) and, in particular, being willing to re-visit ‘old ground’ in the RTW rehabilitation programme if participants had underestimated or not considered a particular aspect of their presentation that could be a hindrance to their successful RTW in the early stages. These findings concur with those of Shames et al. (2007) that rehabilitation specialists must remain flexible and prepared to adapt to the changing needs of the individual with TBI.

Another clinical issue that emerged from the narratives in respect of the experience of RTW rehabilitation was that of the need for ongoing and expert clinical support in order to optimise the potential for the participants to retain their jobs. This has been raised in previous literature (Parente et al. 1991) which found that support groups that address coping strategies for memory problems, role-playing for social situations, people skills, assertiveness, dating, and organisation were extremely effective in assisting with job retention. Furthermore Yasuda et al. (2001) also concluded that the provision of ongoing and long-term clinical support was an essential part of rehabilitation. They further argued that the clinicians should reduce their support as the individual becomes more proficient within their employment but always be available if required.

The importance of involving family members in the RTW rehabilitation process was highlighted further in this theme. Rotondi et al. (2007) found that families and their individuals with TBI conceived of the time frame post-TBI as a sustained crisis. Further complicating matters was the family’s limited understanding of the enduring lifestyle changes resulting from TBI. Thus rehabilitation professionals need to be prepared to invest time and energy in addressing the impact of
treatment interventions and recommendations on family members as well as the person with TBI (Kissinger 2006).

Through linking the information elicited in this theme it was possible to reflect on the Acquisitional Frame of Reference and adapt it into a potential working practice model for occupational therapists working in this clinical area. No such model is currently available. This is discussed in greater depth in the concluding chapter.

6.5.6 Master Theme 5: Impact of Return to Work Rehabilitation on the Occupational Performance of Participants

It was reassuring to note that the participants in the study felt comfortable enough to reflect on both positive and negative impacts of engaging in RTW rehabilitation during their narratives. As stated in the chapter detailing the findings (chapter 5) I did not ask about this issue directly; rather it emerged during the narratives and became a master theme. The positive impact of group based RTW rehabilitation on participants’ perceptions of their own and others’ abilities and disabilities was a surprise to me as the researcher. This may influence the development of more consistent group-based rehabilitation programmes within NWBIS, as opposed to offering individual RTW rehabilitation also. However the importance of ensuring that all patients have concurrent access to individual therapy was also highlighted. The perceptions regarding the positive impact of engaging in RTW rehabilitation as described by the participants of this study support the findings of Kendall et al. (2006) who suggest that people who receive RTW rehabilitation showed a quicker RTW than those who did not. Furthermore they concluded that the RTW rate for persons who have received RTW rehabilitation remains above the ‘natural course’ of RTW rates over many years. Unfortunately the content of the RTW programme being evaluated was not described.
It could be argued that it is not possible to obtain therapeutically relevant information regarding the impact (positive or negative) of a rehabilitation service provision from individuals who have TBI. For example Keith (1998) contends that there is no certitude that individuals who engage in rehabilitation, regardless of the population being studied, are competent to judge the quality of care they receive. However this is a direct contradiction to my ontological and epistemological framework, and would not be an acceptable argument for not taking note of the impressions of the participants in this study. Swaine et al. (2003) evaluated clients’ perceptions of the quality of head injury rehabilitation. Their findings indicated that many adults who have sustained TBI (even those with aggressive behaviours following severe TBI) were sufficiently competent to judge the quality of care they received. Moreover Rossi and Freeman (1979) argue that users of a service may be the only valid source of information about what was actually received.

6.6 Contribution to Occupational Therapy Practice Knowledge
This research explored the lived experience of engaging in RTW rehabilitation following TBI when the individuals had attempted to RTW. The focus of the study was to inform future clinical practice in this area of work. Specifically, as a clinical specialist occupational therapist I was eager to investigate whether there truly is a role for occupational therapy in RTW rehabilitation for individuals with TBI. Work for most people, with or without a TBI, is an extremely important part of life and everyday living. This is an integral part of occupational therapy practice. The findings of this study confirmed that being gainfully occupied is an essential element of well-being in individuals with TBI, and should be facilitated through use of meaningful activity by occupational therapists.

Ivancevich & Matteson (1982) argued that work plays a central role in the overall health and happiness of individuals. Lofquist & Dawis (1969) suggested that the positive relationship between health and well-being, and work can only be achieved when there is a fit between the individual concerned and their
occupational environment. In such a situation there needs to be low levels of stress as well as high levels of satisfaction (Van Harrison 1978). In today’s economic and employment market this is often difficult for individuals without multiple impairments and disabilities to achieve. This can be seen, for example, when university graduates are unable to obtain employment in their chosen fields, or when individuals in their early fifties are made redundant and are considered ‘too old’ to be viable employees in alternative employment. However, when an individual sustains TBI and the multiple possible disabilities that result from this, facilitating a successful person-environment fit through successful RTW rehabilitation would appear to be at best very difficult, and at worst impossible to achieve.

Various neurological rehabilitation services currently attend to the RTW rehabilitation needs of many individuals who have TBI and who are attempting to be more productive. This may, or may not, be in conjunction with other services, such as employment services or voluntary organisations. Over the years legislation has been passed and groups formed to eliminate any form of discrimination against any individual with a disability at the workplace (Disability Discrimination Act 1995, Equality Act 2006, Disability Rights Commission, Equality and Human Rights Commission 2007). However, specialist community based neurological services are not always available to individuals who have TBI, not all patients are aware of the support services available to assist them to RTW, and patients may decline services offered. As a result, not all individuals with TBI or their employers will have the RTW expertise of clinicians at their disposal. In addition, due to improved neurosurgical interventions and improvements in access to healthcare, adults with TBI which would have formerly resulted in death are now surviving, where RTW rehabilitation expertise has yet to catch up. As such there are more survivors of TBI who have limited opportunities to access RTW rehabilitation.
Specialist RTW services and expertise are necessary but lacking in community based adult neurological services (Oppermann 2004, Kolakowsky-Hayner & Kreutzer 2001, Kissinger 2008). Limitations of existing services include the location of the services, personal and community financial challenges and a dearth of trained professionals (Shames et al. 2007). In particular, the increasing incidence of TBI in adults with military personnel incurring significant head injuries in Iraq and Afghanistan (Hlad 2007, Kissinger 2008) illustrates that it is imperative that specific services develop with comprehensive clinical guidelines for individuals, their families and their employers in line with the proposed improvements reducing unemployment generally.

6.6.1 Contribution to Theory & Knowledge About How Individuals With TBI Make Sense of Their Personal & Social Worlds

In order to be able to assist individuals with TBI to be more successful in their attempts to RTW, time needs to be devoted during RTW rehabilitation exploring how they make sense of their personal and social worlds. This is not discussed in the existing literature on RTW rehabilitation. The individual with TBI who attempts to RTW has been portrayed as someone who needs the assistance of experts (Cope et al. 1991), who is mainly a passive participant in the process of RTW rehabilitation (Venderploeg et al. 2008), and who will be either a positive or negative statistic at the end of the RTW rehabilitation process (Ponsford et al. 1995). However the depth and length of the interviews which formed the basis for the results presented in this thesis highlighted the existence of a knowledgeable group of individuals, eager to participate in research and keen that change should occur to help others who may be in similar situations as themselves.

Additionally one particular overriding finding of the research was the optimism of the individual who had sustained TBI and attempted to RTW. The positive outcomes and perceptions they reported despite the traumatic events of illness, loss and long-term complex disabilities, shared by young and older individuals alike were present despite reports of high levels of physical and emotional
distress impacting on their ability to function within the work place. Such findings add significantly to the literature on positive perceptions in having the opportunity to engage productively in occupational activities, and the necessity of ensuring the rights of individuals with disabilities within the work place. Some previous literature has suggested that positive perceptions may increase over time (Shotter 1984, Sabat 1992), while others found that while it didn’t increase, positive impact was stable over time (Brown et al. 2006, Howes et al. 2005). Although we have no comparison of perceptions pre-TBI, the high levels reported by participants suggest the positive impact of surviving TBI and establishing alternative occupational activity is rewarding.

It seems fitting, therefore, that individuals who have sustained TBI, where possible, should be involved in policy and healthcare improvements. This is supported by government and clinical directives. The House of Commons Committee Report on Head Injury in the UK 2001 recommended that statutory services recognise the contribution of the independent sector, and that they collaborate actively with them to provide the best possible service for the patient. They went on to recommend that the Department of Health (DoH) should help charitable organisations, where they are providing core services, to develop these services further. The Neurological Alliance (2002:9) stated that:

“Voluntary organisations have an important part to play in the care of people with neurological conditions [and that such organisations are] experts in representing their service users’ [and have] developed to meet the increased expectations and needs of people with neurological conditions to fill gaps in service provision”.

Furthermore the National Clinical Guidelines produced in 2003 on ABI in the United Kingdom state that:

“The effects of acquired brain injury are long-lasting and that [people affected] and their families require continued care and support, often for the rest of their lives… [There should be] explicit pathways for collaborative working between statutory and voluntary services”. (p.3).
The National Service Framework for Long-Term Conditions (2005) emphasised the requirement for current service models to include:

“Designated… peer support networks including those provided by the voluntary sector” (p.19).

An important finding of this study that contributes to the existing knowledge about individuals with TBI is that they are a potentially valuable resource for assisting others facing similar problems to themselves. The qualitative aspects of this thesis highlighted a desire for continued involvement in services by patients who maintained a variety of roles in: voluntary organisations, family networks, education and sports and leisure facilities. Achieving and maintaining these roles were not always easy for these individuals. Were this path of involvement (for individuals with TBI attempting to RTW) more easy to negotiate, it could assist in minimising the loss of contact with rehabilitation services that some reported; provide a wealth of experience for service providers; and provide an invaluable resource for other individuals who have sustained TBI and facing the reality of preparing for RTW. As seen above, this is a different construction of individuals with TBI compared to that reported in much of the literature to date.

6.6.2 Contribution to Knowledge About Content of RTW Rehabilitation Programmes

Importantly, this study aimed to obtain qualitative data regarding what was actually assistive for individual with TBI engaging in RTW rehabilitation. This has been missing from previous literature. Significantly the data also flagged up critical elements of RTW rehabilitation which have not been specifically included as essential elements of RTW programmes to date and which have been ignored in RTW rehabilitation literature. These include the mode of clinical communication between patients and therapists, and the need for both clinicians and individuals with TBI to accept and work with grief reactions, specifically as part of their RTW rehabilitation process.
**Changes in professional training**

This research broached the subject of pre-TBI employment experiences and the impact of the personal cost of lifestyle losses following TBI. Findings from the area of coping and adjustment following TBI have suggested that where clinicians concentrate on problem-focussed coping with their patients, it promotes positive psycho-social adjustment (Bombardier et al. 1990, McNett 1997, Brown et al. 2006). Problem-focussed coping developed from the theory of Lazarus and Folkman (1984) which suggests that appraising a situation as controllable (Lazarus 1993) elicits strategies that manage distress by confronting and altering the situation, such as information gathering and seeking professional help. Furthermore findings reported in the current thesis and previous research highlight the importance of honest, open communication between patients and professionals (Moore et al. 1991). Findings have highlighted the reality that a lack of confidence and fear on the part of healthcare staff is a considerable barrier to successful rehabilitation for people with impaired cognitive functioning (Sowney & Barr, 2006). The two areas where the communication between clinicians and patients needs to change in clinical practice based on the findings of this study are in the domains of secondary grief reactions and recognising the factors impacting on RTW rehabilitation, such as fatigue, and allocating a named person to accommodate this.

**Clinicians’ need to address the grieving process**

Changes to training and education of health care professionals, for example medical students, nurses, occupational therapists, psychologists (Harwood, 2007), could raise their awareness and confidence and aid with the development of concrete guidelines for communicating personal cost of lifestyle losses, coping with a changed presentation, and coping with grief following TBI. Such training and exposure could also improve healthcare professionals’ skills in dealing with the issue of grief and loss where it is not applicable to the death of a person, but to the loss of a part of self, making resumption of previous roles difficult, and in some instances, impossible. Grief is recognised as a significant process that
needs to be negotiated in TBI recovery (Coetzer 2006), but usually in isolation from RTW rehabilitation. The findings of my thesis suggest that grief and loss adjustment needs to be incorporated fully into RTW rehabilitation in order that individuals with TBI can optimise their chances of successfully reintegrating with a productive society. These findings also complement the holistic approach to neuropsychological rehabilitation advocated by Ben-Yishay et al. (1985), and Schluts & Schkade (2007) model of occupational adaptation towards a holistic approach to occupational therapy rehabilitation.

The question of who should provide bereavement interventions for this neglected group is a critical point for discussion. Given the potential for feelings of loss of control and/or power amongst these individuals and their families, it is crucial that bereavement services are aware of the multi-faceted experience patients endure long-term. Meanwhile, the understanding incorporated into the NWBIS services suggests that the neuropsychologists and occupational therapists are potentially suited to such a supportive role, although they have not fully actualised that role in RTW rehabilitation to date. The importance of support from other similarly grieving patients, and continued contact with their occupational therapy and psychology clinicians after attempting to RTW was important to patients interviewed.

**Inclusion of carers in RTW rehabilitation**

A service facilitated by a combination of clinicians and carers may be suitable for providing support with the grieving process for other carers of individuals with TBI attempting to RTW. This type of support puts carers of patients in contact with families in a similar situation and they provide each other with mutual support, including via the telephone. The use of this method is strengthened by evidence of the suitability of telephone support for managing loss (Nair et al. 2006). However, expertise in bereavement and the resources necessary to provide these additional services within RTW rehabilitation may be difficult to implement. Within community based neuro rehabilitation services, attempts have been made
to establish similarly desired links between clinicians and families and have resulted in promising results for patients and positive feedback on their efforts for professionals.

One potentially useful example from current literature relating to the potential content of RTW rehabilitation programmes is the suggestion regarding assisting individual with TBI to adopt a self-directed approach (Kolakowsky-Hayner & Kreutzer 2007). They offer a framework of steps and questions for individuals with TBI to consider as a therapeutic self-directed approach to RTW. Whilst, in my experience as a clinician, it would be extremely difficult, if not impossible, for any individual with TBI to successfully follow this framework independently, the framework itself does provide a valuable starting point for specialist clinicians to generate a coherent RTW rehabilitation framework with patients. If combined with the findings from this thesis, the other clinically important issues contained within the participants’ narratives, but not relevant for this study, it could be possible to develop particularly comprehensive guidelines that may assist in increasing the success rate of RTW for individuals with TBI. Indeed this was one of the main aims of this study.

6.6.3 Contribution to Knowledge of the Role of the Occupational Therapist in Return to Work Rehabilitation for Individuals with Traumatic Brain Injury

The third aim of this research was to better understand the unique role for occupational therapy in RTW rehabilitation for individuals who have TBI, and explore how this role may best be defined. The profession of occupational therapy has focused for many years on daily occupations as a basis for treatment (Schell et al. 2005). The participants’ narratives brought to light the value of the role of the occupational therapist in being activity and occupationally driven within RTW rehabilitation with this clinical group. This study has highlighted the need to include work simulation in rehabilitation programmes, and to formalise voluntary
placements. Their unique knowledge of occupational and activity places occupational therapists in the ideal position to liaise between the patient and the employer when considering RTW. Furthermore, occupational therapy’s philosophy which values the uniqueness of the individual was identified as important for participants, leading me to be able to develop a working practice model for occupational therapists in RTW rehabilitation in this clinical setting. No such model currently exists.

The role of the occupational therapist in work simulation

It has already been discussed in chapter 2 that individuals who sustain moderate to severe TBI regularly present with impairments of self-awareness and/or distortion of judgement as part of their presentation (Ben-Yishay & Diller 1993, Toglia 1991). In an attempt to address criticism of eliciting narratives for research purposes from individuals with this difficulty, I administered the Awareness Questionnaire (AQ) as part of the inclusion criteria for this study. I have discussed earlier in this chapter that it cannot be assumed that individuals who obtain a clinical score on the AQ are necessarily compatible with phenomenological semi-structured interviewing. A clinical score on the AQ may be achieved, but the individuals concerned may still have difficulty in understanding either that they have deficits, or the full impact of their deficits. They also inevitably have difficulty in fully anticipating the impact of those deficits on function and in assessing their occupational performance in relation to those deficits (Garmore et al. 2005). Thus, although administering the AQ provided information regarding the participants’ ability to be aware of their functional ability in various domains, some still experienced difficulty in verbally expressing their constructions on more abstract concepts such as the impact of not working.

However I consider it assisted in the study as it ensured that the participants did have some insight into their presentations, and thus would be able to participate in the study with less risk of becoming distressed by the process of having to reflect on their experiences. This was ethically very important. My skills as a
specialist clinician and active researcher ensured that I was able to facilitate the participants to relate their narratives. I would recommend that such an instrument is used in future research with this patient group to ensure optimal participant dignity and minimal distress.

Dirette et al. (2008) explored the pattern of the development of self-awareness following TBI, focussing specifically on the importance of occupation. They concluded that when individuals with TBI are unsuccessful in their attempts to participate in familiar occupations, such as work, this became the number one antecedent to gaining self-awareness. Similarly Toglia & Kirk (2000) advocated participation in familiar occupations to foster the development of self-awareness. Bearing in mind the potential concurrent grief reaction that presents with increased awareness of inability to be employed at pre-TBI levels, it is evident that the role of the occupational therapist in initiating the RTW rehabilitation process is a vital one, ideally in collaboration with a neuropsychologist. The occupational therapist’s expertise lies in their core skill of assessment and utilisation of occupations that are purposeful, meaningful, and unique to each individual. Haggstrom & Lund (2007) argued that being engaged in occupations that are meaningful to the individual is intrinsic to the individual’s sense of engagement.

To date, within NWBIS RTW rehabilitation, the role of the occupational therapist in the process of facilitating individuals to re-engage in purposeful occupations that will lead to employment has focused on assisting individuals to obtain the ‘soft skills’ required for employment. These skills are those that are often impaired when individuals have TBI, such as turn taking in conversation, remembering instructions, working as part of a team towards an end result. The findings of this study indicate that further, designated time needs to be allocated to work simulation activities within the clinical setting utilising occupations that are meaningful to each individual. This would assist in the ‘first step’ of developing self-awareness with regards to occupational performance in
employment, and could be monitored jointly by the occupational therapist and neuropsychologist to ensure a therapeutic journey through the grieving process. Work simulation tasks are rarely utilised in RTW rehabilitation programmes as there is little evidence that they are of significant value to the process. However, based on the evidence of this study, occupational therapists need to incorporate this into RTW programmes as a pre-requisite to moving from the clinical and into the employment setting with their patients.

The role of the occupational therapist in adapting work environments to optimise functional ability

Participants in this study spoke of the physical disabilities which impacted negatively on their attempts to RTW, and how this had not been fully appreciated by them during their the rehabilitation period. Occupational therapists have core skills in assessing environments and adapting them to accommodate the physical disabilities of individuals as required, optimising their functional ability. This may be within the individual’s home environment or in public buildings. Haggstrom & Lund (2007) explored qualitatively what impacted on individuals with ABI and their ability to participate in daily occupations. They concluded that the participants in their study found access to buildings and surroundings often prohibitive due to their physical disabilities. However, these coupled with the cognitive (particularly dysexecutive) problems negatively affected individual’s abilities to manage crowds and noise (which were a natural part of accessing buildings, including places of work) and this impacted on their potential to perform activities satisfactorily. Indeed, the participants in this study discussed how this aspect of their RTW rehabilitation had been effectively addressed by the occupational therapist in the work place setting. This was related not only to mobility problems, but also in relation to fatigue and reduced stamina. The role of the occupational therapist in educating the employers, and ensuring adaptations to either the work environment, the working hours or both, had been pivotal in the success (or not) of individuals that successfully RTW.
Development of a working practice model for the role of the occupational therapist in RTW rehabilitation

The findings of this study would support there is a unique role for the occupational therapist in the RTW rehabilitation process with individuals who have sustained TBI. If the elements of RTW rehabilitation, that have been highlighted as being useful from the stories elicited in this study, are mapped against the ‘core skills’ or ‘legitimate tools’ of occupational therapy (Mosey 1986) a model of occupational therapy practice within RTW rehabilitation for individuals with TBI can be established. The value of this working practice model for occupational therapists is that is provides a framework which will guide clinical practice, incorporating the assistive elements of RTW rehabilitation identified by participants in this study (addressing soft skills, working through secondary grief reaction, work simulation, formalised voluntary placements, familial involvement, support groups, no temporal constraints, long term involvement). The model allows occupational therapists to re-visit areas of difficulty with patients if required without them perceiving this as them having ‘failed’. This model is seen below:
6.7 Summary

In order to ensure greater success in RTW with individuals who have TBI there is a need to address the issue of working practice guidelines within RTW rehabilitation. This can be effectively addressed by collaborative multi disciplinary
team-working, with the lead taken by occupational therapy and neuropsychology. Individuals with TBI continue to be knowledgeable and can contribute constructively to the rehabilitation process in assisting others in similar situations to themselves. This is also a recommendation of many government initiatives and neurological rehabilitation guidelines. Government incentives such as the ‘Expert Patient’ needs to be incorporated much more actively in RTW rehabilitation programmes, and be an integral part of the process. There needs to be an explicit acknowledgement by clinicians that individuals with TBI undergo a grieving process when they attempt to RTW and this needs to be accommodated within RTW rehabilitation.

Current RTW rehabilitation processes also need to ensure that occupational therapists engage actively with potential employers of individuals who are attempting to RTW following TBI to ensure that, in accordance with existing legislation, they are becoming more responsive to individual needs to maximise employee well-being and also employee commitment (Herriott 1989). For example the concept of flexible working hours and even flexible working options, such as working from home would reduce the potential for further sickness or absence record of employees (Hammond & Holton 1991). The assessment of flexibility needs to be undertaken considering the needs of the workplace, and the abilities of the employee at any given time. The core skills of the occupational therapist, as identified in the above model, are ideally suited to this role. Whilst there appears to be a role for occupational therapy in initiating the practical elements of RTW rehabilitation within the clinical setting, the findings of this research have emphasised the unique and specialist skills of occupational therapy in being actively involved in the graduated return to work process, and/or formalising of voluntary placements to optimise success for the individual.

The concluding chapter will evaluate the strengths and limitations of the study in light of the research question and the aims of the study. It will also discuss plans for dissemination of the findings and implementation of the findings to ensure a
worthwhile contribution to current RTW rehabilitation and occupational therapy knowledge.
Chapter 7  Summary and Conclusions

7.1  Overview
The strength of this research lies in the contribution it makes to knowledge through having explored the subjective experience of return to work (RTW) rehabilitation for individuals who have sustained traumatic brain injury (TBI) and being able to offer some clinical guidance on the content of the RTW rehabilitation. The study aimed to explore how the participants made sense of their personal and social worlds when attempting to RTW following TBI. The study also aimed to explore whether any aspect of the RTW rehabilitation offered at the North Wales Brain Injury Service (NWBIS) was actually assistive to the process of attempting to RTW. The final aim was to better define the occupational therapist’s unique role in RTW rehabilitation for individuals with TBI. The focus of the study was to inform future clinical practice in this area of work.

The previous chapter illustrated comprehensively the contribution this research has made to knowledge about research methodologies with this clinical group. Recommendations for future research regarding use of semi-structured interviews within an interpretative phenomenological framework were discussed. The findings of this study also contributed to clinical knowledge about RTW rehabilitation.

7.2  The Impact of This Study
The findings of this study have revealed, for the first time, that individuals with TBI undergo a separate and distinct grief reaction when they attempt to resume previous employment. This needs to be explored further and addressed explicitly in RTW rehabilitation by clinicians. This is an original contribution to current literature which may provide key understandings into why the effect of not successfully returning to their previous employment and resuming previous roles and duties has such negative consequences on the individual’s total functioning compared to their functioning if they, for example, are unable to discipline their child.
appropriately. As an experienced specialist clinician it has been difficult to understand why disruption to the process of RTW has such far reaching consequences on individuals’ overall functioning. Through undertaking semi structured interviews with the participants, this knowledge about the secondary grief reaction pertinent specifically to RTW rehabilitation has provided an insight into why engaging in this process can be so devastating for these individuals. This has far reaching impacts on the training afforded to clinicians working in this clinical field. It has also highlighted the need for occupational therapists and psychologists, in particular, to work closely together to assist individuals to progress through the grieving process.

Whilst occupational therapists have traditionally utilised meaning occupations or activity as their medium for treatment with individuals with illness and/or disability, they have in the most recent past neglected activities that could be perceived as work simulation. This may be attributable in part to lack of available resources, changes in occupational therapy training programmes and/or lack of evidence that it holds any real value in today’s health care systems. The findings of this study strongly indicate that work simulation activities would be most beneficial as an essential component of RTW rehabilitation. This may mean looking laterally at available opportunities, accessing voluntary bodies and reaching agreements whereby the volunteering placements could be formalised from a therapeutic perspective and made meaningful in a work simulation capacity for individuals with TBI. This requires further exploration. This would need to be considered in light of findings of previous research identifying that engagement in occupation is often a key strategy that assists the individual with TBI to develop some awareness into the impact of their injury on their performance. As such, any work simulation placement would need to have concurrent psychological input to ensure progress through the grieving process.

In addition, the involvement of patients in assisting others who are going through the RTW rehabilitation process needs to be incorporated in RTW rehabilitation
programmes. Participants identified that they would be willing to support others who are in the early stages of their RTW rehabilitation. In addition they identified that through involvement in this, they could access the long term support that they felt was lacking in current RTW rehabilitation programmes. Whilst incorporating patients into a rehabilitation programme as part of a ‘cure’ whilst they may still be undergoing rehabilitation themselves should not be undertaken lightly, it still needs to be a considered factor in future RTW rehabilitation programmes as an innovative practice.

Familial support during this process also needs to be addressed through combined clinical and self support groups. Initial data has been provided regarding the actual content of RTW rehabilitation groups. This needs to be explored further in future research.

A main finding of the study was about the unique role of the occupational therapist in this area of work. A potential working practice model for occupational therapy involvement has been developed based on the information elicited from the participants’ narratives and occupational therapy core skills as defined by Mosey (1986). No such working practice model currently exists and thus there is no framework for occupational therapists to follow. Whilst the proposed model requires evaluation as to its effectiveness in practice, it would appear to offer a sound clinical basis to justify the long term input of the occupational therapist in a RTW rehabilitation programme with individual with TBI. In addition, it should guide the clinical decision-making process of occupational therapists.

A further significant finding from this study was that of obtaining quantitative data about the financial loss experienced by participants and their related Grafton Manor placement rating (Table 6.1). To date, details regarding the financial cost of sustaining TBI in the literature have focused on the cost of rehabilitation per person, the cost in lost revenue due to the person not working, and similarly with their ‘significant other’. Whilst there is universal agreement that there is
significant financial loss for the individual in question, this is the first time that specific data regarding this issue has been gathered, and related to the changes in their placement rating. Unfortunately, due to the small sample size, it is not possible to evaluate whether there is a significant statistical relationship between both factors. However, a bid has been placed with the North Wales Research & Ethics Committee for an extension to this study in order to obtain this data from a greater sample size, and explore the issue in detail. This could significantly impact on predicting placement requirements for individuals with TBI.

7.3 Further Research

However this study is not without its limitations. While the male female ratio (5:1) is slightly higher than the gender ratio evident after brain injury (3:1) (Linn et al. 1994) the recruitment procedure may have inadvertently recruited participants who were articulate and well adjusted to their current situations. Furthermore all the participants had accessed RTW rehabilitation as part of their overall rehabilitation package following TBI, and had returned to their previous home following their discharge from hospital. Not all individuals who have TBI have access to these community based services, nor do they have a familiar home environment with an inherent supportive network to return to. Thus their experience of RTW may be different. This may highlight a need for further research.

This research has helped to promote an understanding as to what elements of RTW rehabilitation are constructed as assistive and/or beneficial for individuals who are attempting to RTW following TBI. The management strategies and support mechanisms related to managing difficult work based situations could be promoted through long-term multi professional support groups, comprising primarily occupational therapy and psychology. In particular, therapeutic approaches such as cognitive behavioural therapy and work place simulation could be used to challenge flawed work-based coping strategies. In addition, co-existing long-term group support for family members needs to be provided to
good effect to ensure their involvement supports the individual with TBI during difficult times. The exact nature and extent of this group requires further research.

Whilst RTW rehabilitation can be assistive for individuals who attempt to RTW following TBI, for the best success rate the RTW rehabilitation needs to be individually tailored and provided at a pace that can be internalised by the individual in question. Caution should be applied before altering current RTW rehabilitation practices, and attempting to ensure greater conformity. Many studies exploring success in RTW of individuals with brain injury have been criticised for not ensuring that the subject sample are on the same time frame post injury when this issue is being examined (Chard 2006). My study suggests that this is not a valid criticism of studies exploring RTW following TBI. The rate and level of recovery and acceptance is individual to each person, and thus to insist that, for example, at ten months post injury RTW rehabilitation should be commenced is simply not realistic as some individuals would not be ready at this time. The participants involved in this study were all still aiming to improve their productivity within occupational related fields, and the time from the date of injury to the date of interview ranged from 38 months to 118 months. This study thus contends that the longitudinal studies of success in remaining in employment may be flawed as individuals with TBI fluctuate in their performance and ability to sustain control over their strategies to manage their presenting disabilities long-term. As such, a fluctuating picture of success in RTW following TBI is to be expected. It maybe more valuable to undertake further research to explore if there is a pattern in the fluctuations, and whether these fluctuations can be addressed in RTW rehabilitation programmes. Moreover, it may be interesting to explore whether the perceptions of clinicians regarding the success of RTW rehabilitation programmes could be amended in light of an acceptance that there is going to be fluctuating success rate of RTW, and that through their acceptance and accommodation, their practices could change to be more proactive in these instances, as opposed to managing the situations reactively.
Future research could potentially build on the investigations set in motion by this thesis. The experiences of individuals who have attempted to RTW following TBI has been advocated as a subject requiring further research for some time, and similar methods to the current study should explicitly investigate the experiences of a greater range of patients in the UK including: their needs pre- and post-injury, their preferred coping strategies, experiences of support, satisfaction with support, and positive perceptions, amongst other issues. Replication of quantitative investigations could assess the true impact of grief and other bereavement outcomes on RTW, and compare with patients and previously researched groups of individuals with TBI to ascertain the longevity and intensity of their RTW grief experiences. In addition, research could include reports from siblings, spouses, children and other informal caregivers to improve the services provided both before during and after the individual engages in RTW rehabilitation.

This thesis both combined and separated the experiences of participants with regard to type of cognitive ability following TBI. While participants reported a great deal of similarity despite different aetiologies of TBI, participants with TBI and a physical and/or communication disability reported unique experiences of poly diagnosis further to sustaining TBI and a battle for expert healthcare to facilitate successful RTW outcomes. Future research should consider investigating specifically the experiences of patients by the aetiology of their presenting problems. For example, individuals with TBI affecting the cerebellum may have additional requirements not common to the aetiology of other TBI as they experience significant mobility and balance problems in RTW rather than purely cognitive problems.

This thesis has discussed interventions that may be potentially useful to this patient group. Kendell et al. (2006) suggested that the important questions that need to be addressed are which vocational interventions are most effective for
TBI survivors, and how interventions differ in strengths, limitations, and application to TBI populations. The provision of RTW rehabilitation that provides a pathway to return to previous employment is not enough. In a similar vein, the provision of bereavement counselling alone is not enough. The effectiveness of each intervention should be evaluated to ensure it is worthwhile, and to contribute to the knowledge base (Beutler, 2000). Thus, clinicians can avoid implementing ineffectual interventions. Fadyl & McPherson (2009) state that it is still unclear how well recent evidence about vocational rehabilitation after TBI addresses the question of effectiveness and ‘best practice’ (or which approach is best for whom). An ongoing audit of rates of uptake, characteristics of those who avail of services and satisfaction with interventions could inform those providing the RTW rehabilitation as to how the service might be improved, if necessary.

7.4 Reflections on the Research Process
This research was undertaken as part fulfilment of a Doctoral programme in Occupational Therapy. The research process itself has been just as educational as have the findings from the study. The initial two years of the programme were spent identifying a disturbance within the workplace and developing a research question that would feasibly allow me, as the researcher, to explore the disturbance in depth as part of my developing ‘researching clinician’ role. The prospect was daunting and the preparation was challenging. Whilst completing the various ethical approval forms at each stage of the process was intimidating it gave me confidence to undertake further future research in the knowledge that I have an working understanding of the process and requirements. The researching experience itself was, at times, draining in terms of the impact that the narratives had on me. It was also occasionally frustrating, as a clinician, to be unable to follow up themes which as a researcher I did not need to pursue. The transcription process was time consuming. However it provided me with an opportunity to immerse myself in data in a manner that I had not experienced before. This was enlightening as it has made me question how much information is lost to me as a clinician when I only hear it once from patients; that is during a
clinical appointment. The experience in total has been enlightening, rewarding and fulfilling.

Having to focus on an aspect of my clinical practice that was a potentially researchable project that could contribute to existing knowledge was learning a new art in itself. I fell into the usual traps of staring off with too ‘big’ a question: wanting to evaluate the RTW rehabilitation programmes of the community based brain injury services in the United Kingdom; wanting to develop a prescriptive RTW rehabilitation programme, implement it, and evaluate it before marketing it. Most latterly I considered undertaking a quantitative study in any aspect of RTW rehabilitation simply to ‘brush up’ my skills in statistical information. The only common theme in all the above was my interest in RTW rehabilitation. Thankfully, I was guided by one of my supervisory team to research an aspect of my clinical practice in which I was interested, to undertake the research within a framework that complemented my professional philosophy, and that was a feasible project which would contribute to the existing knowledge.

Whilst the experience of engaging with the differing ethical committees was not without its challenges, I consider it reaffirmed to me the responsibility I have as a researching clinician. I undertook the research with individuals who had been through horrendous traumatic and life changing events, often not of their own fault. Whilst they consented to participate in the study in an informed manner, I was very aware of my responsibility to ensure, as far as it was possible, that I did not contribute to their stresses, or de-value their narratives through careless questioning, or not picking up on cues that they may be becoming distressed. The numerous forms relating to consent, and information sheets, then consent verification at the time of the interview made it clear that this was not purely an academic exercise. I was dealing with real people who had real emotions in this research, and they needed to be treated with respect. To this end, I ensured that thank you letters went out, and that they received a summary of the key findings.
of the research, in order that they could see how their input has contributed to the existing literature, and potentially will inform future clinical practice.

I had not anticipated that the interviews would require me to draw on so many of my specialist clinical skills to elicit the narratives from the participants. It has made me aware of the need to be able to transfer professional skills into different situations. However, the success of the interviews in eliciting narratives has given me confidence to undertake further research as indicated in this area of work. An intriguing aspect of undertaking interviews for research instead of for clinical purposes was when issues were raised that, as a clinician, I would have followed up, but as a researcher, had to allow the participant to choose how much information they wished to share. Whilst this was frustrating on occasion, I was never in a position of fearing that I needed to change from my role as researcher to that of clinician during the interviews.

Using interpretative phenomenological analysis (IPA) as a method to analyse the narratives was enlightening as it allowed me to analyse what was said by individuals as well as themes generated from multiple participants. In addition, my interview notes and personal reflections following each interview made the analysis of the transcripts more robust and grounded in the data. Whilst it is an analysis method traditionally used by psychologists in research, it translates well into the profession of occupational therapy. It is considered by Cronin-Davis et al. (2009) to acknowledge the researcher’s influence within the research process and to have a similar philosophy to the person-centred nature of occupational therapy. Whilst descriptive phenomenology could have been utilised to undertake the research, I do not consider it would not have been possible to access such rich narratives had used descriptive phenomenology. My choice of interpretative phenomenology influenced the sampling procedure as I needed to have potential participants identified that had experienced the phenomena of RTW rehabilitation and who could reflect on the experience and provide their interpretations of what they went through. My interpretation of the narratives elicited has ensured that
the voice of the participants was heard. This has not been considered high priority in previous research, hence the gap in literature. The data elicited has contributed significantly to the available literature with both original findings and confirmation of findings in previous literature. I have been asked, based on the findings of this study, to be a co-researcher in multi-disciplinary research evaluating the effectiveness of a different intervention by my psychology colleagues within NWBIS. This is gratifying, and I feel I will be better prepared for the requirements of the process.

The research process and the findings have already been disseminated in peer reviewed Doctoral conferences as detailed below:
Professional Doctorate Conference, University of Brighton, 2006
Professional Doctorate Conference, University of Brighton, 2007
Professional Doctorate Conference, University of Brighton, 2008
Professional Doctorate Conference, University of Brighton, 2009
SUADE Conference, University of Brighton 2009

It is further planned that the findings of the research will be disseminated at presentations at the following conferences next year as detailed below:
6th World Congress on Neurorehabilitation, Vienna, March 2010 (Abstract Submitted)
34th BAOT Conference, Brighton, June 2010 (Abstract Submitted)

In addition, I propose to submit articles for publication in both professional based journals (British Journal of Occupational Therapy, International Journal of Occupational Therapy), and journals focusing specifically on brain injury rehabilitation (Head Injury).

7.5 Conclusion
The depth and extent of the findings in this study have surprised me. In particular the contribution, I feel, this study makes to occupational therapy knowledge is
rewarding. My hope was to contribute to the existing literature on RTW rehabilitation in term of what is assistive for the individuals themselves. To be able to contribute to the body of knowledge on occupational therapy on this topic by identifying how occupational therapy needs to develop to optimise the potential for patients to succeed in this venture has exceeded my expectations. In addition I have been able to develop an existing frame of reference (the Acquisitional Frame of Reference) which was developed for use in the field of mental health, and apply this in a working practice model for the role of occupational therapy in RTW rehabilitation. This is an additional bonus.

Overall the professional doctorate programme has been all encompassing, has taken away much of my free time, and eaten into much of my family and social time as well. However the whole experience has been invaluable in terms of developing my role as a specialist clinician who can contribute to the body of occupational therapy knowledge. Further to undertaking the research I have been successful in obtaining a lead contributor post with the College of Occupational Therapy to develop a teaching module on returning to work following illness and/or disability for practising occupational therapists. I have also been approached by Headway North Wales and am assisting them, based on my research, to apply for a grant to run a pilot scheme to assist individuals with head injury to return to work in North Wales. Within the NWBIS I am approached more frequently for advice by my colleagues regarding patients who want to consider RTW. Within the occupational therapy service in North Wales I was invited to provide a presentation to both managers and clinicians about the value of supporting clinicians to undertake research at postgraduate level with the result that some of my occupational therapy colleagues are now exploring postgraduate research possibilities themselves.

My practice as a specialist occupational therapist within NWBIS has developed significantly as a direct result of enrolling on the Professional Doctorate programme and undertaking this research. I am more aware of how it may feel to
the patients to engage in the process of exploring RTW options and look out for possible features of a grief reaction and am able to support them more therapeutically. I have also presented my working practice model to occupational therapy colleagues and we are in the process of determining how to evaluate and further develop the model within NWBIS. The findings relating to the financial repercussions of not being able to return to previous employment have spurred the interest of the consultant Neuropsychologist and myself, and we are planning to generate further data relating to this new knowledge further to being granted ethical approval.

As such I consider the whole experience to have been worthwhile. It is gratifying that this perception is shared by my colleagues in NWBIS. I plan to continue to undertake research and add to the existing body of knowledge and develop further as a practising occupational therapist.
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APPENDICES
MULTI-DISCIPLINARY TEAM (MDT) PATHWAY

Referral in writing from medical practitioner

Discuss at Multi-Disciplinary referral meeting
  - Request further information if necessary

Decision made

Inappropriate? → Appropriate?

Letter to referer stating why

Community based patient

Appointment sent to patient and referrer within 3 months

Initial assessment by practitioner
  - Database completed
  - Outcome Measure Administered
  - Refer to other team members as necessary

Goal for intervention agreed with patient and MDT

Intervention

Regular review and repeat Outcome Measure 6-12 months

Improvement or Maintain current level

- Continue to provide intervention to maximise patient potential
- Potential reached, MDT and patient agree to place patient on inactive caseload

No Improvement

Re-assess

Further intervention where indicated

Repeat Outcome Measure

No improvement: Report back to referrer and suggest referring to more appropriate agencies

Hospital based patient

Assessed on ward within 5 working days

Intervention and advice as necessary

Discharge from hospital and become community based patient
The Development of a Holistic, Community Based Neurorehabilitation Service in a Rural Area

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Brain injuries have devastating effects for individuals and their families. As in other countries brain injuries are common in the United Kingdom (UK). It is estimated that approximately 100 - 150 per 100,000 of the general population are disabled as a result of a traumatic brain injury (British Society of Rehabilitation Medicine, 1998). Brain injuries are, however, not limited to trauma. Cerebrovascular accidents are another leading cause of brain injury and it is reported that 1.6 - 2.0 per 1000 of the general population in the UK suffer a first stroke each year (Bramford, Sandercock, Dennis et al 1988).

With the dramatic advances made in medical care over the last couple of decades, individuals now often make a good physical recovery following brain injury. Significant developments in the acute care of brain injured individuals has resulted in substantial numbers of survivors living in the community with their families. This increased number of survivors often face a return to their communities without access to rehabilitation programs (Greenwood & McMillan, 1993). It appears that the cognitive, behavioral and emotional difficulties following brain injury pose the greatest obstacles to rehabilitation and also re-employment (Lishman, 1996; Ponsford, Oliver & Currow, 1995). The physical, psychological and cognitive effects of a brain injury have been well described (Loeck, 1995; Lishman, 1998).

North Wales is a rural area on the northwestern coast of the United Kingdom. Both Welsh and English are widely spoken in North Wales. It is an area of outstanding natural beauty. Important sources of economic activity include farming, light industry and Eco-tourism. North Wales has a population of approximately 660,000.

While data regarding the incidence and prevalence of traumatic brain injury for North Wales is limited, preliminary results of surveys appear to reflect national UK data (Coetzee, 1996; Elliston & Rogers, 1996). It has been anticipated that there may be approximately 1,000 survivors of brain trauma with long-term disabilities living in this community (Report of the All Wales Steering Group, 1997).

The North Wales Brain Injury Service (NWBIS) has a North Wales remit, spanning six local authorities. The Service is hosted by the Conwy & Denbighshire NHS Trust, one of the three National Health Service (NHS) Trusts in the area. It is located in Colwyn Bay, a coastal town of North Wales. No community based brain injury rehabilitation service existed in this area prior to the establishment of the NWBIS.

There are three District General Hospitals (DGH) in the area, but no specialist inpatient unit for patients with brain injuries. The DGH provide acute care for brain injured patients. Some sub-acute patients are referred out of area for inpatient rehabilitation. The regional Neurosurgery Unit serving North Wales is located in Northwest England (Liverpool). Visiting neurologists from Liverpool provide a service to patients in North Wales.

A Welsh Office investigation into service provision for brain injured individuals during 1995 identified significant gaps in service provision for individuals with a brain injury and their families (All Wales Steering Group, 1997). Prior to 1995, the voluntary organisation Headway played a major role in lobbying for a brain injury service. During 1997 the North Wales Acquired Brain Injury Strategy Group (NWABISG) was formed to steer the development of services in the region. The NWABISG had representation from the voluntary sector (Headway), medical professionals, commissioners of services (North Wales Health Authority), the local clinical psychology department, social services, public health physicians, therapy services and other stakeholders.

The first appointments to the NWBIS were made during April 1998. The initial remit of the NWBIS was to provide an assessment and consultation service for adults with an acquired brain injury. However, the remit broadened very rapidly to include direct rehabilitation interventions. Several additional appointments to the service were made during 1999 2002. During March 2001 the staff of the NWBIS moved into a community based brain injury rehabilitation unit on the Colwyn Bay Community Hospital site.

The NWBIS is multidisciplinary with input from clinical neuropsychology, neurology, occupational therapy, social work, physiotherapy, speech and language therapy and rehabilitation assistants. The clinical remit is to see individuals of any age with moderate to severe acquired (non-progressive) brain injuries. The Service accepts referrals of non-progressive neurological conditions including traumatic brain injuries, cerebro-vascular accidents, tumours and CNS infections. Traumatic brain injuries make up the bulk of the referrals (Coetzee, 1999). The Service has no upper age limit for most types of referrals and has seen several...
older adults with an acquired brain injury (Coote & Abon, 2001).

The Service works with other health and social services and voluntary sector organisations in the community wherever possible. Close links exist with the University of Wales Bangor School of Psychology as well as the School of Nursing. The NWBIS offers specialist placements for clinical psychology and other students. Opportunities for collaborative research and teaching activities exist between the University and the Service.

Theoretical Model

The effectiveness of brain injury rehabilitation is strongly supported (Cope, 1993). However, no single profession in isolation can serve the complex needs of individuals with a brain injury (Rose & Johnson, 1996). Indeed, Sambon et al (1998) came to the conclusion that superior outcomes were associated with a specialist multi-disciplinary regional service.

Alexander K. Luria's theoretical principles underpinning neuropsychological rehabilitation models are the most influential in approaches to brain injury rehabilitation (Uzefoff, 1997). Wilson (1997) provides a review of the four main approaches to brain injury rehabilitation. These include the cognitive re-training approach, the cognitive neuropsychological approach, the combined approach and the holistic approach (Wilson, 1997). Bees-Visley (2000) and Prigatano et al (1994) give more detailed descriptions of holistic, neuropsychological oriented milieu programs. In this type of program, the patient's individual needs determine the individual therapies they receive. In addition, patients receive group and individual psychotherapy. The therapeutic interventions of the program are embedded in the milieu program, emphasizing social interaction and integration. Essentially these programs are concerned with increasing awareness and acceptance, providing compensatory strategies for cognitive problems and vocational interventions (Wilson, 2002). Clinically there seems to be few concerns with the holistic approach and patients appear to benefit from improved productivity and self-esteem (Wilson, 1997). The approach does, however, require high levels of staffing.

Burnes (1995) asserts that a regional brain injury rehabilitation service should be located within a local community. Cognitive rehabilitation should focus on real life problems (Wilson, 2002). An important advantage of a community-based service is the potential for real life experiences and the implications this has for generalization of therapeutic gains. It is also more likely to successfully include family members in the rehabilitation process.

The NWBIS provides what can essentially be described as a holistic program delivered on an outpatient basis, within a rural community. Interventions are individualised based on an assessment of needs in each case. Bajo and Fleminger (2002) in their recent review emphasize the importance of a patient-centered approach when designing rehabilitation interventions for the individual. In the NWBIS patients may access individual as well as group based interventions and attempts at re-employment or education locally are made as part of a multi-disciplinary intervention. Interventions are provided at the unit, a DGH, community hospitals, GP surgeries or the patient's home, among others.

Programme Description

Referral Criteria

The remit of the NWBIS is to assess individuals with acquired brain injury and to develop comprehensive management plans. Appropriate patients for referral are those with an established diagnosis of an acquired brain injury who have, or are expected to develop, chronic disability needing a long-term, multi-disciplinary, community-based rehabilitation program.

I. Inclusion Criteria: Most of the patients meeting these criteria will have one of the following neurological disorders:

- Traumatic brain injury.
- Hypoxic brain injury.
- Brain infarction due to meningeal or encephalitis.
- Stroke due to aneurysmal subarachnoid haemorrhage.
- Intracerebral haemorrhage.
- Young people with ischemic stroke (Rehabilitation services for older stroke victims are provided by care of the elderly consultant-led teams. These, however, do not have neuropsychological support and the NWBIS may be consulted for neuropsychological assessment of these patients in selected cases).

II. Exclusion Criteria: The Service is not currently configured to provide care for patients with:

- Recent mild head injury and post-concussion syndrome of less than 6 months duration.
- Progressive degenerative or other deforming illness.
- Congenital or developmental neurological or psychiatric disorders.
- Brain disorders attributable to toxic effects of alcohol or
Neuropsychiatric complications of primary epilepsy.

The Service does not function as a "memory clinic" for the diagnosis of patients with memory or other cognitive complaints of unknown etiology.

III. Referral Screening

Referrals are accepted from medical practitioners and screened on a weekly basis by clinicians under the guidance of a consultant neuropsychologist. When information in the referring letter does not document the presence of a chronic acquired brain injury, or detail the severity of the injury necessitating long-term, multi-disciplinary rehabilitation, the referring doctor is contacted and asked to provide further information and the neuropsychologist obtains relevant medical records and scans. These are reviewed to document:

A) Aetiology:
- Is there an established diagnosis of an acquired brain injury due to one of the disorders listed in I above.
- Is there an established diagnosis of one of the disorders listed as exclusion criteria in II above.

B) Severity:
To determine whether the need for chronic, multi-disciplinary rehabilitation has been established, records are examined to define the current degree of disability and to document whether the precipitating injury is classified as moderate - severe. For cases of traumatic brain injury, the records are reviewed to determine the chronicity of the disability as well as the severity of the precipitating injury based on the following criteria:
- History of the injury
- Glasgow coma scale (< 13)
- Duration of retrograde and post-traumatic amnesia
- CT or MRI evidence of intracranial pathology

Assessment

Acceptance of a referral is followed by an initial generic clinical assessment. The initial assessment covers in depth the presenting complaints, details of the injury, developmental and medical history, clinical bedside cognitive screening and a collateral interview with a carer. Where possible, initial outcome data are collected.

Often more professional specific assessments, for example psychometric, neurological, social work or occupational therapy assessments follow. At a weekly referral and case review meeting the treatment plan for an individual patient is formulated and the assessment or intervention of other clinicians within the Service requested. This is a dynamic process and recently care pathways were developed for the Service. These pathways describe the flow of patient care from the acute to the post-acute community phase.

Rehabilitation Interventions

Patients can access any combination of the following individual interventions, based on their needs as identified during the initial assessment:
- Psychotherapy, for both patients and carers, often
- Speech and language therapy, sometimes including communication aids
- Occupational therapy, including vocational rehabilitation as well as functional adaptations
- Physiotherapy, including rehabilitation for balance problems and motor disabilities
- Neurology follow up and review, provision of medical information
- Social work, including advocacy, assistance with benefits and discharge liaison
- Anxiety and anger management interventions
- Clinical neuropsychology, including compensatory strategies for cognitive difficulties

The following group based interventions are provided for patients and carers:
- A memory & concentration group focussing on compensatory strategies
- A weekly drop-in carer support group
- An occupational therapy group for daily living skills
- A discussion & current affairs group

Patients are reviewed regularly by clinicians involved in their care. A specific strength of the program is the provision of neurology reviews. Discussion of assessment results, review findings and therapeutic plans with patients and carers is core aspect of the program. This potentially assists with increasing the self-awareness of patients. Carers are closely involved in interventions and often attend consultations. In addition feedback is obtained from carers on some of the outcome measures.

Outcome Measures

Outcome measures have an essential role in the process of developing and refining rehabilitation programs. The NWBIIS collects the following outcome data: Standardized questionnaires, employment information, and placement data. These are described in more detail below.

The European Brain Injury Questionnaire (EBIQ) (Teasdale, Christensen, Wilmes et al, 1997) is a questionnaire consisting of 63 items related to common difficulties experienced by individuals following brain injury. Items are rated on a three-point scale (0 = 'not at all', 1 = 'a little' and 3 = 'a lot'), regarding the preceding month. The patient and a carer or family member complete the two parallel forms independently. The questionnaire has acceptable reliability and validity (Teasdale, Christensen, Wilmes et al, 1997).

Employment outcomes are rated as follows: 1 = change from employed to unemployed; 2 = change from employed to part-time employment; 3 = no change (including unemployed to unemployed as well as employed to employed at same level); 4 = change from part-time employment to full-time employment and 5 = change from unemployed to full-time employment.

Residential outcome is determined by using the final placement rating score on Eames' (1999) Graton Manor Study Hierarchy of Placements (OMSP). The OMSP is a scale used for rating change in placement status following brain injury. Only
the final placement rating is used by the Service, in view of the rural nature of the area where the service users live (with no inpatient brain injury rehabilitation services available and hence little opportunity to obtain a realistic change score).

It is envisaged that in the future more use would also be made by the service of other outcome measures, for example the Brain Injury Community Rehabilitation Outcome (BICRO) scale (Powell, Reckers & Greenwood, 1998).

Outcomes: Preliminary Results

A recent review of all clinical records in the Service revealed an initial cohort of 24 patients for whom baseline and repeated outcome data of the European Brain Injury Questionnaire (EBIQ) were available. Of the 24 patients included in this review, 16 (66.7%) were male and 8 (33.3%) were female. The average age of the participants was 39.3 years (SD = 12.8, range = 20 - 63). The severity of brain injury was classified as follows for the present sample: mild = 2 (8.3%), moderate = 3 (12.5%) and severe = 19 (79.2%). Individuals were rated as having sustained a severe injury (GCS 8 or lower or LOC more than 24 hours); moderate injury (GCS 9 - 12 or LOC between 30 minutes and 24 hours) or a mild injury (GCS 13 - 15 or LOC less than 30 minutes) (Guilmette, 1997). The two individuals’ classified initially as having sustained mild injuries had problems extending well beyond six months post injury. The average time since injury was 67.9 months (SD = 83.4, range = 3 - 324). Of the 24 patients, 21 (87.5%) sustained a traumatic brain injury and 3 (12.5%) sustained a cerebro-vascular accident. All patients received individualized, multidisciplinary community based rehabilitation.

The average time between administering the first and second EBIQ, respectively, was 10.1 months (SD = 3.8). A Wilcoxon comparison revealed a significant improvement in the subjective self-report of symptoms among participants (T = 53; p = 0.056), whose mean total EBIQ scores were reduced from 127.9 to 114.5. However, while caregivers’ EBIQ ratings decreased from a mean score of 124.3 to 119.4, this did not reach statistical significance (T = 83; p = 0.115).

The average time since injury was 67.9 months. In most cases it was unlikely that the improvements reflected on EBIQ scores were attributable to spontaneous recovery, which often continues to be observed over the first two years following injury. However, as seven patients completed their first EBIQ within two years post injury, we also compared patients’ ratings with this sub-group of recently injured patients excluded. The repeated EBIQ ratings for this group (N = 17) also showed a significant decrease in mean EBIQ scores (T = 26; p = 0.016).

Discussion

Post acute brain injury rehabilitation poses significant challenges to clinicians and probably more so in a rural area with limited access to resources. This paper describes the development and functioning of a community based holistic rehabilitation program for brain injured adults. Preliminary outcomes were also reported. Long term observational studies have an important place in the evaluation of benefits of treatment in lifelong conditions (Elphic, Tan, Ashby & Smyth, 2002).

The preliminary results reported in this paper were encouraging, with 71% of service users having rated themselves as improved. However, these results do not assess the significance of improvements to the same degree. It was thought that this might be a reflection of need to provide more information and support to carers. As a result, a monthly drop-in carer support group was started.

Achieving measurable real world outcomes remains a challenge. Reemployment appears to be difficult to achieve in this rural area, for various reasons, including a shortage of potential employers (Coetzee, Hayes & du Toit, 2002). In addition, some outcomes are currently not given in the Service area and too many clinicians are not well served. Goal setting with patients and carers may serve to make the process of outcome measurement more patient-centered.

Future research assessing the effectiveness of community rehabilitation programs should focus on ecologically valid outcomes, for example placement and change in employment status. These data are collected by this Service and will be used in the future studies to report on the effectiveness of the program.

A strength of the NWBIS rehabilitation program is the individualized nature of treatments. However a stronger focus on group intervention is being considered to strengthen the program. An information and support group is being planned. It is envisaged that this group intervention will foster patient engagement in the therapeutic process and improve patient allocation to specialized groups. These specialized groups may potentially include additional cognitive remediation groups, psychotherapy, and groups for vocational skills and activities for daily living.

This program description did not specifically address the needs of children with a brain injury. Brain injury services for children have traditionally not been as well developed as those for adults (Appleton & Baldwin, 1998). Neurological and life stage developmental issues have a significant influence on children and consequently on rehabilitation needs and services.

The NWBIS has recently initiated a pediatric service to address the rehabilitation needs of children. The current focus is on the development of professional links across North Wales and on the development of a clinical service. This clinical service is currently aimed at providing multi-disciplinary assessment and consultation with other community professionals, family information and support, and direct psychological and occupational therapy interventions.

Integrating biological, psychological, vocational and social elements of rehabilitation within a community based holistic neuroscience rehabilitation program can potentially achieve positive outcomes for brain injured individuals. The individualized nature of the multi-disciplinary interventions for patients of the NWBIS is one of the most important strengths of the program. Providing these interventions within the community where individuals live, enhances the opportunity for generalization of therapeutic gains.

REFERENCES


Spring 2003 - The Journal of Cognitive Rehabilitation


Spring 2003 - The Journal of Cognitive Rehabilitation
## Appendix 3

Summary of Studies Exploring Lived Experiences of Participants

<table>
<thead>
<tr>
<th>Study</th>
<th>Date</th>
<th>Diagnostic criteria</th>
<th>Phenomena explored</th>
<th>Location</th>
<th>Quantitative</th>
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<th>Time taken to collect data</th>
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<td>Darragh, Sample &amp; Krieger</td>
<td>2001</td>
<td>Brain Injury</td>
<td>Practitioner qualities &amp; traits</td>
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<td>Swaine, Dutil, Demers &amp; Gervais</td>
<td>2003</td>
<td>Head Injury</td>
<td>Quality of head injury rehabilitation services</td>
<td>Canada</td>
<td>🍀 undefined questionnaire</td>
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<td>Meaning ascribed to RTW following TBI</td>
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<td>🍀 semi structured interview</td>
<td>🍀</td>
<td>🍀</td>
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<td>Horneman, Folkesson, Sintonen, von Wendt &amp; Emanuelson</td>
<td>2005</td>
<td>TBI</td>
<td>Quality of Life</td>
<td>Sweden</td>
<td>🍀 15 point standardised questionnaire</td>
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<td>🍀</td>
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<td>Petrella, McColl, Krupa &amp; Johnston</td>
<td>2005</td>
<td>TBI</td>
<td>Returning to productive activities</td>
<td>Canada</td>
<td>🍀 semi structured interviews</td>
<td>🍀</td>
<td>🍀</td>
<td>Mean time 58 mns per interview</td>
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<td>Chamberlain</td>
<td>2006</td>
<td>TBI</td>
<td>Surviving TBI</td>
<td>Australia</td>
<td>🍀 unstructured in-depth interviews</td>
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<td>40-60 mns</td>
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<td>Guidetti, Asaba &amp; Tham</td>
<td>2007</td>
<td>CVA &amp; SCI</td>
<td>Recapturing self-care</td>
<td>Sweden</td>
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<td>Newton, Larkin, Mehuish &amp; Wykes</td>
<td>2007</td>
<td>Auditory Hallucinations</td>
<td>Group Cognitive Behavioural Therapy</td>
<td>United Kingdom</td>
<td>🍀 in-depth semi structured interviews</td>
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Appendix 4

Interview schedule of potential flexible topics to cover

Research Question

What is the lived experience of specialist return to work rehabilitation for individuals who aimed to return to work following traumatic brain injury?

Further subsections of this question include:

- How participants feel their prospects in the employment market have changed following their TBI.
- How they learned about the changes.
- What it felt like to learn about the changes.
- How they feel clinical rehabilitation assisted (or not) in any of the above.
- How they have coped with the process of learning about the changes.

An opening question will be utilized to participants relax and narrate their experience.

I would like to hear about your feelings regarding the return to work rehabilitation you engaged in with .......... (Clinician’s name/s). Could you tell me a bit about what happened?

It is envisaged that this question is sufficiently broad and non-intrusive to enable the participant to share what their immediate memories are. The response will be explored with questions arising from their answers.

Further Key questions will include:

- Can you tell me bit about what you are doing now with regards to working/training?
- Is this situation different to before you sustained your injury – In what way?
- If there are differences to before the injury, how did you become aware that this would have to happen?
- If there are no differences, why do you think that is so?
- Were there any parts of your rehabilitation that influenced your return to work?
- Does your current work situation affect other aspects of your life in any way?
Following the initial response, I as the researcher, will phrase subsequent questions in language that reflects the participant’s language. Using their language will enable me to understand the participant’s meaning which are distinct from prior knowledge gained from the literature or experience.

Follow on prompts will be used to guide the interview and ensure data collection to answer the question. These will take the form of: ‘What do you mean?’ or ‘Can you explain in more detail’
Appendix 5  (English Version)

Consent Verification Form For Participants
Version 2, 21st May 2008

Study: To understand the experience of returning
to work (through rehabilitation) following
traumatic brain injury

(The patient should complete the whole of this sheet him/herself)

Participant Identification Number: ______________

(Please cross out as necessary)

- Have you read the Patient Information Sheet? YES/NO
- Do you understand that this research is being undertaken by
  Marian Hooson as part of her requirements to complete
  her Professional Doctorate? YES/NO
- Do you understand that this interview will be recorded only
  for the purpose of this study and once the information has
  been gathered, then the audio tapes will be destroyed? YES/NO
- Do you understand that all the information, including
  your identity, will be kept confidential? YES/NO
• Do you understand that you will not be financially reimbursed for your participation?
  YES/NO
  Your participation is greatly appreciated and should enhance the delivery of future clinical rehabilitation assisting individuals who have sustained traumatic brain injury to return to work.

• Do you understand that you are free to withdraw from this study:
  At any time
  Without giving a reason
  And without affecting your future medical/psychological care
  YES/NO

• Do you meet the following criteria to participate within this study:
  21 years of age or older?
  YES/NO
  Have sustained Traumatic Brain Injury?
  YES/NO
  Held a work position prior to injury that served as your primary income?
    YES/NO

• Do you understand the purpose of this study
  YES/NO

• Do you agree to volunteer for participation within the study and accurately communicate your feelings regarding the clinical rehabilitation you received to assist you to return to work?
  YES/NO

• Have you had the opportunity to ask questions and discuss this study?
  YES/NO
• Have you received satisfactory answers to all your questions?
  YES/NO

• Have you received enough information about the study?
  YES/NO

I state that the above information has been discussed with me prior to the interview, and that the recorded responses are accurate. I consent to participating in the research.

Name (in block letters) ____________________________________________

Signature of participant: __________________________________________ Date:

Name of witness: ______________________

Signature: ______________________ Date:
Appendix 5  (Welsh Version)

Ffurflen Ddilysu Cydsyniad i Gyfranogwyr
Fersiwn 2, 21 Mai 2008

Astudiaeth: Deall y profiad o ddychwelyd
i’r gwaith (drwy adsefydliad) yn dilyn
anaf trawmatig i’r ymennydd.

(dylai’r claf gwblhau’r daflen hon i gyd ei hun)

Rhif Adnabod y Cyfranogwr: ________________

(Croeswch allan fel bo angen)

- Ydych chi wedi darllen y Daflen Wybodaeth i Gleifion?  DO/NADDO
- Ydych chi’n deall fod yr ymchwil hwn yn cael ei wneud gan
  Marian Hooson fel rhan hanfodol i gwblhau
  ei doethuriaeth broffesiynol?  YDW/NAC YDW
- Ydych chi’n deall bydd y cyfweliad yn cael ei recordio ar gyfer
  Pwrpas yr astudiaeth a phan fydd y wybodaeth wedi’i
  Chasglu, bydd y tapiau sain yn cael eu dinistrio?  YDW/NAC YDW
- Ydych chi’n deall bydd yr holl wybodaeth, gan gynnwys
  manylion eich enw’n cael eu cadw’n gyfrinachol?  YDW/NAC
  YDW
• Ydych chi’n deall na fyddwch yn derbyn Ad-daliad ariannol am gymryd rhan? YDW/NAC

YDW

Gwerthfawrogwn eich cyfranogiad a dylai Wella darpariaeth adsefydlu clinigol yn y dyfodol Drwy gynorthwyo unigolion sydd wedi derbyn anaf trawmatig i’r ymennydd ddychwelyd i’r gwaith.

• Ydych chi’n deall eich bod â’r hawl i dynnu allan o’r astudiaeth hon:
  Unrhyw amser Heb roi rheswm A heb effeithio ar eich gofal meddygol/seicoleg yn y dyfodol YDW/NAC YDW

• Ydych chi’n cwrrdd â’r meini prawf canlynol i gymryd rhan yn yr astudiaeth:
  21 oed neu hŷn? YDW/NAC

YDW

Wedi dioddef anaf trawmatig i’r ymennydd? YDW/NAC

YDW

Yn meddu ar swydd o waith cyn eich anaf a oedd yn ffynhonell incwm sylfaenol? OEDDWN/NAC OEDDWN

• Ydych chi’n deall pwrpas yr astudiaeth hon YDW/NAC

YDW

• Ydych chin cytuno gwirfoddoli i gymryd rhan yn yr astudiaeth a chyfathrebu eich teimladau'n gywir O ran yr adsefydlu clinigol rydych wedi'i dderbyn i’ch cynorthwyo i ddychwelyd i’r gwaith YDW/NAC

YDW

• Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth? YDW/NAC

YDW
• Ydych chi wedi derbyn atebion bodhhaol i’ch holl gwestiynau? YDW/NAC
  YDW

• Ydych chi wedi derbyn digon o wybodaeth am yr astudiaeth? YDW/NAC
  YDW

Rwy’n datgan fod y wybodaeth uchod wedi’i thrafod gyda mi gyn y cyfweliad ac mae’r
ymatebion a nodwyd yn gywir. Rwy’n cydsynio i gymryd rhan yn yr ymchwil.

Enw (llythrennau bras) ________________________________

Llofnod y cyranogwr: ________________________________  Dyddiad __________

Enw’r tyst: _____________________________

Llofnod: ____________________________  Dyddiad __________
Appendix 6  (English Version)

Awareness Questionnaire

Patient Form

Name: ___________________________ Patient No: __________

Date: __________________________

1. How good is your ability to live independently now as compared to before your injury?

2. How good is your ability to manage your money now as compared to before your injury?

3. How well do you get along with people now as compared to before your injury?

4. How well can you do on tests that measure thinking and memory skills now as compared to before your injury?

5. How well can you do the things you want to do in life now as compared to before your injury?

6. How well are you able to see now as compared to before your injury?

7. How well can you hear now as compared to before your injury?

8. How well can you move your arms and legs now as compared to before your injury?

9. How good is your coordination now as compared to before your injury?

10. How good are you at keeping up with the time and date and where you are now as compared to before your injury?

11. How well can you concentrate now as compared to before your injury?

12. How well can you express your thoughts to others now as compared to before your injury?

13. How good is your memory for recent events now as compared to before your injury?
1. Much
2. a little
3. about
4. a little
5. much
Worse
worse
the same
better
better

14. How good are you at planning things now as compared to before your injury?

15. How well organized are you now as compared to before your injury?

16. How well can you keep your feelings in control now as compared to before your injury?

17. How well adjusted emotionally are you now as compared to before your injury?
Appendix 6  (Welsh Version)

Holiadur Ymwybyddiaeth
Ffurflen Claf

Enw:________________________________ Rhif Claf:____________

Dyddiad:________________________

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___ 1. Pa mor dda yw eich gallu i fyw’n annibynnol o'i gymharu â chyn eich anaf?

___ 2. Pha mor dda yw eich gallu i reoli eich arian o’i gymharu â chyn eich anaf?

___ 3. Pha mor dda rydych yn dod ymlaen â phobl o'i gymharu â chyn eich anaf?

___ 4. Pha mor dda allwch chi wneud profion sy'n mesur sgiliau meddwl a chof Nawr o'i gymharu â chyn eich anaf?

___ 5. Pa mor dda allwch chi wneud pethau bob dydd o'i gymharu â chyn eich anaf?

___ 6. Pa mor dda allwch chi weld o’i gymharu â chyn eich anaf?

___ 7. Pa mor dda allwch chi glywed o’i gymharu â chyn eich anaf?

___ 8. Pa mor dda allwch chi glywed o’i gymharu â chyn eich anaf?

___ 9. Pa mor dda yw eich cydsymudiad nawr o’i gymharu â chyn eich anaf?

___ 10. Pa mor dda ydych chi am gadw i fynw ag amser a’r dyddiad a lle rydych chi nawr o’i gymharu â chyn eich anaf?

___ 11. Pa mor dda allwch chi ganolbwytio o’i gymharu â chyn eich anaf?

___ 12. Pa mor dda allwch chi fynegi eich meddwl i eraill nawr o gymharu â chyn eich anaf?

___ 13. Pa mor dda yw eich cof o ddigwyddiadau diweddar nawr o’i gymharu â chyn eich anaf?
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14. Pa mor dda ydych chi am gynllunio pethau nawr o'i gymharu â chyn eich anaf?

15. Pa mor drefnus ydych chi o'i gymharu â chyn eich anafiad?

16. Pa mor dda allwch chi reoli eich teimladau nawr o’u cymharu â chyn eich anaf?

17. Sut mae eich emosiynau nawr o’u cymharu â chyn eich anaf?
Appendix 7  (English Version)

Awareness Questionnaire
Family/Significant Other Form

Name: ___________________________ Relationship to patient: ____________________

Patient No: _________________________ Date: ________________

1. Much 2. 3. 4. 5. Much
Worse a little about a little much

Worse worse the same better better

1. How good is the patient's ability to live independently now as compared to before his/her injury?

2. How good is the patient's ability to manage his/her money now as compared to before his/her injury?

3. How well does the patient get along with people now as compared to before his/her injury?

4. How well can the patient do on tests that measure thinking and memory skills now as compared to before his/her injury?

5. How well can the patient do the things he/she wants to do in life now as compared to before his/her injury?

6. How well is the patient able to see now as compared to before his/her injury?

7. How well can the patient hear now as compared to before his/her injury?

8. How well can the patient move his/her arms and legs now as compared to before his/her injury?

9. How good is the patient's coordination now as compared to before his/her injury?

10. How good is the patient at keeping up with the time and date and where he/she is now as compared to before his/her injury?

11. How well can the patient concentrate now as compared to before his/her injury?
12. How well can the patient express his/her thoughts to others now as compared to before his/her injury?

13. How good is the patient’s memory for recent events now as compared to before his/her injury?

14. How good is the patient at planning things now as compared to before his/her injury?

15. How well organized is the patient now as compared to before his/her injury?

16. How well can the patient keep his/her feelings in control now as compared to before his/her injury?

17. How well adjusted emotionally is the patient now as compared to before his/her injury?
Appendix 7  (Welsh Version)

Holiadur Ymwybyddiaeth
Ffurflen Teulu/Rhywun o Bwys

Enw:_____________________________ Cysylltiad â’r claf:__________________

Rhif Claf:___________________________ Dyddiad:_____________

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___ 2. Pa mor dda yw gallu’r claf i reoli ei (h)arian o'i gymharu â chyn ei (h)anaf?

___ 3. Pha mor dda mae’r claf yn dod ymlaen â phobl o'i gymharu â chyn chyn ei (h)anaf?

___ 4. Pha mor dda gall y claf wneud profion sy'n mesur sgiliau meddwl a chof o'i gymharu â chyn ei (h)anaf?

___ 5. Pa mor dda all y claf wneud y pethau bob dydd mae o/hi am eu gwneud o’i gymharu â chyn ei (h)anaf?

___ 6. Pa mor dda mae’r claf yn dod ymlaen â phobl o'i gymharu â chyn ei (h)anaf?

___ 7. Pa mor dda all y claf glywed o’i gymharu â chyn ei (h)anaf?

___ 8. Pa mor dda all y claf symud ei freichiau a choesau o'i gymharu â chyn ei (h)anaf?

___ 9. Pa mor dda yw cydgysylltiad y claf nawr o’i gymharu â chyn ei (h)anaf?

___ 10. Pa mor dda yw’r claf am gadw i fyny ag amser a’r dyddiad a lle mae nawr o’i gymharu â chyn ei (h)anaf?

___ 11. Pa mor dda all y claf ganolbwyntio nawr o’i gymharu â chyn ei anaf?
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12. Pa mor dda all y claf fynegi ei b/farn i eraill nawr o’i gymharu â chyn ei (h)anaf?

13. Pa mor dda yw cof y claf o ddigwyddiadau diweddar nawr o’i gymharu â chyn ei (h)anaf?

14. Pa mor dda yw’r claf am gynllunio pethau nawr o'i gymharu â chyn ei (h)anaf?

15. Pa mor drefnus yw’r claf nawr o’i gymharu â chyn ei (h)anaf?

16. Pa mor dda mae’r claf yn gallu cadw ei th/deimladau dan reolaeth nawr o’i gymharu â chyn ei (h)anaf?

17. Sut mae emosiynau’r claf nawr o’u cymharu â chyn ei (h)anaf?
Appendix 8  (English Version)

Awareness Questionnaire
Clinician Form

Clinician Name: ___________________________ Date: _____________

Patient No: ________________________________

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<td>much</td>
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<td>Worse</td>
<td>worse</td>
<td>the same</td>
<td>better</td>
<td>better</td>
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</tbody>
</table>

1. How good is the patient's ability to live independently now as compared to before his/her injury?

2. How good is the patient's ability to manage his/her money now as compared to before his/her injury?

3. How well does the patient get along with people now as compared to before his/her injury?

4. How well can the patient do on tests that measure thinking and memory skills now as compared to before his/her injury?

5. How well can the patient do the things he/she wants to do in life now as compared to before his/her injury?

6. How well is the patient able to see now as compared to before his/her injury?

7. How well can the patient hear now as compared to before his/her injury?

8. How well can the patient move his/her arms and legs now as compared to before his/her injury?

9. How good is the patient's coordination now as compared to before his/her injury?

10. How good is the patient at keeping up with the time and date and where he/she is now as compared to before his/her injury?
1. How well can the patient concentrate now as compared to before his/her injury?

2. How well can the patient express his/her thoughts to others now as compared to before his/her injury?

3. How good is the patient's memory for recent events now as compared to before his/her injury?

4. How good is the patient at planning things now as compared to before his/her injury?

5. How well organized is the patient now as compared to before his/her injury?

6. How well can the patient keep his/her feelings in control now as compared to before his/her injury?

7. How well adjusted emotionally is the patient now as compared to before his/her injury?

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<tr>
<td></td>
<td>completely</td>
<td>severely</td>
<td>moderately</td>
<td>minimally</td>
<td>not at all</td>
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</tbody>
</table>

8. To what extent is the patient's accurate self-awareness impaired by his/her brain injury?
**Appendix 8  (Welsh Version)**

**Holiadur Ymwybyddiaeth**  
**Ffurflen y Clinigydd**

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<td>Llawer</td>
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</tbody>
</table>

1. Pa mor dda yw gallu'r claf i fwy'n annibynnol o'i gymharu â chyn ei (h)anaf?

2. Pa mor dda yw gallu'r claf i reoli ei (h)arian o'i gymharu â chyn ei (h)anaf?

3. Pha mor dda mae'r claf yn dod ymlaen â phobl o'i gymharu â chyn ei anaf?

4. Pha mor dda gall y claf wneud profion sy'n mesur sgiliau meddwl a chof gymharu â chyn ei (h)anaf?

5. Pa mor dda all y claf wneud y pethau bob dydd mae o/hi am eu gwneud o'u gymharu â chyn ei (h)anaf?

6. Pa mor dda mae'r claf yn gallu gweld nawr o'i gymharu â c(h)yn ei (h)anaf?

7. Pa mor dda all y claf glywed o'i gymharu â chyn ei (h)anaf?

8. Pa mor dda all y claf symud ei freichiau a choesau o'i gymharu â chyn ei (h)anaf?

9. Pa mor dda yw cydgyssylltiad y claf nawr o'i gymharu â chyn ei (h)anaf?

10. Pa mor dda yw'r claf am gadw i fyny ag amser a'r dyddiad a lle mae nawr o'i gymharu â chyn ei (h)anaf?
11. Pa mor dda all y claf ganolbwyntio nawr o'i gymharu â chyn ei (h)anaf?

12. Pa mor dda all y claf fynegi ei farn i eraill nawr o'i gymharu â chyn ei (h)anaf?

13. Pa mor dda yw cof y claf o ddigwyddiadau diweddar nawr o'i gymharu â chyn ei (h)anaf?

14. Pa mor dda yw'r claf am gynllunio pethau nawr o'i gymharu â chyn ei (h)anaf?

15. Pa mor drefnus yw'r claf nawr o'i gymharu â c(h)yn ei (h)anaf?

16. Pa mor dda mae'r claf yn gallu cadw ei th/deimladau dan reolaeth nawr o'i gymharu â chyn ei (h)anaf?

17. Sut mae emosiynau'r claf nawr o'u cymharu â chyn ei (h)anaf?

18. I ba raddau mae hunanymwybyddiaeth gywir y claf wedi’i amharu gan ei (h)anaf i’r ymennydd.
Letter of Invitation to Participate in Research
Version 2.0, 21st May 2008

North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road, Colwyn Bay
CONWY LL29 8AY

Dear ,
I am currently studying for the award of Professional Doctorate in Occupational Therapy in the field of traumatic brain injury. This is in conjunction with the University of Brighton. Part of attaining the award involves completing a study in my area of clinical practice.

I wish to explore the feelings held by individuals who have sustained traumatic brain injury of the specialist rehabilitation they received to assist them in their venture to return to work. This will involve participating in a semi-structured interview with me which will be audio taped.

I enclose a Participation Information Sheet with this letter. I would like to ask that you read the contents carefully. If you decide you would like to be considered for my study, you and a ‘significant other’ in your life need to complete an Awareness Questionnaire. This is enclosed with the Participation Information Sheet. This will help me to decide whether you fall within my inclusion criterion for the study. This questionnaire is similar to ones you have previously completed with your psychologist. I shall write to you to let you know if you will be included in my study.

You do not have to take part in this study. If you decide not to, there will be no difference in the rehabilitation opportunities offered to you from clinicians based at the North Wales Brain Injury Service.
Please complete and tear off the strip below to indicate whether or not you wish to be considered for this study. Many thanks for taking the time to read the enclosed.

Regards,

Marian Hooson, Clinical Specialist Occupational Therapist

I do/do not wish to be considered for this research.

Name:

Address:
Appendix 9  (Welsh Version)

Llythyr o Wahoddiad i Gymryd Rhan mewn Ymchwil
Fersiwn 2.0, 21 Mai 2008

Gwasanaeth Anaf i’r Ymennydd, Gogledd Cymru
Ysbyty Cymuned Bae Colwyn
Ffordd Hesketh, Bae Colwyn
CONWY LL29 8AY

Anwyl,
Rwyf ar hyn o bryd yn astudio am Ddoethuriaeth Broffesiynol mewn Therapi Galwedigaethol yn maes anaf trawmatig i’r ymennydd. Mae hwn ar y cyd â Phrifysgol Brighton. Mae rhan o ennill y cymhwyster hwn yn cynnwys cwblhau astudiaeth yn fy maes arfer clinigol.

Dymunaf ymchwilio i deimladau unigolion sydd wedi derbyn anaf trawmatig i’r ymennydd o’r adsefydliad arbenigol a dderbyniwyd ganddynt i’w cynorthwyo i fentro yn ôl i’r gwaith. Bydd hyn yn cynnwys cymryd rhan mewn cyfweliad lled-strwythdedig gyda mi a fydd yn cael ei recordio.

Amgaeaf Daflen Wybodaeth Cymryd Rhan gyda’r llythyr hwn. Gofynnaf i chi ddarllen ei gynnwys yn ofalus. Os byddwch yn penderfynu yr hoffech gael eich ystyried ar gyfer astudiaeth, dylech chi a ‘rhywun o bwys yn eich bywyd’ gwblhau Holiadur Ymwybyddiaeth. Amgaeir hwn gyda’r Daflen Wybodaeth Cymryd Rhan. Bydd hwn yn fy helpu i benderfynu a ydych yn ffitio i’r holl ychydig yr astudiaeth. Mae’r holiadur hwn yn debyg i’r holl y gwnaethoch gwblhau gyda’ch seicolegydd. Byddaf yn ysgrifennu atoch i roi gwybod a ydych wedi’ch cynnwys yn fy astudiaeth.
Nid oes raid i chi gymryd rhan yn yr astudiaeth hon. Os byddwch yn penderfynu peidio cymryd rhan, ni fydd yn gwneud unrhyw wahaniaeth i'r cyfleoedd a gynigir i chi i adsefydli gan glinigwyr a leolir gyda'r Gwasanaeth Anaf i'r Ymennydd Gogledd Cymru.

Cwblhewch a thorrwch y bonyn isod i nodi a hoffech gael eich ystyried ar gyfer yr astudiaeth hon. Diolch yn fawr i chi am eich amser i ddarllen yr amgaeedig.
Yn gywir

Marian Hooson, Therapydd Galwedigaethol Clinigol Arbenigol.

Hoffwn/ni hoffwn gael fy ystyried ar gyfer yr ymchwil hwn.

Enw:

Cyfeiriad:
Appendix 10  English Version

Participant Information Sheet
Version 2, June 2008

Title:  A qualitative investigation of the individual’s
        Lived experience of returning to work
        Following traumatic brain injury

Study: To understand the experience of returning
        to work (through rehabilitation) following
        traumatic brain injury

I am currently studying for the award of Professional Doctorate in Occupational Therapy in the field of traumatic brain injury. This is in conjunction with the University of Brighton. Part of attaining the award involves completing a study in my area of clinical practice. You are being invited to take part in this study. Before you decide it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of this study?
This research aims to find out the value of return to work (RTW) rehabilitation for individuals who have sustained traumatic brain injury (TBI). There are many discrepancies in the reported success of such rehabilitation with this patient group. The success rate varies from 10%-77%. There is no information from the individuals’ perspective as to how useful they find the rehabilitation programmes they engage in. I want to find out how you felt about the rehabilitation you received. I hope that this will inform my practice regarding whether any changes need to be made to future
clinical rehabilitation to improve the success rate for individuals. In order to do this you need to participate in an interview with me which will be audio taped.

**Why have I been chosen?**
You have been asked to take part because you have had a traumatic brain injury (for example as a result of being in a car crash or being attacked) and are currently registered as a patient with the North Wales Brain Injury Service. You have also attempted to return to your previous employment. I shall be asking about 10 other people to take part who are similar in circumstances to you.

**Do I have to take part?**
It is up to you to decide whether or not you wish to take part. If you do take part you will be given this Information Sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive from the North Wales Brain Injury Service now or in the future.

**What will happen to me if I take part?**
If you agree to take part you will be invited to the Brain Injury Service for up to two one-to-one appointments with the researcher. This would be similar to appointments you have at the Brain Injury Service. During these appointments you will be asked again to consent to take part. Then you will have a discussion with me, as the researcher, about your experience of return to work rehabilitation. This discussion will be audio taped. You will be shown how the audio tape equipment works before we start the discussion. If you want to switch the equipment off at any time during our discussion you will be free to do so. I, as the researcher will also be taking notes. The interview will take no longer than 1 ¼ hours.

You will be asked to take regular breaks during the discussion so that you can have refreshments, toilet break, and cigarette break if required. This break time is incorporated into the 1 ¼ hours of the discussion. This should minimise the risk of over fatiguing. Should the interview run over the scheduled time for any reason, I, as the researcher will endeavour to re-arrange to meet with you to continue our discussion at another time.
What do I have to do?
You will be asked to visit the Brain Injury Service. If this is inconvenient for you we will try to schedule the appointment nearer to your home.

What is the procedure being explored?
The procedure being tested is return to work rehabilitation. It consists of the following steps:
1. Interviewing you for your perceptions of rehabilitation you have received.
2. Possible further appointment exploring any emerging themes in greater depth.
3. Giving you the opportunity to discuss the findings and ask questions.

What is the alternative?
The alternative is to continue with the standard treatment you already receive at the Brain Injury Service. Your current treatment will not be affected in any way by agreeing or not agreeing to take part in this research.

What are the side effects of taking part?
The research should not cause any side effects or discomfort.

What are the possible disadvantages of taking part?
Occasionally people may become upset and feel low when they have to talk about their brain injury and how it affects them and their attempts to return to work. If this happens you will be given the opportunity to talk this through with one of the clinicians at the Brain Injury Service. Counselling will also be available through the Service. You continue to have access to clinicians at the North Wales Brain injury Service and can ask to be referred for an appointment with a psychologist to talk through any issues at any time. You can do this either by telephoning the Service on 01492 807521 and asking for an appointment to be booked for you, or you may ask a clinician who remains involved with you to arrange an appointment on your behalf. If you are aware that you may need an appointment with a psychologist during the course of the discussion, you may also ask me, as the researcher, to arrange an appointment for you.
What are the possible benefits of taking part?
You may benefit from this research by gaining a better understanding of your brain injury and how it has impacted on your ability to return to your previous employment. Previous research has shown that rehabilitation works better when a person understands, and is able to share with others, the nature and the consequences of their brain injury.

What if something goes wrong?
If you were to agree to take part in this research and subsequently have any concerns about any aspect of the research, you can approach me, as the researcher directly to discuss these. The names of persons to direct complaints to are also provided at the end of this leaflet. The usual NHS complaints procedures are also available to all research participants.

Will my taking part in this study be kept confidential?
All information that is collected about you during the course of the research will be kept strictly confidential. The transcribing of the audio tapes will be undertaken by administration staff experienced in this practice and employed by the Conwy & Denbighshire NHS Trust. They are bound by their professional codes of confidentiality. The computer equipment used by them for transcription will be the property of the Conwy & Denbighshire NHS Trust, and be encrypted. Once transcribed, all further data relating to this study will be stored on a computer that is the property of the Conwy & Denbighshire NHS Trust that has been encrypted by the Information Governance Manager at Conwy & Denbighshire NHS Trust.

Any information about you that leaves the Brain Injury Service will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?
This study is being organised me, Marian Hooson as part of my degree, Professional Doctorate in Occupational Therapy at the University of Brighton. Conwy & Denbighshire NHS Trust Research & Development Department will meet additional costs of the research.
What will happen to the results of the study?
The results of this study will tell us whether return to work programmes are generally assistive to individuals who have experienced traumatic brain injury. The result of this study will be written up in my dissertation for my degree. The results may also be included in a published research report. No participants will be identified in the dissertation or the report.

Who has reviewed the study?
The North Wales Central Research Ethics Committee & the University of Brighton School of Health Sciences Ethics Committee have approved the study. Conwy & Denbighshire NHS Trust Research & Development Department have also approved the study.

Contact for further information:
Marian Hooson
North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road
Colwyn Bay
CONWY
Tel: 01492 807521

If you take part in this study you will be given a copy of the Information Sheet and a signed consent form to keep.

In case of complaints concerning the conduct of research, these should be addressed to:
Mrs Lesley Ross
Patient Services, Clinical Support Unit, HM Stanley Hospital, St Asaph LL17 0RS
Or
Dr Graham Stew
University of Brighton

Thank you for reading this and for considering taking parting this study.
Appendix 10 Welsh Version

Taflen Wybodaeth i'r Cyranogwr
Fersiwn 2, Mehefin 2008

Teitl: Ymchwiliad ansoddol i brofiad personol unigolyn wrth ddychwelyd i’r gwaith
Yn dilyn anaf trawmatig i’r ymennydd.

Astudiaeth: Deall y profiad o ddychwelyd
i’r gwaith (drwy adsefydliad) yn dilyn
anaf trawmatig i’r ymennydd.

Rwyf ar hyn o bryd yn astudio am Ddoethuriaeth Broffesiynol mewn Therapi Galwedigaethol ym maes anaf trawmatig i’r ymennydd. Mae hwn ar y cyd à Phrifysgol Brighton. Mae rhan o ennil y cymhwyster hwn yn cynnwys cwblhau astudiaeth yn fy maes arfer clinigol. Fe’ch gwahoddir i gymryd rhan yn yr astudiaeth hon. Cyn i chi benderfynu, mae’n bwysig eich bod yn deall pam y cynhelir yr astudiaeth hon a’r hyn a fydd yn cael ei gynnwys. Rhowch amser i ddarllen y wybodaeth ganlynol yn ofalus a thrafod gyda ffrindiau, teulu a’ch meddyg teulu os byddwch yn dymuno. Os bydd unrhyw beth yn aneglur neu os hoffech wybodaeth bellach, mae croeso i chi ofyn i mi. Rhowch amser i benderfynu a ydych am gymryd rhan neu beidio.

Diolch i chi am ddarllen y daflen wybodaeth hon.

Beth yw pwrpas yr astudiaeth hon?
Nod yr astudiaeth yw darganfod gwerth adsefydliu dychwelyd i’r gwaith (DIG) i unigolion sydd wedi derbyn anaf trawmatig i’r ymennydd (ATY). Mae nifer o anghysondebau mewn llwyddiannau a adroddir am adsefydliu gyda’r grwp cleifion hwn. Mae’r raddfa llwyddiant yn amrywio rhwng 10% - 77% Nid oes unrhyw wybodaeth o safbwynt yr ‘unigolion’ o ran pa mor ddefnyddiol yw’r rhaglenni adsefydliu maen nhw’n cymryd rhan ynddynt. Hoffwn ddarganfod sut rydych chi’n teimlo am yr adsefydliad a gawsoch. Gobeithiaf bydd hyn yn rhol gywodaeth i’m
harferion o ran a oes angen newid pethau yn ymwneud ag adsefydlu clinigol i’r dyfodol i wella cyfraddau llwyddiant i unigolion. Er mwyn gwneud hyn, bydd raid i chi gymryd rhan mewn cyfweliad gyda mi a fydd yn cael ei recordio.

**Pam y dewiswyd fi?**

Gofynnwyd i chi gymryd rhan oherwydd eich bod wedi cael anaf trawmatig i’r ymennydd (er enghraifft, o ganlyniad i fod mewn damwain car neu ymosodwyd arnoch) ac rydych wedi’ch cofrestru ar hyn o bryd gyda Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru. Rydych hefyd wedi rhoi cynnig ar ddychwelyd i’ch swydd blaenorol. Byddaf yn gofyn i oddeutu deg o bobl eraill sydd ag amgylchiadau tebyg i chi gymryd rhan hefyd.

**A oes raid i mi gymryd rhan?**

Eich penderfyniad chi yw a ydych am gymryd rhan neu beidio. Os byddwch yn cymryd rhan, byddwch yn cael y daflen wybodaeth hon i’w chadw a byddwn yn gofyn i chi lofnodi ffurfiau hydysynio. Os byddwch yn penderfynu cymryd rhan, mae’r hawl gennych i dynnu allan unrhyw amser heb roi rheswm. Ni fydd hyn yn effeithio ar safon y gofal byddwch yn ei dderbyn nawr neu i’r dyfodol gan Wasanaeth Anaf i’r Ymennydd Gogledd Cymru.

**Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?**

Os byddwch yn cytuno cymryd rhan, byddwch yn cael eich gwahodd i ddod at y Gwasanaeth Anaf i’r Ymennydd am hyd at ddau apwyntiad un wrth un gyda’r ymchwilwydd. Byddant yn debyg i’r apwyntiadau byddwch yn eu cael gyda’r Gwasanaeth Anaf i’r Ymennydd. Yn ystod yr apwyntiadau, gofynnir i chi eto am eich cydsyniad i gymryd rhan. Yna byddwch yn cael trafofaeth gyda mi, yr ymchwilwydd, am eich profiadau o adsefydlu i ddyrchwelyd i’r gwaith. Bydd y trafofaeth hon yn cael ei recordio. Byddwn yn dangos i chi sut mae’r cyfarpar recordio’n gweithio cyn i ni ddechrau’r trafofaeth. Os byddwn am ddiffodd y cyfarpar unrhyw amser yn ystod y trafofaeth, mae croeso i chi wneud hyn. Byddaf i, fel ymchwilwydd hefyd yn cymryd nodiadau. Ni fydd y cyfweliad yn para mwy 1¼ awr.

Gofynnir i chi gymryd egwylion rheolaidd yn ystod y trafofaethau, er mwyn i chi gael lluniaeth, amser i fynd i’r toiled ac amser i ysmygu os bydd angen. Mae’r amser hwn yn cael ei gynnwys yn y drafodaeth awr a chwarter. Dylai hyn leihau’r risg o orflino.
Os bydd y cyfweliad yn mynd dros amser am unrhyw reswm, byddaf i, yr ymchwilydd yn gwneud fy ngorau i ail-drefnu i gyfarfod â chi i barhau â’n trafodaeth rhywbryd eto.

Beth y mae’n rhaid i mi ei wneud?
Gofynnir i chi ymweld â'r Gwasanaeth Anaf i’r Ymennydd Os yw hyn yn anghyfleus i chi, byddwn yn ceisio trefnu'r apwyntiad i chi yn agosach at eich cartref.

Pa weithdrefn sy’n cael ei archwilio?
Y weithdrefn sy’n cael ei phrofi yw adsefydlu dychwelyd i’r gwaith. Mae’n cynnwys y camau canlynol:
- Eich cyfweld i holi am eich barn ynghylch yr adsefydliad rydych wedi'i dderbyn.
- Apwyntiadau pellach posibl i ymchwilio i themâu a ddaw i’r golwg ymhellach.
- Rhoi’r cyfle i chi drafod y darganfyddiadau a gofyn cwestiynau.

Beth yw’r dewis arall?
Y dewis arall yw parhau â'r driniaeth safonol rydych yn ei derbyn gan y Gwasanaeth Anaf i’r Ymennydd. Ni effeithir ar eich triniaeth bresennol mewn unrhyw ffordd drwy gyfrif neu anghyfryd neu cymryd rhan yn yr ymchwil hwn.

Beth yw’r sgil-effeithiau wrth gymryd rhan?
Ni ddyli’r ymchwil hwn achosi unrhyw sgil-effeithiau neu annifyrrwch i chi.

Beth yw’r anfanteision posibl wrth gymryd rhan?
Weithiau, bydd pobl yn cynhyrfu a theimlo’n isel pan fyddant yn gorfod siarad am eu hanafiad i’r ymennydd a sut mae’n effeithio arnynt wrth geisio dychwelyd i’r gwaith. Os bydd hyn yn digwydd, byddwch yn cael cyfle i siarad am hyn gydag un o’r clinigwyr yn y Gwasanaeth Anaf i’r Ymennydd. Bydd omsela ar gael drwy’r gwasanaeth hefyd. Byddwch yn parhau i gael mynediad at glininwyn yr y Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru ac fe gewch ofyn am gael eich atgyfeirio am apwyntiad gyda seicolegydd i siarad am unrhyw o’r materion hyn unrhyw amser. Cewch wneud hyn un ai drwy ffonio’r gwasanaeth ar 01492 807521 a gofynnwch i ni drefnu apwyntiad i chi, neu mi gewch ofyn i glinigwyd sy’n parhau i fod yn gysylltiedig â chi i drefnu apwyntiad ar eich rhan. Os ydych yn ymwybodol y
byddwch angen apwyntiad gyda seicoleg gydd dros gyfnod y trafodaethau hyn, cewch ofyn i mi, fel ymchwilydd, i drefnu apwyntiad i chi.

**Beth yw’r manteision posibl wrth gymryd rhan?**
Mae’n bosibl byddwch yn cael budd o’r ymchwil hwn dwy ddeall eich anaf i’ch ymennydd yn well a sut mae wedi effeithio ar eich gallu i ddychwel y i’ch swydd flaenorol. Mae ymchwil blaenorol wedi dangos bod adsefydlu’n gweithio’n well pan fydd yr unigolyn yn deall ac yn gallu rhannu ag eraill natur a chanlyniadau eu hanaf i’r ymennydd.

**Beth os aiff rhywbeth o’i le?**
Os byddwch yn cytuno gymryd rhan yn yr ymchwil hwn a bydd gennych unrhyw bryderon o ganlyniad, yn ymwneud ag unrhyw agweddd o’r ymchwil, mae croeso i chi ddod ataf i fel ymchwilydd i drafod yr hain yn unigynyrchol. Rhoddir enwau’r bobl y dylid cyfeirio cwynion atynt ar ddiwedd y daflen hon. Mae gweithdrefnau cwyno arferol y GIG hefyd ar gael i bawb sy’n cymryd rhan yn yr ymchwil.

**A fydd fy rhan yn yr ymchwilied hwn yn cael ei gadw’n gyfrinachol?**
Bydd unrhyw wybodaeth a gesglir amdanoch yn ystod yr ymchwilied hwn yn cael ei gadw’n holol gyfrinachol. Bydd staff gweinyddol profiadol yn y maes hwn, a gyflogir gan Ymddiriedolaeth GIG Gogledd Cymru, yn trawsgrifio’r recordiadau sain. Fe’u rhwymir gan eu codau cyfrinachedd profesiyonol. Eiddo Ymddiriedolaeth GIG Gogledd Cymru fydd y cyfarpar cyfrifiadurol a ddefnyddir gan ddefnyddwg i drawsgrifio a byddant wedi’u hamgryptio. Pan fyddant wedi’u trawsgrifio, bydd yr holl ddata pellach sy’n ymwneud â’r astudiaeth hon yn cael eu cadw ar gyfrifiadur o eiddo Ymddiriedolaeth GIG Gogledd Cymru a amgryptiwyd gan yr Rheolwr Llywodraethu Gwybodaeth yn Ymddiriedolaeth GIG Gogledd Cymru.

Byddwn wedi tynnu eich enw a’ch cyfeiriad oddi ar unrhyw wybodaeth amdanoch sy’n gadael y Gwasanaeth Anaf i’r Ymennydd, fel nad oes modd eich adnabod oddi wrthi.
Pwy sy’n trefnu ac yn ariannu’r ymchwil?
Trefnir yr astudiaeth hon gennyf i, Marian Hooson, fel rhan o fy Noethuriaeth Broffesiynol mewn Therapi Galwedigaeth ym Mhrifysgol Brighton. Bydd Adran Ymchwil a Datblygiad Ymddiriedolaeth GIG Gogledd Cymru yn dod i’r adwy gydag unrhyw gostau ychwanegol.

Beth fydd yn digwydd i ganlyniadau’r astudiaeth?
Bydd canlyniad yr astudiaeth hon yn dweud wrthym a yw rhaglenni dychwelyd i’r gwaith o gymorth cyffredinol i’r rhai sydd wedi profi anafiadau trawmatig i’r ymennydd. Bydd canlyniadau’r astudiaeth hon yn cael eu hysgrifennu fel traethawd ar gyfer fy ngradd. Mae’n bosibl bydd y canlyniadau hefyd yn cael eu cynnwys mewn adroddiad ymchwil a gyhoeddwyd. Ni fydd modd adnabod unrhyw un a gymerodd ran yn y traethawd na’r adroddiad.

Pwy sydd wedi adolygu’r astudiaeth?
Mae Pwyllgor Moeseg Ymchwil Canolog Gogledd Cymru a Phwyllgor Moeseg Ysgol Gwyddoniaethau Iechyd Prifysgol Brighton wedi cymeradwyo’r astudiaeth. Mae Adran Ymchwil a Datblygiad Ymddiriedolaeth GIG Gogledd Cymru hefyd wedi cymeradwyo’r astudiaeth.

Am fanylion pellach, cysylltwch à à
Marian Hooson
Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru
Ysbyty Cymuned Bae Colwyn
Ffordd Hesketh
Bae Colwyn
CONWY
Ffôn: 01492 807521

Os byddwch yn cymryd rhan yn yr astudiaeth hon, byddwch yn derbyn copi o’r daflen wybodaeth a ffurflen gydsynio a lofnodwyd i’w cadw.
Os bydd unrhyw gwynion ynghylch y ffordd mae’r ymchwil yn cael ei ymgymryd, dylid eu cyfeirio at:

Mrs Lesley Ross
Gwasanaethau Cleifion, Uned Cefnogi Clinigol, Ysbyty H M Stanley, Llanelwy LL17 0RS

Neu
Dr Graham Stew
Prifysgol Brighton

_Diolch yn fawr i chi am ddarllen hwn ac ystyried cymryd rhan yn yr astudiaeth._
Appendix 11  English Version  

Consent Form

Study Number: _____________

Patient Identification Number For This Trial: _________________

A Qualitative Investigation of Individual’s Lived Experience of Returning to Work Following Traumatic Brain Injury

Researcher: Marian Hooson

1. I confirm that I have read and understand the information sheet dated June 2009 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. □

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. □

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Brighton, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to access my records. □

4. I agree to my GP being informed of my participation in this study. □

5. I agree to taking part in the above study □

Name of Patient  Date  Signature

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Name of Person taking Consent  Date  Signature

When completed, 1 for patient, 1 for researcher site file, 1(original) to be kept in medical notes
Appendix 12  English Version

Letter of Invitation to Significant Other to
Complete Awareness Questionnaire
Version 1, June 2008

North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road, Colwyn Bay
CONWY  LL29 8AY

Dear ,

I am currently studying for the award of Professional Doctorate in Occupational Therapy in the field of traumatic brain injury. This is in conjunction with the University of Brighton. Part of attaining the award involves completing a study in my area of clinical practice.

I wish to explore the feelings held by individuals who have sustained traumatic brain injury of the specialist rehabilitation they received to assist them in their venture to return to work. This will involve participating in a semi-structured interview with me which will be audio taped.

I enclose a Participation Information Sheet with this letter. I would like to ask that you read the contents carefully. If the individual for whom you are caring decides they would like to participate in the study, you will need to complete the Awareness Questionnaire which is enclosed with the Participation Information Sheet. This will help me to decide whether the individual for whom you are caring falls within my inclusion criterion for the study. This questionnaire is similar to ones you may have previously completed with other researchers in our Service. I shall write to the individual for whom you are caring to let them know if they will be included in my study.
Please complete and tear off the strip below to indicate whether or not you consent to completing the Awareness Questionnaire. Many thanks for taking the time to read the enclosed.

Regards,

Marian Hooson, Clinical Specialist Occupational Therapist

I do/do not wish to be considered for this research.

Name:

Address:
Llythyr Gwahodiadiad at Rywun o Bwys yn eich Bywyd i
Gwbllhau Holiadur Ymwybyddiaeth
Fersiwn 1, Mehefin 2008

Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru
Ysbyty Cymuned Bae Colwyn
Ffordd Hesketh, Bae Colwyn
CONWY LL29 8AY.

Anwyl,
Rwyf ar hyn o bryd yn astudio am Ddoethuriaeth Broffesiynol mewn Therapi Galwedigaethol ym maes anaf trawmatig i’r ymennydd. Rwy’n gwneud hyn ar y cyd â Phrifysgol Brighton. Mae rhan o’r astudiaeth am y ddoethuriaeth yn cynnwys cwblhau astudiaeth yn fy maes o arferion clinigol.

Rwy’n dymuno archwilio teimladau unigolion sydd wedi derbyn anafiadau trawmatig i’r ymennydd am yr adsefydlad arbenigol maent wedi’i dderbyn i’w cynorthwyo i ddychwelyd i’r gwaith. Bydd hyn yn cymmwd rhan mewn cyfweliad lleddystrwythuredig gyda mi a bydd recordiad sain yn cael ei wneud.

Rwy’n amgáu Taflen Wybodaeth Cymryd Rhan gyda’r llythyr hwn. Gofynnaf i chi ddarllen ei chynnwys yn ofalus. Os bydd y sawl rydych yn gofalu amdano/i yn penderfynu yr hoffent gymryd rhan yn yr astudiaeth hon, bydd angen i chi gwbllhau’r Holiadur Ymwybyddiaeth sy’n cael ei gynnwys gyda’r Daflen Wybodaeth Cymryd Rhan. Bydd hyn yn fy nghynorthwyo i benderfynu a yw’r sawl rydych yn gofalu amdano/i yn dod o dan y meini prawf i’w cynnwys yn yr astudiaeth hon. Mae’r holiadur hwn yn debyg i’r rai y mae’n bosibl rydych wedi’u cwblhau gydag ymchwiliwyr eraill yn ein Gwasanaeth. Byddaf yn ysgrifennu at yr unigolyn rydych yn gofalu andano/i i roi gwybod a fyddant yn cael eu cynnwys yn fy astudiaeth neu beidio.
Cwblhewch a torrwch y bonyn isod i nodi a ydych yn cydsynio i gwbllhau'r Holiadur Ymwybyddiaeth. Diolch yn fawr i chi am ddarllen yr amgaedig.

Cofion

Marian Hooson, Therapydd Galwedigaethol Arbenigol Clinigol

Dymunaf/nid wyf yn dymuno cael fy ystyried i'r ymchwil hwn

Enw:

Cyfeiriad
Appendix 13 English Version

Information Sheet for the Friend/Relative
Version 1, June 2008

Title: A qualitative investigation of the individual’s
Lived experience of returning to work
Following traumatic brain injury

Study: To understand the experience of returning
to work (through rehabilitation) following
traumatic brain injury

I am currently studying for the award of Professional Doctorate in Occupational Therapy in the field of traumatic brain injury. This is in conjunction with the University of Brighton. Part of attaining the award involves completing a study in my area of clinical practice. The person for whom you are caring and/or have a strong relationship with is being invited to take part in a study. Before they decide it is important for both them and you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friend/relative if you wish. Ask me if there is anything that is not clear or if you would like more information. Your friend/relative has three weeks to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of this study?
This research aims to find out the value of return to work (RTW) rehabilitation for individuals who have sustained traumatic brain injury (TBI). There are many discrepancies in the reported success of such rehabilitation with this patient group. The success rate varies from 10%-77%. There is no information from the individuals’ perspective as to how useful they find the rehabilitation programmes they engage in. I want to find out how your friend/relative perceives the rehabilitation they received and see whether any changes need to be made to future clinical rehabilitation to improve the success rate for individuals. In order to do this they need to participate in an interview with me which will be audio taped.
**Why has your friend/relative been chosen?**

They have been asked to take part because they have had a traumatic brain injury (for example as a result of being in a car crash or being attacked) and are currently registered as a patient with the North Wales Brain Injury Service. They have also attempted to return to their previous employment. I shall be asking about 10 other people to take part who are similar in circumstances to them.

**Do they have to take part?**

It is up to them to decide whether or not you wish to take part. If they do take part they will be given this information sheet to keep and be asked to sign a consent form. If they decide to take part they are still free to withdraw at any time and without giving a reason. This will not affect the standard of care they receive from the North Wales Brain Injury Service now or in the future.

**What will happen to them if they take part?**

If they agree to take part they will be invited to the Brain Injury Service for up to two one-to-one appointments with me, as the researcher. This would be similar to appointments they have at the Brain Injury Service. During these appointments they will be asked again to consent to take part. Then they will have a discussion with the researcher about their experience of return to work rehabilitation. This discussion will be audio taped. They will be shown how the audio tape equipment works before we start the discussion. If they want to switch the equipment off at any time during our discussion they will be free to do so. I, as the researcher will also be taking notes. The interview will take no longer than 1 ¼ hours.

They will be invited to take regular breaks during the discussion so that they can have refreshments, toilet break, and cigarette break if required. This break time is incorporated into the 1 ¼ hours of the discussion. This should minimise the risk of overfatiguing. Should the interview run over the scheduled time for any reason, I, as the researcher will endeavour to re-arrange to continue the discussion at another time.

**What do they have to do?**

They will be asked to visit the Brain Injury Service. If this is inconvenient for them we will try to schedule the appointment nearer to their home.
What is the procedure being explored?
The procedure being tested is return to work rehabilitation. It consists of the following steps:
1. Interviewing them for their feelings about the return to work rehabilitation they have received.
2. Possible further appointment exploring any emerging themes in greater depth.
3. Giving them the opportunity to discuss the findings and ask questions.

What is the alternative?
The alternative is to continue with the standard treatment they already receive at the Brain Injury Service. Their current treatment will not be affected in any way by agreeing or not agreeing to take part in this research.

What are the side effects of taking part?
The research should not cause any side effects or discomfort.

What are the possible disadvantages of taking part?
Occasionally people may become upset and feel low when they have to talk about their brain injury and how it affects them and their attempts to return to work. If this happens they will be given the opportunity to talk this through with one of the clinicians at the Brain Injury Service. Counselling will also be available through the Service.

They continue to have access to clinicians at the North Wales Brain injury Service and can ask to be referred for an appointment with a psychologist to talk through any issues at any time. They can do this either by telephoning the Service on 01492 807521 and asking for an appointment to be booked for them, or they may ask a clinician who remains involved with them to arrange an appointment on their behalf. If they are aware that they may need an appointment with a psychologist during the course of the discussion, they may also ask me, as the researcher, to arrange an appointment for them.

What are the possible benefits of taking part?
They may benefit from this research by gaining a better understanding of their brain injury and how it has impacted on their ability to return to their previous employment. Previous research has shown that rehabilitation works better when a person understands, and is able to share with others, the nature and the consequences of their brain injury.

**What if something goes wrong?**

If they were to agree to take part in this research and subsequently have any concerns about any aspect of the research, they can approach the researcher Marian Hooson directly to discuss these. The names of persons to direct complaints to are also provided at the end of this leaflet. The usual NHS complaints procedures are also available to all research participants.

**Will their taking part in this study be kept confidential?**

All information that is collected about them during the course of the research will be kept strictly confidential. The transcribing of the audio tapes will be undertaken by administration staff experienced in this practice and employed by the Conwy & Denbighshire NHS Trust. They are bound by their professional codes of confidentiality. The computer equipment used by them for transcription will be the property of the Conwy & Denbighshire NHS Trust, and be encrypted. Once transcribed, all further data relating to this study will be stored on a computer that is the property of the Conwy & Denbighshire NHS Trust that has been encrypted by the Information Governance Manager at Conwy & Denbighshire NHS Trust.

Any information about them that leaves the Brain Injury Service will have their name and address removed so that they cannot be recognised from it.

**What do I have to do?**

If your friend/relative agrees to take part in the study they will need to complete an Awareness Questionnaire that is enclosed with their Information Pack. I enclose the same Awareness Questionnaire for you to complete about your friend/relative. It should not take more than 10 minutes to complete. I also enclose a Consent Form for you to complete if you decide to complete and return to enclosed Awareness Questionnaire. I enclose a stamped addressed envelope for you to return to the Awareness Questionnaire to the North Wales Brain Injury Service.
Who is organising and funding the research?
This study is being organised by Marian Hooson as part of her degree, Professional Doctorate in Occupational Therapy at the University of Brighton. Conwy & Denbighshire NHS Trust Research & Development Department will meet additional costs of the research.

What will happen to the results of the study?
The results of this study will tell us whether return to work programmes are generally assistive to individuals who have experienced traumatic brain injury. The result of this study will be written up in Marian Hooson’s dissertation for her degree. The results may also be included in a published research report. No participants will be identified in the dissertation or the report.

Who has reviewed the study?
The North Wales Central Research Ethics Committee & the University of Brighton School of Health Sciences Ethics Committee have approved the study. Conwy & Denbighshire NHS Trust Research & Development Department have also approved the study.

Contact for further information:
Marian Hooson
North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road, Colwyn Bay
CONWY Tel: 01492 807521

If your friend/relative takes part in this study they will be given a copy of the Information Sheet and a signed consent form to keep.

In case of complaints concerning the conduct of research, these should be addressed to:
Mrs Lesley Ross
Patient Services, Clinical Support Unit, HM Stanley Hospital, St Asaph LL17 0RS
Or
Dr Graham Stew
University of Brighton

Thank you for reading this and for considering taking part in this study.
**Appendix 13**

**Welsh Version**

*Taflen Wybodaeth i’r Cyfaill/Perthynas*

*Fersiwn 1, Mehefin 2008*

**Teitl:** Ymchwiliad ansoddol i brofiad personol yr unigolyn wrth ddychwelyd i’r gwaith

Yn dilyn anaf trawmatig i’r ymennydd.

**Astadiaeth:** Deall y profiad o ddychwelyd

i’r gwaith (drwy adsefydiad) yn dilyn anaf trawmatig i’r ymennydd.

Rwyf ar hyn o bryd yn astudio am Ddoethuriaeth Broffesiynol mewn Therapi Galwedigaethol yr maes anaf trawmatig i’r ymennydd. Mae hwn ar y cyd â Phrifysgol Bright. Mae rhan o ennill y cymhwyster hwn yn cynnwys cwblhau astudiaeth yn fy maes arfer clinigol. Mae’r sawl rydych yn gofalu amdano/i a/neu rydych â pherthynas gref ag o/hi wedi derbyn gwahoddiad i gymryd rhan yn yr astudiaeth hon. Cyn iddo/i benderfynu, mae’n bwysig bod pawb yn deall pam y cynhelir yr astudiaeth hon a’r hyn a fydd yn cael ei gynnwys. Rhowch amser i ddarllen y wybodaeth ganlynol yn ofalus a thrafod gyda’ch ffrind, neu berthynas os byddwch yn dymuno. Os bydd unrhyw beth yn aneglur neu os hoffech wybodaeth bellach, mae croeso i chi ofyn i mi. Mae gan eich ffrind/perthynas dair wythnos i benderfynu cymryd rhan neu beidio.

Diolch i chi am ddarllen y daflen wybodaeth hon.

**Beth yw pwrpas yr astudiaeth hon?**

Nod yr astudiaeth yw darganfod gwerth adsefydlu dychwelyd i’r gwaith (DIR) i unigolion sydd wedi derbyn anaf trawmatig i’r ymennydd (ATY). Mae nifer o anghysondebau mewn llwyddiannau a adroddir am adsefydlu gyda’r grŵp cleifion hwn. Mae’r raddfa llwyddiant yn amrywio rhwng 10% - 77% Nid oes unrhyw wybodaeth o safbwynt yr ‘unigolion’ o ran pa mor ddefnyddiol yw’r rhaglenni adsefydlu maen nhw’n cymryd rhan ynddynt. Rwyf am ddarganfod beth mae eich ffrind/perthynas yn ei feddwl o’r adsefydlu maent wedi’i dderbyn a gweld a oes angen newid unrhyw adsefydlu clinigol yn y dyfodol i wella cyfradd llwyddiant i unigolion. Er mwyn gwneud hyn, bydd raid iddynt gymryd
rhan mewn cyfweliad gyda mi a fydd yn cael ei recordio. Er mwyn gwneud hyn, bydd raid iddo/iddi gymryd rhan mewn cyfweliad gyda mi a fydd yn cael ei recordio.

**Pam bod eich ffrind/perthynas wedi’i ddewis?**
Gofynnwyd iddo/iddi gymryd rhan oherwydd ei f/bod wedi cael anaf trawmatig i’r ymennydd (er enghraifft, o ganlyniad i fod mewn damwain car neu ymosodiad) ac mae wedi’i g/chofrestru ar hyn o bryd gyda Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru. Mae wedi ceisio dychwelyd i’w swydd flaenorol. Byddaf yn gofyn i tua deg o bobl eraill gymryd rhan sydd ag amgylchiadau tebyg iddo ef/hi.

**A oes raid iddo/i gymryd rhan?**
Ei b/phenderfyniad o/hi yw cymryd rhan neu beidio. Os bydd yn cymryd rhan, bydd yn cael y daflen wybodaeth hon i’w chadw a byddwn yn gofyn iddo/i losnodi ffurflen gydsynio. Os bydd yn penderfynu cymryd rhan, mae’r hawl ganddo/i i dynnu allan unrhyw amser heb roi rheswm. Ni fydd hyn yn effeithio ar safon y gofal bydd yn ei dderbyn nawr neu i’r dyfodol gan Wasanaeth Anaf i’r Ymennydd Gogledd Cymru.

**Beth fydd yn digwydd iddo/i os bydd yn cymryd rhan?**
Os yw wedi cytuno cymryd rhan, bydd yn derbyn gwahoddiad i ddod at y Gwasanaeth Anaf i’r Ymennydd am hyd at ddau apwyntiad un wrth un gyda mi, fel ymchwiliwydd. Bydd hwn yn debyg i’r apwyntiadau maent wedi’u cael eisoes gyda’r Gwasanaeth Anaf i’r Ymennydd. Yn ystod yr apwyntiadau, gofynnir iddynt eto am eu cydsyniad i gymryd rhan. Byddant wedyn yn cael trafodaeth gyda’r ymchwilydd am eu profiad adefydlu i fynd yn ôl i’r gwaith. Bydd y drafodaeth yn cael ei recordio. Byddwn yn dangos iddynt sut mae’r cyfarpar recordio’n gweithio cyn dechrau’r drafodaeth. Os byddant am ddiffodd y cyfarpar unrhyw amser yn ystod ein trafodaeth, byddant yn rhydd i wneud hyn. Fel ymchwilydd, byddaf hefyd yn cymryd nodiadau. Ni fydd y cyfweliad yn para mwy na 1 ¼ awr.

Byddant yn cael eu hannog i gymryd egwylion rheolaidd yn ystod y drafodaeth fel eu bod yn cael lluniaeth, mynd i’r toiled ac ysmygu os bydd angen. Bydd yr egwyl hon yn rhan o’r 1 ¼ awr o drafodaeth. Dylai hyn leihau’r tebygolrwydd o flino. Os bydd y cyfweliad yn mynd dros amser am unrhyw reswm, byddaf i, yr ymchwilydd, yn gwneud fy ngorau i ail-drefnu i gyfarfod â fo/hi i barhau â’n trafodaeth rhywbryd eto.
Beth y mae’n rhaid iddo/iddi ei wneud?
Gofynnir iddynt ymweld â’r Gwasanaeth Anaf i’r Ymennydd. Os nad yw hyn yn gyfleus, byddwn yn ceisio ail drefnu’r apwyntiad yn agosach i’w cartref.

Beth yw’r weithdrefn sy’n cael ei harchwilio?
Y weithdrefn sy’n cael ei phrofi yw adsefydliad i ddychwelyd i’r gwaith. Mae’n cynnwys y camau canlynol:
1. Eu cyfweld i gael gwybod eu teimladau ynghylch yr adsefydliad i ddychwelyd i’r gwaith maent wedi’i dderbyn.
2. Apwyntiad pellach posibl i archwilio unrhyw themâu eraill a ddaw i’r golwg yn fwy dwys.
3. Rhoi’r cyfl i ddynt drafod y darganfyddiadau a gofyn cwestiynau.

Beth yw’r dewis arall?
Y dewis arall yw i barhau â’r driniaeth safonol mae eisoes yn ei derbyn gan y Gwasanaeth Anaf i’r Ymennydd. Ni effeithir ar eu triniaeth arferol mewn unrhyw fodd drwy gytuno ne

Beth yw’r sgil-effeithiau o gymryd rhan?
Ni ddylai’r ymchwil achosi unrhyw sgil-effeithiau nac annifyrrwch.

Beth yw’r anfanteision posibl o gymryd rhan?
Weithiau, bydd pobl yn cynhryfu a theimlo’i isel pan fyddant yn gorfod siarad am eu hanafiad i’r ymennydd a sut maen i’w ei arnochogwr ar gyfer yr un o’i clinigwyr a Gwasanaeth Anaf i’r Ymennydd. Bydd cwsnsela ar gael drwy’r gwasanaeth hefyd.

Bydd yn parhau i gael mynediad at glinigwyr yn y Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru a gellir gofyn am gael atgyfeiriad am apwyntiad gyda seicolegydd i siarad am unrhyw o’r materion hyn unrhyw amser. Gellir gwneud hyn un ai drwy ffonio’r gwasanaeth ar 01492 807521 a gofyn i ni drefnu apwyntiad, neu gellir gofyn i glinigwyr sy’n parhau i fod yn gysylltiedig drefnu apwyntiad ar ei r(h)an. Os yw’n ymwybodol y bydd angen apwyntiad gyda seicolegydd dros gyfnod y trafodaethau hyn, mae croeso iddo/i ofyn i mi, fel ymchwilydd, i drefnu apwyntiad.

Beth yw’r manteision posibl wrth gymryd rhan?
Mae’n bosibl bydd yn cael budd o’r ymchwil hwn drwy ddeall ei (h)anaf i’r ymennydd yn well a sut mae wedi efeithio ar ei (g)allu i ddychwelyd i’w swydd flaenorol. Mae ymchwil blaenorol wedi dangos bod adsefydlu’n gweithio’n well pan fydd yr unigolion yn deall ac yn gallu rhanu ag eraill natur a chanlyniadau eu hanaf i’r ymennydd.

**Beth os aiff rhywbeth o’i le?**
Os bydd yn cytuno cymryd rhan yn yr ymchwil hwn a bydd ganddo/i unrhyw bryderon o ganlyniad, yn ymwneud ag unrhyw agweddi o’r ymchwil, mae croeso i chi ddod ataf i fel ymchwilydd i drafod y rhain yn uniongyrchol. Rhoddir enwau’r bobl y dylid cyfeirio cwynion atynt ar ddiwedd y daflen hon. Mae gweithdrefnau cwyno arferol y GIG hefyd ar gael i bawb sy’n cymryd rhan yn yr ymchwil.

**A fydd ei r(h)an yn yr ymchwiliad hwn yn cael ei gadw’n gyfrinachol?**
Bydd unrhyw wybodaeth a gessglir amdano/i yn ystod yr ymchwiliad hwn yn cael ei gadw’n holol gyfrinachol. Bydd staff gweinyddol profiadol yn y maes hwn a gyllogir gan Ymddiriedolaeth GIG Gogledd Cymru yn trawsgrifio’r recordiadau sain. Fe’u rhwmir gan eu codau cyfrinachedd profesiynol. Eiddo Ymddiriedolaeth GIG Gogledd Cymru fydd y cyfarpar cyfrifiadur a ddefnyddir ganddynt i drawsgrifio a byddant wedi’u hamgryptio. Pan fyddant wedi’u trawsgrifio, bydd yr holl ddata pellach syn ymwneud â’r astudiaeth hon yn cael eu cadw ar gyfrifol ac amgriptiwyd gan y Rheolwr Llywodraethu Gwybodaeth yn Ymddiriedolaeth GIG Gogledd Cymru.

Byddwn wedi tynnu ei (h)enw a’i chyfeiriad oddi ar unrhyw wybodaeth amdano/i sy’n gadael y Gwasanaeth Anaf i’r Ymennydd, fel nad oes modd eich adnabod oddi wrth y wybodaeth.

**Beth y mae’n rhaid i mi ei wneud?**
Os yw eich ffrind/perthynas yn cytuno cymryd rhan yn yr astudiaeth, bydd raid iddo/i gwblhau Holiadur Ymwybyddiaeth a amgaeir yn y Pecyn Gwybodaeth. Amgaeaf yr un Holiadur Ymwybyddiaeth i chi gwblhau am eich ffrind/perthynas. Ni ddylai gymryd mwy na 10 munud i’w gwblhau. Rwyf hefyd yn amgáu Ffurflen Gydsynio i chi ei chwblhau os byddwch yn penderfynu cwblhau a dychwelyd yr Holiadur Ymwybyddiaeth amgaeedig.
Amgaeaf amlen barod â stamp i chi ddychwelyd yr Holiadur Ymwybyddiaeth i Wasanaeth Anaf i'r Ymennydd Gogledd Cymru.

**Pwy sy'n trefnu ac yn ariannu'r ymchwil?**
Trefnir yr astudiaeth hon gan Marian Hooson, fel rhan o’i Doethuriaeth Broffesiynol mewn Therapi Galwedigaethol ym Mhrifysgol Brighton. Bydd Adran Ymchwil a Datblygiad Ymddiriedolaeth GIG Gogledd Cymru yn dod i’r adwy gydag unrhyw gostau ychwanegol .

**Beth fydd yn digwydd i ganlyniadau'r astudiaeth?**
Bydd canlyniad yr astudiaeth hon yn dweud wrthym fod rhaglenni dychwelyd i’r gwraith o gymorth cyffredinol i’r rai sydd wedi profi anafiadau trawmatig i’r ymennydd neu beidio. Bydd canlyniadau’r astudiaeth hon yn cael eu hysgrifennu fel traethawd ar gyfer gradd Marian Hooson. Mae’n bosibl bydd y canlyniadau hefyd yn cael eu cynnwys mewn adroddiad ymchwil a gyhoeddwyd. Ni fydd modd adnabod unrhyw un a gymerodd ran yn y traethawd na’r adroddiad.

**Pwy sydd wedi adolygu'r astudiaeth?**
Mae Pwyllgor Moeseg Ymchwil Canolog Gogledd Cymru a Phwyllgor Moeseg Ysgol Gwyddoniaethau Iechyd Prifysgol Brighton wedi cymeradwyo’r astudiaeth. Mae Adran Ymchwil a Datblygiad Ymddiriedolaeth GIG Gogledd Cymru hefyd wedi cymeradwyo’r astudiaeth.

**Am fanylion pellach, cysylltwch à**
Marian Hooson
Gwasanaeth Anaf i'r Ymennydd Gogledd Cymru
Ysbyty Cymuned Bae Colwyn
Ffordd Hesketh, Bae Colwyn
CONWY
Ffôn: 01492 807521

Ixii
Os bydd eich ffrind/perthynas yn cymryd rhan yn yr astudiaeth hon, byddwch yn derbyn copi o’r daflen wybodaeth a ffurflen gydsynio a lofnodwyd i’w cadw.
Os bydd unrhyw gwynion ynghylch y ffordd mae’r ymchwil yn cael ei ymgymryd, dylid eu cyfeirio at:
Mrs Lesley Ross
Gwasanaethau Cleifion, Uned Cefnogi Clinigol, Ysbyty H M Stanley, Llanelwy LL17 0RS
Dr Graham Stew
Prifysgol Brighton

Diolch yn fawr i chi am ddarllen hwn ac ystyried cymryd rhan yn yr astudiaeth.
North Wales Brain Injury Service  
Colwyn Bay Community Hospital  
Hesketh Road, Colwyn Bay  
CONWY 0029 8AY  

Dear Doctor  

Re: Patient’s name, address, date of birth  

I am writing to inform you that the above named person has volunteered to participate in a research study conducted at the North Wales Brain Injury Service. The research project will gain an understanding of the value of return to work rehabilitation as perceived by the patient in a group if individuals who have sustained traumatic brain injury. I have included a copy of the Patient Information Sheet.  

The North Wales Central Research Ethics Committee has approved this study. We will inform you if your patient’s participation has any unexpected adverse consequences.  

Yours sincerely,  

Marian Hooson  
Clinical Specialist Occupational Therapist  
North Wales Brain Injury Service
Appendix 14 Welsh Version

Llythyr at y Meddyg Teulu
Fersiwn 1.0, 6 Mawrth 2008

Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru
Ysbyty Cymuned Bae Colwyn
Ffordd Hesketh, Bae Colwyn
CONWY LL29 8AY

Annwyl Feddyg

Ynhychl: Enw, cyfeiriad a dyddiad geni’r claf

Ysgrifennaf atoch i roi gybwod i chi fod y sawl a enwir uchod wedi gwirfoddoli i gymryd rhan mewn astudiaeth ymchwil sy’n cael ei wneud gan Wasanaeth Anaf i’r Ymennydd Gogledd Cymru. Bydd y prosiect ymchwil yn dod i ddeall gwerth adsefydly dychwelyd i’r gwaith yn ôl barn y claf mewn grwp o unigolion sydd wedi dioddef anaf trawmatig i’r ymennydd. Amgaeaf gopi o daflen wybodaeth i gleifion.

Mae Pwyllgor Moeseg Ymchwil Gogledd Cymru Canolog wedi cymeradwyo’r astudiaeth. Byddwn yn rhoi gybwod i chi os bydd cymryd rhan yn y prosiect yn achosi unrhyw broblemau annisgwyl.

Yn gywir

Marian Hooson
Therapydd Galwediagaethol Clinicolg Arbenigol.
Gwasanaeth Anaf i’r Ymennydd Gogledd Cymru
Appendix 15

Audit trail of the data collection & analysis fieldwork

Patients identified by clinicians within the NWBIS Service

Potential participants, significant other & key clinician within NWBIS invited to complete AQ.

Participant recruitment for semi structured interview based on fulfilling inclusion criterion and inter-rater compatibility score on AQ

Audio taping of interview

Reflective log of each interview undertaken by researcher within 30 minutes of completing each interview

Researcher listened to each interview twice

Verbatim transcript of the interview

Notes on transcriptions made further to two readings (red pen & blue pen)

Themes categorisation made by researcher (black pen) and verified by experienced researcher in IPA during the analysis process

List of initial themes developed & modified from the data and researcher notes (10 themes)

Final list of themes (5 themes) & sub themes generated from the available data
Appendix 16  Example of Transcript With Initial Interpretative Phenomenological Analysis

Participant:
13 Okay before I had the brain injury I was working
14 in the finance department in the [Location]
15 name] County Council my remit covered
16 ummm...the ummm...protection that was in
17 charge of the anti-protection and performance
18 management policy training and development
19 and the staff of about...a team of about ten
20 people working for me and my responsibility
21 covered payment of about sixteen million a year
22 an income of about sixty or seventy million
23 pounds a year...I was also responsible for
24 making sure that statistics and performance
25 was managed for all that income and
26 expenditure.
27
28 A1. Researcher:
29 Right.... What do you do now?
30
31 Participant:
32 After I had the traumatic brain injury I went back
33 after six months...ummm...after my - hesitation - ? did confidence
34 consultations with the brain injury placed RTW.
Hesitations december

↓ confidence.

unit...ummm...it was a phased return to work < v confidence
and a phased return probably lasted I think
about twelve months...and during that
time...ummm...I could come and go pretty < v confidence.
much as I pleased and eased my way back in.
when I finally got to a settled remit at the end of
the phase return period...ummm...it was
transformational - not
his decision.
I couldn't do

Loss of control
over decision making.

Can't do

Information
provision

advice was that I shouldn't have anything
with...ummm...stressful deadlines or anything
that was likely to cause me further stress, so
the fraud side and the performance
management side which were the ones that had
sort of time scales involved and probably high
stress levels were dropped...and now I do three
days a week covering just creative stuff
effectively which I can do pretty much at my
own pace most of the time...ummm...so I just
do policies procedures...ummm...and training.
Not as fulfilling

Not compared to
pre-monobud.

A2. Researcher:
Okay. What did it feel like finding out that you
couldn't go back to the same job that you were
doing?

Participant:
Devastating...ummm...until ummm...the
strange thing about it was when...when I went
back after six months on the phase basis it
became pretty clear during that first twelve
months in the meetings I had with yourself and
[the psychologist] that the likely hood was that I
would have to have a restricted role and most
likely not work full time...and for some months
before the formal decision was taken to actually
go part time on restricted duties...I was fully aware that that was what the outcome was
going to be...but strangely enough when the
actual deadline came when I had the meeting
with yourselves and the personnel department
to formalise matters it absolutely knocked me
sideways. Ummm... and it took me some
months to come to terms, and you know after I
sat and analysed really...why this was because
it's not as if it came as a surprise overnight...no
I should have been in a position where I was
quite prepared for this and once the decision
had been taken...ummm...it shouldn't really
have had any effect on me. But it took me
months to come to terms with it...and...I don't
know why...I mean...the sort of I'd like to come
to terms with the fact that you're not a young
man anymore...you know you can't do the
things you did when you were younger and all
that sort of thing...I suppose it's...it's partly an
ego thing...ummm...but you think you're not
invincible...you've got to adjust but ummm...it
had a far more traumatic effect on me
psychologically than I ever expected it would
do.

48 December
Okay. What is it exactly that you have had to come to terms with?

Participant:

The sort of personality that I have...I'm always very ambitious...you know I'm not most likely the person who would have chosen to retire at fifty five or even sixty five...I would always need something to drive me on I would have something I was trying to achieve. And I suppose in some respects even though I'm still able to contribute at work it was a case of having to come to terms with...my learning power was vastly reduced and my career prospects were vastly reduced because realistically ummm...I can't progress within my job and you know they're sort of...they're keeping me on out of a sense of loyalty and responsibility. Ummm...more than anything else because clearly my old job remit still has to be fulfilled and it's become a lot more expensive to do it the way they are now than keep me on ummm...so my promotion prospects within my current employment are probably not diminished and probably non-existent and I don't really have any option but to move else where because again I can...certainly in the shortened immediate term I can only consider part time work and realistically most employers are going to be swayed by the fact I've suffered a brain injury and my health hasn't been good ummm...over the last few years so...the chances are they wouldn't take a chance on me anyway...so I
Appendix 18

Mayo TBI Severity Classification System

A. Classify as Moderate-Severe (Definite) TBI if one or more of the following criteria apply:
   1. Death due to this TBI
   2. Loss of consciousness of 30 minutes or more
   3. Post-traumatic anterograde amnesia of 24 hours or more
   4. Worst Glasgow Coma Scale full score in first 24 hours <13 (unless invalidated upon review, e.g. attributable to intoxication, sedation, systemic shock)
   5. One or more of the following present
      - Intracerebral haematoma
      - Subdural haematoma
      - Epidural haematoma
      - Cerebral contusion
      - Haemorrhagic contusion
      - Penetrating TBI (dura penetrated)
      - Subarachnoid haemorrhage
      - Brain Stem Injury

B. If none of criteria A apply, classify as Mild (Probable) TBI, if one or more of the following criteria apply:
   1. Loss of consciousness of momentary to less than 30 minutes
   2. Post-traumatic anterograde amnesia of momentary to less than 24 hours
   3. Depressed, basilar or linear skull fracture (dura intact)

C. If none of criteria A or B apply, classify as Symptomatic (Possible) TBI if one or more of the following symptoms are present:
   - Blurred vision
   - Confusion (mental state changes)
   - Dazed
   - Dizziness
   - Focal neurological symptoms
   - Headache
   - Nausea
Appendix 19  Example of Transcript

What works? Returning to work following traumatic brain injury.

Interview 3

A. Researcher:
Right …can you tell me a bit about what you were doing before, with regards to work and how that has changed to what you’re doing now?

Participant:
Okay before I had the traumatic brain injury I was working in the finance department in the [named] County Council my remit covered ummm….the ummm…protection that was in charge of the anti-protection and performance management policy training and development and the staff of about…a team of about ten people working for me and my responsibility covered payment of about sixteen million a year an income of about sixty or seventy million pounds a year…I was also responsible for making sure that statistics and performance was managed for all that income and expenditure.

A1. Researcher:
Right…. What do you do now?

Participant:
After I had the traumatic brain injury I went back after six months…ummm…after my consultations with the brain injury unit…ummm…it was a phased return to work and a phased return probably lasted I think about twelve months…and during that time…ummm….I could come and go pretty much as I pleased and eased my way back in. when I finally got to a settled remit at the end of the phase return period…ummm…it was decided that I couldn’t work on a full time basis and I couldn’t go back to my previous remit…so it was a case of deciding on what to take out of the…effectively there was three elements to the previous job, there was the fraud side, the performance management side and the policies stroke training development side…ummm… the advice was that I shouldn’t have anything with…ummm…stressful deadlines or anything that was likely to cause me further stress, so the fraud side and the performance management side which were the ones that had sort of time scales involved and probably high stress levels were dropped…and now I do three days a week covering just creative stuff effectively which I can do pretty much at my own pace most of the time…ummm…so I just do policies procedures…ummm…and training.
A2. Researcher:
Okay. What did it feel like finding out that you couldn’t go back to the same job that you were doing?

Participant:
Devastating…ummm…until ummm…the strange thing about it was when…when I went back after six months on the phase basis it became pretty clear during that first twelve months in the meetings I had with [the occupational therapist] and [psychologist] that the likely hood was that I would have to have a restricted role and most likely not work full time…and for some months before the formal decision was taken to actually go part time on restricted duties…I was fully aware that that was what the outcome was going to be…but strangely enough when the actual deadline came when I had the meeting with yourselves and the personnel department to formalise matters it absolutely knocked me sideways. Ummm… and it took me some months to come to terms, and you know after I sat and analysed really…why this was because it’s not as if it came as a surprise overnight…no I should have been in a position where I was quite prepared for this and once the decision had been taken…ummm…it shouldn’t really have had any effect on me. But it took me months to come to terms with it…and…I don’t know why…I mean…the sort of I’d like to come to terms with the fact that you’re not a young man anymore…you know you can’t do the things you did when you were younger and all that sort of thing…I suppose it’s…it’s partly an ego thing…ummm…but you think you’re not invincible…you’ve got to adjust but ummm…it had a far more traumatic effect on me psychologically than I ever expected it would do.

A3. Researcher:
Okay. What is it exactly that you have had to come to terms with?

Participant:
The sort of personality that I have…I’m always very ambitious…you know I’m not most likely the person who would have chosen to retire at fifty five or even sixty five…I would always need something to drive me on I would have something I was trying to achieve. And I suppose in some respects even though I’m still able to contribute at work it was a case of having to come to terms with…my earning power was vastly reduced and my career prospects were vastly reduced because realistically ummm…I can’t progress within my job and you know they’re sort of…they’re keeping me on out of a sense of loyalty and responsibility. Ummm…more than anything else because clearly my old job remit still has to be fulfilled and it’s become a lot more expensive to do it the way they are now than keep me on ummm…so my promotion prospects within my current employment are probably diminished and probably non-existent and I don’t really have any option
but to move else where because again I can...certainly in the shortened immediate term I can only consider part time work and realistically most employers are going to be swayed by the fact I’ve suffered a brain injury and my health hasn’t been good ummm...over the last few years so...the chances are they wouldn’t take a chance on me anyway...so I think psychologically it may well have been linked with having to come to terms with...if you like maybe it’s overstated to say the end of your productive life but certainly all my ambitions and aims had suddenly come to a dead stop.

B. Researcher:
Right. Did you...were you able to isolate that to just within your working life or was there any generalisation into your every day life...aspects of your life?

Participant:
I think it was mainly working life but yes there was generalisation in terms of ummm...I wouldn’t say I was dead doomy and pessimistic in you know I might think right my life is over but I’ve never been one to dwell on...you know when am I going to die but I found myself thinking...well the chances are I’m not going to live to a ripe old age. I’m not sitting there dwelling on the thing but it does...it’s crossed my mind because [my daughter] is only sort of eight now you know I sort of embarked on the fatherhood thing very late on in life and I sometimes think well...you know I...maybe I’m not going to see her getting married and you know all that sort of stuff...not in...not in a sense that I would just be sitting there dwelling and getting depressed about it all the time but I’ve had to come to terms with the fact that realistically ummm...it’s more likely that I will die relatively young than apposed to...you know in my eighties or nineties.

B1. Researcher:
Right.

Participant:
I’m not saying I’m going to be missing out on certain sort of family things because of that.

B2. Researcher:
Okay. You say that the....not being able to return to your previous job full time has had a traumatic psychological effect on you...can you tell me a bit more about that?

Participant:
Ummm...what...you’ve known me for quite some time now...you know I like to be in the centre of everything ummm...you know one of the things that drives me is you know is ambition...you know
and I’m quite ego driven as well and I like to be involved you know I’m very much as you say in Welsh ‘Ceffyl Blaen’ ummm….so I think having…to realise that maybe…that wasn’t going to be feasible anymore…because it is quite strange at work they pussy foot around me with a lot of things because they don’t want to place any undue strain on me which is commendable you know since this has happened…but in other senses what I’ve found over the last few months is…is creeping back where there’s something critical going on…they tend to sort of involve me more than they would do in the earlier days and I suppose that that’s been a help…I mean this thing that we’ve had recently where I did the extra work…I mean I suffered a lot for it but spiritually I find it…I found it extremely sort of uplifting and rewarding even though I’m still…well I was still suffering the after effects you like…the sort of exhaustion in a physical and mental sense. But feeling needed and wanted and being able to contribute on a really sort of productive level gave me a huge boost to my sort of ummm…self respect really.

B3. Researcher:
Right. Okay. So in terms of the help you’ve had to return to work can you tell me a bit about how you experienced that?

Participant:
Uh…yes…I mean…what that showed me more than anything…initially I was quite reluctant to come involve to the brain injury unit for no other reason than I didn’t think that I had that much of a problem…there were people far more in need of the service than myself. Because I hadn’t suffered the classic sort of after effects of a brain injury in terms of serious speech defects and ummm… loss of…use of ummm…..some of my limbs. I assumed that I had affectively, completely got over the thing and it was just a matter of having a bit of ummm…a bit of recuperation and then going back to work. When I was eventually persuaded by the speech therapist to come and see you it was with some reluctance…and it took quite a few meetings with yourself and [the psychologist] before it began to sink in that even though there were no obvious after effects to the brain injury there were far more subtle ones that I would never have spotted on my own and now with the benefit of…the best part of what…over two years now…been coming to the brain injury unit…looking back with hind sight if I’d have taken my own course I hate to think where I would be now, because I would certainly have gone back to work on a full time basis and would certainly have gone back to work to my old job description and my employers also told me that they valued the input that you and [the psychologist] were able to give them because effectively it was unchartered territory for them…you know they’ve obviously had employees who have had a stroke or that sort of thing before but by and large very few of them returned to work. So having to actually deal with a member of staff who had suffered traumatic brain injury it was unchartered territory for them. And they probably would have been…quite similar to myself in the…they would
have assumed I had been signed off by a doctor ummm…as being fit for work and there was no real reason ummm… to do anything other than the standard policy for somebody who has been on long term sick…just have a phased return to work over a period of one month and then at the end of one month be supposedly fully functional again. So it’s pretty clear that if I hadn’t had the input of the brain injury unit I would of certainly run the chance of getting back into very…very…serious health problems very quickly.

C. Researcher:
Okay. What did you find from that rehabilitation that was helpful for you?

Participant:
For a long…long time the conversations I had with you and [the psychologist] I didn’t really catch on…I remember thinking I was going to meet these people and I’m doing bugger all with them…I’m just sitting there talking and…it was quite enjoyable you know…I was having really enjoyable conversations with them…but I didn’t think there was any point to it in so much as you know…it didn’t seem like treatment as such, it was only much further down the line that I realised that…you know the treatment was actually very subtle…it was just not a case of saying right you know…you’ve got a cut on your hand and we’re going to put a plaster on it…it was more than anything…it was…these conversations were designed to make me come to terms with what had happened and the effect it was going to have on me and how to adjust ummm…and even though I’m quite a deep thinking sort of person it took quite a long time to realise that the therapy was…all those supposedly inane conversations that we were having that just seemed to be about the time of day was actually part of the treatment. Ummm…and I suppose with somebody like myself who is very head strong and strong willed and quite determined…any other approach probably wouldn’t have worked, it needed maybe a fairly sneaky sort of subtle approach to get through to me [laugh]

C1. Researcher:
Right, okay.
From looking at where you are now…do you think…can you think of anything that you wish had been provided in addition to help you in returning to work?

Participant:
No I don’t think there is…because you know as far as I can see ummm…I had people I know who have experienced brain injury like strokes later in life and they haven’t had a fraction of the help and support I’ve had. You know from day one ummm…in [district hospital] within you know a couple of days of the scan confirming I’d had a brain injury…you know I’d seen dieticians,
physiotherapists, speech therapists the lot and then I sort of had this intense period where I was
going to see the speech therapist in [local town] she identified clearly that there was a problem
which needed referring to yourself, again probably it was this thing…this lack of self recognition I
think with hind sight [the SALT] had realised that I was over aspiring in terms of my return to work
because my initial thought was that I would be back at work in a month at the latest.  And I mean I
puzzled a long time why the speech therapist had referred me to you because by the time…you
know I did initially had some problems with ummm…the wrong words coming out but it wasn’t to
the point where I was having real difficulty in communicating.  So it did puzzle me for a long time
why I had been referred to yourselves and I think what it had boiled down to she had recognised
subtle symptoms that if they hadn’t been treated would probably have left me on a very self
destructive path, so you know at every stage really the…the sort of rehabilitation and recovery
has been good but if I had seen people who had been much older with virtually no physiotherapy
no sort of real ummm…cognitive sort of help so I consider myself in that sense to be very…very
lucky…that you know I didn’t slip through the net and I was picked up.

C2. Researcher:
Do you think it would have been helpful for you to have been involved in a group returning to
work…rehabilitation…group of people who have suffered from traumatic brain injury who want to
return to work and explore things in a group?

Participant:
Me personally I would say no…ummm….even though I’m quite precocious and I talk very openly
with you…ummm….I wouldn’t have been that suited to that sort of approach.  Having said that I
can see to certain personality types it would have been a big help…you know some people
respond better in a one to one sense where as others respond better in you know in a group
sense so…having that option I would say would definitely be rational depending on the
personality type.

C3. Researcher:
Right…what about involvement of….I mean in your case, your wife ummm….do you think
involvement of whoever you’re living with would have assisted in returning to work?

Participant:
Yeah...yeah.

D. Researcher:
What sort of help do you think would have been beneficial?
Participant:
One of the…I mean we’ve talked about this before…one of the with my wife was…you know she worked all those years in the doctors surgery and hearing people moaning she’s had the sympathy bypass and also I am the sort of personality that needs a bit of pushing now and again ummm…and she can she that…but sometimes I do believe she was far too hard on me…possibly again because she didn’t realise…the same as I didn’t…quite how subtle some of these after effects were and how potentially damaging they sort of were, you know because the days that I’d be at home…in some ways it was easier to go to work because ummm…I’d have less to do than the jobs that my wife would sort of …I want this, that and the other done before I come home…and I think she’d been got very frustrated even though generally she’d been very supportive…she used to get very frustrated when I would just sit at home…I used to get so exhausted I’d just be sleeping or on days where I would get quite down…she….she found it difficult to relate to that…and I used to get very frustrated…and strangely enough you know when we had this issue where I had that sort of problem with the interaction with the steroids at Christmas…I mean we met at that time and [the psychologist] wanted to see her as well. I think from that time onwards there has been a noticeable difference in my wife’s perception on things ummm…because I remember at the time even before you know she was on the point of leaving me because she felt I’d betrayed her with all the stuff that was going on and the paranoia. And when I printed off some stuff when it became clear when you first told me you thought it was an interaction with the drugs…I sort of looked on the internet and found some stuff and I printed some stuff off for her and even before she met the psychologist it was fairly clear that she was beginning to understand things that she had never really thought about before and seeing things more from my perspective than hers. So I think including the partner is probably very relevant in most cases but the big problem with that is obviously…you can take the horse to water but they won’t necessarily drink you have to have the partner who is actively prepared to take part. You know we were lucky when the wheels came off for me at Christmas…ummm…and [the psychologist] said he would like to see my wife as well…she’s a fairly private person who doesn’t open up very easily. I thought yes I can see the sense in this but I don’t think she will…and I was very relieved when she actually agreed to it and there’s no doubt it did make a big difference.

D1. Researcher:
Right…was there anything…about the…the rehabilitation that you had that disappointed you…or made you think well that could have been done better?

Participant:
No I don’t think there was…I mean ummm….I’ve got nothing but praise for the way I’ve been treated really…you know from in particular the brain injury unit I mean you liaised with the employer and whenever the employer has been deemed to be stepping out of line…ummm…you sort of reminded them of their responsibilities very quickly and it got to the point where you know…if you snapped your fingers they would jump ummm…and it was a nice feeling really to have that sort of back up ummm…but again I think it helped in that sense because…I think you decided at a fairly early stage that I wouldn’t be the sort of person that would take advantage of that amount of leeway and I suppose that sort of approach can be quite difficult if you’ve got somebody who is prepared to swing it a little bit…you know it’s…for that sort of approach to work you’ve got to have total honesty from all sides and the employer has to be committed to ummm…doing what is best for the employee brain injured patient and the….the employee has to be totally honest and not take advantage of the situation….otherwise you know the mediation that you bring in really would…would be very difficult because it would appear to one side or the other to be bias and unfair.

D2. Researcher:
Right…okay. In recognising that you are different now to before all of this happened what sort of coping strategies have you had to…to develop to manage the changes in you?

Participant:
Ummm…some of the coping strategies that have been recommended by you and [the psychologist] I’m not very good at doing ummm…like writing things down and not pushing myself to hard and whatever. I’m not a very disciplined person in that sense, I think that’s just part of my personality but it’s come down to things like that I need to be reminded ummm…I have quite sort of substantial problems with short term memory and when I say short term memory I’m talking literally minutes…..you know….I mean going up stairs and not knowing why I’m there….ummm…things just disappear in mid sentence that….I mean that would happen to everybody sometimes in their life but is it…it’s much more of a regular occurrence that sort of thing now ummm…the other thing is I’ve had to become a lot….and I mean a lot more laid back and placid and I was quite a volatile sort of personality and I would get wound up about all sorts of things and I would lose my temper very…very easily but I would come down very quickly as well it wasn’t as if I’d go ranting and raving for hours and hours or anything I would just fly off the handle in a split second but within two or three minutes I’d cooled off. I’ve realised that since the brain injury, things like that have a hugely detrimental effect…ummm…and I have to try and avoid that sort of situation so I avoid confrontation far more that I ever would have done…whereas before I wouldn’t back off from anything I tended to sort of meet things head on, not necessarily be aggressive but I certainly wouldn’t back away from anything now I’m far more likely to back
off….not necessarily for the easy life but I know that getting wound up I can feel….literally physically feel my blood pressure rising….ummmm…I mean there was an incident at work a couple of months back where ummm….there was somebody kicking off at the counter with one of the girls and nobody was giving her any support. The boys that worked in the office were just sitting there…thinking it was a big joke and I thought it was way out of line so I went down to try and sort this guy out and it got sort of fairly hairy and it sort of…it sort of surprised me you know where as in the past I would have treated that all a sort of side show and been sort of quite…the adrenaline would have been going…not enjoyed it but certainly would have relished that sort of confrontation…and….I mean my heart was pounding and I could feel my face going red and I was dizzy and disorientated just through getting wound up in that sort of split second when that guy sort of was threatening to come over the counter and…that’s a huge difference so you know…I’ve definitely cooled down in that sense I’m far more placid at home and everything like that. But with other strategies, in terms of memory type things like that I’m not very good…I know what should be…I know what I should be doing but I’m not necessarily doing them.

D3. Researcher:
Is that because you don’t remember to do them or is it because you don’t want to do them or can’t be bothered to do them?

Participant:
One of the things…I know we’ve talked about this before is I’ve got one of the definite after effects of stroke is…. is…this obsession with not doing things for no particular reason. Ummm…you know…opening post…paying bills that sort of thing and it will cause me stress because I know this has got to be done and that has got to be done and I just won’t do it. The more somebody asks me to do it the less likely I am to do it and I can’t come to terms with that and that’s one of the things we’ve discussed you, me and [the psychologist] to try and come up with a way of coping with that. And that’s one aspect where I don’t seem to have improved at all. So maybe like some of these coping strategies…but maybe there’s an element of that coming in where I know I’m suppose to cope in that sense and I don’t do it just to be bloody minded for no rational reason.

E. Researcher:
Right.
With regards to your current work situation how does that impact on other aspects of your life?

Participant:
Obviously there’s the financial stress ummm…you know what I mean I’ve lost forty percent of my income forty percent of my pension ummm…we’re digging into our savings to compensate for that now and when they finish it keeps crossing my mind that we…we will have to make some serious decisions about life style about where we live…ummm…so clearly there’s quite an substantial knock on effect in terms of you know…your life…I mean everyone’s got stress in their life and I think everyone needs a certain amount of stress in their life.  I think if…if it just too easy and it becomes complacent you just drift and vegetate…a certain amount of stress is a positive feature in anybody’s life…but I found myself thinking more about the financial side of things more so in the last few months because of the way economy has gone…you know sort of restricts options all round of in terms of…if we did have to sell the house we have always said there is a huge amount of equity in there…ummm…and that was always our fall back position…even if prices drop substantially we still have a massive amount of equity in the house but…the fundamental problem would we be able to sell it full stop regardless of you know the amount of equity in there…it looks like for the next couple of years just selling under any circumstances…especially a house of that sort of size is going to be a problem so you know there’s quite substantial financial stresses that have come in the wake of ummm… going part time, but then if you balance them against the stresses, if I’d have gone back as I originally planned…remember you telling me at one time that you reckon there was a good chance I would have had a stroke within six months…a stroke within six months if I’d have gone back to what I was doing well its unlikely that I would have got away physically and mentally and relatively lightly in the…in the sense that I would have been able to compensate for most of the damage if I’d have had another one the odds are it would have hit and miss where it hits in the brain ummm…so if it was something that hit me in a far more fundamental level in terms of speech or understanding or sort of ummm…the physical side the chances are I wouldn’t have been able to work at all and on that basis you know it’s not just the case of losing twelve or thirteen thousand a year it would be the case of having to live on a pension of under eight…so in that sense even though it has brought on financial stress in a way it’s far less financial stress that I would have faced up to if you hadn’t made me come to terms with the limitations and adjust my life style accordingly.

E1. Researcher:
Right….okay. can you remember when you first became aware and accept that you still had difficulties that were going to impact on your return to work as apposed to just accepting what other people were saying to you that there were difficulties that would hinder you?

Participant:
I think that this issue…that I was likely not to be able to work full time was taking around sort of
November 2006 and I think it was probably in the two or three months leading up to
that…that the penny finally began to drop that I had actually suffered significant brain
damage…up until then you know when I was going through the therapy but I was still not up to
the interview…yeah these conversations are quite enjoyable because [the psychologist] and
[occupational therapist] are really nice people and I enjoy their company but I didn’t regard it as
anything significant in terms of my recovery it was probably during that sort of summer 2006 you
know leading up to the Christmas period when the formal decision was made, I think I… I began
to realise that even though the symptoms didn’t manifest themselves you know in a really obvious
way like…not being able to use my arm or not being able to talk properly that there was still a
significant sort of ummm….limitation in my functionality…it was just if you like the luck of the draw
that ummm….that the bit of the brain that had been frazzled was something that I could
compensate for in the most part. And I think there was an incident where ummm…I use to find
that I use…I was limping quite badly you know I was dragging a leg quite a lot at one stage, and
other days there would be nothing at all in a physical sense and some days there would be and I
can’t remember if one of the people… I wasn’t sure if it was one of the other doctors in the
hospital or one of the people here but they sort of pointed out that the brain compensates for the
bit that’s not working and re-routes the passages, but if it’s a bit run down and tired it sort of
basically well I can’t help you out today you’ll have to get on with it yourself…hence you know the
problems with mobility and things and I think you know that…that helped me realise that even
though the symptoms weren’t that obvious that there was actual damage there. I think that point
made me realise ummm…I think that was quite a milestone from my perspective.

E2. Researcher:
Right…okay. Can I ask what was your income…in what way has your income changed?

Participant:
It’s gone down by about twelve thousand a year…and I lose forty percent of my pension.

Researcher:
Okay.

Participant:
And I mean…what’s made that worse of course is…you know over the last twelve months, the
outgoings have sort of rocketed in terms of petrol prices going up, mortgage rates going up,
energy rates going up so…so I’m quite substantially worse off in terms of disposable income
ummm…up to now it hasn’t impacted hugely on our life style but that is largely because we had
these investments that were intended to pay off my mortgage before you know…by the time I retired…we’ve been digging into those and ummm….and there’s enough there for another sort of nine or ten months and at that point I think there will be a real financial squeeze.

E3. Researcher:
Okay. If you had to give any advice on what sort of rehabilitation is necessary for somebody who suffers the same…sort of…problem as you…who suffers from a traumatic brain injury…what…what sort of things would be essential for any return to work rehabilitation programme?

Participant:
I look back and think…I often think where I’d be now if it hadn’t been for your involvement…and it doesn’t bear thinking about…I would recommend anybody who’s in my situation and is offered a chance at some sort of cognitive therapy ummm…to grab it with both hands, obviously it depends on the individual in terms of personalities and you know…how prepared they are to communicate and whatever I’d dare say you and [the psychologist]…the likes of [the psychologist] would have strategies for dealing with different types of personalities anyway…but you know…I…I would say…I don’t know…you could never say whether it was a life saver…I could have had another stroke and it could have been massive or fatal but certainly it was one of the best decisions I’ve ever made was to take up the offer to…ummm….to be referred to the brain injuries unit.

F. Researcher:
In terms of your rehabilitation, is there anything else you want to say about it…that I’ve not asked you about?

Participant:
It’s…I think it’s…it’s been really sort of comprehensive I’ve always…I’ve always had something to fall back on and I mean one of the…I mean I thought quite sometime ago do I still need to be…I mean we discussed this a few months back…do I still need to be seen. And I think yes….like a sort of fall back mechanism it’s not as critically as it was in the early months but it’s still very important and I think that this was shown when the wheels came off at Christmas…ummm….I mean I was very close to being sectionable at that time…I was able to phone here and I was…you know you were there the following morning at eight o’clock in the morning ummm…and I was able to see [the psychologist] and that sort of ummm…a comprehensive analysis of what seemed to have gone wrong and then I mean…I saw [the psychiatrist]…was in [the neuro psychiatrist]?...
Researcher:
Mmm…

Participant:
The GP told me…the one that actually prescribed the wrong tablets…he said oh it’s quite good that you’ve been able to see them quickly because if I’d have referred you ummm…it would have taken three months for you to be able to see a psychiatrist…which you know I think puts it in perspective…so…it was clear at that point for various reasons I was still definitely not out of the woods because I mean the reasons I was picking up all these infections is because I was mentally very low and my immune system had dropped off and everything like that so...you know and quite severe depression so…it had all been a vicious circle so…if you like the physical and the mental were quite closely linked. Ummm…so when the physical did actually sort of tip over into the mental side of things…you were there…and I mean the alternative at that point probably would have been to section me. You know and everything that comes with that you know apart from ummm…if you like the actual expense involved from…from the national health perspective if I’d have been sectioned it begs the question what sort of effect would that have had on my subsequent rehabilitation from that…ummm….you know because that sort of thing is still fairly heavily stigmatised…ummm….I would have then been very lacking in confidence as to whether I was fit to go back to work, whether I was fit if you like to be head of the family….there would have been all sorts of fall out from that sort of scenario. And I think only for the fact that the brain injury unit was there and available virtually at the drop of a hat…that you know within the space of less than a week I saw you, the psychologist and neuro psychiatrist ummm…and that was probably what stopped me ending up in the local mental hospital.

F1. Researcher:
Right. So long term follow on support is very important?

Participant:
Yes, and I think…you know…the difficulty there is when to pull the plug because…I mean…most people once they’ve got to a certain level of recovery…there is going to be an element of bravado… and they think…yeah I’m fine, but the patient isn’t necessarily the best person to judge you know…I mean…you know me quite well now and I’m a pretty deep thinking and intelligent person and I understand quite well the workings of the mind, largely out of sheer interest and largely because…I mean well that’s been my business for the last thirty years…sort of if you like…psycho analysing people in…in…in…if you like…in a fraud investigation sense ummm…so I’ve got quite a good understanding but even somebody of my mind set had clearly got it wrong in terms of where I was at…at various times. Even after the point where if you
like…I’d come to terms with the fact that…I did have a significant dent in my life and then it was going to have a serious long term impact on the way I lived and worked, even after that point I still made sort of under estimations at various points…right up until fairly recently when I did that extra work and I remember you telling me you’ve done three weeks extra but it’s going to take you a lot longer to get over that three weeks and…you know you weren’t joking and…you know I…it really has caused me enormous problems. I mean…okay…something like that is a learning curb…that you can learn from your mistakes…but it’s a very fine line where if you like…if you make a mistake then you will suffer short term for it or you make a mistake that you could have a substantial and traumatic effect on your long term prospects and recovery. So in that sense…I think you know the long term involvement with the brain injury unit is very beneficial.

**Researcher:**
Okay.

**Participant:**
I suppose maybe you can get to a point where the bulk of your recovery is complete…but…it only takes a very small thing to knock you off track…to maybe slip back quite a long way.

You know maybe I’m talking absolute rubbish there but…but that’s the way I feel.

**F2. Researcher:**
Okay…that’s fine…I don’t have anymore questions at the moment…anything else you need to say?

Participant turned recording machine off.
Appendix 20  Example of Field Notes Taken During Interview

- Talking about pain & fatigue
  - Wine
  - Tired

- Joking
  - Mentioning more needed
  - Started writing

- Digestion
  - Nausea
  - Eyes felt up

- Failing to remember words
  - Really had to think hard to recall memory
  - Remember words

- Current work & income
  - Unsteady
  - Learned about
  - Declared my contract

- Acceptance
  - Great eye contract helps fill up

- Living & more
  - Self-filling held being lengthy

- Volunteer work
  - Used hands to emphasise more
  - Learned forward
  - Emphasised that others didn't understand my...shamed feel

- We...learning
  - ??
  - In volunteer placement

- Painful & future prospects
  - Chapped arm & shoulder, cramping
Emitted edentulous physical presentation

Confidence

Comparisons and powers in severe situations

Occupational returning to trail in years

Role of related clinicians

Frustation - fatigue

Role of CT

Financial impact

Daily experience

Interview Notes

Lips don't hurt. Grasping with eyes.

Responded:

Feels beliefs plus intense in age

Laughing explanation. "Time to the floor" in bed. School nurse from cimic to explored in hospital painted not return now.

Could not run for more schools.

Related families. Not admitted to school staff.

Feeling pain in hands

Weak atmosphere

Activities very difficult. Headache

Interviewed. Struggling

Stuttering worse on speech. More classified. Had down disappointed.
Interview with [Name]

Contradictions:

Plan doesn't seem to mesh

Contradiction:

Remember: she'd had more

Track of facts:

Volume 4: 1.44

Note:

Ending period through the role... discussion... held highly while talking about music topics.
Appendix 21 Example of Reflective Log Generated From Interview to Analysis

Interview M1

Points of reflection immediately following interview:

- Value of group attendance for rehabilitation
- How individual is perceived by friends/family and work colleagues
- Outside of rehabilitation, what is useful: significant other, encouragement from others
- Impact of TBI on paid work prospects
- Areas of difficulty: Memory
- What gets out of the rehabilitation: Attendance - long term + more frequent initially
- Other agencies that helped
- How does doing unpaid work impact on individual - being occupied
- Based on experience and feelings what is required for future RTW rehabilitation programmes - some good info here - see notes
- Meaning of work to the individual prior to TBI
- Meaning of work now - change
- Meaning of not working
- Income prior to TBI
- Current income
- Benefits received
- Circumstances, still unsure about this
- Current contribution to society of past - loss of friends, community
- Current and pre-injury level of self expectation - re-defining of normality
- Focus more on mistakes than achievements - how this is managed
- What would be useful now?
- Impact of RTW on other areas of life
- What constitutes good/effective rehabilitation?

Notes whilst listening to recording 1st time:

Fact that I had practiced on friend with TBI was good and assisted in my wording of questions. Lots of pauses in the interview as he collected his thoughts.

- Putting himself down a lot - not aware of during interview 1, 2, 3, 4, 5.
- Unusual, he said he wasn't feeling better.
- He is getting used to giving current self-reporting
- Lots of room for self-improvement and further intervention noted in need.
Impacts on whole lifestyle - what he wants to do, had to redefine 'normal', but just an employment issue - self confidence, self image, self esteem, etc.

Perception of rehabilitation different to mine (my beliefs and understanding?)

Continued presentation of past TBI problems meant he is still in rehab. My perception was that continued active engagement with clinicians was 'rehab'.

Interesting!

The financial aspect of paid employment was very important pre injury.

Perception of volunteering... Good base from which to move - but still wants to be active in the decision re type of volunteering he does. CONTROL???

- Different person now - lost a lot, lost him (very important!!!), uncertainty with losses, different outlook on life and living, lost carefree self, changes in ability to interact with others - Loss confidence.
- Wellbeing (Very important!) Obtained through voluntary work at present.
- Accepting of changes relating to work potential. Initially angry. Still sometimes hankers for his old working ability.
- Rehab experience has been positive. Negative is lack of peer support. Lack of opportunity to speak with others in same situation. Not able to access rehab due to geography. Can look back and see improvement. Focusing on physical rehab - self-monitoring is poor still. Realizes need to actively engage to get best out of RTW rehab. Not always done that.
- Frustrated with non-visible injuries as they impact on his ability to return to paid employment. Not discussed fully enough in rehab. That is reason for focusing his efforts onto difficulties that can be seen by others e.g. ataxia.

Rehab needs to be multi professional. Needs to be more often in initial stages to provide support cos it's difficult to come to terms with not returning to previous work. Very upsetting. Difficult to get past the realization. Hard to stop being angry initially.

- Some rehab tasks difficult to understand why he had to do them - many months on he saw the point when reflecting with clinicians.
- Still afraid that he will never measure up to others' standards. (Very important).
- Intolerance of apathy presenting on others with brain injury now. Wants everyone to fight to get as best as they can.
Group rehab would be good in some instances. Get support... Very important.

Want s to work. For money, but needs to be occupied in the meantime so that he could start doing something... visit him. A great opportunity to have a support group. He needs to be supported in the meantime.

Importance of family support with RTW rehab. Practical (travel and transport) and emotional (more when he died and he couldn't get to where he wanted to be). Accepting of his anger and antecedents relating to...Ongoing care in the community. His behaviour has been such... does not exist.

Recall the incident where no does of... is not needed to be. He is in a situation where he does not need any more... in that situation, where no does of...
Appendix 22  English Version

Letter of Thanks to Participants

Dear participant,

I wish to take this opportunity to thank you once more for agreeing to take part in my study as part fulfillment of my Professional Doctorate in Occupational Therapy at the University of Brighton. As discussed at our interview, I now need to transcribe the recorded interviews and analyze the data contained within the written transcripts.

I shall provide you with a summary of my findings once the analysis is complete and has been approved by my supervisors.

Thank you once again for your invaluable contribution and time.

Kind regards

Marian Hooson
Clinical Specialist Occupational Therapist
Annwyl gyfanogwr,

Hoffwn gymryd y cyfle hwn i ddiolch i chi unwaith eto am gytuno i gymryd rhan yn y astudiaeth fel rhan o fy Noethuriaeth Proffesiynol mewn Therapi Galwedigaethol ym Mhrifysgol Brighton. Fel y trafodwyd yn ein cyfweliad, rydw i nawr angen trawsgrifio’r cyfweliadau wedi’u recordio a dadansoddi’r data o fewn y trawsgrifiadau ysgrifenedig.

Cewch crynodeb o fy narganfyddiadau ar ôl i mi gwblhau’r dadansodiad ac ar ôl iddo gael ei gymeradwyo gan fy arolgwy. 

Diolch i chi unwaith eto am eich cyfraniad a’ch amser amhriadiady.

Cofion cynnes

Marian Hooson
Appendix 23  English Version

Dear participant,

I wish to take this opportunity to thank you once more for agreeing to take part in my study as part fulfillment of my Professional Doctorate in Occupational Therapy at the University of Brighton. As discussed at our interview, I have now analyzed the data generated from the interviews, and am providing you a summary of the findings for your information. More detailed findings will be presented in professional journals over the next twelve months. Should you wish to be kept informed of any publications, please let me know.

The data collected has been grouped into five ‘master themes’ with ‘sub themes’ within those. They are summarized in the following table:

Table: Summary of Themes

<table>
<thead>
<tr>
<th>Master Themes &amp; Sub Themes</th>
<th>Sample of Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Personal Cost of Lifestyle Losses</td>
<td></td>
</tr>
<tr>
<td>a) Loss of personal qualities</td>
<td>“I’ve lost the person I was”</td>
</tr>
<tr>
<td>b) Loss of collegial verification</td>
<td>“The laughter the commaderie of it all … supervising lads, telling people what to do … I miss that”</td>
</tr>
<tr>
<td>c) Amended Future Aspirations</td>
<td>“My promotion prospects within my current employment are probably diminished”</td>
</tr>
<tr>
<td>d) Redefining Wellbeing</td>
<td>“I get a feeling of wellbeing from doing voluntary work at the moment”</td>
</tr>
<tr>
<td>2. Impact of TBI on Perceptions of RTW &amp; Occupational Activity</td>
<td></td>
</tr>
<tr>
<td>a) Volunteering</td>
<td>“Volunteering is to put something back… I used to enjoy it”</td>
</tr>
<tr>
<td>b) Re-training</td>
<td>“I’m ready for any work opportunities that come my way now”</td>
</tr>
<tr>
<td>c) Returning to previous employment</td>
<td>“It was decided [by the clinicians] that I couldn’t work on a full time basis and I couldn’t go back to my previous remit”.</td>
</tr>
<tr>
<td>4. Factors Impacting on Engagement in RTW Rehabilitation</td>
<td></td>
</tr>
<tr>
<td>a) Disruption to physical functionality</td>
<td>“But in the gym I have got motivation ‘cos I want to walk better and faster, and I want to look normal”.</td>
</tr>
<tr>
<td>b) Emotional ability &amp; stability</td>
<td>“It absolutely knocked me sideways. I was so angry… ummm … It wasn’t my fault”.</td>
</tr>
<tr>
<td>c) Therapeutic relationship</td>
<td>“It’s just a case of the team of people around you just cajoling you and helping you make your own decisions. That’s my experience”</td>
</tr>
</tbody>
</table>
### 4. Assistive elements of RTW rehabilitation

| a) Vocational | “… My employers also told me that they valued the input that you [the brain jury service] were able to give them |
| b) The Personal Perspective | “The only way I describe it is that lots of people start ummm … aging over a period of time and I believe that; BANG. I became like … like an old man all of a sudden … overnight |
| c) Therapeutic expertise | “… I can get in touch … you haven’t wiped your hands clean of me, and I know that if I reach a problem in six months (…) that I could get in touch with you again so… that’s always quite comforting” |
| d) Familial Involvement | “I’m glad I came home with the help and support from my family (…) If I’d had no family to go back to … completely different story …” |

### 5. Impact of RTW rehabilitation on the occupational performance of participants

| a. Positive | “You kept in contact with my former boss, writing letters (…) you may have met him, I can’t recall really (…) So people can’t really look down at you because you’ve had the pat on the back and the piece of paper to say ‘he’s okay’. That helps a lot” |
| b. Negative | “I think to be honest it was a little bit early for me with my injury because I was still a bit too out of it to cope with them” |

These themes, combined, addressed my research aim of wishing to obtain an in-depth insight into the experience of engaging in RTW rehabilitation. Your combined descriptions of the meaning of ‘work’ before your brain injury provided insight into what you felt you had lost when not gainfully employed. The descriptions of changes in perceptions of return to work after brain injury showed how being gainfully occupied after brain injury assumed more importance than being engaged in paid employment. The third theme describing the factors that impacted on the ability of individuals to engage in return to work rehabilitation provided insightful descriptions of difficulties that the participants in this study were confronted with that may not always be considered by clinicians. Assistive elements of return to work rehabilitation provided understanding of the meaning that engaging in the rehabilitation held for you as a group. The final theme illuminated how worthwhile you found the return to work rehabilitation experience.

The above themes and other information which you gave me at interview have provided significant knowledge about what is actually assistive in RTW rehabilitation for individuals with TBI. You have also provided information that has clarified the unique role of occupational therapy in this process and how it needs to develop to meet the needs of the individuals with TBI. I plan to present my findings at conferences next year.

I thank you once again for your invaluable contribution to this piece of work. I think one of the main findings that we, as clinicians, need to take on board is that individuals with TBI continue to be knowledgeable, and be ‘experts’ in their own right on what is helpful to them when trying to re-establish their roles after leaving hospital. As a Service, we shall be exploring how we can utilise
your knowledge and experiences to further assist others who may be in similar situation as yourselves.

Kind regards

Marian Hooson
Clinical Specialist Occupational Therapist
Appendix 24 Summary of Presentations Relating To This Study

The research process and the findings have already been disseminated in peer reviewed Doctoral conferences as detailed below:

Professional Doctorate Conference, University of Brighton, 2006
Professional Doctorate Conference, University of Brighton, 2007
Professional Doctorate Conference, University of Brighton, 2008
Professional Doctorate Conference, University of Brighton, 2009
SUADE Conference, University of Brighton 2009

It is further planned that the findings of the research will be disseminated at presentations at the following conferences next year as detailed below:

6th World Congress on Neurorehabilitation, Vienna, March 2010 (Abstract Submitted)
34th BAOT Conference, Brighton, June 2010 (Abstract Submitted)
Appendix 25  North Wales Central Research Ethical Approval Form

North Wales Central Research Ethics Committee
Room 1036
Glen Clwyd Hospital
Bodelwyddan,
Denbighshire,
LL18 5UJ

Telephone: 01978 728377
Facsimile: 01978 725366

16 JUN 2008

11 June 2008
Ms Merlyn Hooson
Occupational Therapist
North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road
Colwyn Bay, CONWY
LL29 8AY

Dear Ms Hooson,

Full title of study: A qualitative investigation of the individual’s Lived Experience of Returning to Work Following Traumatic Brain Injury

REC reference number: 08/WN02/4

Thank you for your letter of 9th June 2008, responding to the Committee’s request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.
Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rd forn.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<td>Sponsored Application</td>
<td>2</td>
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<td>Investigator CV</td>
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<tr>
<td>Protocol</td>
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<tr>
<td>Covering Letter</td>
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<tr>
<td>Summary/Synopsis</td>
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<td>Letter from Sponsor</td>
<td></td>
<td>17 March 2008</td>
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<tr>
<td>Peer Review</td>
<td></td>
<td>28 February 2008</td>
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<tr>
<td>Compensation Arrangements</td>
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<td>Interview Schedules/Topic Guides</td>
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<tr>
<td>Questionnaire: Awareness Questionnaire</td>
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<td>20 March 2008</td>
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<tr>
<td>Letter of invitation to participant</td>
<td>2</td>
<td>21 May 2008</td>
</tr>
<tr>
<td>Letter of invitation to participant - Significant Other</td>
<td>1</td>
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<tr>
<td>GP/Consultant Information Sheets</td>
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<tr>
<td>Participant Information Sheet, Significant Other</td>
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<td>Participant Information Sheet</td>
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<tr>
<td>Participant Consent Form, Significant Other</td>
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<td>Consent verification form</td>
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Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study
The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.epa.nhs.uk.

68/WMc02/4  Please quote this number on all correspondence.

With the Committee's best wishes for the success of this project.

Yours sincerely

Mr Christopher Penfold
Chair

Email: tracy.hughes@new-tr.wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to:
Mrs Jayne Ingles, Faculty Research Administrator, University of Brighton
Mrs Lona Tudor-Jones, R&D Manager Conwy & Denbighshire NHS Trust